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# Living on the edge: Families' experience of developmental disability and mental illness across the life cycle

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# LIVING ON THE EDGE:

# FAMILIES' EXPERIENCE OF DEVELOPMENTAL DISABILITY AND MENTAL ILLNESS ACROSS THE LIFE CYCLE

By

Don R. Roth

Honours Psychology, Wilfrid Laurier University, 1990

THESIS
Submitted to the Department of Psychology
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# *Preface*

In recent years, there has been a trend toward more holistic, qualitative forms of inquiry in human research, particularly so in the field of psychology where scientific methods have become entrenched. Yet many years ago, in fact well over 150 years ago, a distinguished writer by the name of Ralph Waldo Emerson reflected on how to understand truth and capture meaning.

> *Empirical science is apt to cloud the sight, and, by the very knowledge of functions and processes, to bereave the student of the manly contemplation of the whole. The savant [learned person] becomes unpoetic. But the best read naturalist who lends an entire and devout attention to truth, will see that there remains much to learn of his [or her] relation to the world, and that it is not to be learned by any addition or subtraction, or other comparison of known quantities, but is arrived at by untangible sallies of the spirit, by a continual self-recovery, and by entire humility...*
>
> *When I behold a rich landscape, it is less to my purpose to recite correctly the order and super-position of the strata, than to know why all thought of multitude is lost in a tranquil sense of unity...*
>
> *A wise writer will feel that the ends of study and composition are best answered by announcing undiscovered regions of thought, and so communicating through hope, new activity to the spirit.*
>
> Ralph Waldo Emerson. (1836). *Nature*

It is my sincere wish that the stories presented in this thesis document capture the essence of the "landscape" shared by families. Furthermore, I hope that by focusing on family experiences and strengths, this research process and document may tap into new energy and conviction for social change, justice and community living.

# *Acknowledgements*

First and foremost, I extend my sincere thanks to the family members who participated in this research through the Support Clusters Project. I have greatly appreciated the opportunity to hear your stories of struggle and success. You have taught me a great deal about the value of life. As an important part of evaluating the Support Clusters Project, this research process has continually grounded members of the evaluation team in your perspectives.

I give special thanks to my advisor Geoff Nelson for his patience and his friendship as we went through a valuable learning process together. Geoff, your openness and personal approach made this a truly enjoyable project. I also extend special thanks to John Lord for his guidance through this process giving of his knowledge, his time and himself. To the members of my thesis committee, Steve Chris and Richard Walsh-Bowers, I offer my gratitude for your insightful comments and challenges that made this research process and final document worthy of the family life histories I have attempted to understand and appreciate.

I thank my friend and partner, Margaret Anne, for her support and encouragement to complete a significant chapter in my life, including this research process and the Community programme over the last two years.

# *SUMMARY OF THE RESEARCH*

This qualitative research document provides an in-depth description of families' experience of both developmental disability and mental illness (i.e., "dual diagnosis") across the life cycle. This thesis is devoted to listening to family members as they tell their story beginning with the early years of family life, then through childhood and adolescence, and into young adulthood with their family member. This research describes the process of how families developed a framework to interpret and make sense of the world around them. Then, the research integrates these families' experience over the life cycle with models of family stress and coping in the literature (e.g., Hill 1949, 1958; McCubbin & Patterson, 1983; and Olson, 1988) and expands these models to more fully capture the meaning for families and the impact of cultural values. This research is completed by family members' reflections on the future as they began a new project called the Support Clusters Project.

The Support Clusters Project was a 30-month research demonstration project that strove to build on families' strengths through two main activities. First, by developing a network of support around the family, including supporters from informal networks (e.g., extended family and friends) and supporters from formal service provision networks, the project addressed the isolation described by families in this research. Then second, this "cluster" of people engaged in problem-solving and educational activities to further develop

skills and help change the context of stressful interactions among members of the families' networks. The present research with families, then, was important to fully understand the potential impact of the Support Clusters Project. This research also provided family members the opportunity to tell their stories with dignity and helped communicate to other people in the community families' history of struggle and success.

As a member of the evaluation team at the Centre for Research and Education in Human Services, I have used eight in-depth interviews with family members including mothers, fathers and siblings as the primary source of information. I have also used observational data from meetings of a Parent, Family, and Friends Support Group in the project, and observations of two support clusters completed over a period of six months by members of the evaluation team.

This research document is organized into "chapters" to reflect the complexity of families' life history; chapters which present families' stories begin with a summary of one family's experience, then in greater detail develop patterns and themes across all families in the study. In the early years of family life, the stories told by families reveal the emergence of a formal support system which expressed the cultural value of "fixing the person" in segregated environments. Then, over the course of the life cycle, this research shows how the exclusion of informal supporters and families' competencies in these early solutions compounded the problems experienced by the person and

her or his family. In the childhood years, families' struggled in their attempts to adjust to a family life style that differed from their expectations. This was a critical period of exploring family values in which mothers emerged as important leaders in the family and the community. For example, where families were able to commit themselves to developing a shared philosophy and vision of the family, mothers were able to exercise the leadership necessary to effect changes in their community, rather than simply "carry the burden." However, in the teenage years, parents and siblings described the growth of professional services into the community that did not support families' control or provide continuous support for their family member.

In spite of families' efforts and strengths, by young adulthood, individuals given the "dual diagnosis" label had often experienced oppressive circumstances such as abuse, a lack of friendships, and a lack of purpose in the mainstream culture. Family members found themselves with little access to ongoing, practical support from either their informal or formal networks, but had found a small, select group of people who were willing to understand and who the family could trust. Looking toward the future, family members remained concerned about how they were going to support their family member and help her or him find a meaningful life as a fully included, rather than "serviced," member of the community. The impact of cultural values on the person and his or her family were an important part of this discovery process.

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# *CHAPTER 1*

# *INTRODUCTION*

Welcome to the introductory chapter of this thesis document. This work represents the efforts of many months of learning and labor intertwined with fun and excitement. I trust that you have had enough courage to read beyond the "transcendental" reflections of Emerson along with my other prefatory writings, and I hope that you now have an eagerness to learn, and at points perhaps labor, but mostly listen and hear the value of families' stories.

## ***Why this Thesis is Important***

This thesis presents families' life histories of struggle and perseverance with a family member given multiple disability labels. These stories are grounded in the realization that there is no "pot of gold" at the end of the rainbow, but that rainbows themselves are beautiful, and sometimes even magical. I have used a qualitative analysis and writing style so that you as a reader might listen and hear families' voices as they tell their stories of courage, strength, and conviction. Through the writing of this thesis then, I hope to describe a positive vision of families' lives so that you might better understand and value their life experiences.

I have organized these writings into chapters to create an atmosphere that may be helpful for the reader to think about different time periods. For example, we often organize meaningful events and experiences around a period of time or a "chapter" in our lives upon which we later reflect. These memories often mark key transitions in our lives upon which we actively create meaning. Thus, I believe "chapters" create a structure that facilitates learning about the unfolding life process experienced by families in this study. In contrast to traditional organizational headings, such as "results," I also wanted to symbolize that each phase of families' stories deserves equal emphasis or weighting with all other sections of this document. As you shall read, symbols are an important part of learning to appreciate a rainbow.

In the remaining sections of Chapter 1 below, I have discussed "who I am" in relation to this work and the background to the intervention and research contexts. Then, in Chapter 2 and Chapter 3, I have outlined important sources of literature in relation to both disabilities and families. In Chapter 4, I have offered a clear statement of purpose, explored the research assumptions, and their implications for the approach and research relationship. I then, in Chapter 5, outlined the methodological considerations and ended with preparatory notes for the next chapters of family text. In Chapter 6 through Chapter 10, I have included a description and analysis of family life experiences across five stages, based on listening to family members. In Chapter 11, I have developed themes of meaning across the family life cycle. Finally, in Chapter 12, I have offered several personal insights and learnings, and evaluated my efforts toward achieving the main purpose of this research.

### *About the Writer*

The topic of family history and understanding of issues related to multiple, complex disabilities had several appealing qualities as it integrated my interests in both research with families as well as my interests in disability issues. My interest in family issues grew out of family values and experiences growing up in a Mennonite tradition and then later reading such books as *The Family Crucible* written by Napier and Whitaker (1978). My interest in issues related to disabilities began with the realization that we are all only "temporarily able-bodied" after an accident left a close friend with permanent paralysis. As I reflected on my own history, this event formed an anchor point around which I made a decision to attempt undergraduate courses on a part-time basis. I have written briefly about anchor points and their symbolic value in the family life cycle later in this document.

About one year after entering university, I worked on a part-time basis in a direct service capacity with residents with complex, multiple disabilities at a local institution and began taking related courses at Wilfrid Laurier. Around this time, I had begun to feel I had found some direction and applied myself academically to "see how far I could go" in post-secondary education.

I then had an extremely fortunate opportunity - I was offered and accepted a position in the Community Psychology programme - a choice I have never regretted and have continually savoured. Upon entering the programme, I was immediately drawn to a placement at the Centre for Research and Education in Human Services exploring a new model of working with people with disabilities, their families and people in their support networks called the Support Clusters Project.

### *The Support Clusters Project*

The Support Clusters Project was a 30-month demonstration project aimed at addressing the historically-based obstacles and issues confronting individuals who have received a "dual diagnosis" label and their families. This diagnostic category refers to an extremely wide range of individual characteristics and life circumstances; it broadly encompasses people who experience conditions reflective of both a developmental disability and mental illness. Individuals and their families who experience a range of such complex issues have encountered significant barriers to accessing resources, in part due to the fact that the Ministry of Community and Social Services and the Ministry of Health in the province of Ontario traditionally have addressed developmental and psychiatric concerns as distinctive and exclusive categories.

The purpose, then, of the Support Clusters Project was to initiate a community-focused approach to overcome such systemic barriers, among others. This community approach included building upon the existing social support networks of families and subsequently developing opportunities for education and learning that were consumer-driven. The role of the two project staff was to engage families and their support networks in a group process based on an empowerment philosophy. In a study on the process of personal empowerment, Lord (1991) defined empowerment as "processes whereby individuals achieve increasing control of various aspects of their lives and participate in the community with dignity." (p. 7) Thus, the key components of the project included: building social networks; a learning or educational component; and, an explicit empowerment framework enabling personal control and choice toward a focus on community living.

Consistent with this philosophy, an enabling model of help-giving assumes competencies exist and thus seeks to create opportunities for competencies to be displayed or acquired (Dunst, Trivette, & Deal, 1988). In contrast to traditional models which directly or indirectly blame individuals and families for their life circumstances, the enabling model aspires to create a process for effective growth-promotion. Thus, the enabling approach attempts to create partnerships that focus on solutions with contingent help-giving from other informal (e.g., friends and extended family) and formal (e.g., case managers and teachers) network members. This novel approach to facilitation was a crucial part of the project given the historical complexities of co-existing developmental disability and psychiatric struggle.

### *The Research Context*

As an integral part of the Support Clusters Project, an evaluation research process was used to understand how effective this social support and educational approach would be in working with persons with multiple disabilities and their families. Because of the action research orientation of this evaluation, the research methods needed to be comprehensive and flexible (e.g., emergent design, see Lincoln & Guba, 1989) to truly reflect an understanding of both the outcomes (i.e., what happened) and the processes (i.e., how it happened) of the project from a number of different perspectives. Additionally, this action-oriented design was focused on collecting data that are useful to adapt various aspects of the project during its formal operation (e.g., see Patton, 1986).

As one step toward these goals, other members of the evaluation team and I conducted in-depth qualitative interviews with family members to begin to grasp their family history. Although such research on families' experiences with developmental disability as well as mental illness was represented to a relatively small degree in existing literature, there was no literature understanding families' experiences with "dual diagnosis." This exciting research with families was not only a truly original topic area but the research methodology discussed further below, was also atypical of mainstream research. In the next two chapters, I have presented literature on "dual diagnosis" and families to prepare the reader and set the context for this work.

# *CHAPTER 2*

# *BACKGROUND AND REVIEW OF "DUAL DIAGNOSIS" LITERATURE*

## *"Dual Diagnosis": A Problematic Label*

The use of the concept "dual diagnosis" is a complex issue involving pragmatic and ethical issues. Given the history of problems associated with diagnostic procedures in mental illness (e.g., reliability and validity of the DSM III-R) and classification systems of developmental disability, the pragmatics of diagnostic procedures become even more complex when attempting to jointly, yet meaningfully, express the living conditions with both systems simultaneously. For example, Reiss (1990) suggested that different prevalence rates of "dual diagnosis" were the result of different methodologies. To illustrate the variance in identifying "dual diagnosis", population surveys from case files typically reported a range of 10-11% of persons with a developmental disability also have a psychiatric concern; by using behaviour rating scales or structured interviews, 15-22% of individuals with a developmental disability are "dually diagnosed"; and investigations using the full range of mental health symptoms reported rates of about 40% (Reiss, 1990).

Reiss (1990) utilized a multiple-criteria rating system, the "Reiss Screen of Maladaptive Behaviours", to identify the prevalence of various factors in the lives of persons given a "dual diagnosis" label. The Reiss Screen consists of seven rating scales (aggressive disorder, psychosis, behavioral depression, physical depression, avoidant disorder, dependent personality disorder, and paranoia), six special maladaptive behaviour items (e.g., drug abuse), and total score based on the 26 items overall. In a sample of 205 persons participating in a community-based day program, Reiss found issues of social inadequacy (45.8%), symptoms of personality disorder (25-45%), anger and aggression (18-25%), and affective disorder for about one in every six people. However, the results of this study also suggested that drug abuse, self-injury and suicidal tendencies are rare symptoms in this population. Reiss concluded that very serious forms of mental illness afflict relatively few persons with a developmental disability, yet, such persons are more vulnerable to personality problems associated with dependency, over-sensitivity in relationships, and social inadequacy.

Understanding the "dual diagnosis" label also involves a series of assumptions, professional biases and ethical considerations tied to a service system that determines the assignment of such a label (Borthwick-Duffy & Eyman, 1990). In a state-wide sample of 78,603 people in California, Borthwick-Duffy and Eyman (1990) examined characteristics of "dual diagnosis", patterns of residential placement associated with various mental disorders, and behaviour problems associated with psychiatric diagnosis. These authors found that among this "administrative sample" of persons in the system those classified as "mildly retarded" are more likely (54.3%) to also receive a psychiatric diagnosis. The percentage of labelling "dual diagnosis" in this large sample declines continually across moderate, severe, and profound levels of retardation for a total prevalence rate of approximately 10%. Data provided by Borthwick-Duffy and Eyman showed that of the people in their sample given a "dual diagnosis", 5.1% resided at home with a parent(s) or relative, while institutional, community facility, and health facility placements accounted for 18.6%, 18.4%, and 8.3%, respectively. Interestingly, these data also showed that residential placement with a parent(s) or relative accounted for a greater number of placements than all other categories combined when people had exclusively received a developmental disability label.

Borthwick-Duffy and Eyman (1990) conducted a step-wise discriminant analysis to investigate the behavioral problems associated with psychiatric diagnosis in persons with a developmental disability. In their regression model, three factors emerged as the best predictors of "dual diagnosis" in contrast to solely "mental retardation": social skills, cognitive ability, and social maladaption (i.e., extrapunitive behaviour such as aggression). The interpretation of such findings can be made from several perspectives, however (Borthwick-Duffy & Eyman, 1990).

According to these authors, the assumption that accurate diagnoses have established labels which truly reflect persons living conditions may lead to a number of conclusions:

> * The more severe the level of retardation, the less likely an individual is to experience psychiatric problems;
> * Clients [people] with psychiatric disorders are distinguished primarily by extrapunitive behaviour (e.g., aggression); and,
> * Out-of-home placement is more likely for people with psychiatric disorders. (pp. 591-592)

Alternatively, one might assume that such diagnoses are dependent on a number of system variables related to perspectives and biases on developmental disability and mental illness. Thus, Borthwick-Duffy and Eyman suggest alternative conclusions may emerge:

> * The likelihood of *being referred* for psychiatric evaluation and subsequently given a dual diagnosis is related to an individual's cognitive functioning level;
> * Certain behaviours are more likely than others to prompt caregivers to refer an individual for psychiatric evaluation... Overall, problem behaviours that are more social in nature are those that lead to a dual diagnosis;
> * Differences in proportions across [residential] placements are more a function of the labelling process than of actual trends in placement;
> * One reason that problem behaviours are also common among those who have not been diagnosed with psychiatric disorders is because many of these individuals... have not been referred for evaluation; and,
> * A second explanation for the differences across retardation levels supports the diagnostic overshadowing phenomenon, suggesting that profoundly retarded people are less likely to be diagnosed as having a psychiatric disorder because the complexities associated with their intellectual handicaps result in a tendency to attribute their abnormal behaviour to low IQ rather than an emotional disorder. (p. 592)

Borthwick-Duffy and Eyman concluded that until a variety of assumptions is clearly examined, studies may reflect aspects of the service delivery system, such as assessment procedures, as much as any of the individuals it attempts to serve. In fact, it may be that such studies to date have actually investigated aspects of the various service systems more than anything else at all and surely represent the political nature of the development of such classification systems.

Zigler and Burack (1989) reviewed a number of research papers completed over the last several decades on personality development as related to developmental disability. At the risk of sounding trite, these authors suggested that the literature indicates people with developmental disabilities are influenced by the same types of developmental variables and life events that affect the personalities of the general population with the same degree of complexity. In fact, Zigler and Burack openly challenged the status quo research on personality development:

> Personality theorists must do much more than merely substitute personality stereotype for the cognitive stereotype already in place. No two mentally retarded individuals have exactly the same experiences... One encounters wide variability in the personality structures of mentally retarded persons just as there is for individuals of average intellect. Nor are these personality characteristics unchangeable. (p. 229)

Clearly, the assumptions underlying different approaches to research must be recognized and understood given the social and political nature of the research process, including interpretation of findings.

Zigler and Burack also pointed out several areas of vulnerability with specific reference to persons with disabilities, for example, social deprivation which may lead to "positive-reaction" (e.g., high attention-seeking behaviours) and "negative-reaction" (e.g., withdrawal) tendencies. Further, low expectations of success and hence low aspirations for the future are one result of personal life histories all too familiar with failure. These authors also suggested this history of perceived failures may lead to problem-solving styles characteristic of "outerdirectedness" (i.e., the search for others' solutions to problems due to a pervasive distrust of oneself). These types of "social problems" associated with life history may increase burden on direct caregivers and other social supports. However, findings such as these may also indicate that areas of competence and strengths of individuals given labels as well as similarities between "special needs" populations and "normal" populations are not adequately represented, nor emphasized, in the literature.

Keys, Fletcher, Holmes and Schloss (1989) suggested that the Reiss Screen, and the Psychopathology Inventory for Mentally Retarded Adults (PIRMA) created by Matson (1988) represents sufficient technology for identifying and evaluating "dual diagnosis". Thus applied research on effective interventions may be the most important focus in the area of "dual diagnosis". These authors offered several critical questions for creating linkages between theorists and practitioners in such applied research. These important questions concern how to overcome: differences in culture between interventionists and researchers; patterns of negative history; and competition for limited resources between researchers and practitioners. The evaluation research component in the Support Clusters Project was an excellent example of collaboration between project staff (i.e., interventionists) and the resesearch team at the Centre for Research and Education. Beyond the scope of the present work, however, remains the task to create an atmosphere of collaboration among professionals rather than immersion in typology and "scientific" inquiry that does little to change the living conditions experienced by such persons.

In 1991, The Association for Persons with Severe Handicaps (TASH) based in the United States published several ethical and practical concerns about the use of the "dual diagnosis" classification label. These concerns included:

> * The stigma of another label;
> * Improper institutionalization of people who are "dually diagnosed";
> * Creation of new in-patient units based on presumed mental illness;
> * Use of aversive procedures, punishments, and psychotropic medications as acceptable treatments; and,
> * The lack of responsibility in either the mental health or mental retardation systems which results in some individuals receiving no assistance. (p. 20)

In fact, the final concern raised by TASH was an important impetus to the Support Clusters Project.

### *Defining 'Dual Diagnosis" in the Support Clusters Project*

The leaders in the Project and others in the community believed very strongly that persons with both a developmental disability and a mental illness were a population under-served by formal service delivery systems. The eligibility criteria created by the community-based Steering Committee for participation in the Support Clusters Project were more open-ended than traditional clinical approaches that utilize strict diagnostic procedures. To establish an individual's experience with a developmental challenge, the Committee recommended that two or more of the following be demonstrated:

1. Past or present labelling of developmental challenge by an educational, medical or social service system.
2. Past or present involvement in programs or services typically designated for persons with a developmental challenge.
3. A general recognition by self / family / service providers that the person has a developmental challenge.
4. Life skills problems synonymous with cognitive / intellectual impairment (i.e., requires guidance or assistance with living such as shopping, working, money management, time-concept, travel, etc.).

In addition, the person should be able to engage in most activities of daily living without individual care and guidance and possess the ability to express with sufficient skill her or his wants and needs.

To establish the individual's experience with a psychological concern, the Committee suggested that two or more of the following should be displayed:

1. Past or present labelling of a psychiatric, psychological or emotional concern by educational, medical or social service system.
2. Past or present involvement in a program or service typically designed for persons with a psychiatric, psychological or emotional concern.
3. A general recognition by self / family / service providers that the individual has a psychiatric, psychological or emotional concern.
4. Displays or has displayed disruptive behaviour to the family, community or service providers such as - social withdrawal, suicidal thoughts or attempts, violent acting out, suspiciousness, paranoia, hallucinations, chronic depression, chronic or irrational fear, inappropriate or anti-social behaviour.
5. Past or present use of prescribed medication to control psychiatric symptoms.

Note: "past" means within the last 5 years.

In addition to the criteria outlined above, the Steering Committee recognized several "problems in living context" associated with dual diagnosis. The following criteria were also considered in the decision-making process: social isolation of the individual, disconnection or exclusion from community resources, subjectively experienced poor quality of life, dependence on others to ensure basic needs are met, and a lack of skills necessary to negotiate improvements in any of the previous areas for her or himself. The committee also explicitly recognized the difficulty of identifying individuals for participation in the project and struggled to avoid the use of criteria that paralleled a traditional deficit-analysis and orientation (i.e., an approach focused on "what's wrong with people" and how such problematic individuals need to change). I have more fully explored how to move beyond this deficit-oriented approach in ways described by Dunst and his colleagues (1989) in the literature review below. Other work by Borthwick-Duffy and Eyman (1990) on the criteria for establishing a "dual diagnosis" has demonstrated the influence of assumptions and values on how variables, such as social skills and aggressive behaviour, are interpreted. Thus, the deficit-analysis ultimately places responsibility for change on the individual or "blames the victim" (Ryan, 1971).

In the following chapter, I have reviewed numerous articles pertaining to the family and its experience of disability issues. In particular, I have focused on research exploring models of understanding family life experiences over time and the potential applications of such models where disability issues exist. I have also reviewed literature related to a new framework for interventions that attempts to build on families' competencies and strengths. However, I first explored a systems framework for understanding "what is the family?" and how members interact with one another.

# *CHAPTER 3*

# *BACKGROUND AND REVIEW OF FAMILY LITERATURE*

## *The Systems Perspective*

Given that the sum, or life experience of the family, is greater than the whole of the individual parts, family meanings and culture may be captured more fully from a family systems perspective. Rather than focus at an individual level, the systems perspective attempts to understand the culture of families as a gestalt of interacting marital, parental, and sibling subsystems (e.g., Schultz, 1984). In the early 1960s, a gradual shift from interest in intrapsychic factors or individual characteristics to social factors in the study of human conditions reflected an increasing recognition for the context of health and psychological wellness (Levine & Perkins, 1987). This shift initiated a dramatic change in the way practitioners approached various interventions and to a lesser degree at that time the way researchers framed their approach to "scientific" inquiry. Because the importance of this shift and its relation to interventions such as the Support Clusters Project are difficult to overstate, I will briefly review several features of family systems theory.

The critical assumption of family systems theory is that to understand an individual in the system, she or he must first be understood as a part of a larger whole (Schultz, 1984). Napier and Whitaker (1978) framed this basic assumption in an analysis of six general components of family systems: stress, polarization and escalation, triangulation, blaming, diffusion of identity, and stasis. These authors suggested that acute situational, interpersonal and intrapersonal stress are all important features of understanding the family context, its internal and eternal energies. Polarization and escalation is a phrase used to describe the process of how interpersonal conflicts develop over time. First, people become entrenched at extreme positions and then intensify the level of conflict in a reciprocal feedback loop. For example, one member of the family may raise the stakes with threatening expressions that serve to further "polarize" the other party, and inturn have negative effects on the member who initially "raised the stakes." This feedback loop may spiral the conflict in a positive direction (i.e., away from the normal level) or in a negative way (i.e., back toward the normal level).

Several decisive features of the family system then are the individual's relationships with others, and her or his roles and functions as part of the whole system (Schultz, 1984). One way a third party to a conflict functions in a family is to triangulate and stabilize the system by acting as a scapegoat. For example, Napier and Whitaker illustrated a situation where a child mediated the conflict between her or his parents by becoming a "sick" or "problem" child upon whom the family could focus its' attention, rather than the primary source of conflict - the marital relationship. Where families experience tense and significant conflicts that involve either internal or external sources, there is a danger that individual members lose the ability to move in and out of the system freely. Family members ultimately lose almost any degree of independence and autonomy; in fact, the family becomes an entity unto itself and individuals lose their personal identities (Napier & Whitaker, 1978). Breaking out of these patterns, however, may mean the family must face "the fear of immobility and stasis, which is really the fear of death," according to these authors (p. 89). In essence, living with problems that are known may be easier and thus motivate an avoidance of exploring an unfamiliar, yet potentially more positive future.

The systems perspective also acknowledges that transactional patterns of influence within the family may be used to understand how family members grow together and change over the life-span or family "career". Carter and McGoldrick (1988), for example, outlined various features of the changing family system across the life cycle. These authors attempted to provide a model which incorporates the "intergenerational connectedness" of the system over time, beginning with parent's families of origin, thus emphasizing the transition into young adulthood. They also emphasized the need to recognize the social, economic and political context at each phase of the family over time. These factors not only define the context in which families operate, but also define the available resources, cultural expectations and meaning of life experiences for families. For example, these authors pointed out:

> While it used to be that child rearing occupied adults for their entire active life span, it now occupies less than half the time span of adult life prior to old age. The meaning of the family is changing drastically, since it is no longer organized primarily around this activity. The changing role of women in families is central in these shifting family life cycle patterns... In fact the present generation of young women is the first in [North American] history to insist on their right to the first phase of the family life cycle - the phase in which the young adult leaves the parents' home, establishes goals, and starts a career. (p. 11)

These changes in understanding "the family" have great influence on how people interpret and understand the world around them. Carter and McGoldrick (1988) warned, however, that:

> Thus our paradigm [or way of thinking] for American families is currently more or less mythological, though statistically accurate, relating in part to existing patterns and in part to the ideal standards of the past against which most families compare themselves. (p. 12)

Thus expectations are carried across generations and integrate in unique fashion with the second-order changes of the family system itself. These continual integrations of expectation and change occur across the family life cycle from leaving home as a young adult, to marriage, the birth and growth of new children, and into later life (Carter & McGoldrick, 1988).

The family systems framework is also compatible with an ecological model described by Bronfenbrenner (1977, 1979). In the ecological model, individual competencies and patterns of behaviour are examined within a multi-level and dialectical context of larger social environments such as the family, school and workplace, as well as broader political, economic, and cultural influences. Thus family systems are embedded within very complex environments. The movement toward a systemic community view of individuals and families is more fully understood in the ecological perspective summarized in the notions of interdependence, cycling of resources, adaptation, and succession (Heller, Price, Reinharz, Riger, & Wandersman, 1984). The notion of interdependence suggests that elements of the macro- and micro-level systems influence one another and cycle various resources in and out of the overall system. Adaptations occur then as individuals and families both repeat patterns of interaction and develop new patterns within the successive contexts of the community.

To understand the links between micro-level and macro-level environments of the ecological model, Gallimore, Weisner, Kaufman, and Bernheimer (1989) suggested that parents construct "ecocultural niches". These niches are designed to link the family's values and goals through everyday routines to the broader culture. From their study of 102 semi-structured interviews with developmentally disabled persons and their families, these authors asserted that the "construction of the daily routine and its activity settings is mediated by central family themes that give meaning to parents' decisions concerning their daily routine" (p. 219). Thus families actively attempt to shape their world and counteract the forces which are imposed upon them by constructing various aspects of their daily activity settings: the people involved, values and goals, the nature of specific tasks and their rationale, and the "scripts" which prescribe patterns of interaction in the family (Gallimore et al., 1989).

To examine family patterns and culture from a constructionist perspective, Dunst, Trivette, and Deal (1988) provided an assessment and intervention model which captures three dimensions: needs and aspirations, family functioning style (i.e., strengths and capabilities), and social support and resources. A fourth component of their model, the nature of help giving behaviour, represents the repertoire of potential skills and techniques used by interventionists to facilitate an "optimal alignment" of the three interacting dimensions and strongly influence the family systems and culture.

One focus of the present research in the Support Clusters Project was to explore the linkages between various dimensions of family culture that are grounded in families' perceptions about their experiential life course and career. Although other distinctive themes and categories were expected to emerge and become central to the present study, the dimensions presented by Dunst and his colleagues were useful "tools" as a starting point to help organize the methodological approach. In the early stages of this work, however, it was equally true that these dimensions of assessment and intervention may have ultimately proved to be *not* very useful in the development of a grounded theory. To an extent this occurred as new themes did emerge and became integrated in new, innovative ways more reflective of the life situations in the context of the Support Clusters Project. Regardless, I have discussed the conceptual dimensions provided by Dunst and his colleagues below and expanded with relevant literary sources as these sources did help to build on my understanding of families and disability.

### *Family Needs and Aspirations*

In general, needs may represent the varying degrees of perceived difference between actual states and desired states, whereas aspirations may have a slightly different connotation involving ambition and achievement. Although aspirations may be thought of as a direct subset of particular needs as suggested by Dunst et al. (1988), aspirations may also reflect a broader vision of a family's future less restricted to the more mundane demands of daily routines. Traditional needs theorists have focused on understanding needs and aspirations as constructs oriented toward individuals that are ubiquitous to the human condition. For example, Maslow (1954) proposed a hierarchy of needs that motivate individuals to change their living conditions through various stages ranging from basic physiological needs through esteem needs, among others, to self-fulfilment or self-actualization. However, more recently, the construct "needs" is recognized as a highly personalized and environmental phenomenon that must be identified and prioritized from the family's perspective (Dunst et al., 1988). This orientation attempts to understand the complex and multi-faceted linkages between needs, aspirations, and motivation as a process of personal empowerment that is both an individual and an environmental or institutional phenomenon, rather than a personality characteristic (e.g., Rappaport, 1981; 1987).

The concept of "environmental press" discussed by Dunst and his colleagues (1988) seeks to recognize a family's perceived needs as a product of complex environmental forces, associated with an ecological model. For example, Singer and Irvin (1991) listed the following structural and functional needs of caregiving families of persons with developmental disabilities, chronic mental illness, and traumatic brain injury: respite care, financial assistance and in-home care-giver support, social support, and counselling in conjunction with education and learning opportunities in adaptive coping skills. The perception of such pervasive "environmental press" has important implications for families participation in various human services programs and the success of such interventions (Dunst et al., 1988).

Although many studies approach dynamics of the family system (e.g., crisis and coping) from a deficit-oriented model examining the negative impact of either mental illness or developmental disability, a more recent trend is to examine the strengths such families display. In a recent qualitative study, Todis and Singer (1991) investigated the perceptions of parents who adopted several children with multiple handicaps. Among parents, these authors found quite different perceptions of typically stressful events (e.g., medical interventions) as opportunities to "demonstrate mastery". However, the ability to maintain such positive appraisals was strongly linked to strong intrafamilial resources and community supports (Todis & Singer, 1991).

It seems probable that many of the quantitative focused research projects that have attempted to understand family needs and aspirations as "family deficits" have found such families experience a host of stress-related events suggestive of maladaption and dysfunction. It is equally true that such methods of inquiry, their inherent assumptions, and fragmented examination of component parts of family life will over time build an impressive body of literature that "solidifies" researchers' perceptions and approaches to working with such families. However, as Gottlieb (1985) eloquently stated, "there is no evidence that any life events are disease specific in the same way that exposure to a certain type of virus leads to a certain type of flu" (p. 10). Clearly, the construction of family needs and aspirations should be approached from a more neutral set of assumptions, if not a positive orientation, aimed at understanding the family in a holistic way.

### *Family Functioning Styles*

The functioning styles of both "normative" families and families experiencing crisis have been strong areas of interest to researchers over the last several decades. Dunst et al. (1988) proposed that functioning style may be defined as an aggregate of unique ways of dealing with life events that are likely to be employed in response to particular life events to promote growth and development. Other researchers have attempted to understand functioning as a composite of the family environment overall. For example, the Family Environment Scale (FES) provided by Moos and Moos (1981) assesses three social domains of the family (relationships, personal growth, and system maintenance) and includes 10 subscales related to functioning (e.g., cohesion, conflict, and organization). Recent work by Dyson (1991) with the FES showed that functioning in families with children who experienced developmental disabilities was not rated as significantly different from "normal" families with the exception of three subscales: achievement, moral-religious emphasis, and control. However, her work showed that families of children with disabilities rated higher on these dimensions suggesting family stress is not synonymous with dysfunction but more congruent with a competence model of functioning. She thus concluded that more individualized programs that build on family strengths are needed, yet surprisingly concluded that intervention should be focused on "fixing" the child (e.g., increasing competence) and "changing parental perception."

Consistent with a phenomenological approach, McCubbin and Patterson (1983) suggested that the family's subjective definition of a particular stressor is a critical feature in building understanding of the resilience of families. According to these authors, family crisis is considered:

> As distinct from stress, which is a demand-capability imbalance, crisis is characterized by the family's inability to restore stability and by the continuous pressure to make changes in the family structure and patterns of interaction. (p. 10)

Thus the family's meanings, as reflective of values and past experiences in dealing with change and meeting crises (McCubbin & Patterson, 1983), are critical to sensitize other members of the community, including researchers, to varying styles and processes of family functioning.

McCubbin and Patterson (1983) utilized the Double ABCX model of families' stress and distress processes (i.e., positive and negative attributions of stressors, respectively) to understand the continuum of adaptive and maladaptive family responses which preempt or lead into cyclical family crises. The ABCX model presented by Hill (1949, 1958) depicts the development of "X" - the family crisis, over time as the "pre-crisis" interaction of "A" - the stressor, "B" - the family's resources and "C" - the family's perception and meanings attached to their life circumstance. In the Double ABCX model, McCubbin and Patterson (1983) link the pre-crisis, or crisis development phase, to a two stage post-crisis phase, the family adjustment and adaptation response (FAAR).

The family adjustment phase of the post-crisis shows that demands and hardships associated with crises "pile-up" on the family, and then, potential coping strategies are utilized (e.g., avoidance, elimination, and assimilation - efforts to accept and accommodate the demands of the crisis into the family system). These strategies, based on families' perceptions of new and existing resources as well as the pre-crisis process overall, are focused on adjusting roles and patterns of family interaction. According to the FAAR model, these adjustment efforts determine the family's position along a "bonadjustment -

maladjustment" continuum. These efforts are likely to encounter resistance from a variety of sources to varying degrees, however.

In the adaptation phase, families go beyond issues of resistance to focus on two levels of crisis accommodation: restructuring and consolidation. There are four factors associated with the restructuring phase aimed at second-order or systemic change: an awareness that something needs to change, efforts to develop a shared definition of the problem, a search for agreement on solutions and methods of implementation, and finally, an adaptive coping strategy that attempts to maintain the integrity of the family system and its members. In the second level of accommodation, consolidation, the family moves toward a "shared family life orientation and meaning" that provides a sense of legitimacy for the family as they engage their community.

Thus, restructuring and accommodation together influence the intra-familial "fit" between each of its members and the family system overall, as well as the "fit" between the family and the external community. However, this seemingly linear progression (i.e., crisis -> adjustment -> restructuring -> consolidation) does not lead the family system to point of stasis, but rather a second continuum ranging from bonadaptation to maladaptation. Under conditions perceived as maladaptive, families may perpetually revisit crises. Given such cycles of family crisis, families may demonstrate the resilience to repeatedly orchestrate efforts to restructure and consolidate. Alternatively, the family may experience exhaustion and potentially dissolution. It is important to note, however, that stress may never reach crisis proportions and that social support is the critical mediator which provides the family system with more resistance to major crises and a more adaptive predisposition to recover from crises when they occur (McCubbin & Patterson, 1983).

The Circumplex Model of family systems, provided by Olson (1988), attempts to capture three important dimensions of a family systems profile: cohesion, adaptability, and communication. Cohesion is a concept referring to the degree of affiliation between the members of the system and optimally demonstrates an ability to balance both a degree of individuality and a sense of group belongingness. In the Circumplex Model, cohesion ranges along four main points of a continuum from disengaged (i.e., complete noninvolvement) to enmeshed (i.e., over-involved to the extent that individuality is lost). Adaptability is the extent to which the patterns of interaction in the family system are flexible and demonstrate the ability to change. Adaptability also has four main points along a continuum ranging from chaotic to rigid. Communication is considered the mediating dimension in the model which influences the negotiation strategies for adjustment along the continuums of adaptability and cohesion. For a further review of family stress and coping, Singer and Irvin (1991) provided an extensive overview and integration of research.

### *Social Support and Resources*

According to Gottlieb (1985), the measurement of social support has largely occurred under three broad areas of inquiry: social integration/participation, structure and function of social networks, and intimate social relationships. At the broad, macrolevel of social integration/participation, research has focused on understanding people's involvement with institutional settings, voluntary associations, and informal participation at the community level. The value of investigating such aspects of social integration is the hypotheses offered about how to construct optimal social environments (Gottlieb, 1985), and the recognition that social realities constructed by individuals are embedded within, and influenced by, a larger cultural context.

The second area of research is concerned with components of social network analysis such as the structure and supportive functions of informal and formal networks of support. Here researchers are interested in the ways in which an "individual's personal community of associates" become adaptive or maladaptive and the effects that patterns of interaction may have on individual growth and wellness (Gottlieb, 1985). Finally, the domain of intimate relationships in the social support literature has focused on qualities of social relationships such as "affective potency" and provision of emotional support. Gottlieb (1985) asserted that "the character and strength of the respondent's most profound social ties" is the critical variable in understanding an individual's level of wellness and resilience.

Within the model provided by Dunst and his colleagues (1988), social support may be broken down into five domains or categories of support: relational, structural, functional, support satisfaction, and constitutional. Relational supports are those social relationships such as marital and employment status which represent the potential availability of support from an informal network. Structural supports are those dimensions of social networks traditionally researched from a quantitative perspective, for example, network size, density, and reciprocity of help giving and receiving. Functional support refers not only to the quantity and quality of assistance available but also the process of how such help is accessed and utilized.

Trute and Hauch (1988) investigated social network and family attributes, similar to those outlined briefly above, in a sample of 36 families who had adjusted well to the birth of a developmentally disabled child, as assessed independently by pediatricians and a social worker. There is little evidence concerning which aspects of social support facilitate a family's adjustment to the birth of a child with complex needs (Trute & Hauch, 1988), and by plausible extension, patterns of family life thereafter. Their exploratory analyses indicated that "successful" families typically had few persons in their support networks, yet these individuals were abundant in their provision of support. The authors attributed this finding in part to the isolation of parents in such situations and the multi-dimensionality of support from family members. Further, these authors believed that a feature of successful families was selective density in the family network and maintenance of a "loose constellation of ties" with networks of friends. It may be that low density networks of friends may be associated with more novel information and advice helpful to families (Trute & Hauch, 1988). This "strength of weak ties" contrasts with previous research by Kazak and Wilcox (1984) which demonstrated that such family networks were typically very dense. Clarifying these seemingly disparate findings for this research context was one potential outcome of the present work with families.

Constitutional support refers to the degree of fit or match between the desired help and the availability of specific types of support. Dunst and his colleagues (1988) suggested that the degree of congruence is a significant mediator in establishing positive patterns of family style and functioning, thus emphasizing the complex contextual nature of the links between help giving and help receiving. Support satisfaction is the subjective evaluation of the degree to which assistance is perceived as helpful, again typically assessed within quantitative/clinical paradigms. Recent work by Frey, Greenberg, and Fewell (1989) suggests that mothers and fathers vary on the aspects of social support associated with satisfaction and adjustment. In their study, fathers' adjustment was higher when criticism in the network was low, yet unrelated to the actual amount of support. On the other hand, mothers' adjustment was just the opposite: higher given more support, yet unrelated to the amount of criticism. Constitutional support in conjunction with support satisfaction from a qualitative form of inquiry then, are important concepts that emerged in the present work. Understanding families' positive and negative experiences and perceptions of social support (e.g., the specific areas which are perceived as helpful and harmful, see Dakoff & Taylor, 1990) may greatly enhance our understanding of the linkages between families' needs and aspirations and functioning style. Perhaps more importantly, such findings are directly applicable to enhancing our sensitivity and awareness when conducting assessments and interventions from an enabling and empowering perspective.

Families' culture of social support and resources may be investigated along two dimensions: informal and formal support networks. Informal supports are individuals in a social network such as family members, extended family and other relatives, friends, and neighbours whereas formal support networks primarily consist of employed professionals such as case management workers, psychiatrists, and other mental health professionals. Research on building and mobilizing informal family support networks conducted by Dunst, Trivette, Gordon, and Pletcher (1989) has supported the principles of constructive participation. Through a community action-based project, Source of Help Received and Exchange (SHARE), these authors investigated how to facilitate networks among families with a challenged member under low, middle and high economic status conditions. The goal of the project was to promote interdependent and self-sustaining networks. The results indicated that all families, regardless of economic status, benefited from reciprocal exchange of resources. Also, to expand networks for all types of families, resources should be identified, mobilized, and controlled by the family. Consistent with the significance of reciprocity in helping relationships supported by Riessman (1990), Dunst and his colleagues concluded that professionals should adopt a facilitative role in assisting families as partners. Families and professionals can work together to access and exchange resources and thereby build capacities and an enhanced sense of mutual giving and receiving.

To create the partnerships suggested by this literature on building family strengths and capacities, a necessary first step is to listen and understand families' stories. In the next chapter, I have outlined the purpose of this research, the assumptions that were important to frame the work, as well as the approach and research relationship.

# *CHAPTER 4*

# *PURPOSE OF THE RESEARCH: ASSUMPTIONS, APPROACH, AND RELATIONSHIPS*

## *Purpose and Objective of the Research*

The purpose of this research was to describe the meanings of the life experience and culture of families in the Support Clusters Project. More specifically, the research was motivated by a desire to clarify and express the unique perceptions of families' personal meanings of lived experience over the process of the family life cycle or "career". A primary objective of this research, then, was to create the understanding necessary to support families' control in such life situations and thereby increase awareness in the community. Thus, families' stories of success and struggle were the key ingredient for grounding this research in the resilience of families coping in the culture.

## *Assumptions of the Research*

Gergen (1985) proposed that the social constructionist movement - toward understanding knowledge as a process of social exchange - was emerging in modern psychology. Therefore, as Gergen encouraged, inquiry in human relations should be focused on discovering the processes by which people describe, explain, and account for the world. A number of assumptions are thus inherent in such a research paradigm. For example, Gergen asserted that peoples' perceptions of the world, and hence understanding, are "social artifacts" integral to historical and cultural relationships relevant to a particular context during specific time periods. Therefore, the "longevity of an understanding" is dependent on social processes such as negotiation within a context (i.e., the development of a shared understanding), rather than traditional research criteria such as validity (Gergen, 1985). Given a new orientation and set of assumptions about human social relations, an alternative methodology to traditional scientific methods was needed. This alternative methodology found roots in the fields of anthropology and sociology.

Lincoln and Guba (1985) provided a naturalistic method of inquiry to understand social constructions. The axioms of a naturalistic paradigm include:

> * Realities are multiple, constructed, and holistic.
> * Knower and known are interactive, inseparable.
> * Only time- and context-bound working hypotheses (idiographic statements) are possible.
> * All entities are in a state of mutual simultaneous shaping, so that it is impossible to distinguish causes from effects.
> * Inquiry is value-bound. (Lincoln & Guba, 1985, p. 37)

These assumptions contrast the assumptions of positivistic inquiry which maintain "objectivity" is both desirable and attainable. The focus on the process of social exchange and the transactional nature of the inquiry are important concepts to grasp, to effectively study how personal meanings develop and in fact are "negotiated" (Lincoln & Guba, 1989) within social contexts.

Assumptions are inherent in all research contexts, for example, those outlined above for a naturalistic paradigm. The particular assumptions of the research context will form a crucial foundation upon which the decision-making processes concerning methodological tools and techniques, sources and types of data, analysis procedures, and conclusions are based. The following assumptions were adapted from a variety of my experiences and readings in the Community Psychology programme and at the Centre for Research and Education. These assumptions provided the core guides for the present work:

**(1)** *The study of human relations is grounded in a relativist, social construction paradigm in which different levels of meaning exist within and between particular contexts.* Consequently, the research process and instruments (e.g., in-depth interview and observations) must reflect the interpersonal nature of the inquiry and must be rooted in participants' everyday conceptions of their life experience.

**(2)** *Understanding the personal meanings of lived experience through qualitative, phenomenological inquiry is an effective tool for engaging persons in constructive social change.* Thus, the study of process issues is extremely important to develop a theory of action and for understanding complex, multiple patterns. Along with prolonged engagement, a process of ongoing feedback to both participants and researchers is a critical mechanism to adapt and ground the research process to establish robust, trustworthy data.

### *The Research Approach*

The approach used in phenomenological research is to study "lived experience" through thoughtful description that captures the essence of experience and leads to insight and understanding of personal meanings (van Manen, 1990). Thus, "the task of phenomenological research is to construct a possible interpretation of the nature of a certain human experience" (p. 41), for example, the personal meanings of families' experience with "dual diagnosis". Over time, lived experiences gather hermeneutic or interpretive significance (van Manen, 1990). That is, as individuals, we construct frames of reference based on the meaning of particular life experiences. These meanings then act as cumulative layers of a more complex "lens" through which we interpret events in our world.

Thus, human science research involves both phenomenology and hermeneutics in the process of discovery.

> Phenomenology because it is the descriptive study of lived experience (phenomena) in the attempt to enrich lived experience by mining its meaning; hermeneutics because it is the interpretive study of the expressions and objectifications (texts) of lived experience in the attempt to determine the meaning embodied in them (van Manen, 1990, p. 38).

To return to the analogy, phenomenological research then is twofold; it involves gaining insight into the meanings of life experience as viewed through the "lens", and also the process of how the layers of past experiences and their attached meanings came to construct the lens.

As a qualitative phenomenological study, I have conducted this research within the *Grounded Theory* framework outlined by Strauss and Corbin (1990). These authors suggested that a holistic theory of life meanings may be "inductively derived from the study of the phenomenon it represents" (p. 23). Research questions within a grounded framework are typically oriented toward action and process with the main goal of discovering relevant categories and relationships among them (Strauss & Corbin, 1990). As categories and relationships emerge, they are provisionally tested with a focus on utilization. Creative discovery, then, is the key process that draws together the raw data, analysis, and theory as interdependent components of the investigative process. Thus, within reasonable parameters established in the research context, a conceptually dense, well-grounded and integrated theory is constructed (Strauss & Corbin, 1990).

### *The Research Relationship*

Consistent with the importance of the relationship between the researcher and participants proposed by Lincoln and Guba (1985), I have outlined my entry to the setting, how I worked while I was there, and the process through which I remained in the setting well beyond the parameters of this thesis.

### *Entry to the Setting*

As I outlined in the introductory section, in late September, 1990, I approached the Centre for Research and Education in Human Services to work on the Support Clusters project to complete a partial requirement of the practicuum course in the Community Psychology programme at Wilfrid Laurier University. I was very interested in the project for several reasons: I had previous interest and experience working with children with complex disabilities; I had a very strong interest in working with and understanding families; and finally, I believed it was also very important to work with a project in its very early stages and learn about developing an evaluation suited to an innovative intervention. I became involved as a member of the evaluation team with the intention of completing the practicuum requirement in April, 1991; however, by the winter months of 1991 (February/March) I was already engaged in discussions with the Centre Co-ordinator concerning how I might stay connected with the project. These discussions led to an agreement that I would work part-time on the project evaluation over the summer months and develop a thesis proposal to do more in-depth work with families than possible under the more formal evaluation. This agreement led to a proposal to the steering committee to do thesis work based on the evaluation activities already built-in to the project (see Appendix A).

### *Consent*

As a 30-month demonstration project, the initial proposal for funding the Support Clusters included a built-in research component. Thus participation in the evaluation of the project was conceived as part of the design of the intervention itself; however, this meant that the development and use of rigorous ethical guidelines and practices required careful consideration. In general, the role of project staff included introducing the project to potential participants and explaining its various dimensions, while the evaluation team role of gaining voluntary informed consent proceeded once participants entered the project (see Appendix A).

### *Feedback to Participants*

As part of an action-research design, feedback was conceptualized as an ongoing component of the research process. As outlined in Chapter 5 on methodology, participants had access to both transcripts of interviews and summaries which I wrote as part of the initial stages of analysis. Participants also received feedback, and revised a summary of their shared experiences discussed in meetings of the Parents, Family, and Friends Support Group, described in greater detail in the methodology section. As part of the final feedback process, I presented the findings of this study to the both a General Support Cluster meeting and the project Steering Committee. Copies of the report were also made available to participants who were not in attendance.

### *Remaining in the Setting*

During the period that this thesis was being completed, I was able to develop a full-time research position working at the Centre for Research and Education. Consequently, I worked on a number of projects, including the Support Clusters project which at the time of completion of this thesis was entering its final stages as a demonstration project. In addition, I was able to carry the valuable experience gained in this work into a new evaluation project, jointly sponsored by the Ministry of Community and Social Services and the Ministry of Health called the "Dual Diagnosis Initiative", funding a number of demonstration projects province-wide. The effect of these developments was that I was able to remain connected to the project participants, staff, steering committee and future of the project.

### *Understanding Personal Influence and Growth*

Given that the phenomenological process is a highly personal means for developing a grounded theory, it is my thoughts and my self which becomes the essence of the theory of "lived experience". Then, as Cull-Wilby (1990) has written:

> It is in the writing that I attempt to bring others through the process I have travelled... It brings me to the point of appreciating what it means to be human... Because it is mine, it is truth; truth as I understand it. (pp. 6-7)

To capture the essence of my journey in this research process, and how that may impact on the developing theory, I have recorded several belief statements in a previous section that have guided this work. I have included my reflections with the theory as appropriate and written a final chapter reflecting on this research process.

In the next section on methodology, I have outlined various aspects of how I attempted to achieve the main purpose of this research. Specifically then, I have outlined my attempt to describe and create an understanding of the meaning of family life experiences related to multiple, complex disabilities. The following section includes discussion on who was involved in the research process; the issues involved in designing an approach to the study; and, the specifics of the methods used and their analysis. These procedures are linked with sources of literature that helped develop my understanding of qualitative research in both contextual and substantive ways.

# *CHAPTER 5*

# *METHODOLOGY*

## *Participants*

The participants in this research were all involved in the Support Clusters Project. In the family interviews, a total of eight mothers, four fathers, and three sisters from different families participated. There were five male and three female individuals, ranging in age from 15 to 31 (the average was about 22 years-of-age), with a dual diagnosis label in these families. Only one person with such a label attended the actual interview. Through the broader Support Clusters Project activities and evaluation, I have personally met all but two of these individuals, several of them on many different occasions.

## *Sources of Data*

As I have outlined, my role as a phenomenological researcher in this project was important to recognize. I had been connected with some of these individuals and families for over a period of 20 months at the time of writing this document. Beyond this thesis project, I was also a member of the evaluation team continuing to work with the participants, staff and steering committee till the completion of the 30-month Support Clusters Project.

This qualitative thesis research utilized three principal sources of data.

(1) As part of the Support Clusters Project, members of the evaluation team conducted in-depth qualitative interviews (see Patton, 1990) with families in which one member has received a dual diagnosis label. In the present analysis, I have included eight interviews with families (see Appendix B for interview guide). I was involved in six of the interviews and other team members completed the other two. These interviews ranged in length from two hours to three and one-half hours and were tape recorded and transcribed verbatim for an average length of 32 pages, single-spaced. These interviews were scheduled at a time and place of the participants' choosing. All chose to be interviewed in their own homes, typically during the afternoon or early evening. Each participant received a copy of his or her interview and a summary that I had written.

(2) As a second source of data, I have read and summarized observational data from the meetings of two families' support clusters. I collected the data from one cluster while a different member of the evaluation team attended the meetings of the second cluster. These data span the length of the cluster's participation in the project for over a six-month period and are used in a secondary role outlined below. Project documents such as the

minutes recorded by project staff of these support cluster meetings were used to augment the observational data.

**(3)** As an extension of the project, families decided to form a "Parent Support Group". This additional "support cluster" was an important source of *observational data* and validation of the research, for example, through *focus group* techniques. I attended meetings of the parent support group collecting observational data. These data were then fed back to the members of the group for discussion. As we charted and recorded the discussion, a more precise and accurate reflection of their shared experience emerged (see Appendix C for the summary).

The relationship between these sources of data should be stated clearly. I have treated the in-depth interviews as *the primary source* of data. Further, I used the other data sources in a secondary role, analyzing them independently, and then used to confirm or disconfirm aspects of the grounded theory of family culture. The key criterion for making such judgments concerning analysis procedures was "saturation" of understanding key themes that emerge, within reasonable parameters for this project. To illustrate this secondary role, through involvement in the Parent Support Group sufficient data were collected to largely make the project documents analysis repetitive and unnecessary. However, through prolonged engagement in support cluster meetings, the observational data remained important to triangulate and ground the emerging theory, described further below. On an intuitive level, as I analyzed the data, my continued participation in the project and attendance at further cluster meetings, conducting many more interviews than included in this analysis, strengthened my confidence in the research findings and process.

### *Methodological Issues*

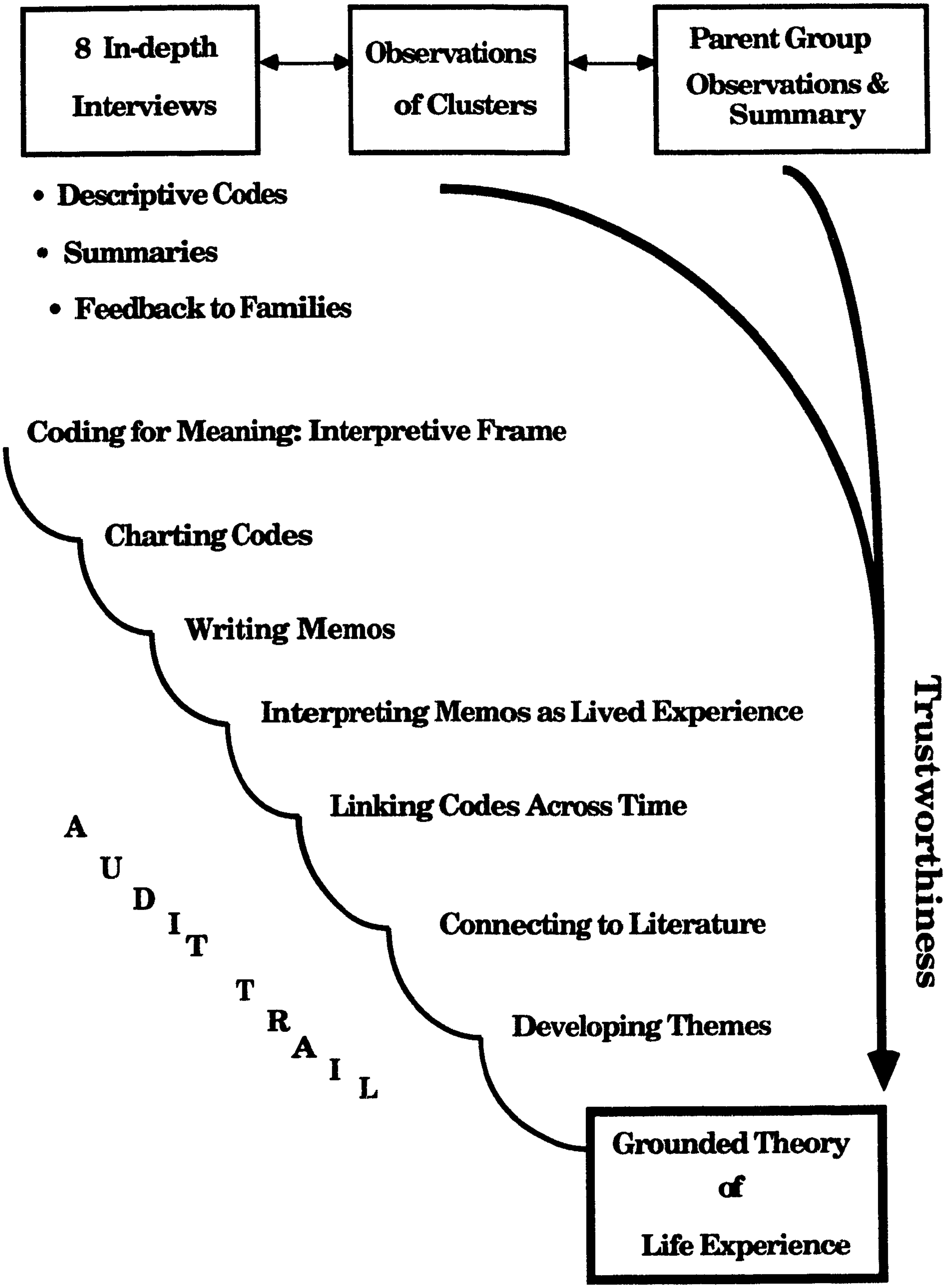
Lincoln and Guba (1985) have provided extensive discussion on four criteria for establishing the reputability or "trustworthiness" of data analysis and conclusions in qualitative inquiry process: dependability, credibility, transferability, and neutrality. In the naturalistic paradigm, dependability is a concept used to understand that although replicability is theoretically impossible, within any one research context the factors of instability can be managed. Lincoln and Guba outlined two methods for establishing dependability: fairness and accuracy. For example, they recommended an examination of both the account keeping process for "fair" representation of multiple perspectives and the final product for corroboration or "accuracy" of data entries.

Credibility refers to a process of representation for multiple realities and truths which then reflect a precise "truth value" to people in the context of inquiry (Lincoln & Guba, 1985). Credibility can be established in a variety of ways including prolonged engagement, persistent observation, and triangulation. Prolonged engagement refers to a process whereby the researcher is sufficiently immersed in the culture of the research context to build trust and detect distortions of truths in both her or himself and the respondents (Lincoln & Guba, 1985). In the present work with Support Clusters, I have been involved from the outset (October, 1990) and have witnessed three rounds of eight clusters as a member of the evaluation team. Persistent observation refers to a process of engaging and participating in the culture until the data are saturated with the atypicalities of the culture. As a member of the evaluation team, others and I have attended the meetings of several support clusters from the initial meeting to their conclusion, in addition to more periodic contact with all clusters.

Triangulation is the process of comparing and asking questions about various sources of information, different methods used in investigation, and perceptions of other researchers. The purpose of triangulating sources, methods, and researchers is that more enduring "truths" and greater faith in them will emerge by examining a number of different constructions from a number of different perspectives. Other methods of establishing credibility such as peer debriefing and negative case analysis are discussed further by these authors. Several key elements of triangulation in this research process included: membership on the evaluation team at the Centre; my ongoing contact with an advisor and a committee member; and, the use of multiple methods such as in-depth interviews, observations, and group dialogue (see Figure 1).

*Figure 1*

*Immersion and Analysis Process*



The applicability of research findings in other contexts or transferability is dependent on the degree of similarity between the "sending and receiving" contexts (Lincoln & Guba, 1985). The researcher is required to provide a "thick" and rich description of the time and context in which research occurs so that other researchers may examine the findings for transferability. The concept of neutrality recognizes that research is value-bound; neutrality is a characteristic of data that are confirmable, not a characteristic of the researcher, however (Lincoln & Guba, 1985). Thus, confirmability can be achieved by examining the "audit trail". This process involves tracking the raw data through its reduction and analysis to its reconstruction and synthesis (Lincoln & Guba, 1985). I have charted the process of an audit trail (see Figure 1 above) and included a more detailed description of this process below. A number of materials such as researchers' process notes, information on the development of instruments, and a systematic method of organizing codes are important elements to this process.

### *Data Analysis Procedure: Grounded Theory*

Two of the key procedural dimensions in conducting the open, axial, and selective coding involved in a grounded theory analysis are making comparisons and asking questions (Strauss & Corbin, 1990). In an open coding process, questions create labels or codes and then comparisons are judgments that determine the similarity or dissimilarity of the given labels. In previous work (Glaser & Strauss, 1967), this research process has been referred to as the "constant comparative method". Categories emerge from the labels and then are richly described and embellished to create more complete profiles of particular phenomena, for example, social support and resources. In turn, axial coding procedures take these profiles and create patterns or connections between categories and subcategories. Finally, selective coding identifies the "story line" or themes around which other categories are related, formed into a coherent package, and then validated against the data. Thus the process may be considered cyclical as the raw data, typically from several interviews, are broken down into fragments by asking questions, then compared and pieced together into a new, integrated whole.

### *Analysis Procedure with Family Interviews*

Each of the family interviews was tape recorded and transcribed by members of the research team at the Centre for Research and Education in Human Services. As the principal researcher on this aspect of the overall project, I carefully listened to each interview while reading the transcription on the computer. Thus I was able to make any subtle changes in wording, punctuation, or spelling mistakes that are inevitable when transcribing approximately 20 hours of discussion, often in groups. I was greatly impressed with the ability of my friend and co-worker who completed the primary work on this task. I formatted the transcripts to have about a three-inch margin and printed single spaced hard copies that identified each passage of discourse by the first initial of each participant. Each transcript received an anonymous code (e.g., Y5) to protect confidentiality and for the purpose of setting up an audit trail. Copies of these transcripts were made available to all participants.

I then carefully read through each transcript and wrote notes in the expanded margins on parts of the text which I believed to be important descriptive phrases (e.g., "in vivo" codes). I also wrote simple paraphrases and marked quotations that I believed were significant in the family's experience. Directly upon completing that procedure for each interview, I read over the marginal notes and wrote a summary of those key descriptive codes attempting to capture the essence or "snapshot" of their story of family life history, including direct quotes (see Figure 1). These summaries did not identify the names of parents, siblings or family last name, ranged from four to seven pages in length, were single spaced, and made available to each of the participants.

After careful consideration and consultation with my advisor and a committee member on how to proceed (i.e., I was lost - immersed - even drowning in data), I decided to divide the next phase of analysis by time periods in the family life cycle which seemed to be marked by critical transitions. These transitions, such as moving into the school system in childhood and then later into early adolescence, for example, are roughly consistent with the lifespan developmental psychology literature and the framework for viewing the family used by Carter and McGoldrick (1988). These authors focused on life cycle transitions as points in time where second-order changes occur in the family system. Then, reading across family interviews, I explored families' shared experiences and their differences through each of the five phases over time. The tracking procedure for establishing an audit trail became crucial at this point.

For each of the five phases, I read the summaries and sections of transcripts to create a "big picture" of what was happening and families' perceptions. I then mapped out this "big picture" in a form similar to a flow diagram or chart. Then, I went back into the transcripts and pulled out specific codes and charted them in a code book with transcript identification and page numbers under various topic headings, such as "early experiences of family life with a new child," for example. Thus, I could at any point in the code book return to the specific transcript and page number, the foundation for an audit trail. Once these codes were charted, I looked across the transcripts attempting to discover similarities and differences.

Codes that emerged as very similar or distinctive across the families were written into memos. Memos were written as more fully developed passages that introduced particular family experiences in greater depth providing quotations from interviews, and their references. Memos often began by specifying the number of families and the specific transcript numbers for referral back to the code book, and thus the transcript, and then as discussion of a code developed, linkages were established with sources of confirming literature. For each topic area, such as "early experiences of family life with a new child" above, I also outlined my impressions of the meaning of families' lived experience. These more interpretive sections were later drawn together into a summary and linked to sources of literature for each the five phases used to describe the family life cycle.

In each of Chapters 6 through 10, I have begun with a short family story for that time period based on the summaries I wrote from in-depth interviews. By leading each chapter with a snapshot of a person's "family story," I have intended to emphasize family members' viewpoints so that you as a reader remember the most important "voices" in this document. In each chapter, I then examined family perceptions of family life with the person and their interactions with formal support services and their relationships with informal supporters. At the end of each chapter, I have written a summary of key developments in the family and drawn connections to the literature. In particular, I have attempted to link models of family stress and coping from the literature into this research context. Again, after some consultation with committee members, I believed this format would bring clarity to the writing and effectively link families' experiences across the life cycle.

In Chapter 6 and 7, I have presented issues of family history in "The Early Years," and "The Childhood Years," respectively. In Chapter 8, family stories of life with a teenager mark the transition from childhood in search of an adult life. In Chapter 9 and Chapter 10, respectively, I deal with issues of struggling to make the transition into young adulthood in this cultural context and then as family members, their thoughts looking to the future. In Chapter 11, I have written about themes across the family life cycle. Finally, in Chapter 12, I have offered personal insights toward the meaning of families' experiences and evaluated my main objective in this research process.

Please note that all quotations in the chapters below do *not* contain the names of people involved in this study. For their privacy, the names I have chosen bear no resemblance to the participants, and any recognition by you as a reader is purely coincidental, or more likely, based on a shared life experience.

# *CHAPTER 6*

# *THE EARLY YEARS*

"The Early Years", as I have called the initial phase of this exploration of family history, relates families' very early memories of the birth of new child in the family and the first few years of family life thereafter. In general, this section covers the time period ranging from birth to approximately age five. Given the average age of the individuals in this study, the following discussion refers to the time period of the late 1960s and early 1970s.

## *Margaret and Her Family in the Early Years*

*Margaret was born into a middle class Canadian family environment. There was little cause for concern when Margaret was born, but over the first year of her life mom and dad became increasingly concerned about her slow development. At 11 months of age, Margaret received her first diagnosis and was labelled as a person with organic brain damage. Given a gloomy forecast for her potential development, the family began a long career with professional services with a lot of hope that answers and solutions could be found.*

*At an approximate age of 18 months, the family's first experience with an agency assessment began with an invasion of their privacy by a group of people who were never introduced; this ended with a rejection from the service. Until about 2-years-of-age, the family used a physical habilitation method to build Margaret's basic physical movements of her arms and legs as well as systematically introduce sounds, shapes, and colours. A crawl box was also used regularly to help Margaret with coordination of gross motor tasks and mom explains, "I crawled a lot of miles, because I had to go beside her." In fact, the family was tied into a routine where the entire dining room was set up for habilitation. Just past the age of 3, when Margaret was walking and able to speak a few words, several behavioral problems emerged as "Margaret had a very, very tiny attention span, and was very, very active and on the go all the time." These were days without breaks as Margaret had trouble sleeping and needed a strict routine to keep from becoming extremely upset.*

*At the age of 4, these problems were exacerbated when Margaret's mother became ill. Given there was no respite available in the community, the family was forced to separate for the first time with mom in the hospital and Margaret living with an older couple the family had met through a local agency. This forced Margaret's sister to grow up quickly - "she was a little adult" with lists of responsibilities and places to go. The pattern of family separation continued with two institutional placements into the Children's Psychiatric Research Institute (CPRI) for several weeks at a time which "wasn't a very pleasant way to get a break. It was a desperation move."*

# EARLY EXPERIENCES OF FAMILY LIFE WITH A NEW CHILD

## A Beautiful, Happy Child

Most of the parents' first memories of family life involved very positive characteristics of their new child. They recalled the brightness and beauty in their child. For example, one mom remembered "I don't think there is a picture in the house where he isn't smiling... He had a laugh that was infectious - once he started, everybody had to laugh." Another mom also recalled her son as a "really loving child, really affectionate."

## An Active Child

Many parents described their child as very active or busy while others recalled a more passive detached disposition. One mom recalled "He wasn't just a busy toddler - he was going all day and all night." Another mom noted that "Because she was such an active child, it was really hard to ask her grandmother [for help]... those were days without breaks." In most of these families, this activity level involved mischievous actions, as the person was "faster than a speeding bullet" as well as demonstrating aggressive tendencies in one case. It also meant that barriers, such as locked doors, had to be used to prevent damage to other family members' property. As one sister thought about the early impact on family life she said, "I remember getting mad about that and you put locks on all the doors, on the outside, because if you left the door unlocked [she] would go in and destroy it - pull everything out."

## Social Detachment

Several parents stressed that their child was a loner or preferred a more detached observational role in the family right from the very beginning. These families recalled their child posed no special problems and was really never any bother. "He smiled a lot and would sit in a corner and rock and observe. He enjoyed observing people as opposed to being involved and that's always been with him," said one mother. Another mom recalled that "When she was young I had youngsters come in and play with her - try to play with her... But they didn't know what to do. They weren't used to a retarded child... she's always been a loner I think. She's always kept to herself."

## Delayed Development and Competence

Parents often mentioned there were noticeable "differences" in the development of their child. Mothers recalled that these delays often involved a lack of verbal language skills and poor gross motor coordination, for example walking. "Waiting for him to go through those first steps of doing things, including the crawling or the walking, or any of those things, or the first words, they did not happen - not like they did for other people."

Families described the frustration posed by these developmental delays. In two families, mothers experienced difficulty convincing their husbands there really were problems. One mom remarked that "we didn't know what was wrong with him, so the early years were frustrating waiting for him to develop."

In contrast, two families stressed their child demonstrated very early competencies in developmental tasks such as walking and talking at any early age, while a third saw competencies as well. As one parent explained, "If anything, you might have said he was quite bright at that point." Another mom suggested there were hidden talents which meant that you had to know her daughter because "she was never a talker... she never went into great sentences... and yet, she can speak two languages and understand two languages... she picked it up right away." Another mom also remembered that professionals didn't know her daughter's ability to say many of the words in her vocabulary and explained she understood all the expectations laid out for her. "One thing I've noticed... she always picks up on things, which has amazed a lot of people. She really does."

## Our Child Has a Label

All children received a diagnostic label early in life. Within the first year of family life, four children had received a diagnostic label, many of these labels involved brain damage. In three of these cases, the labels were established at the time of birth. The other four children were given diagnostic labels by age five, averaging just over three years-of-age, including cerebral palsy, autism and hyperactivity. None of these diagnostic labels was entirely accurate, and in some cases, according to parents and diagnostic assessments later in life, entirely wrong. Several families attached the timing of this labelling process to a critical event in the life cycle of the family.

## A Critical Event

All families pointed to an early experience that crystallized the need for their concern. These "events," although different in almost all cases, acted in a similar way as a reference or anchor point for families reflecting on their past. An anchor point is simply a life event around which people associate strong memories and emotions of love, anger, or relief, among others. Then later, these points in time mark transitions of great meaning and symbolic value. In many families, people reflected on the symbolic value of their early encounters with the medical community, seeking help with understanding "what's wrong" or dealing with specific problems such as seizure activity. In one family, the anchor point most dramatically involved issues with the school system.

In two families these early events involved abuse that exploited the vulnerabilty of their child. Tragically in one family, a father responded to his own frustration by physically abusing the child, which mom believed caused further withdrawal as well as brain damage. In this family the marriage was very unstable and full of conflict prior to the birth of their child. At the age of three, and with another newborn just arriving, the marriage broke down and ended in divorce. As mom explains, "It wasn't a good atmosphere in those days at all." In a second family, their child was sexually molested at an early age. He was "left with a concussion and that was when he withdrew even more and then he withdrew from us. Then he hardly ever smiled and he never laughed, and he never cried anyway."

# PARENTS' EARLY EXPERIENCES WITH PROFESSIONAL SERVICES

*"It was the era of thinking that somehow there was someone there who really had all the answers and who knew a lot more about [our child] than we did... everybody was an expert, except us."*

## Beginning a Constant Search for Answers - What's Wrong?

Most families recalled the beginning of an earnest search for answers from professionals. And as one mom suggested, she began this search "with a lot of hope... that we were really going to find something out." However, this search for answers was quickly transformed into a search for new labels and separation of the family.

## Searching for the Right Diagnosis

Families commonly described a very early process of trying to find some answers from professionals. This process involved "going from place to place" because doctors "keep referring you and keep referring you." One mother explained that "I kept plodding back to the hospital and the speech therapists and all these people and they just kept dealing with it - or me and him trying to cope with the situation, not knowing what was wrong."

## Early Separation of the Family

In two families, this constant search led to placement and assessment in a psychiatric ward. In one family the child, at four years of age, stayed for a three month separation; while in another, the child around three years of age, was in and out of the ward, in part because there was no other way for the family to get a much needed break. As one parent recalled "It sure wasn't a pleasant way to get a break. It was a desperation move. There was no pleasure in it. And she invariably came home sick." In a third family there was a great deal of pressure to institutionalize the child. "All those doctors and advice and everything... it was like 'institutionalize her' a lot of that kind of talk."

## "Fixing" The Child

*All eight families recalled attempts to "fix the child."* Six families recalled the therapy/teaching techniques recommended by professionals. Some of these focused on physical development; others focused on changing traits of personality. Two other families described the impact of early medication for their child. In one case the medication was used to create a routine; in the other case the wrong medication compounded the problems with side effects.

*In all eight families these attempts to "fix the child" had detrimental effects.* In three families, these interventions compounded the problems the children were experiencing. "They were trying to tell me he was just lazy. Anyway, that was probably the worst thing they could have done [because] when I tried to force the issue with him, he went into his shell and he wouldn't even try." Another parent recalled that the early attempts to teach him magnified his low self-esteem because there was no accommodation or recognition of his strengths. One mom recalled her daughter learned a disabled role. "As soon as we would pull up into that place [a therapy centre] she would start walking real funny... and that's what she would associate with that place.. and then she had this really bad limp and she could hardly move."

In the other five families, parents recalled that these interventions created or intensified their problems as a family unit. For example, these interventions created situations in which families had to rely on professionals, medication, a strict routine involving many people, and were told to not expect very much. Ultimately families were abandoned through the cracks of service delivery and shuffled to the next service very early in their experience with their child. One mom explained that "they [professionals] are wasting all that time looking for a prop... all these different things. So it was very, very frustrating. All those years - 10 years of that, going around and around."

## Struggling with the Hierarchy of Expertise

Along with the search for a proper diagnosis, families described in clear detail their experience with the hierarchy of expertise. "It was very, very frustrating because nobody was listening. Nobody wants to listen to the parents really... they're the experts and so they know. And that is their routine and they wouldn't bend." This perception of the treatment parents received seems to be common in these families' experiences as another mom explained, "They did different tests and things and they just kept telling me, 'He's slow. Leave him alone and he'll be fine. He'll come along'. But he was very slow and he didn't come along." Very early some parents recognized these problems in their relationships with medical professionals. One mom recalled the condescension "When I questioned him, it was like 'well accept the facts, deal with it.. the sooner you accept it, the better off you'll be.'"

Other parents needed time to reflect on the entire process for this meaning to develop. For example, doubting her self, one mom recalled a doctor saying,

> *"Take her home and give her lots of love." I can still remember that. It was so absolutely horrible. It was condescending, it wasn't what I expected... I guess I wouldn't accept that now, but at the time I just did what anybody told me to do. So that was a big disappointment to us.*

### The "Deficient" Family: "Everybody was an Expert, Except Us"

The forces that created feelings of personal inadequacy were described by two parents. As highlighted above, one mother clearly stated that, "It was the era of thinking that somehow there was someone there who really had all the answers and who knew a lot more about [our child] than we did... everybody was an expert, except us." Another mom described the pressure to segregate her daughter and "professionalize" their relationship.

> *I felt like she needed a segregated setting in a way... it was like "nobody can watch your kid because they have got to be a professional to do it." You have that feeling... and doctors promoted that a lot... that feeling of you can't do this and it's too much and she will never amount to anything... and you feel insecure....*

As this mother indiciated, there were strong links between the prescribed "fix" and the expectations held by professionals about the ability of families to handle the situation. This context of "help-giving" fed into negative perceptions of the person and his or her abilities as well as neglected to build on families' expertise.

### *Summary and Analysis of Family Experience in the Early Years*

Along with the joy of a newly arrived baby, the early family experiences with their child showed the seeds of emerging concern, and even tragedy. While families seemed genuinely happy with the birth of their child and recognized her or his positive characteristics, there was also a recognition of different sides to their experience. On the one hand, they remembered a very beautiful and in some ways competent child, yet on the other hand, parents showed concern for their child's social and physical development and clearly pointed to the beginning of behavioral problems as the person continued to grow over the first few years of life. Thus a "dichotomy of extremes" emerged in families' perception of their child. As highlighted by the Parent, Family and Friends Support Group, the inconsistency of the person's behaviour remained and even escalated as part of the families' struggle.

Very early in their lives together, families were faced with situations in which they had little potential to control and some of the children were victims of abuse. Coyne and Downey (1991) discussed various aspects of social environments in relation to the development of psychological disorders. In their review of research on sexual abuse and other forms of victimization, they briefly examined a number of studies which demonstrated the linkage between such abuse and the development of a variety of mental health problems. Several other literature reviews on abuse and people with disabilities, including Senn (1988) and the Advocacy Resource Centre for the Handicapped (1990), have pointed to extremely high prevalence rates of sexual and other forms of abuse experienced by people with disabilities.

In trying to cope with the uncertainty of what was "wrong with their child", many families misplaced their faith in solutions from a service system, external to the family. Thus families were faced with the stress of not knowing what was wrong and finding themselves unable to get answers and support from the system, lived in an atmosphere of ambiguity. Families were seeking help and instead found constant pressure to separate the family, which did occur in two families at this early stage, and pressure to segregate their child to obtain other specialized services.

In Hill's ABCX model (1949; 1958), the family crisis "X" was based on the pre-crisis interactions between the stressor - "A", the family's resources - "B", and their perceptions - "C". However, as demonstrated through these families' stories, the stressor was not a single event or form, but rather multiple. The "stressor" was both internal to the family (i.e., the dichotomy of the person's behaviour) and external to the family in the lack of practical aid received. Since the service system confirmed the child was the problem and then attempted to "fix-it", the family began to shape one layer of perception about the service system.

This "fixing" approach formed the basis of mistrust as family members had witnessed the inability of professionals to follow through on their explicit and often implied claims. Instead, each of the families saw the harm done to their child in the name of "treatment." Then, in addition to family members' negative relationships with professionals, the lack of perceived help and practical aid compounded families experience of the initial stress (i.e., the "A" in Hill's model) related to their new child. These events created the foundation for "family themes" or perceptions as noted by Gallimore et al. (1989) that may be carried by the family and applied in different contexts across time. For example, families started to clearly form a criterion which they applied with great scepticism and caution to professionals later in life: *"What are you going to do for my family?"* The families' resources at this early stage, however, were never addressed effectively or built into the response as Dunst and his colleagues (1988) asserted was necessary to develop effective coping strategies. Thus, families framework for understanding their experiences, "C" in Hill's model, for years to come was shaped by early and very negative forces of their social environment.

# *CHAPTER 7*

# *THE CHILDHOOD YEARS*

In many of the families there was a rapid increase in the level of stress as children reached the childhood years, roughly age 5 through age 12. The people in this study described many of their experiences as a family with a lack of resources to deal with the pressures associated with their children. In addition to these pressures, they were faced with stress typical of living in Canadian society that everyone encounters. As one mother said, "We didn't have any money. We were just like any other couple struggling along with little kids and trying to buy a house." However, in total during this time period, three marriages had ended in divorce. In two families, differences in methods of dealing with their child fed into the cycle of stress that ultimately ended in divorce. In a third family, marred by a poor marital relationship from the outset, this additional stress simply pushed their relationship over the edge. Many families which stayed together were aware of the pressure to divorce. One mother explained, "We've been luckier than most - some marriages crumble under the pressure and we've been very, very fortunate."

## *William and His Family in the Childhood Years*

*William was born into a middle-class Canadian family. As an infant William was very active, and then as a toddler he was formally diagnosed by professionals as hyperactive. However, as the family described the real problems started when William began school and was unable to conform to "typical" patterns of behaviour and the expectations created for that environment. These inabilities to conform took both academic and social forms involving poor concentration on tasks and very disruptive behaviour. William quickly became the focus of attention and well-known for the behaviours that resulted from his inability to conform. In fact, this focus has remained with William throughout his life. At age 6, William was admitted to the Children's Psychiatric Research Institute (CPRI) for psychological assessment and was dually diagnosed as mildly mentally retarded with "sensory interaction" problems.*

*However, the diagnosis did not seem to lead to solutions for the family struggles. The family had begun to feel isolated as others in the community found William and his behaviours intolerable. These perceptions ultimately led to William being objectified, "segregated and shipped home." Mom and dad were repeatedly told by many community organizations including the church, the school and Boy Scouts, "you'd better take him home... just get it out." Other friends and extended family members couldn't understand why mom and dad didn't just give him a good strapping to sort him out.*

*Looking back, mom and dad feel they should have questioned the "experts" stronger rather than having misplaced their faith in others who were "more educated" to make some of the key decisions. These so-called "expert solutions" weren't helping William and the family, only teaching him frustration, avoidance and withdrawal. In fact, he quite effectively learned to manipulate situations so that he could go home. In contrast, there were a few people who understood that William needed clear expectations and enough structure to develop respect in his personal relationships, rather than develop patterns of manipulation out of fear. This, however, required a commitment to William and the family, and acceptance of him as a person.*

# FAMILY MEMBERS' EXPERIENCES OF FAMILY LIFE

## Becoming the Centre of Attention

Almost all parents and siblings recalled their family member became the focal point of family life as everything seemed to revolve around her or him. This meant that siblings often did not get the attention they wanted. "And, it bothers him - but he feels deprived in life to a sense that I was paying attention to [his sister] a lot of times," one mother noted. A sibling recalled, "I just remember that [my brother] was always the centre of attention, so I never really had time to talk to anyone... When I was young I just always felt like I never got any attention."

## Siblings Denied a Childhood

In many families, siblings took on responsibilities and roles beyond their years. As stated clearly by one sibling, "I've been an adult all my life. I haven't really experienced a childhood." There were many adult roles adopted by siblings including protector and comforter. As one mom recalled, "Quite often she'd get in the middle - if he was getting into trouble with somebody... She would be the protector. She's sort of had to play that role quite often in her life, especially in the growing up years." Another mom recalled her daughter tried to compensate for the behaviour of her sister by being well-behaved to an extreme; however, her daughter remembered that "we didn't ever do anything as a family." Other families remembered doing everything together. In one family dialogue, mom began:

> *Then Colleen just stayed at home with dad and became a little adult - she was a little adult. She was a really responsible little girl. You must remember all that?*
>
> *[Colleen responded]*
>
> *Yes, I remember that. You used to write out little lists for me and then I'd do everything on the list and go different places for lunch and after school.*

## Lack of Informal Support: Turning Inward

Several parents remembered their struggle to ask for support from other people in their network. One mom recalled:

> *It was really hard to ask her grandmother who did live in town - but it was hard to ask for a lot of that [help] because she was busy. She had her own family, she had a part-time job. So as willing and as good as they were in many ways to try to help, it just wasn't something you could, in all fairness, ask.*

Other mothers recalled the lack of empathic support they received from close relatives and other supports. "Most of the time he didn't do anything wrong [and] when he was with them he was perfect. But they didn't live with all these other things that he did." Another mom echoed "It's just like normal kids, the parents have to go through so much with them, but once they're out, oh they're wonderful kids, 'Oh, you've got wonderful kids', and they're not, at home they give their parents a hard time."

The reaction of families to the lack of available support was one of turning inward and avoiding such "supporters."

> *We may have done an injustice and we may not have in the sense that we tried very hard to keep our problem very much right here inside our own little family unit right here. We've tried very hard not to put it on the rest of the family or on our friends.*

But Mom and dad also remembered arguing with friends about how to deal with their child and rejected their authoritarian advice:

> *Most of our friends have not been supportive basically. During those years saying, "well why don't you just give the guy a kick," you know "what's the matter with him", so we often had little arguments about how to deal with certain situations.*

## SEARCHING FOR A PLACE IN THE EDUCATIONAL SYSTEM: PARENTS' EXPERIENCES WITH A NEW BUREAUCRACY

### The Transition to School: A Real Problem

Several families highlighted that the transition to school was an anchor point where they recalled many problems starting. As one mom recalled "He was not a problem child for us. He started having difficulty when he started school - when he had to be more social." Another parent recalled the struggle to get her child involved - "I really used to struggle to get her there. I would get her on the bus and I would come in [the house] and just cry and say this is horrible."

## An Inability to Conform

Many of the families recalled their child was simply unable to conform to the expectations of the school environment. Abilities and behaviours that families had accommodated at home were no longer accepted as the child entered the competitive learning environment. Some of the children were unable to remain focused on tasks for a period of time, while others struggled with academic demands. "He just didn't really conform to what he should be doing in the class. He didn't want to sit - he couldn't sit and he couldn't seem to concentrate on one thing at a time. He was just wandering." These inabilities often resulted in educators telling parents that their child simply didn't "fit in" and they made it clear other "alternatives" would have to be pursued. As one parent recalled "Eventually it led to them phoning up and saying 'you'd better take him home'... It was like [the school was saying] 'this is a problem and we want it out of here.' I really didn't feel that they wouldn't want to cooperate if it was a good student. But it was like 'we don't need this problem just get it out'."

## Rejected and Segregated from Mainstream School

**All eight children were rejected and excluded from typical, mainstream school environments.** One family never even experienced an attempt to integrate their child in early educational years. It seemed clear from the beginning there would be no place for their child as she was kept in a segregated service system and then institutionalized.

Some children began in mainstream programs and attended special education classes and then later moved into total segregation, while for other parents there simply seemed to be no choice in making the decisions.

> *They sent him to a regular school but it was for mentally handicapped kids only - the whole school... And as I say, I really didn't think he belonged there but I had no choice in it - so he was to go there. There wasn't any integrated things then.*

In another case a mother explained that "He went to normal kindergarten school and they said he could not be in their program - [they said] he couldn't function there and that he would need to be in special education."

## Segregation Creates and Escalates Problems

Several families pointed to the school environment as contributing to and even creating the behaviour problems their child developed. Two families recalled how their child learned to manipulate people. One parent explained, "He was always segregated and shipped home, that's where he wanted to be anyway... [so] whenever he got in a situation he didn't like, he acted out and we got the phone call and he came home." Several other parents noted that their children were grouped with children who had behaviour problems. This environment was not seen as appropriate and later contributed to the onset of physical aggression in their children. As one mom explained, "And that was when they started sending me home letters saying that my son was 'an extreme behaviour problem' which was a brand new thing for us... [But] ever since then, that was when the violence started. I'm not necessarily blaming the school, maybe half. I think that it was also the frustration of his illness."

Six of the families noted that behaviour problems seemed to escalate during the childhood years. As one mom recalled, "when he was little [he went] from a very well-behaved child, perfectly well-behaved, as he got older the behaviour pattern kept changing and things kept getting worse. You could never predict what he was going to do." In another family, the unpredicatable behaviour became part of a pattern that fed into physical aggression against family members. Mom explained that:

> *At times it was really heartbreaking. I've been here when he's lashed out at me and I've had to hold him until he's under control. And I've sat and listened to him in bed at night where I've talked to him and sat beside him when he's cried his heart out and said "why did I do that? I didn't mean to hit you..." [He was] very confused not understanding why he did it.*

Several parents recalled how the idea of segregating their child didn't seem to fit at all. "I think back now, I don't really think that was the answer at all, to set them apart in a little spot all by themselves - it's not how they learn." Another mom suggested that the segregated setting offered too much stimulation for her child to learn.

## **"Integrated," Yet Segregated**

Several families recalled how early attempts to "integrate" their child in a segregated classroom in a public school failed. One dad recalled these attempts to "integrate" with disgust. "It's like a parade and then you get paraded back out again. You get paraded in front of the quote 'normal' kids. It's humiliating." In a second family, the child learned to manipulate the option of going back to the segregated class. "It was sort of disastrous when she had a [segregated] class to go to so she would just act out and go back and have the teacher herself... she knew, why should I go and sit with 40 kids when I can go and have a teacher and paint....she picks up on that very good." In another family's experience the teacher used to isolate their son. "They have a little room in the classroom - it's almost like a little closet room - where she would just separate him and put him there by himself so he wouldn't disrupt the class."

## Misplacing Faith in "Experts"

The trend from early years that "everybody was an expert, except us" continued for some families as family expertise was not recognized or supported. As one dad suggested, "Being as young as we were, we felt that 'Oh those people are educated and they know what's best. We'll go along with this'. We probably should have questioned it a lot stronger at the time." Mom echoed, "These were the educators. These are the people who know how to deal with these things so you often didn't question. I do today... but you didn't at the time because you thought 'they know what they have to do'."

# PARENTS' EXPERIENCES WITH PROFESSIONAL SERVICES

## The Constant Search for Answers

As in "The Early Years," many parents found themselves still searching for the right diagnosis well into childhood years and beyond. Two families actually obtained an accurate diagnosis, but then had the dream of "fixing" their child shattered. For example, one mom recalled that "When they identified the syndrome then all these things that had been happening and the picture we had all through his life up to that point all started to fit what was going on... but how do you deal with it?! We didn't know." One family struggled with intrusive assessments that didn't provide the help they wanted in the end.

> *All they do is ask a lot of very personal questions - nothing pertaining to the child... we had to take [his sisters] out of school to go to meetings and then the girls would sit around and nobody would talk to them... that was a lot of hustling for me and my husband to take off work without pay to go... and then in the long run we didn't get the help we wanted.*

## No Community Support: Mom's Stress Reaches a Peak

Two of the families were able to purchase live-in support to help with caring for the family, although this did pose a financial burden. Others reaching out for help remembered that "We went to [a psychiatric research institute] and things just seemed to go from bad to worse and it seemed like nobody in the school system really wanted to deal with him." Another mom felt she was close to a nervous breakdown and reached out for help; the help she received was her child placed in an institution which she explained did improve some of his problems. Another mom realized the depth of her anguish and frustration as she explained, "I slapped him and slapped him... I realized there was a serious problem here and that if I didn't get help something terrible was going to happen because now I couldn't control it... I was really out of control."

In the majority of families, mothers generally carried the burden of care for the child in addition to many other responsibilities and were feeling alone. In three divorced families, mothers did not receive support in dealing with their child. For example, one mom recalled that "[my husband] never wanted to believe that there was anything wrong... It was me who trudged all the years back and forth... and I felt like a one [wo]man band trying to get somewhere with it." One single mom, alone in her struggle experienced periodic breakdowns and voluntarily entered crisis clinics over these years using foster care to provide for her children.

## Forced to Separate the Child from the Family

Six families were forced to separate their child from the family during the childhood years. A seventh family experienced such profound pressure to separate and institutionalize their child that although the child remained out of an institution, the tension and disagreement between the parents ultimately fed into a divorce. Typical of the lack of support offered parents, one mother recalled:

> *One child care worker told us to give him up. My husband nearly strangled her... what she said [was] "If you can't manage him, you should give him up for adoption." Are you going to tell a parent, a person that, that they should just give their child up?! And my husband - he just stormed out because he was going to strangle her. You don't tell people that... And [our son] knows that. So that's why he's very frustrated when he goes to a meeting or whatever... And my husband is very aggressive too when he goes to those meetings because he's fed up, because he's tired of telling people the problem and nobody wants to do anything about it.*

## Moving to the Institution

During the childhood years, four families were forced to place their child in an institution. This time of separation was really hard on families as one mom explained:

> *We saw the residential setting and they really felt he could benefit from being there. That was probably a real wrench for us because he had never been away from home - everything we did, we did as a family... so that was kind of a tough time for us, a real separation time....*

Another mom recalled that:

> *We thought that she was going to get a lot of help with the behaviours that had become more intense... I don't think frankly that we were able to look at the bad things, I know I wasn't. Because sometimes when you're up against it, you say to yourself "Okay, now do we all go down the tube, or do we find something?" And the something probably saved the rest of us.*

These feelings of self-preservation were echoed by other parents who felt alone in their struggle and abandoned in the community. Others who were forced to separate had to contend with the blame others thrust on them. One mom explained that her ex-husband and his family "felt that I'd done the worst thing in the world... he felt that I'd given [our son] up. I hadn't given him up in my mind, I just didn't have him at home... [but] not once did they offer any help. I did all this myself."

## Children's Aid: The Foster Parent Alternative

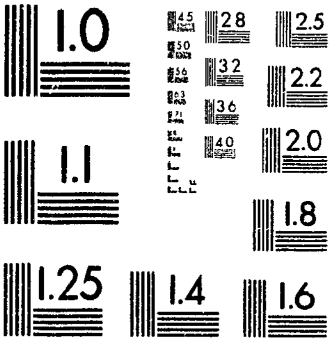
Two families chose to access foster parents through Children's Aid, in part that was one way to keep control and influence in their child's life. This also meant a lack of permanency in the child's and the parent's lives as one mom explained, "he'd wear out his welcome basically, and he ended up shuffled around a few foster homes [and then a group home]... It was never a permanent setting, it was only meant for a period of time."

## Creating New Community Alternatives

One family began to work with others on new community initiatives to change the system. This new activity brought them a new awareness of barriers to families making change and created new strengths.

> *We started working with these people and at the same time, we had gained some strength... We started to become more and more disenchanted with what we saw... because there's a lot of talk [from professionals] about how "we welcome parents to become involved" in institutions, but then when you are they don't know quite what to do with you.*

# 2 of/de 2



During this time community movements were beginning to become established and professionals were beginning to recognize the critical role of informal supports in the life of people with disabilities. However, a variety of means to effectively include the family and others were not well developed, or even understood as critical.

### *Summary and Analysis of Family Experience in the Childhood Years*

Families continued down a road they felt was uncharted as they saw their children with disabilities becoming the focal point for family life. This required a lot of energy to deal with as parents struggled to create a "normal" family atmosphere. One mother recalled taking a course on balancing family member's needs. The childhood years seemed particularly important in the life cycle of the family as new members were added and early fears for the wellness of their child had escalated to very significant problems, beyond the capacity of resources that families had to cope.

Families began to see their needs for support were not being met as they "re-aligned" their roles to help deal with the mounting pressure from demands on their time, for example, siblings described greater responsibilities. Three families had experienced divorce and all experienced a lack of informal support from typical community networks such as churches and social clubs, their friends and extended family members. Families also experienced an escalated struggle with professional services trying to understand what was going on with their child, and then based on "informed" opinion how to best help their child.

This process of ongoing change is consistent with the family adjustment and adaptation phase described in the work by McCubbin and Patterson (1983). As these authors extended the "ABCX" model of Hill (1949; 1958), they proposed that families may repeatedly visit crisis situations over time, and that families attempts to adjust and adapt would also have consequences on their perceptions of the initial source of stress. For example, the role re-alignment in many families created new sources of stress, particularly for siblings and for mothers. This re-alignment also involved trying to find a common or shared meaning of their experiences (McCubbin & Patterson, 1983) Where such shared meanings did not develop, marriages ended; thus, mothers were alone to learn about the joy and value of a human life, and to carry the burden. For example, in one divorced family, mom described how her efforts to structure learning for their child were undermined by an overly "soft" approach taken by his father.

> *His father never seemed to deal with the problems. He never wanted to believe there was anything wrong... maybe now he believes... but our marriage fell apart... It wasn't the reason why we split up, but it certainly had a big part in everything.*

In this phase of the family life cycle, the significant role played by mothers emerged with resounding intensity. As one of the significant adjustment strategies used by families in this study, mothers' often carried the burden alone. However, these experiences of carrying this burden with no community supports often led to the forced separation of the child from the family through institutional placement or foster care. In other research, Traustadottir (1991) used in-depth interviews and participant observations of a parent support group to explore the meaning of gender in relation to the family care of children with disabilities. The results of her work showed that mothers carried both the burden of caring for the child, for example, doing the work of accessing systems and providing nurturing care. Her work also highlighted that mothers made the bottom line decisions in regard to services and institutional placement, often describing such events in the singular "I", rather than "we" as a couple.

Recognizing the cultural influences on the family, Traustadottir also noted that most of the parents thought the restrictions placed on mothers were simply a "normal" part of the traditional mothering role. When mothers challenged the assumptions about conforming to traditional, selfless roles, mothers were faced with many additional pressures, including guilt, that arise from the cultural assumptions of care. This experience of guilt was clearly expressed by one mother in this study, quoted above. In contrast to mothers, the fathers in her study were described as supportive in three ways:

financially, emotionally of mothers' dedication to their child, and helping out with care in the home.

At this point, families faced the school system as a second major institution with many new obstacles. Finding their child in a competitive environment and unable to conform, all families experienced the rejection of their child from mainstream education. This rejection parallels their early experience with the medical community in trying to "fix" their child through various methods. However, in this school context the idea was to socially isolate in order to correct the problems - or at least make sure the "problems" didn't adversely affect any other children in their learning. Giangreco and Putnam (1991) reviewed a great number of research documents which weave into strong support for integrated education. In their analysis, these authors have suggested that both structural adaptations and people resources are key dimensions. In regard to class structure, their analysis showed that planned opportunities for contact with peers, cooperative learning models and adaptation of curriculum fed into successful inclusion. As one mother in the present study asserted:

> *[Integration] is more for the social and behavioral things... She will learn to do that [sit], but if she is with a bunch of kids who are acting out - she will never learn to sit... I don't expect Theresa to learn Canadian history. I don't care if she ever learns that. But, the fact that she is sitting with kids her own age and learning how to sit there and participate when she can.*

Giangreco and Putnam also described the potential roles of teachers, paraprofessionals, and classmates, among others as "people resources" critical to achieving "full inclusion."

In the present work, some parents still placed trust in professional solutions; while other parents continued to critically analyze these professional interventions and the effects on their child; these family members began to rekindle a trust in themselves more and more. However, some parents simply began to believe there were no options - at least none for them.

These patterns of accumulating stress and the absence of support leading to separation of the family, consolidated their negative perceptions of the service system. In a study of the closure of an institution in British Columbia, Lord and Hearn (1987) explored the context of family life just prior to moving into the institution. These authors found that the "wearing down of the mother" was the most consistent factor of family experience that lead to institutionalization. Feeding into this "crisis of institutionalization" was the pervasive pressure felt by families that they had no real supporters and no clarity in seeking other options (Lord & Hearn, 1987). Underlying this pressure to institutionalize their family member, Lord and Hearn suggested that the predominant cultural beliefs also supported a segregated, institutional environment as an appropriate and "helpful" response. Many families in this present study also incorporated these cultural assumptions that valued an institutional, formal service response to family stress. They became hesitant to ask their friends and other family members (i.e., informal supporters) for help, since the bureaucracy was "designed" to fulfil that role in the culture. Instead of receiving help, families became increasingly isolated which compounded their perception of stress.

Thus families began to recognize the loss of the "family dream," implicit in North American culture. The dream of the little house with a white picket fence was never meant to be theirs, and in some cases was never considered desirable. In all families though, the only "picket fences" were the barriers between the life parents and their children expected and their reality. The build-up of these barriers, now spanning over a decade, that produced feelings of frustration and guilt now began to turn to anger and even remorse.

# *CHAPTER 8*

# *THE TEENAGE YEARS*

By this stage in the family life cycle, families had seen many professionals come and go along with many programs and "fix-oriented" treatments. Family members witnessed the transition, during the ages 12 to 18, from "tendencies to realities" as a variety of problems could no longer be avoided. The issues related to a dual diagnosis began to take form in this stage in spite of all the attention and, perhaps, partly because of the attention and its impact on the family. Such a negative influence is particularly plausible given the context of cultural expectations in this transition phase toward adulthood, including increased independence and positive peer relationships. However, as I looked over the interview transcripts, I realized that families had touched on a few key issues and then quickly moved into the issues of daily concern in the young adulthood years and focused on issues in the present. Thus, the data for this chapter are more limited than several of the others. In adolescence, two young men were given an additional label of schizophrenia; one women was diagnosed as clinically depressed; and all other teenagers began to experience an escalation of a variety of serious behavioral problems. *In all eight individuals, the developmental issues were present first, and the psychiatric/mental illness concerns developed later, emerging as significant by late adolescence and the teenaged years.*

## *Mark and His Family in the Teenage Years*

*Around 11 years of age, Mark's family experienced a strong crisis and mom called on Children's Aid. Mark was institutionalized for one year and mom says that helped a lot because he did improve somewhat. Mom knows that Mark is a unique person who requires a special kind of attention for a variety of reasons. However, once placed in a segregated "community" setting, the service workers knew after a few months that this was the wrong environment for Mark; they never shared that viewpoint with the family until after Mark had been there for years. At the facility, mom described the unsupervised medication trial Mark was put on that failed and then the subsequent pressure to again commit him into a long-term care facility. By not succumbing to this pressure the family agreed to have Mark at home for longer periods of time, alone.*

*Prior to his return home last summer, the family was able to get a complete assessment which showed new problems mom believes should have been sorted out 15 years ago. Mom explained they didn't do in-depth assessments because "nobody wants to listen to parents," and that assessments must include Mark because his voice needs to be heard. As a knowledgeable professional, mom has recognized and rejected medical solutions, specifically those which involved "pushing pills."*

*Community living has been a constant struggle for the family. The process of engaging the service system is very complex because as mom explained, no one directs you to the proper channels and services are not well coordinated. Mark also very clearly communicated he doesn't want anymore doctors - he is tired of going through the professional regiment. What Mark wants are real friends in his life, but people he meets seem to be a negative influence. The pressure to find somewhere for Mark to live remains because the family cannot find relief from the stress. Mom pointed to the injustice that "all these kids that have been put away in different places through no fault of their own, just because they did not get the proper help at the right time."*

# PARENTS' EXPERIENCES WITH THEIR TEENAGER IN SOCIAL AND EDUCATIONAL SERVICES

## Through the Cracks of Service Delivery: Access and Continuity

Parents recalled that as their child became a teenager the family got more involved trying to sort out the gaps in service delivery as mandates became more specific and the dual nature of their children's problems had become more pronounced. One mom felt the problems were at a systemic level of service coordination. "I don't think it's fair for me to make a judgment [about responsiveness of services] because a lot of organizations are specific, for specific things like mental retardation, mental health. I think they try in their own way, but because David has a dual diagnosis, he just never fit in. He didn't fit in - that's one reason why a lot of it wouldn't work out...". She also indicated how the family's repeated problems in getting support from services impacted on her point of view.

> *Every time I go for some kind of help, and I get it, but then it ends because there's a breakdown in the make-up of the whole resource organization... They're there for you, you give them what they're expecting from you and all of a sudden things are changing in the situation and it's not there anymore... I know you have to do it on your own, everybody does, but when there is a real problem with somebody like that in your family, you're going to need ongoing help for the rest of your life.*

Other parents began an almost desperate search. "We were looking for anything at that point that could continue with his education... of course like every other program, they have a waiting list a mile long, and he was at the end of it. First of all, his age was against him... so they felt it was too late to really start with him". Another mom recalled the frustration and sense of futility that began to develop.

> *I am on the phone, and if I have to be on the phone - I have to organize myself to be on there all day - calling... nobody here cares a damn... Nobody is here to listen to you. So this is it. You spend hours and hours [on the telephone searching]. Nobody knows anything. And William falls into the cracks of things because either he's too young, or he's too old. He's not handicapped. He's not this, he's not that... I am so exhausted I don't know anymore.*

## Losing Trust in Expert Solutions

Families discussed how they continued to lose faith in solutions based on a professional model of expertise. This distrust seemed to build on their experiences in the early and childhood years, but now be generalized across educational, medical and social services. Five of the families remembered aggressive and hostile "therapies" and recommended to "fix" their teenager. With professionals clinging to the fix, parents began to openly reject an approach they saw as "an eye for and eye." One father remembered, "The more he did these inappropriate behaviours the worse the treatment he was getting from them [at the school] so that they were trying to handle it in their disciplinarian way and all it was doing was compounding." In another family, mom rejected the advice of a behavioral consultant who suggested humiliating her daughter to effect a behaviour change. Mom remembered "I guess it's a technique they use for mentally handicapped people, it is in the books... a lot of people learn that kind of methods. It's the old ways and I can sense that right away." Another family recalled how their son was simply rejected from services in desperation of not knowing how to handle the problems and support the person. "A couple of times he got kicked out and he'd get kicked out for a week or a day or two - that's how they would handle it if he was having problems there." This type of solution also fed into isolation of the family from formal support systems that had begun in early childhood when parents' daughters and sons were sent home from school.

## Caught in the Continuum of Service

*All eight teenagers continued to experience segregation in the educational system.* Four of the teenagers experienced total segregation. Several attended the same instructional school with a residential option so that about 20 people in total actually lived on the site. All of these parents saw their teenaged daughter or son as inappropriately mixed, or rather isolated with other adolescents with problems and no real access to more "normal" same age peers who could act as more appropriate role models. For example, one mom recalled "David is not a violent, rebellious sort of person, and some of the kids there were that way. David was very into himself and very lovable... he's more lovable than anything." Another family remembered the negative influence of peers in the segregated setting, encouraging their son to get involved in delinquent behaviour.

The other four families experienced the "segregated-integrated" model of education in which their teenager was often placed in a segregated class on the grounds of a public school. One mom explained the dilemma faced by her child's experience in the segregated class.

> *The first year she was there, she didn't do very well, so she had to stay there again. The second year she was there, she did so well, that they didn't want to move her anywhere else. I said, "she can't win! If she fails she stays here; if she does well she stays here!" Incredible!*

## Abandoned in the Community

Many families were beginning to feel abandoned in the community. One family struggled constantly for a sense of legitimate family involvement with their child who was placed through social services. Another family member bluntly stated "Being in the community we're not getting the support that we would like... one childcare worker said 'if you can't manage him, you should give him up...' Are you going to tell a parent that they should give up their child?! And my husband he just stormed out because he was going to strangle her." One mother discussed her pattern of personal breakdowns and admissions into the hospital, and how her son had to be admitted outside of their hometown to receive services because "there was nothing here for him to go to."

### Building Family Expertise and Action

Many families recalled that during the teenaged years they began to find a new source of strength; this marked the flowering of self-trust, believing in their own knowledge and abilities. As one mom explained "I started to realize it didn't take a professional to know. Back then [in the early years] I believed I couldn't do anything." Another family took an active role in educating the school system about their son's illness. They discussed several examples of their efforts bringing educators together to discuss issues and offering literature on psychiatric disabilities to teachers and other students. Other families began this process by rejecting the "hierarchy of expertise" thrust upon them in the early years.

Two of the families began working in the community and were key players in the development of a family-based respite care organization to support community living, at present funded under the provincial government. One mother explained how the action and building process started.

> *We started to work with a group of people who were looking at a project that looked at the whole system and how that might change... Anyway, because of what we were doing, and meeting some of the people we were meeting, we really began to feel strength and that what we knew was right and some of the things we were seeing, and really looking at, we realized weren't any good. We also saw things changing, like Marianne [our daughter] changing too. And not for the good. Like these things like "oh yes, when she goes there [to the institution], there will be all these people who are really trained and they'll be able to do so much more." We didn't see any of that happening. In fact, if anything, we saw Marianne losing her personality, losing her personhood. So we started trying to find a way to bring her out.*

# FAMILY MEMBERS' EXPERIENCES OF FAMILY LIFE WITH A TEENAGER

## Lack of Friends Becomes an Important Issue

Typical of all adolescents, friendships outside of the family play a very important part of developing self-esteem and a sense of belonging in the world.

**All eight teenagers struggled to have even one real friend.**

One mom talked about how this problem escalated:

> *Tom just sort of separated himself and he made himself an enemy almost instantly and they [other kids] just didn't like him. And when he did meet anybody, we always tried to encourage it. We'd say "come on, bring them on home. We'll do something, we'll go out together." It just never seemed to go anywhere. Tom was never able to make friends or to feel comfortable with young people his own age, whatever his age. The problem as he gets older is harder because he gets along very well with kids, young kids and they like him.*

Another mom explained, "he tried so hard to have friends and they nicknamed him 'shadow' and he thinks they're his friends - they're not his friends. And as soon as they get rough with him or call him names he can't take it any more. That's when he had his first breakdown." In other families the person began to seek friendships through or with a sibling. In one family dialogue mom began:

> *David has no friends. He hasn't had a birthday party with his peers since he was seven. So he relies a lot on Mary [his sister] for his friendships and sometimes that's a bit of a burden, a lot of a burden on her. It's like she has this older brother, but he's not actually an older brother...*

> *[And Mary continued]*
>
> *A lot of David's dreams are connected to my friends. He likes them. He wishes he could have them as girlfriends. I try to explain to him that it's not that way - they're just his friends... [but there] I'm trying to understand it myself and explain it to him. I'm putting myself as an adult again and he knows it.*

The issues of friendship extended to the need for intimacy in relationships outside the family as well.

### Marginalized to Death

Three teenagers attempted suicide. In two families teenaged boys who were marginalized from the community, abused and having no friends acted to end their lives. In a third family, an abused daughter attempted a "passive" suicide by refusing to eat and drink, becoming violently ill, and requiring admission to the hospital for an extended period.

## *Summary and Analysis of Family Experience in the Teenage Years*

This stage solidified families worst fears about the educational and medical service systems. The systems were not able to solve the issues and rather than focus on how to better *live with the person*, service interventions increasingly aggravated the problems families were experiencing. As these individuals reached the teenage years, families encountered "gaps" in the service system in accessing appropriate programs. Families also became aware of a second flaw in the system: the lack of continuity. Building on families' experiences in the early years of being shuffled from one service to the next, this lack of access and continuity now built into a pervasive sense of abandonment in the community. Some families began to take action and worked toward changing the problems they faced; they began to understand that they must trust the answers that came from within themselves. Other parents and family members felt a sense of hopelessness; in the paragraphs below, I have begun to answer a key question, "why?".

Taylor (1988) asserted that the response of professional services to such problems was the creation of a service continuum model for individuals with a disability - essentially, institutionalizing the community. In this model, people must "graduate" through less and less restrictive environments. By graduating to higher levels, usually scaled along an independence criterion, people must earn the right to choose for themselves. In a quotation used above, one mother clearly articulated how this impacted on the family. She expressed great frustration around the inability to implement decisions with the school and a sense of failure associated with being trapped between levels of a so-called "community-based" educational system. Thus, the continuum from segregated to integrated education represented a service structure that maintained the power of decision-making in the hands of professionals, and did not support inclusion for these individuals and their families.

Families also witnessed an increasing gap between the "social norms" and the status and experiences of their child, as she or he often had few friends, if any. In some families, siblings described filling an important void for the person by including and nurturing their involvement in their own peer relationships. Hutchison (1990) has noted the importance of friends in the culture to create a sense of personal value; "friendship teaches people acceptance." In particular, friendships during the teenage years provide opportunities and challenges to grow into adulthood roles. But more than role models and friendships, Hutchison also noted the importance of intimacy and affection in relationships, for example outside of group home staff and other human service workers. Instead of personal value and intimacy, the lack of friends and marginalization from the mainstream culture contributed to the anguish internalized by several individuals. These individuals had learned the messages of the culture that a failure to thrive in the competitive social environment meant "worthlessness." Three individuals attempted to take their own lives.

These individuals and their families were beginning to become aware of the results of oppression which Goldenberg (1978) has defined. "To be oppressed is to be rendered obsolete almost from the moment of birth, so that one's experience of oneself is always contingent on an awareness of just how poorly one approximates the images that currently dominate a society." (p. 3) Then, through strategies of containment (e.g., segregation) and expendability (e.g., feelings of worthlessness), Goldenberg suggested that individuals and even entire populations may be marginalized out of existence. As individuals given a "dual diagnosis" label attempted to make the transition into young adulthood and into the culture, understanding the process whereby some families overcame these oppressive barriers to find personal power was an important issue for this study.

Olson (1988) hypothesized that families who balanced both cohesion and adaptability would more likely to demonstrate effective coping. I believe that families who became more involved and cohesive in their approach to living with their family member during the childhood years now demonstrated more effective responses as they began to build on their strengths. These families gave their members the courage to engage other members of the community to address their experience of social injustice. Further, I believe that at the core of this cohesion in the family was a critical analysis of their social environment, consistent with Goldenberg's theory of oppression. Thus given the strength of conviction, families developed the tools to be adaptive in their approach which formed the second dimension in Olson's model. As one father said, "we act just like a palm tree leaning over in the wind and we keep coming back up again." To extend the analogy, the philosophical underpinnings or "roots of the palm tree" enabled families to survive the inability to create and control an everyday routine - the ability to be flexible in the face of seemingly irrevocable stress.

I believe that cohesiveness in family relationships provided families *the structure* to persevere, but that adaptability provided *the means* to persevere. Thus, families had to balance both the structure and the means to be "successful." As Olson (1988) suggested, communication is the link that mediates the balance between cohesion and adaptability. However, Olson's family-centred model must be extended to include the social context of the service system that had emerged as a significant player within the family. As noted in earlier phases of the family life cycle, particulary in the early years, families' communication with the service system was effectively blocked through a "hierarchy of expertise." Then, through the wrong definition of support (e.g., segregation and institutional placement) and a lack of access and continuity to services compounded families' stress throughout the childhood and teenage years. This lack of communication directly, and very negatively, impacted on families' ability to create balance in their relationships.

Gallimore and his colleagues (1989) asserted that families construct a routine to accommodate or "fit" their values. As these researchers discussed, "construction of the daily routine and its activity settings is mediated by central family themes that give meaning to parents' decisions concerning their routine..." (p. 219) However, in the context of families' experiences related to "dual diagnosis," families also needed to construct values that "fit" with the *inability* to construct a routine, given their family members' unpredictable nature and the lack of support in the community.

# *CHAPTER 9*

# *THE YOUNG ADULTHOOD YEARS*

At this stage in the family life cycle, six of the families were struggling to keep their family member living at home in the community while in two families, the individual given the "dual diagnosis" label was living in a residence outside of the home.

## *Alex and His Family in the Young Adulthood Years*

*As Alex grew into a young adult, the family's day-to-day activities revolved increasingly around creating a consistent and calm environment for him. They describe the most difficult thing in living with Alex is the day to day frustration of dealing with his illness and never knowing how the day is going to go. They have learned never to get too excited and recognize that Alex's normal level of stress is the same as most people's experience of stress at its peak. It has been a real struggle though, to avoid having their lives revolve around Alex. As dad explained, "I wish it wasn't a rut, but it is a rut." Family members have found it a constant challenge to carve out their own personal space to become a whole person.*

*The political nature of the service delivery system impacts directly on the family. For example, the psychiatrist working with Alex had advocated for change in the hospital system; but, in doing so she had lost the privileges required to give Alex the referrals necessary to obtain other services. The family has repeatedly experienced the hospital bureaucracy as nonresponsive.*

*More recently, under the Mental Health Act, Alex has acquired the right to refuse treatment and must consent to his parents' involvement. Alex has relied on his mother to help him through the maze and this new twist provides families with an additional barrier to helping their family member. Mom says, "When I complain or talk to someone, the ones I don't like tend to say 'Well, have you got him on a list for a group home?' I'm not asking for that kind of an answer. I might be asking for a little bit of 'Are you listening to me?' - the kind of listening skills that I try to give to people. And also, I'm asking for support for him to be here [at home]... Maybe they can't provide any answers... but it's really discouraging." What the family doesn't want is to separate and have Alex living with too many people in a "boarding house" that doesn't build on his skills and experience. The family wants Alex to be able to live like everybody else with different options. And Alex would like to live in an apartment of his own someday, which to others outside the family seems unrealistic.*

## FAMILY STRUGGLES IN LIVING WITH THEIR FAMILY MEMBER AS A YOUNG ADULT

### Living On The Edge

**All families discussed aspects of "living on the edge" with their family member.**

*Coping with Uncertainty*

The uncertainty of family life was described by all families in different ways, perhaps most effectively by one mother.

> *I think the most frustrating thing about dealing with Greg is the day to day frustration of dealing with his illness and never really knowing how the day is going to go. So we all live on edge here. When he's in a psychotic state, he can't be left alone. So we take turns. So Peter and I very seldom get to go out as a couple. It's really, really hard. It's hard for him. We're lucky in that he understands that the medication is there to help him. He hasn't had any voices or hallucinations since he started the medication, but he still experiences the delusions.*

*Two Steps Forward, One Step Back*

Many families talked about their experience struggling to mature into adulthood relationships. In some families, they discussed this pattern with their family member in terms of skill and social development. For example, one parent said:

> *He's gone through a lot of ups and downs where it seems like he's making a lot of successes. We're going ahead and then all of a sudden we'll go back... It just seems to go like that. in some ways the last couple of years. I almost feel like we're going backwards instead of making gains. Maybe he's hit his limitations of how far he can go and maybe we're expecting more and he can't give it. I'm not sure.*

And another mom similarly reflected on their life together,

> *We're learning. We've been pretty close to the limit though these past couple of years, especially since school ended. It's been tough and yet Cari keeps going ahead two steps, and then back one. That kind of thing. We see great things happening in her life, so that's the nice part.*

In other families this forward/backward, up and down pattern was discussed by family members in terms of their own lives. One mom explained her struggle with guilt that "I don't know where to go with him, I don't know how much I want to take, or I can take anymore. I feel guilty about that... [but] I just can't seem to get on with my own life when Richard is stagnating. I just can't seem to do it." This notion of having one person with an identified "problem" become the central player in all of the families has been a constant struggle over the years.

### Learning to be a Whole Person

**For all families, learning to develop other aspects of their lives, independent of their family member and disability issues, has been a key challenge.** This has been a struggle within the family as one mom captured the tension directly. "How can you cope with him when you're trying to do other things?" On a broader level, this challenge to become whole has also meant that family members need to share responsibilities with the community to work for social change. The challenge of working out of a rut was expressed in one family dialogue with researchers. Dad opened the discussion saying, "I mean we're in a rut in that we can't seem to get out of it... we have something to offer the community. It's a good thing." Mom then took the conversation to a deeper level of her experience. She explained,

> *I had felt it a lot this year. Particularly, I felt myself not able to do some of the stuff I should do. Not able to make the phone calls I should make. Not able to follow up. Just plain saying 'I can't do it'. And I think it's for a lot of reasons; the busyness and just getting tired of always being out there trying to forge ahead... And I realized that probably some things could go along quite well without me... and the family have really helped out a lot and maybe it's time that some of that is going to continue after this [support clusters project] too because I was very close to being just not able to go on -- at my limit.*

This passage, again underscores the importance of mothers in carrying the burden of care.

## Finding Purpose and Meaning

Consistent with the broader culture, as their family member entered the world of young adulthood a crucial question was implicitly asked by the individuals with a dual diagnosis and their families: "What am I going to do with my life?" In one family it was expressed as simply as the need to find "somewhere to go, or something to do." In other families this lack of purpose had more immediate and destructive consequences which they discussed. For example, when explaining the results of a recent hospitalization, one mom described a vicious cycle of desperation. After her son came home, she explained:

> *The only difference was [that] he wasn't as depressed and the medication was helping him. He wasn't screaming and yelling at his sister. He wasn't pacing the floor and keeping me up all night and hearing things. What was the same was he came home and he did nothing. That only happens for so long and then he becomes depressed and starts hearing voices again. [There's] nothing in his life... so it's a big circle [and] it's going to come back unless he has something to keep his mind going somewhere else other than inward.*

# FAMILY COPING STRENGTHS IN LIVING WITH THEIR FAMILY MEMBER

## Learning a Unique Perspective

**All families talked about learning to appreciate the subtleties of life on a day by day basis and the importance of "perspective."**

### *Enjoying Life "One Day at a Time"*

In one family dialogue mom explained their strengths as follows.

> *The fact that we've learned to take life one day at a time which isn't a negative thing, it's very positive. We learned a lot of patience... I would say the biggest thing is learning patience and taking life one day at a time and really enjoying life one day at a time because I feel that there's a positive thing to everything that happens....*
>
> *[Dad agreed with mom]*
>
> *It does add perspective - it just gives you new life when you have to deal with so much stress that other people wouldn't be able to deal with at all... Problems - they bring gifts to you. Sometimes you can't see them right at the moment; through the haze of the stress you can't see it. But later on you pick up a little bit of knowledge and a little better way of dealing, not only with your family, but also with other people outside of the circle.*

*The Value of Life*

> *What I have learned from Theresa is more about life. More about love and caring and understanding. I think if I was to look at someone who doesn't have a child like Theresa, has not experienced what I have experienced, I see they have missed a lot. Because I have learned to accept people. I have learned to accept myself more and more because if I am going to accept her self, I have to start accepting me. It gives a whole new essence to life. Even though it can be difficult, I think there is a lot of positiveness that Theresa offers in life to people, if they are not afraid of it. Like I really can say honestly that I know what true love, unconditional love is. Which I don't think a lot of people can say, and that is something that makes it worthwhile in the end.*

As I introduced in the summary of the teenage years, this "family perspective" formed a crucial part of the "root system" that helped family members make sense of and attribute meaning to their life experiences. Meaning, then, provided the strength for some family members to build on their capabilities and face the challenges in the community directly.

## A Distinct Sense of Self

One of the key features that families pointed to as contributing to their strengths was the ability to create and maintain a sense of themselves, to a degree independent of issues related to their family member's illness. When speaking of his participation in an educational music program, one father suggested, "That in itself is a form of doing something for myself which makes me feel better, which makes me feel more whole, which makes me more up to spending time [with my son]." Another mom spoke how she maintained a distinct sense of her self.

> *The way I've learned to live with the situation with Paul, the way to describe it to anyone, is that I have a little venetian blind in my brain and when I'm living my normal life, I don't even think of Paul as being the problem... I've been a hard one to get involved... I don't want to go too in-depth, I think is the bottom line for me... It would make me dwell on it more... I don't have to be everything [for Paul] because I can't be everything. I've realized that.*

Other mothers reflected on their recognition that they do have personal limits in dealing with the problems and do need to draw the line for their own preservation.

### A Sense of Family

Balanced against the need for personal space, family members talked about having a sense of being included in an effort larger than themselves as individuals as a critical feature of their ability to cope. In a family dialogue during one interview, the sense of unity was expressed this way. As one sibling said, "I just look at mom and dad and think 'they can do it. I can do it too'. I know they've gone through a lot more than I have." But dad disagreed, "Not really..." and mom went further to explain "You've been in there right along with us." In another family, dad summarized the feeling that it came down to a sense that "we're all in this together."

## Finding a Positive, Upward Spiral

For all families, the ability to find a positive, upward spiral was both a daily struggle and a key strength. Perhaps best described, the ability to find and maintain this positive pattern grew out of a collective determination that the "family struggle" would not defeat them - it became a battle of conviction and social justice.

## Victimized, But Not Victims

A great deal of family theory and practice has examined the negative impact of stress in the family and the downward spiral of family functioning under prolonged conditions of stress. In fact, the values or assumptions expressed in previous research has suggested that many families under stress cope in negative ways, adopting a "victim" status, based on their appraisal of the situation and the absence of a positive societal response.

Individuals and their families in this study have clearly been victimized in the past through abuse and the lack of support they have experienced. But they are not victims, and they must constantly fight against such status. "Day by day we carry on. I'm not a quitter. I am a survivor. So we look for other ways of dealing with the problem... but I don't know for how long." Another mom recalled the motivation they found when small bits of their dream became a reality. "I'm sure that not everything people hope for happens. But when you see some of it starting to happen, it keeps you going."

### Searching and Growing

One significant aspect of how families began to understand their world was the ability to focus themselves on a positive vision of their future. One mom approached this strength directly as she said, "I think you always have to search and try to keep growing." Another mom said "We see great things happening in her life... We just have to try to minimize the effects of the bad times, and keep looking ahead." Other families looking to the future struggled with trying to find such a positive spiral of events. They spoke of how family members needed to accept the reality of the situation and work from there, rather than attempting to live with false dreams.

### Value Steps in Building

For family members, having the ability to appreciate and value the small steps in a building process was a key learning that enabled them to create opportunities for success.

> *Having that kind of understanding [of our daughter] I think calls on us too, to be responsible to say "maybe everything can't be just the way I want it to be." We have to start in some small ways and value, I wouldn't really call them small but some people might, value the building of a relationship and value the building of Maggie's competency to just walk in there and say "Good morning" and be able to stay for a little while. And know that's really valuable. Not, "what is she really doing when she's only there for half an hour." So it calls on us to recognize where Maggie is at.*

# PARENTS' EXPERIENCES WITH PROFESSIONAL, FORMAL SUPPORT SYSTEMS

## The "Catch-22" of Formal Support: The Strings Attached

For many family members, professionalized services still presented many problems. In part, the problems outlined below were associated with all of "the strings attached" to receiving services that made parents and siblings openly wonder whether it was "worth the hassle."

### *Supporters That Need Support*

For families already experiencing stress, the additional demands placed on them from people in their support networks compounded, rather than relieved the stress. As one dad explained, "Sometimes it's more frustrating dealing with the fact that there is a respite worker and then there isn't. It's a catch-22." One of the main problems with professional services identified by families was that paid workers were struggling to work with the person and recognize the person's whole life experience.

### *Choice and Control as Recipients of Service*

For some families, how services were provided was the key to changing the system to be responsive to their needs. One mother explained the family's struggle to find personalized services.

> *So we have to get something [a source of funding] in place that is not attached. That's why I'm not so anxious to use Special Services At Home for it either. Because that's attached to living at home. We might fight and fight for something and finally get it, and then it wouldn't be the right thing... So it has to be something that is portable with our daughter.*

### *Picking up the Pieces*

Some families talked about the dilemma of allowing well-intentioned people to work with their family member. One parent explained that:

> *It's like no matter how much you want to do something, no matter how much you think it is great and think "well, we'll be able to do it," and she may seem like she's going to do it. If everything is not working, it will be a total disaster. And then the after effects are hard to undo. I find that other people do not realize it and she gets back [home] and that stays and it can last for years. I have experienced a few of those.*

This type of lasting effect and the fear it may produce is a large piece of the stress-puzzle facing families, 24 hours a day, seven days a week.

## Distinguishing Between the System and the People: Supporters who Understand

Many families clearly distinguished the formal service system from the people who work within it. Families all pointed to particular individuals who were responsive to their needs as a family and and had developed good relationships with their family member. But as one mom explained, the problems with the lack of support were glaringly obvious.

> *We need something, some support. Fifteen hours a week is no support when you're trying to carry on... and live a normal life. You can't. You can't go anywhere. I can't go out for dinner, I can't because there's nobody who would look after Gord, who is capable of looking after Gord. You have to have somebody who understands the problem... not just any Joe from the street to come and look after him. He doesn't need a babysitter like that. You have to know how to deal with him... The worker we have is very good. He keeps Gordon busy and they seem to have a good relationship.*

## The Consequence of Inaction: Living in the Interim

**All families talked about the effect of inaction as they watched their family member living in between the cracks of service systems.** As one mother exclaimed:

> *You know you have a child with a unique problem. You should know exactly what to do, Plan 'A', Plan 'B'. Nobody ever had a Plan 'A' or a Plan 'B' if something happens. No backup, no nothing. You have to wait months and months. So what do we do in the meantime?*

This notion of action was picked up directly later during the same interview when she said,

> *Action is the word. That puts it in a nutshell. This is because there are so many thousands of people out there who are frustrated and who are probably worse off than I am that need help right away, really instantly.*

The result of this inaction is also injustice as mom explored the deeper meaning of this for individuals with a dual diagnosis and their families.

> *People should know where to go instead of going around and around and [getting] caught up in all that red tape... It's incredible in the society that we live in now, there should be some resources... How come it's not there?!*

Concern for other families who may be experiencing the same difficulties finding support and access was a common thread among parents.

## Learning to Claim Personal Responsibility

By this stage of their "career" families were more confident in their approach to working with professionals. Quite often, however, this involved recognizing the difference between "dealing with services and actually getting the services" that were needed. One mother, when speaking of her role in helping her daughter become integrated in the community, explained how she grew to understand her relationship with professionals.

> *I started to realize it didn't take a professional to know. Back then [in the early years] I believed I couldn't do anything. Anything that I thought was the right way to go - I didn't have the confidence to do it. I thought I needed a professional to say 'do it,' but that type of professional was really going the opposite to what I believed. So, I think because I have changed too, I sort of accepted the fact that, hey, I do know what I am talking about and do know what I am doing. And while I am more sure, the more I am sure, the more I have a better way of presenting it to them. So they have changed too, but I think it [my approach] makes a big difference.*
> *Because I think if you go into it with a negative attitude - if you feel insecure about what you feel, I think you might get bulldozed quite easily. Or you could, and I don't think professionals do it intentionally. I think the thing is a lot of times they don't know - so they have got to look like they know everything.*

In this passage above, one parent explained in detail how her personal growth and experience interacted with changes she was beginning to see in professionals' attempts to provide services. It also highlighted the recognition held by many parents of the constraints put on people trying to work in the system. Most importantly, she clearly reflected an intertwined web of acceptance: the person with disabilities and the caregiver (mom, dad, sibling) must be accepted for both their weaknesses and strengths. Thus, family members who began to recognize their personal strengths were able to accept the responsibility to do their own work and took action. Similarly in the parent group meetings, one mother suggested that supports need to recognize that "getting involved with the person and the family means accepting them for who they are."

## PARENTS' EXPERIENCES WITH INFORMAL SUPPORT SYSTEMS

### Acceptance, But Little Practical Support

When speaking of their relationship with an informal network, all families talked about the void between acceptance of the problems and actually receiving instrumental or practical support for a variety of reasons. During a family dialogue, dad began to explain the process of withdrawing from potential supporters:

> *We've tried with other people... but after a day or two they've come back and said "We tried. We're sorry. We can't do it." And Rich can be that way - he can really break down a person fast. Rather than aggravate the people, we just said "No. We won't do that anymore. We'll find ways ourselves."*

> *[And mom continued]...*
>
> *Our families are understanding. We don't have any problem with that. They are supportive. But they're not involved in the everyday things.*
>
> *[Dad concluded]*
>
> *Or on any type of regular basis - there's nothing like that.*

## A Small, Select Group

All families reported having a small, select group of informal supporters whom they felt they could access. These supporters, often only one person, formed a thin line between the family and professional services so that very quickly in a time of need families attempted to access the formal network of service provision. In some cases, the informal group was small because of geographic distance between family members living in Canada, while in others this was due to the guilt that families felt asking for help, recognizing other people have their own needs and interests as well. Yet in other families there was blocked communication with extended families and in some cases open hostility.

## People With Experience

A significant problem encountered by many families is that many members of their informal network simply did not have experience working with people with complex disabilities. As a result of less experience and understanding of the issues, involving informal supporters actually created problems for some families. In one family, informal supporters were too sympathetic toward the person and failed, from mom's perspective, to challenge her daughter appropriately. Where families had access to informal supporters with such knowledge and experience living or working with people with disabilities, these contacts were highly valued and considered useful. As one mom indicated:

> *They know what it is like personally to have a child with special needs and some of the things you come up against. And they are very easy to relate to because you don't have to go through your whole life history. They know. There is a lot you don't have to explain... because they have been there, or are doing it themselves.*

### *Summary and Analysis of Family Experience in Young Adulthood*

Throughout the childhood and teenage years, family life increasingly revolved around the person with the identified needs. Now into the young adulthood years, the family "lived on the edge" in many different aspects of family life. "Uncertainty" became a predominant family theme in relation to life with their family member. For example, family members often struggled with balancing a sense of independence (i.e., a sense of wholeness as individuals) and interdependence with other members of the family unit. The ability to achieve this balance was a key family strength discussed by participants in this study. However, this struggle to find an optimal level of cohesiveness as a family (Olson, 1988), and to avoid becoming "enmeshed" (Napier & Whitaker, 1978) was endless.

In all families supporting the person at home, the focus of family life had become managing crisis after crisis. McCubbin and Patterson (1983) have suggested that families' adaptation and adjustment strategies may lead to perpetual crises. However, as discussed in the previous chapter summary, these family-centred models must be expanded to include the "support systems" and community resources external to the family (see, for example, Singer & Irvin, 1991). Additionally, models that explore community resources available to the family system must also be understood within the context of the cultural environment - the expressed values and assumptions of the society, in particular as related to the role and function of such community resources in supporting families.

The undeniable irony presented to families was that service systems intended to help them often demanded their life circumstances deteriorate to crisis situations before help could be accessed. As stated clearly by parents in their support group with family and friends, "You have to go all the way to a crisis before you can get help." In spite of this deficit-orientation, effective formal supports were needed to respond to changing family needs. Family members had already witnessed the withdrawal of major systems, such as the school at age 21, and they now struggled with a history of increasing isolation.

Thus families at this stage found themselves in a strange dilemma of having systematically become more dependent on a fragmented formal service system and less able to access informal supporters who were a potential source of ongoing support. In a review of literature by Kessler, Price, and Wortman (1985), a number of studies taken together reveal that although people appear to know what to do when asked how to provide support, in actual times of crisis,

> support attempts are often ineffective... It appears that support providers find it very difficult to tolerate the distress caused by encounters with crisis victims. For this reason they often engage in behaviours such as minimizing the victim' problems or attempting to be cheerful, behaviours that reduce their own distress... (p. 548).

Although informal family supporters had attempted in practical ways to help, both the supporters and family members found the ensuing difficulties of the "helping behaviour" a greater burden than actual support. However, informal support people in this study had often been separated from such family issues at very early stages of the family life as service systems attempted to respond and were perceived as knowledgeable experts in the culture. Then, as the issues related to the person with a dual diagnosis and her or his family became steeped in layers of history, the support needs also became greater and people were less able to respond from the families' perspective. Consistent with this finding, the results of many studies point toward a common theme that "those in greatest need of social support may be the least likely to get it" (Kessler et al., 1985, p. 549). Simultaneously, then, to an increasing awareness of the failure of traditional service approaches, families expressed a need for greater continuity and connection to supporters who could deal with the practical, everyday issues in the life of their family and the person.

Consistent with the small, select group of supporters described by family members in this study, Potasznik and Nelson (1984) found that families' satisfaction was greater when their support networks contained a small number of people who were actively supportive and engaged. Trute and Hauch (1988) also found family caregivers had few active supports, but such supporters were multi-dimensional in nature. In the present study, these informal support people and a few, if any, professionals with good relationships with the person formed a very thin but crucial line between "the institution" and families' ability to support the person at home. Thus, family members were able to count on very few people to actually "do something when it needed to be done," without having to ask, being referred, telling their life story and then receiving inadequate service or ultimately be rejected because their family member still "didn't fit". Ironically, the institution did not change this pattern as family members didn't want to "upset the cart" at the residence and be perceived as "uncooperative".

At this stage, two simultaneous streams of family consciousness in thinking about the world of professional services emerged. In some ways parents had developed a strong appreciation for the issues that professionals in the system faced everyday trying to work on behalf of families. However, families also clearly expressed that professional issues were different from family issues because the entire context and meaning changes **when you live with the person, 24 hours a day, seven days a week**. Gallimore and his colleagues supported this difference in meaning as they discovered the "irreplaceable roles of parents versus other caregivers." Pomeroy and Trainor (1991) have further noted the political context of governments which view professional caregivers as indispensable and suggested that:

> What families need to remember is that they are also indispensable. If families do not see themselves as key players, no one else will... When families deny that they have any influence [in mediating their family member's mental health problems], the result may be to inadvertently undermine their own case for recognition as major caregivers. (pp. 30-31)

However, balanced against these notions of "indispensability" are the key strengths of family members in maintaining a distinct sense of themselves found in this study.

Family members lived and continue to live in the reality of a competitive society marginalizing their family member out of its consciousness, often finding little concrete purpose and meaning. One family member reflecting upon this issue suggested that it may be the purpose of marginalized people to pull society back to the existential value of belonging - to act as a constant reminder of our collective need for humility and compassion. Further, I challenge you as a reader to imagine a world where reminders of value are unnecessary - what could life be like for marginalized people.

Increasingly at this stage, families began to explore and critically analyze the assumptions and values underlying North American culture. One critical dimension of our culture is linear growth. Wachtel (1989) discussed the dominant culture as holding a "growth ideology" - the fundamental belief that more is better. He suggested that our economic culture based on competition and the "need" for material possessions has transcended our social and spiritual culture to dictate an insatiable desire for linear, progressive growth (e.g., faster cars, bigger houses). As these linear definitions of growth become integral to how we understand human development over the life cycle, particularly in the young adulthood years, the expectations set for individuals can become destructive barriers to self-fulfilment, and very simply, an insurmountable barrier to happiness.

Consistent with such a focus on assumptions, Moses (1988) discussed how families in which a person experiences disabilities may develop and enhance their lives in the face of "irrevocable change." He suggested that the birth of a child with disabilities begins a grieving process over a set of expectations and dreams that span generations of a family. By sharing the cultural and "family dream" and thus letting it go, he further proposed that such grieving may lead to opportunities for enhanced creativity and acceptance of the "reality" of living with people with different abilities. In one of the initial meetings, members of the Parents, Family and Friends Support Group watched a recorded video of Moses addressing these issues.

Observational data showed that there was much agreement among parents with his analysis.

Parents in this study clearly expressed their ongoing struggle to cultivate their child's full capabilities, while accepting her or him as a person, and now as a young adult in the culture. Moreover, parents then had to "negotiate" a process toward their vision with professionals in at least two different service systems (i.e., services for mental health issues and services for development disability challenges). One of the ways families built on their strengths was to develop a unique perspective and philosophy that challenged the assumptions of the dominant culture. For example, one family participating in this study had adopted a Native Canadian ideology, consistent with a more holistic view of the life cycle, self-healing and relationships (see for example, Romanic, 1988, on healing circles). Other family members focused more squarely on their understanding of the value of life and the belief that "problems bring gifts." One of the key gifts discussed by family members was their ability to value the steps in a "life building process." In this process, family members witnessed the person become more connected in small, but significant ways to the community and thus were able to demonstrate his or her abilities, rather than difficulties. Providing opportunities that enable the strengths of the person and his or her family to be demonstrated or built-upon should be the key function of families' relationships with professionals and their help-giving behaviour (Dunst et al., 1988).

# *CHAPTER 10*

# *FAMILIES LOOKING TO THE FUTURE*

## *Theresa and Her Family Looking to the Future*

*As Theresa and her mother look to the future, they realize Theresa has always had a community-oriented lifestyle including the home and family. Mom described Theresa's self-perception that she is no different from other people. So Theresa feels she does not belong in a segregated setting with people with disabilities. She will follow through with what's expected of her... "look what's done with supports and done with a routine and a schedule around it," said mom with hopefulness in her tone.*

*But Mom explained that "I feel like I am all alone... being a single parent... I find that what I lack is a support system." As she indicated, "having that support around me would give me more confidence because that's how I lose hope... And I am still scared because I don't know if... if something else happens whether I can pull back up again." Being a single parent also creates the fear that Theresa might be alone in the world should something happen to mom.*

*Friends and family without the experience don't understand and are even fearful of Theresa. Mom suggested that the lack of communication between members of her various networks does not matter to her though unless there were some practical purpose behind it. When friends do understand because they have had experience, mom recognizes these people have enough of their own stress and doesn't want to burden them with her problems. Mom said these people understand the challenges and you don't have to go through your whole life history because "they have been there."*

*Mom is worried about the future of community services. She described the dilemma that parents including herself now face. They have worked very hard to set up community-based programs and then are excluded as their children grow older. It is an enormous responsibility - "We are getting to a point where we are burned out because we have kept going, and obstacles in our way. Now we are still sort of faced with 'where do our kids go now'... I don't have the time. I don't have the energy, but if I don't..." Who will?*

### Where do We Go Now?

*All families discussed concern for where their family member will live and how she or he will fit into the community.* One father and mother discussed the issue as follows. Mom began:

> *Something I think parents like us are concerned about - when we start getting to middle age and then we think - What if something happens to us? Where are these people - our children - going to go? They're adults but they're not. They have some serious problems.*
>
> *[dad continued]*
>
> *And for him to be out on his own right now... I would give it a maximum of three months and he would be in trouble with the law. For kids like that to wind up in the jail system... it certainly wouldn't help...*
>
> *[mom added]*
>
> *It's scary no matter how you look at it. You understand society doesn't want somebody breaking the law, but on the other hand... if they wind up in the jail system it's not going to do any good... Our goal is that... if something happens to us, there's still something there for Mark - that he can go and live and be part of the community.*

Based on this type of concern, finding appropriate supports for their family member seemed a priority. As families looked toward the future, it became clear that a continual struggle they faced was the enormous responsibility of simply trying to help their family member "fit in" with the broader society. One parent discussed her efforts over the years to build support systems in the community, yet remained uncertain about the ability of community support systems to create a safe place. In her words,

> *It is really sad when you think about it, but we [parents] are getting to a point where we are "burned out" because we have plugged along all these years and kept going, obstacles in our way. Now we are still faced with "where do our kids go now?" I mean, you have to get on it again and now I'm looking at getting involved in a group home - planning and developing group homes. I don't have the time. I don't have the energy, but if I don't... there will be nothing there... or heaven forbid if I died tomorrow, she has nowhere to go. That's a scary, scary feeling.*

Siblings also shared this concern.

> *I know that in two years I will be gone [moved out of the family home]. But I know that I am going to have to deal with it. I know that when I'm in college I'm going to be worrying every day... Where's my brother, where's my brother? Is he in an apartment? It's going to be constantly on my mind.*

Other families also had silent fears about the future for their family member. "It's a worry really. When I get by myself, I wonder what's all going to come out of everything, especially after I'm gone. I'm afraid she might go back - really back..." Somewhat paradoxically, these fears were not alleviated by the fact that the person already lived in a residence.

One family expressed strongly that finding appropriate support for their son did not mean finding a group home; it meant finding options. In a family dialogue, dad began:

> *The whole idea of a group home - why do these people think that every parent wants to dump their child into a group home? We don't want to do that, and I'm sure we're not alone...*
>
> *[mom commented further on her son's desire for apartment living] Now people look at me and say "are you kidding? He can't live by himself," but that's what he wants right now... It's just like anybody else. We all have the option to change our minds and say "no this isn't what I thought it was." We all have that option to try new things and that's what he wants.*

## Finding the Right Circle of People

All families discussed their need to find the right circle of people to support the family and the person with a dual diagnosis. This support circle should cross the boundaries of informal and formal support systems to create a solid base of continuous support. In some cases this support system was needed as a back-up; in other cases families hoped to find a group of people who could be trusted and then work together, focusing on how to build a life with the person so that she or he could accomplish dreams and control her or his own destiny. One mother indicated her need to have relationships with supporters move beyond relief to help change the context and improve her ability to solve problems.

> *I need to have someone help me focus and get relief. That will help me to build up confidence. I need structured support in a crisis situation, not respite because it makes me feel really bad. I'll lie in bed all weekend thinking "Oh now I've really failed." I need to have support to solve problems. You do need respite for the relief, but you need to problem solve to get ahead so that the next time you know what to do.*

## Sustaining an Upward Spiral

Many families discussed their vision of a how to "get ahead" and radically change the nature of the relationships between citizens and professionals by working together. As one mother reflected on her hopes for the work of the support cluster as they began the project, she said:

> *I believe in the community process - I'm never quite sure how it's going to turn out, but I believe in the process of networking... It isn't just what people say or what comes out of it, but there's something really magical that happens when a group of people get together around somebody else... it gives you strength and it gives you a different view of things.*

Other families were focused on strategies to effect such social changes. These strategies included educating professionals and helping form a parent support network to prevent other families from experiencing the hardships with the service system described by these families over the life cycle.

### *Summary and Analysis of Family Experience: Toward the Future*

Looking toward the future held little change from the past and present for families. As parents discussed in their support group with family and friends, it was quite easy for their "dreams for the person to become condensed into today, the next morning, or night." Family members were very aware of the uncertainty about the future that created fear. Thus, families' desire to plan a future, rather than react to ever changing events and situations was related to a very real need for stability and a sense of permanence. Smith and Tobin (1989) reviewed several elements of "permanency planning" as parents and their families of persons with disabilities aged into later stages of the life cycle. These authors discussed literature related to residential, legal and financial planning as key concerns among families in their work.

Many family members had become clear on their strengths and needs regarding the level of support that was necessary to keep their family member at home. They were not naive in their assumptions about the possibilities for large scale change, but parents reflected a continual concern for having enough support as they attempted to build a whole life for themselves and their family members. However, as Pomeroy and Trainor (1991) have noted in their work with families of people with mental illness, the cultural assumptions embedded in service delivery systems have remained a great barrier to effective family support. These authors suggested that:

> In many cases, families are drawing upon a professional ideology that is simply not up to the challenge of caring for the seriously mentally ill in the community. Resources are directed towards extremely costly forms of service: inpatient care, hospital daycare, crisis intervention, which are relevant to only a small portion of the daily living experiences with their relatives. (p. 28-29)

Pomeroy and Trainor further outlined a "future worth imagining," for families. This future included "real input to the system; better care for people who need it; a positive impact on resources devoted to the problem; a base of family organizations which ensure that self-help is available and that advocacy is focused." (p. 36) However, most families in the present study thought about the future in relation to their family members' sense of self-worth and personal growth into the community, and in certain aspects away from the dominant ideologies in the culture. Moreover, this future vision had to incorporate issues related to their family member's "dual diagnosis" label, making the systems and resources issues much more complex.

# *CHAPTER 11*

# *THEMES OF MEANING ACROSS THE FAMILY LIFE CYCLE*

One of the key frameworks I used to interpret the life experience of families through their perceptions of stressful events and available resources was based on the work of Hill (1949, 1958). As adapted by McCubbin and Patterson (1983), this framework was designed to track the interaction between families' perceptions of stress and resources available to them over time, and then to describe families' adaptation and adjustment strategies. Olson (1988) then created a model in which communication mediated the links between two main dimensions of family life: cohesion and adaptability. Cohesion referred to the level of consistency and involvement in the family relationships, while adaptability referred to the level of flexibility to move in and out of different roles, for example. I have integrated this literature throughout this work and I have also considered the additional role of cultural values which encompass the individual, his or her family, the community and political context (see, for example, Bronfenbrenner, 1977, 1979). On the following page, I have provided a table to summarize what I believe to be the major findings of this research process described in the previous chapters (see Table 1).

*Table 1*

*Families' Experiences of "Living on the Edge" Across the Life Cycle*

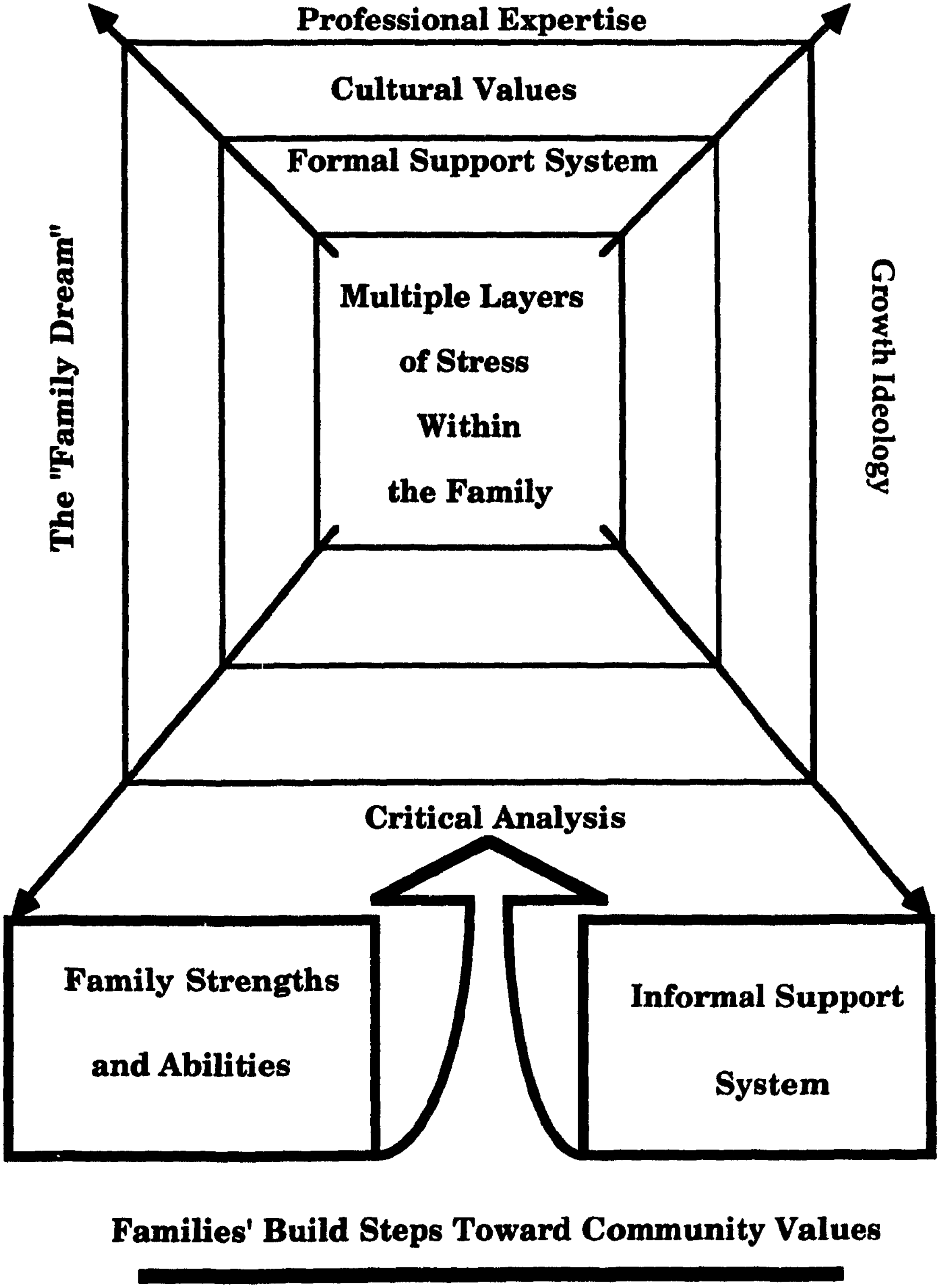
| | EARLY YEARS | CHILDHOOD YEARS | TEENAGE YEARS | YOUNG ADULTHOOD | TOWARD THE FUTURE |
|---|---|---|---|---|---|
| **STRESS WITHIN THE FAMILY** | • Joy, yet Concern<br>• Victims of Abuse | • Inability to Conform<br>• Siblings take on Adult Roles<br>• Marital Stress & Divorce | • Lack of Friends<br>• Marginalized to Death | • Planned Uncertainty<br>• Finding Purpose & Meaning | • Where Do We Go Now? |
| **FAMILY STRENGTHS & ABILITIES** | • Searching for Answers<br>• Identify Harmful Impact of "Treatment" | • Commitment to Process of Accommodation<br>• Mothers take Leadership | • Consolidating Values<br>• Taking Action | • Critical Analysis<br>• Sense of Self<br>• Sense of Family | Finding an Upward Spiral |
| **INFORMAL SUPPORT SYSTEMS** | • Expertise is Excluded | • Unhelpful Advice Parallels "Fixing" | • Need for Belonging | • Lack of Experience<br>• A Small, Select Group<br>• Emotional, not Practical Support | • Building the Right Circle of Ongoing Support |
| **FORMAL SUPPORT SYSTEMS** | • Hierarchy of Power<br>• Label and "Fix"<br>• Encourage Family Separation | • Institutional Placement<br>• Segregation Escalates Problems | • Institutionalize the Community<br>• Caught in the Continuum | • The "Catch-22"<br>• Dependence on Fragmented Systems | |
| **ROLE OF CULTURAL VALUES** | • Child Ought to be "Fixed"<br>• Professional Expertise is Most Valued | • Living up to the Cultural "Family Dream" | • Adjust Services to Maintain Value System | • Combatting the Linear Growth Ideology | • Acceptance of Individuality<br>• Enabling Focus |

Based on these findings from families' stories, I have discussed themes of meaning across the life cycle in this chapter. First, however, to fully describe the major patterns and themes of transition as families moved across the life cycle, I have provided an illustration of families' life history (see Figure 2). As depicted in this figure, the response to multiple layers of family stress was to envelope the family with the formal support system. This dominant role for services was supported by cultural values and assumptions, primarily the value of professional expertise, and yet added to the family stress. Families' expertise and their natural sources of informal support were excluded, however (see Figure 2). Other cultural values such as the "family dream" and expectations of growth toward independence were also a source of stress to the family, often producing conflict in the family that led to divorce and isolation of family members. As families began to build small steps toward more community-oriented values, they were supported by a few close informal supporters and their own strengths as family members. Their critical analysis of "the system" and the negative influence of cultural values provided a touchstone for families to "persist" in the culture, and, in spite of the culture.

*Figure 2*

*Living on the Edge:*

*A Community Analysis of Family Stress and Coping*



### *Living on the Edge: The Strength to Persist*

Through their years of experience, families had amassed an impressive, yet tragic record of repeated attempts, successes and failures with their family member. Families indeed "lived on the edge" and faced countless uncertainties along with many divisive forces including divorce, foster and institutional placements, competition for attention, and the need for a distinct sense of self. This was not a valiant struggle of martyrdom, but rather a struggle of necessity.

I believe the necessity to persist through many years of struggle gave families a critical awareness of the limitations and harmful impact of the broader cultural environment. Their daughters and sons could not compete or conform or make close friends; rarely included, they were forced as individuals and consequently as families to live on the edge of the social world around them. However, the freedom to attribute the nature of the family problems to an external set of environmental conditions rather than internalize them also freed families to recognize their personal strengths and capacities as a family. In a qualitative research study on the empowerment process in people with disabilities, Lord (1991) found that experiences of powerlessness were attributed to the environmental conditions, rather than the specific form or degree of the disability. The key factor, then, was the interpretive response by the social environment to the physical or psychological condition which gave the condition a "disabling" or a "handicapping" meaning for the person and the family.

Thus, finding decision-making and control elusive qualities in their lives, families were forced to separate out a balance of responsibility for themselves and for others; this was the key ownership process for family members. Families' assessment of the discrepancy between the resources available in both the service and informal support systems and those they were able to access, encouraged families to clearly recognize the faults attributable to external sources. Thereby, it also helped families to acquire the will to survive, rather than become victims of the "gaps" in social values and culture most often expressed in a more limited scope as "gaps in services." Families did not have to solve the deficiencies of their supports, but were motivated to persist in spite of them. This ownership process for families parallels work by Lord (1991) with individual's with disabilities in which the development of self-efficacy, or taking responsibility for one's abilities, was a key element in the process of some individuals' process of personal empowerment.

### *Life Experiences as "Oxymorons": Contradictions in Meaning*

A highly consistent pattern among families was the inconsistency between their expectations and their actual experiences of events that unfolded over the years. There were many examples of this pattern of contradiction, such as "home tutoring at school", respite services that needed strong family support, responsive community support systems that "abandoned" families, legitimate family involvement in institutional care, among others. The stress of such contradictions produced an existential gap where families consciously and continually were forced to question "what does this really mean?" What they learned was to find the answers within themselves, not by misplacing faith in others, but by learning to trust their own insight and perception. Thus, a key coping strength was the ability to interpret contradictory life events as having a philosophical, teaching value that assisted family members through "their reality" of struggle.

### *In Retrospect: Claiming the Responsibility to Act on Family Strengths*

Looking back over their family history, many family members talked about a re-evaluation of their experiences in light of new information. The common thread through much of their shared experiences was a return to their basic intuitions about "what was best" for their family and the person. Often this was reflected in comments such as *"looking back I realized..."*. In hindsight, then, families were able to identify their strengths and bring them forward into a variety of contexts in the present, working with service providers, informal supports and their family member given the psychiatric and developmental labels. This self-analysis created the opportunity for family members to give themselves feedback, taking stock of where they had been, what had happened and how they might better approach issues in the future.

Thus, over the life cycle, family members engaged in a continual process of integrating and re-integrating new experiences and information related to the uniqueness of their family member and the inadequacy of the response to the families' identified needs.

### *Iatrogenics of the Medical Model*

One of the key themes throughout the life experience of families in this study was the harm induced by the application of a medical - scientific model. This model of "fixing the person" by separating the person from her or his nature environment was repeatedly attempted across a continuum from institutional placement to segregated schools with their family member (for further discussion, see Nelson, 1983). The basic assumption manifest within the medical and social service systems that the person could be treated successfully in isolation was clung to in steadfast desperation. In part this unfounded conviction was due to the fear produced by recognizing or even admitting the scope of the problems with the social and cultural context that contributed to family functioning and the life of the labelled individual.

As the philosophy underlying services began to change over the 1970s, 1980s, and into the 1990s, families witnessed creative efforts to respond to family needs but those efforts required more work of family members already under stress. Families also witnessed the creation of a service continuum in the community that maintained control and decision-making power in the hands of professionals, rather than family caregivers. Families directly experienced the "institutionalization of the community" as a response to their need for access and continuity in family supports. In part this was due to the systematic withdrawal of informal supports such as extended family and friends, as the system of formal services expanded to fulfil a role that sustained and was consistent with the culture of individualism, rather than community. However, the lessons learned by this generation of families was that formal services cannot theoretically or in practice build on family strengths and meet their needs to the degree necessary. In fact, they, along with their family member with disabilities, learned "the hard way" that misplaced faith in a deficit-oriented treatment approach would not build a meaningful life for the person or the family as whole.

### *'The Planned Life of Uncertainty"*

Although decision-making and control were elusive qualities of family life, the family was forced to attempt conscious and deliberate steps at each stage of the person's life. Families were forced to question: Should she go to that school? Should he stay in that program? Can we leave her at home alone? Will he ever have a real friend? Can we support her to find a job and contribute to the community? Ranging from the very significant points of life transition to the very mundane everyday life decisions that other members of the community often make unconsciously, these family members had to actively plan. The added feature of this planning process over the life cycle which made it unique was the day-to-day uncertainty of the person and the response of the formal and informal community around the individual and her or his family.

This "planning for uncertainty" often produced a perception of separation from the anticipated natural flow of family members' personal lives; for some members it meant stagnation, while for others such as siblings, it meant acceleration into adult roles. As spontaneity began to diminish in the person's life, spontaneity also left the family system as siblings matured for responsibilities beyond their years and parents struggled with how to keep it all together, sometimes failing. When the person became separated and segregated from mainstream social environments, family members and in particular mothers also followed into more separated and compartmentalized lives, discussed further below.

Thus, each individual family member's life was involuntarily put on a schedule that matched the person's growth and the effects of an often harmful environment. From this matching process, family members developed a keen awareness of the assumptions underlying systems in our culture and began to form a "lens" of critical thinking. For example, they appreciated the thin line or "tightrope" balancing act required to be "successful" in our competitive culture as shown by their early experiences with the educational system.

### *Making the Transition Through Isolation*

Connected to "living on the edge," over the early and childhood years family life became more squarely focused around the person given the disability labels. As the person moved into more segregated and "deficit specific" environments, the family had several options. One option chosen by family members was to make clear distinctions between various parts of their lives. For some fathers this meant leaving the person and the family through a divorce process; for others it meant out-of-home residence for the person with disabilities, given the lack of supportive in-home services available - this was *not* abandoning the person, it was finding a life. A second option developed by some family members was to get directly involved in community development work. Out of their frustration and anger, these people grew to become key players in their own communities by constantly learning about the political process of service delivery and advocating for change (see Figure 2).

In part, these experiences of working for change prepared some of the families and increased their willingness to become involved in the Support Clusters Project. In spite of the uncertainty, they already understood the potential benefits of having a small, focused group working together with their different strengths and capacities. Others imagined the potential of not being alone in their struggle and were ready to end their search for continuity and stability.

# *CHAPTER 12*

# *REFLECTIONS ON MEANING AND SELF-EVALUATION*

As I have gone through a lengthy process with this research project, I have been continually grounded in the life experience of families. Throughout this work, and in this chapter, I have included my perspective on the meaning of these life experiences. I have offered below a few personal insights about families' experiences and "where to go from here." However, my only wish is to carry the messages I have learned from families. I do not wish for you as a reader to listen to my voice, but ground yourself in the life experience of these families.

## *Meaning of 'Dual Diagnosis"*

I learned what families have already known for a long time - that the meaning of "dual diagnosis" was very different for different people. Families also knew that the meaning of "dual diagnosis" is necessarily arbitrary because it is just a label. Labels are a political tool, not a family support technique. As one dad said, "These people are special people who don't need to be labelled - not at all actually... Not labelled, but to be treated with dignity and respect." Extending that respect to family members is also necessary. My experiences have been that these individuals and their families have a keen insight and understanding of their social environment. However, the social context of experiencing both developmental and mental health problems is that family members often feel they are "not believed" by others in the community, sometimes the extended family, and especially as they attempted to access services and educational systems. Increasing the awareness of key "gatekeepers" (i.e., people who control valued resources such as neighbors, store owners, friends, and humans service workers) in the community about the nature of co-existing developmental disability and mental illness is one necessary first step.

### *Meaning of Families' Experiences Across the Life Cycle*

Much of the meaning of families' life experiences has already been explored in this research. However, I have offered a few additional comments below about the empowerment process and hope for the future.

#### *The Empowerment Process*

I believe that families who were able to endure the ambiguity of searching for answers and then went on to develop shared values became much stronger. The leadership provided by mothers in these families was a key element to their success in negotiating this process within the family and then with the broader community support systems, such as the school. Consistent, then, with the definition used by Lord (1991), this process helped families to "achieve increasing control of their lives and participate in the community with dignity." But more than that, however, these families had to create the opportunities to achieve control because their social environment did not provide for or support them. As Rappaport (1987) has suggested, empowerment is both a personal process and characteristic of enabling environments. Thus considering both aspects of the definition, I believe that none of these families was "empowered." For these families to be fully "empowered," significant changes to the social and cultural context were required at least in their direct experience.

### *Hope and Strength*

Families were willing to carry their share of the work to support their family member in the community; they have attempted to do just that for many years. They were even willing to help workers in service systems become more responsive and effective in their work; in effect, to "support their supporters." I realized from families' experience, however, that over-extending one's self is not necessarily conducive to mental health. Family members had already learned to try not to let disability issues become dominant in every single aspect of their lives. But part of that safe distancing meant there was a role for outside assistance to follow through on desired changes and even initiate them when family members need to just "get on with their lives."

I believe the hope of these individuals and their families is grounded in finding and claiming their own strengths and abilities. However, this hope further rests with the community to own and act upon its share of the responsibility to support these individuals and their families; that means taking initiative, and accepting the individuality of the person and her or his family.

### *Meaning of Families' Experiences with Service Systems*

Based on the process of listening to families' stories, I have provided a number of insights about how human services, or formal support systems, might become effective in supporting the person and his or her family.

(1) First, human services to support the person and his or her family must be individually tailored. If nothing else, I have been grounded in the uniqueness of each individual and her or his life experience and abilities. Trying to alter conventional services to be responsive to people given a "dual diagnosis" label will not likely be successful in the long-term because, as I have learned from families, people supporting their family member must be innovative and adapt on a daily basis. I am *not* suggesting that services be provided to segregate the person from community life, but rather services that

help integrate the person to become a full and participating member of the community should be provided.

(2) Second, human services that are supportive, will create opportunities for the person and his or her family to be involved in key decision-making processes. That means the agency mandates must be secondary to the wishes of the person and her or his family and that human service workers will have to create a new style of supporting families' competencies (see for example, Bennett, Lingerfelt, & D.E. Nelson, 1990).

(3) Third, to be effective human services must build upon the competencies of the person, family and their informal supporters, such as extended family members and friends. Clearly, the strengths of the community offer the continuity and access to resources needed by the person and her or his family. To be effective, then, human services must provide a structure (i.e., the means, not a building) that helps re-connect informal supporters into the practical issues of everyday day life for the family, without over-burdening them. That also means understanding the history of encouraging separation of the person from their immediate family. This assumption of "fixing the person" in isolation because families were seen as incompetent, was also adopted by informal supporters and created perceptions of inability and inadequacy. These changes will not happen overnight, but surely efforts can start.

(4) Fourth, and perhaps a prerequisite to the other points above, the assumptions and values that have shaped the role of human services in our culture must be recognized and challenged. Because we have these assumptions embedded into our cultural perspectives, it is difficult to imagine a world without them. Historically, human services most likely began as an expression of certain values of caring for humankind. Thus my assumption about human service workers is that they hold such values and do their very best to express them. However, the predominant role human service systems now play is much more progressive and assertive in creating values than reflecting them. In fact, we can no longer imagine a world without human services. Why is it also true that we can hardly imagine a world with a network of unpaid people who support others to live in the community?

## *Evaluation of the Research: A Process of Self-reflection*

As I clearly stated, the main purpose of this research project was to describe the meanings and life experience of families in the Support Clusters Project. I wanted to understand the life history and context of these families and then communicate their message to others in the local community and elsewhere. I believe that I have achieved this purpose through a rigorous research process that included ongoing feedback and relationships with family members. This project has been beneficial in a number of ways I have outlined below as contributions to families, myself as the researcher, and the understanding of others.

*Contributions to Families*

I believe that this research process and document has made several important contributions to both families in the research study and other families also "living on the edge" in the community. For those in the study, this research process has provided them with a record of their family story that has been repeated many times over many years - many said they had never before received a copy of such a document, but have often thought it would be so much easier to simply make a tape and hand it over at service intake meetings. In response to the interview transcript, one family member said, "It's been really nice to have it so that that we can look it over and see how far we've come." Families also received a very comprehensive summary of the interview transcript, to which one father responded, "We have a whole basement full meaningless information - now we have something we can actually use." The interviews were long and sometimes tiring, but many family members experienced this listening process as extremely valuable. Many people found it challenging to be asked about their strengths and abilities saying, "That's hard to answer - we've never been asked that before."

I believe this listening process also helped set a responsive tone for the entire Support Clusters demonstration project - that families' stories were valued and important to hear. The summary of the support group was presented to the steering committee after which one parent responded, "Our feelings and concerns were expressed openly, which we were never able to do before... Don has said it exactly, as we, our family, has felt for so many years." This research process also demonstrated the value of having family members tell their own story, indirectly connecting some family members with project staff to make presentations to funders. This research document will feed into the overall evaluation of the Project and become part of a publication at the Centre for Research and Education.

Beyond the Support Clusters Project, and the families participating in this research, this document will be shared with the local community and others interested in family support issues. Thus, sharing families' stories with other members of the community, researchers, and human service workers will help to increase others' understanding of these families' perspectives and thereby contribute toward more responsive community supports for families.

### *Contributions to the Researcher*

I have learned and matured a great deal in this research process. Family members have taught me to trust my instincts and my knowledge of family life in working with people - to be a human being first, and then bring whatever skills I offer as a "professional" second. They have taught me to think critically about the world of human services and how we all share a responsibility to work toward social justice. I also learned a great deal about the commitment and perseverance an effective qualitative research process requires and that the benefits far outweigh the struggle.

### *Contributions to Understanding of Family Support*

The principal learning of this research process concerns how the layers of families' experience built a perceptual framework for interpreting the world around them. This learning is consistent with the stated purpose of the research. Thus, this research process and document has discovered many elements of the history of family stress processes in relation to "dual diagnosis." As a secondary learning process, I have established linkages between these families' life histories and sources of published literature throughout this document. A key learning was that family-centred models such as those provided by Hill (1949, 1958), McCubbin and Patterson (1983), and Olson (1988) must be understood within the cultural context (for a further analysis of social-political context, see Prilleltensky, 1990).

# References

Advocacy Resource Centre for the Handicapped. (1990). *Responding to the abuse of people with disabilities.* Toronto, Ontario: ARCH.

Bennett, T., Lingerfelt, B.V., & Nelson, D.E. (1990). *Developing individualized family support programs: A training manual.* Cambridge, MA: Brookline Books.

Borthwick-Duffy, S.A., & Eyman, R.K. (1990). Who are the dually diagnosed? *American Journal on Mental Retardation, 94,* 586-595.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32,* 513-531.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and by human design.* Cambridge, MA: Harvard University Press.

Carter, B., & McGoldrick, M. (1988). Overview - the changing family life cycle: A framework for family therapy. In Carter, B., & McGoldrick (Eds.), *The changing family life cycle: A framework for family therapy* (Second edition, pp. 3-28). New York, NY: Gardner Press.

Coyne, J.C., & Downey, G. (1991). Social factors and psychopathology: Stress, social support, and coping resources. *Annual Review of Psychology, 42,* 401-425.

Cull-Wilby, B.L. (1990). *The change in the researcher doing phenomenology.* Paper presented at the Qualitative Health Research Conference in Edmonton, Alberta, February.

Dakoff, G.A., & Taylor, S.E. (1990). Victims' perceptions of social support: What is helpful from whom? *Journal of Personality and Social Psychology, 58,* 80-89.

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

Dunst, C.J., Trivette, C.M., Gordon, N.J., & Pletcher, L.L. (1989). Building and mobilizing informal family support networks. In G. Singer & L. Irvin (Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (pp. 121-141). Baltimore, MD: Paul H. Brooks.

Dyson, L. (1991). Families of young children with handicaps: Parental stress and family functioning. *American Journal on Mental Retardation, 95,* 623-629.

Frey, K.S., Greenberg, M.T., & Fewell, R.R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. *American Journal on Mental Retardation, 94,* 240-249.

Gallimore, R., Weisner, T.S., Kaufman, S.Z., & Bernheimer, L.P. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed children. *American Journal on Mental Retardation, 94,* 216-230.

Gergen, K.J. (1985). The social constructionist movement in modern psychology. *American Psychologist, 40*, 266-275.

Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory.* Chicago: Aldine.

Goldenberg, I.I. (1978). *Oppression and social intervention: Essays on the human condition and the problems of change.* Chicago, Illinois: Nelson-Hall.

Gottlieb, B.H. (1985). Social networks and social support: An overview of research, practice, and policy implications. *Health Education Quarterly, 12*(1), 5-22.

Griangreco, M.F., & Putnam, J.W. (1991). Supporting the education of students with severe disabilities in regular education environments. In Meyer, L.H., Peck, C.A., & Brown, L. (Eds.), *Critical issues in the lives of people with severe disabilities* (pp. 245-270). Baltimore, Maryland: Paul H. Brookes.

Heller, K., Price, R.H., Reinharz, S., Riger, S., & Wandersman, A. (1984). *Psychology and community change: Challenges of the future* (Second edition). Pacific Grove, CA: Brooks/Cole Publishing.

Hill, R. (1949). *Families under stress.* New York: Harper & Row.

Hill, R. (1958). Generic features of families under stress. *Social Casework, 49*, 139-150.

Hutchison, P. (1990). *Making friends: Developing relationships between people with a disability and other members of the community.* Downsview, Ontario: The G. Allan Roeher Institute.

Kazak, A.E., & Wilcox, B.L. (1984). The structure and function of social support networks in families with handicapped children. *American Journal of Community Psychology, 12*(6), 645-661.

Kessler, R.C., Price, R.H., Wortman, C.B. (1985). Social factors in psychopathology: Stress, social support, and coping processes. *Annual Review of Psychology, 36*, 531-572.

Keys, C.B., Fletcher, R.J., Holmes, P.A., & Schloss, P.J. (1989). Bridging the two cultures of dual diagnosis: Research and service. *Research in Developmental Disabilities, 10*, 277-284.

Levine, M. & Perkins, D.V. (1987). *Principles of community psychology: Perspectives and applications.* New York, NY: Oxford University Press.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage Publications.

Lincoln, Y.S., & Guba, E.G. (1989). *Fourth generation evaluation.* Newbury Park, CA: Sage Publications.

Lord, J., & Hearn, C. (1987). *Return to the community: The process of closing an institution.* Kitchener, Ontario: Centre for Research and Education in Human Services.

Lord, J. (1991). *Lives in transition: The process of personal empowerment.* Kitchener, Ontario: Centre for Research and Education in Human Services.

Maslow, A.H. (1954). *Motivation and personality.* New York: Harper.

Matson, J. (1988). *Manual for the Psychological Inventory for Mentally Retarded Adults.* Orland Park, IL: International Diagnostic Systems.

McCubbin, H.I., & Patterson, J.M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage and Family Review, 6,* 7-37.

Moos, R.H., & Moos, B. (1981). *Family Environment Scale.* Palo Alto, CA: Consulting Psychologist Press.

Moses, K. (1988). *Lost dreams and growth: Parents' concerns.* Resource Networks Inc. Maple Ave., Evanston, IL.

Napier, A.Y., & Whitaker, C.A. (1978). *The family crucible: The intensive experience of family therapy.* New York, NY: Harper & Row.

Nelson, G. (1983). Community psychology and the schools: From iatrogenic illness to prevention. In R.F. Morgan (Ed.), *The iatrogenics handbook: A critical look at research and practice in the helping professions.* Toronto, Ontario: IPI Publishing.

Olson, D.H. (1988). Family assessment and intervention: The circumplex model of family systems. *Marriage and Family Review, 11,* 9-48.

Patton, M.Q. (1986). *Utilization-focused evaluation* (Second edition). Beverly Hills, CA: Sage.

Patton, M.Q. (1990). *Qualitative evaluation and research methods* (Second edition). Newbury Park, CA: Sage.

Pomeroy, E., & Trainor, J. (1991). *Families of people with mental illness: Current dilemmas and strategies for change*. Toronto, Ontario: Canadian Mental Health Association/National Office.

Potasznik, H., & Nelson, G. (1984). Stress and social support: The burden experienced by the family of a mentally ill person. *American Journal of Community Psychology, 12*, 589-607.

Prilleltensky, I. (1990). On the politics of abnormal psychology: Past, present, future. *Political Psychology, 11*, 767-785.

Rappaport, J. (1981). In praise of paradox: A social policy of empowerment over prevention. *American Journal of Community Psychology, 9*, 1-25.

Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American Journal of Community Psychology, 15*, 121-147.

Reiss, S. (1990). Prevalence of dual diagnosis in community-based day programs in the Chicago metropolitan area. *American Journal on Mental Retardation, 94*, 578-585.

Riessman, F. (1990). Restructuring help: A human services paradigm for the 1990s. *American Journal of Community Psychology, 18*, 221-230.

Romanic, G. (1988). *Women's healing circles: Manual I.* Barrie, Ontario: Soaring Hawk Enterprises.

Ryan, W. (1971). *Blaming the victim.* New York, NY: Random House.

Schultz, S.J. (1984). *Family systems therapy: An integration.* New York, NY: Jason Aronson.

Senn, C.Y. (1988). *Vulnerable: Sexual abuse and people with an intellectual handicap.* Downsview, Ontario: The G. Allan Roeher Institute.

Singer, G.H.S., & Irvin, L.K. (1991). Supporting families of persons with severe disabilities: Emerging findings, practices, and questions. In Meyer, L.H., Peck, C.A., & Brown, L. (Eds.), *Critical issues in the lives of people with severe disabilities* (pp. 271-312). Baltimore, Maryland: Paul H. Brookes.

Smith, G.C., & Tobin, S.S. (1989). Permanency planning among older parents of adults with lifelong disabilities. *Journal of Gerontological Social Work*, *14*, 35-59.

Strauss, A.L., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage Publications.

The Association for Persons with Severe Handicaps. (1991). Resolution on people with mental retardation who are also diagnosed as mentally ill. In Meyer, L.H., Peck, C.A., & Brown, L. (Eds.), *Critical issues in the lives of people with severe disabilities.* Baltimore, Maryland: Paul H Brookes.

Todis, B., & Singer, G.H.S. (1991). Stress and stress management in families with adopted children who have severe disabilities. *Journal of The Association for Persons with Severe Handicaps*, *16*(1), *3-13.*

Trute, B., & Hauch, C. (1988). Social network attributes of families with positive adaptations to the birth of a developmentally disabled child. *Canadian Journal of Community Mental Health*, *7*(1), 5-16.

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Ontario: Althouse Press.

Zigler, E., & Burack, J.A. (1989). Personality development and the dually diagnosed person. *Research in Developmental Disabilities*, *10*, 225-240.

# Appendix A

# Ethics

## Purpose of the Thesis Research:

The purpose of the proposed research is to describe the meanings of the life experience and culture of families in the Support Clusters Project. More specifically, the research is motivated by a desire to clarify and express the unique perceptions of families' personal meanings of lived experience over the process of the family life-span or "career". A primary objective of this research, then, is to create the understanding necessary to increase families' control in such life situations and thereby increase awareness in the community. Thus, families' stories of success and struggle are the key ingredient for grounding this research in the resilience of families coping in the culture.

## Review of the Research Process:

The Support Clusters Project is a 30-month research demonstration project designed to provide support to families in which a member has been "dually diagnosed". The Health Innovation Fund provides the financial resources through the Sunbeam Centre to a local resource office (at Community Resources) which disperses and manages the funds. The Centre for Research and Education is a non-profit organization that olds the contract to complete the evaluation of the project. As a member of this particular evaluation team I have been involved in the project since its start-up (approximately October 1990).

### *Role of Project Staff*

As the primary recruitment people, project Staff are responsible for explaining the purpose of the project and its evaluation. Staff provide information, receive and forward written consent forms for participation in the project and the research. This consent is received prior to contact by the research team.

### *Role of Research Team*

The research team is responsible for the evaluation of the project overall in a number of different facets, and reports to the steering committee on an ongoing basis. Specific to this thesis, however, three sub-sections of this research have been proposed to be included: baseline interviews with families, observations of a family and friends support group, and observations and minutes of two clusters from their inception to conclusion in the project. The evaluation team discuss the nature of the project and the role of the evaluation with the participants prior to the baseline interviews - both in a telephone conversation and at the time of the interview (see Appendix A).

Interest in the proposed thesis research grew out of the evaluation already in process. In July of 1991, I along with the evaluation team proposed that I conduct a more thorough investigation using data already collected and in process.

The emergent nature of this research is some cause for concern. Although it may be construed as largely an archival analysis of data already collected, this does <u>not</u> mean people's right to informed consent and confidentiality are not important. I have attempted to address these issues in several ways:

(1) Providing information and obtaining consent from the steering committee - several members of the committee are also participants in the project and the research.

(2) Providing a letter to family members more explicitly outlining the use of research materials collected in the project (see Appendix C).

(3) As a member of the evaluation team, I have been personally accessible to participants in the project in a number of ways, for example, providing personal copies of their interviews.

(4) Ensuring that no data is collected for this proposed thesis that is not pertinent to the evaluation of the project, and hence, an integral part of the research demonstration process of Support Clusters.

### Tape Recordings:

The tape recordings are presently stored in a secure file cabinet along with other confidential materials, only accessible to members of the research team. At the conclusion of the project the tapes will be erased.

### Risks and Benefits:

*Risks:*

(1) Personal stories about family life in crisis can evoke strong negative feelings about past events and situations. These stories need to be treated with respect and not serve to further "victimize" families.

(2) Relatedly, it would be easy to focus on these negatives as past research has often overemphasized and produce a final document that shows in some way the inadequacy of the family and its abilities. I will consciously use a positive framework to interpreting these histories and try to shape the interviews themselves by asking about family strengths and resources.

*Benefits:*

(1) Participants have had a long history of information intake interviews and forms to receive services. In most, if not all cases, participants have not had the opportunity to tell the real story about their experience from many different points of view.

(2) Participants will be given the opportunity to tell their stories in a place of their choosing, for example in their homes, rather than across a desk in an office.

(3) Participants will be able to receive a copy of their transcript and summary.

(4) The listening and feedback process will confirm the value of participants' experiences, and begin to validate their very real concerns for the future.

(5) This research will also present an opportunity to link families with one another based on their common experiences and concerns, thus showing families that they are not alone in their isolation and difficulty which may become internalized, rather than attributed to an external environment of service provision, for example.

(6) The themes and patterns that grow out of the research will be highly important to share with the service community in a confidential way, thus being useful as a document to stimulate education and change.

**Feedback:**

Feedback will occur in several ways. As part of the ongoing research process, participants will have copies of their transcript and summaries of their own interview made available to them. They will also receive a first draft of the overall analysis. No later than Thursday, September 3, 1992, I will present the completed findings to the project steering committee and provide a written summary. I will specifically invite family members to attend this meeting and hope to engage them as co-presenters of the research. I will also mail the written summary in final form to families that participated in the thesis research.

## General Information and Statement of Confidentiality: Family Baseline Interviews

Note: Prior telephone contact with family members introduced the research team and the purpose of the research. Interviews were scheduled in the privacy of families' homes at a time of their choosing. Consent was also received to use a tape recorder. Confidentiality extended to the contents and care of the tape.

Introduction: (Researcher introduces self and the Centre for Research and Education)

I believe that the Support Cluster Staff have discussed with you the fact that this is a research demonstration project and that you have agreed to take part in the documentation that will go hand-in-hand with the development and growth of your support cluster. The overall purpose of our documentation is to assess how effective this process will be with families and our community. What this means for you is that a member of the research team will be contacting you at various points in the project to conduct personal interviews. After this initial interview, we will likely be calling you in about 6 to 8 months to follow up on what we talk about today. As well, we shall be observing Support Cluster meetings when they get underway, and perhaps any other activities or events that take place as part of the project.

Opportunity for questions and discussion

In this first interview, we would like to do a number of things. First, we would like to hear your story - your perceptions, thoughts and feelings about how things have worked out in the past for you and (your family member), how things are going right now, and perhaps some of your goals for the future. We would also like to talk about your present support systems, both formal and informal. By formal we mean services and/or programs -like doctors, respite services, day programming, and so on. By informal, we mean family, friends, community participation and so on.

This project is "action research" based. What this means is that the information we find out during the documentation process will be shared at regular intervals with individual clusters, the steering committee, and the support cluster staff. The goal of using this method is to ensure that learnings are reviewed with the appropriate participants in an ongoing manner, so that the process and methods can be adapted along the way to ensure the best possible outcomes for clusters. But, the information you share with us is confidential and will only be shared within the documentation team. When we share our learnings with staff and the steering committee, it will be done in a way that does not identify individuals, but general patterns and themes that are growing out of the documentation. Our reports to the funder will be presented in a way that respects the privacy of participants.

Opportunity for questions and discussion.

## Consent of the Support Clusters Steering Committee

Evaluation Update

July 4, 1991

From our initial feedback and involvement with participants in the project, it seems clear that families have an extremely rich story to tell. Understanding their perceptions of stress, resilience and issues related to social support are a very important foundation for this project. As part of our ongoing efforts to be responsive to the needs of the support clusters project and its participants, the evaluation team would like to augment the research and evaluation already in process.

As a member of the evaluation team, Don Roth has completed the practicuum component of the Community Psychology program at Wilfrid Laurier University. This Masters level program also requires a thesis in the second year. Thus the evaluation team proposes that Don stay associated with the support clusters project and complete the thesis requirement conducting a more indepth exploration related to the issues outlined above. This thesis would not extend participants' involvement in the project thus adding more stress and work etc., but rather be an integral part of the ongoing data collection and analyses.

Several people have expressed interest in working on this thesis with Don.

Advisor:

Dr. Geoff Nelson (Wilfrid Laurier University)

Committee Members:

Dr. Steve Chris
Dr. Richard Walsh
Dr. John Lord

## Letter to Family Members

Dear (Participants in the research project)

In the past year, as part of your involvement with the Support Clusters Project you and members of seven other families have participated in an interview with a member of the evaluation team (Joanna Ochocka, John Lord, Eric Macnaughton, Arthur Lukey, Shelley Adams, and Don Roth) from the Centre for Research and Education in Human Services. This interview focused on your past experiences growing up as a family and dealing with issues related to dual diagnosis. The purpose was to get an understanding of families experiences up to the start of the project and then to compare this history with how the Support Clusters project worked. To more fully understand families' experiences, we are working to pull together three different sources of information for this chapter of the final document:

(1) baseline interviews with eight families;
(2) observations and feedback from the Parent's, Family, and Friends Support Group; and,
(3) observations and minutes from support cluster meetings that are related to the topic of family history.

The interviews will form the main part of the work. Number (2) and (3) above will be used as sources that may support the interview findings or show new or different patterns.

As a research team, we wanted to give you all a brief up-date on how things were going and highlight a few other details. As part of the team, I (Don) have been working on this section of our work for the final document. I have been able to spend a great deal of time pulling together the common patterns between your experiences as family members as well as some of the issues unique to each of your families' lives. As a graduate student at Wilfrid Laurier, I am also required to work on a thesis project. This part of the evaluation work with Support Clusters fit nicely with my own personal interests and so I proposed to the steering committee several months ago that we simply join the two. As part of the evaluation of the project, this would not add any additional interviewing or take up the further time on the part of people in the project and yet provide the necessary means for "getting the story straight". The steering committee agreed that this type of work was important to get the message out there properly. Please note that this work is part of the Support Clusters Project and has been conducted with the utmost respect for your confidentiality. *No one other than the evaluation team working on Support Clusters has access to your interview and all public documents will not identify individuals.*

**You are entitled to receive:**

1) a copy of your interview with Centre staff (almost all are transcribed)
2) a summary of the interview written by Don (almost all are completed)
3) a copy of the summary from the Parent Support Group (some of you may already have a copy)
4) a summary of the overall analysis that combines these sources of information in a way that does not identify individuals (this eventually becomes a public document, but right now is in a very preliminary stage)

In addition to the list of information that is yours, you can also be involved in this research as much (or as little) as you want. For example:

- Tell us what you think of the interview, the summaries, etc.
- What would you like to see done with the information that becomes public (for example, who should get it besides the steering committee)?
- Would you like to be involved in any way in presenting some of the public information to the steering committee or elsewhere? It is your story and after working on this project for some time it seems clear to us that you can tell it better than anyone else.
- Any other way that comes to mind?

*Please call Don at either number listed below (or write) to talk more about this information or any concerns, questions, etc. (or please leave a message and I'll get back to you)*

Thanks for all your help. We look forward to talking with you in the near future.

Sincerely,

Don Roth
John Lord

Please write:
Centre for Research and Education
in Human Services
P.O. Box 3036, Stn. C.,
Kitchener N2G 4R5
Or call the office:
26 College St.
Kitchener, Ontario
Or call Don at home

# Appendix B

## Family Interview Guide

## Family Interview Guide

I'd like to get a grasp of your experience with ______. It would be helpful if we could begin by getting a sense of your early life with ______, and then look at how things are for you now.

Pause -- ensure the family members present are comfortable with this approach.

1.1 Could you begin by describing the first years of your family life with ______.
Probes: # of children? how _______ fit in? feelings of control?

1.2 When ______ went to school, what issues did you face?
Probes: acceptance or labelling? segregation or integration? feelings of control?

1.3 When ______ became an adolescent, what issues did you face?
Probes: acceptance or labelling? segregation or integration? feelings of control?

1.4 Could we begin by getting a sense of your life now with ______.
a) Who lives with you here?
Probe: Other members of your family?
b) Tell me about each persons relationship with ______.
Probe: How they participate together.
c) Who else is likely to be involved in the support cluster?

1.5 Could you describe a day in your life with ______.
What would a week be like?
Probes: morning? day programs? primary care person? evenings? weekends? feelings about these (above list)? feelings of control?

1.6 In terms of your relationship with ______, what would you say is going well at the moment?
In terms of your relationship with ______, what would you say is not going well at the moment?

1.7 Personally, how do you feel about the life track your ______ (daughter, son etc.) is on?

1.8 In what areas of your life would you like to have more control?
Probe: How are you coping?

## Section II: Competence

2.1 In your opinion, what do you perceive to be your strengths when dealing with _____?

2.2 In your opinion, what areas do you perceive to be somewhat difficult when dealing with _____?

2.3 Based on what we just discussed (strengths and difficulties) how competent do you feel in dealing with your son/daughter who has been labelled with a dual diagnosis? (1-7 scale)

2.4 How competent do you feel in dealing with community services when trying to secure needed supports? (1-7 scale)

2.5 In terms of your participation in the Support Clusters project, what do you hope to gain in terms of personal competencies?

2.6 What kinds of information and/or education do you feel would help you work more effectively with your son/daughter? (each area is rated on a 1-7 scale for current skill and knowledge)

2.7 In terms of your responsibilities with/for _____, what events do you find stressful?

## Section III: Social Supports

3.1 Please list your formal supports and why you and/or your child has been/is currently involved.

3.2 Generally speaking, how responsive, hospitable, open do you feel these services/programs are to meeting your/your son's or daughter's individual needs and concerns (rated on 1-7 for each of the above list)
Could you explain how you feel about this level of responsiveness?

3.3 Generally speaking, how easy is it for you to access needed formal supports?
How do you feel about your access to community supports?

3.4 Do you have any perceptions about the difference between agencies and services that seem easier/friendlier?

**3.5** Please list your informal supports and your relationship to this person. How would you describe each of these people's relationship with _____?

When comparing the people who relate to ______ how consistent or varied is each person's approach?
Please review the lists and note what kind of support these people provide such as practical aid, information, emotional support, etc.

**3.6** Generally speaking, how responsive, hospitable, open do you feel these people are to meeting your/your son's or daughter's individual needs and concerns (rated on 1-7 for each of the above list)
Could you explain how you feel about this level of responsiveness?

**3.7** Generally speaking, how easy is it for you to access needed informal supports?
How do you feel about your access to informal supports?

**3.8** Are there any characteristic of some of your informal supporters which set them apart from others and somehow make them more or very supportive?

**3.9** What do you generally do in response to an emergency or crisis situation (concerning your daughter/son labelled with a dual diagnosis)?

## Section IV: Communication

**4.1** When you have concerns about your daughter/son/brother/sister, with whom do you feel you can share these concerns?

**4.2** Generally speaking, how well would you say you and your informal network currently communicate with one another (rated on 1-7 scale)?
How do you feel about this level of communication?

**4.3** Generally speaking, how well would you say you and your formal network currently communicate with one another (rated on 1-7 scale)?
How do you feel about this level of communication?

**4.4** When you share your concerns, what degree of support and direction do you feel the following people provide for you? (all rated on 1-7 scale: spouse/partner, family, friends, co-workers, service providers, other)
Any further comments, concerns or issues?

# Appendix C

## Parents, Family, and Friends Support Group

# From the Parents, Family, and Friends Support Group
# A Summary of our Past Meetings
# Revised on November 4, 1991

## Reasons for Meeting in this Group

The discussion revolved around making a difference for ourselves, for others, and in the project overall.

*For Ourselves:*
- To build on our capacity to respond and help
- To create a helpline or directory (for example, phone numbers of other parents and names of agencies, etc.)
- To put anger in its place and work together

*For Others:*
- To get the community involved
- To increase others' understanding of the person and our history together
- To help other individuals and younger families coming along through the system

*In the Support Clusters Project:*
- To act as an advisory group in the project
- To take ideas to our individual support clusters

## Problems in Living Experienced by Families

The discussion of these issues focused on three broad areas: isolation, urgency, and value.

*Isolation:*
- Feel isolated in the community; a sense of "what do I do", "where do I go", yet never really get anywhere
- It is very hard to make others understand our constant struggle... so we keep it to ourselves
- Integration has been done poorly in the past
- Labels do not help; labels are "double-edged swords" because we need them to get services yet experience segregation

*Urgency:*

- Few assessment services available
- Assessments seem incomplete and may not include the family
- Parents need to get pushier to get noticed - demand everything and yet may not get help anyway
- Right now you have to go all the way to a crisis before you can get help

*Value:*

- We know our family members are valuable to society, but we always have to prove it to others
- It is worth getting involved, but that's hard to justify when members of families may not have a personal commitment
- Getting involved means accepting the person for who she or he is but there seems to be a lack of compassion

## Experiences and Struggles with our Family Member

*Our Struggles:*

- The inconsistency in the person's behaviour
- We work very hard to get things (like programs) set up and just when things look very positive - everything collapses
- Trying to get inside the person's head to understand how she or he sees and understands the world
- The person may have different ways of linking or may not link events and consequences
- How do you learn to accept that there is no explanation rather than constantly question - it's always a "Catch-22"
- Dreams for the person can become condensed into today, the next morning, or night
- It's very difficult to make plans
- Getting to know how to handle and diffuse situations before they escalate
- The person has very few friends of the same age (if any) due to very few social skills and experiences
- As family members, there is a strong tension between rights and responsibilities and that produces great frustration (for example, the problems created by the new Mental Health Act)

## Experiences and Struggles with Professional Services

*Our Struggles:*

- * We get the wrong kind of help; there are many examples:
  - we get blamed
  - we get ignored
  - we don't get taken seriously or believed
  - we are told "you're over-reacting", or "you're blowing it out of proportion"
  - we might get a diagnosis but we need to help the person's development all the way along
  - we get the shuffle from one professional to the next, and the next...
  - everytime there is a problem she/he gets sent home and that creates isolation
- * Lack access to services
  - long waiting lists
  - mandates for services are too restrictive (for example, age limits and time constraints)
- * "Professionalism" carries the weight to get things done long after we have struggled for the same changes
- * The wishes of the family are constrained by bureaucratic red tape

## Thoughts About the Future

- * We need to create a safe place for people to live
  - a sense of stability
  - not dumping onto siblings
  - not a high pressure setting (for example, a farm with animals)
  - individualized with enough structure
  - potential to provide respite to each other
- * We need to educate the public
- * We need to get people working on the same track
- * We need to develop some real community programs