VIEWS FROM THE "OTHER" SIDE:
PARENTAL PERCEPTIONS OF THE INDIVIDUALIZED EDUCATIONAL PLAN (IEP) PROCESS

by

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TABLE OF CONTENTS

ABSTRACT

With the passage in 1975 of the Education of All Handicapped Children Act (EHA) in the United States, parents of children with disabilities were provided a voice in the educational decision-making process as conceptualized through the development of an Individualized Educational Plan (IEP). Since that time research has studied the nature of this involvement as it relates to the role of parents at IEP meetings. This qualitative study sought to discover how parents of four children with mental disabilities, each experienced the IEP process (i.e., initial contact with the school; IEP meeting and plan development; implementation; monitoring; and evaluation of the IEP) over the course of their child's school experience. The participants shared information about their initial experiences with school system personnel up to the present time of this research study. The findings reveal that there are a number of barriers to the IEP process. Parents feel that the IEP process is compromised by the attitudes of school system personnel toward both child and parent: that these attitudes further interfere with the IEP process by creating a relationship where parents feel they cannot trust and respect those individuals in the school system who hold these attitudes. Parents feel that the process is further complicated by the nature of teacher professionalism they experienced and by the issue of ownership with respect to their child's program. The issue of ownership may be rooted as much in the attitudes of teachers as it is in the historical relationship between special and regular education. Parents used a number of strategies to breakdown these barriers with each achieving various degrees of success.

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DEDICATION

Dedicated to:
Bill and Gina; May and Donald; Beverley, Robert and Molly; Charlie, Barbara and Jeffery, and
to all parents of children with disabilities whose struggle for appropriate education for their children inspired this research project.

It takes a
whole
village to
educate a child

African Proverb

CHAPTER ONE

Introduction

The following extract is from a letter that was inspired by a conversation between a parent and her daughter's teacher of four years, in which the teacher had made reference to her daughter's level of "cognitive impairment."

> . . . amidst the trials and tribulations of IEP planning and meetings. . . . When we talked on the phone, and you referred to the level of cognitive impairment of Jessica, I felt as though I had quite unexpectedly been washed away in a tidal wave of oblivion. I do not see Jessica as impaired. I see her as different than most of us in general terms, but different is not impaired. Synonyms for impaired are defective, damaged, ruined, incapacitated, mutilated--synonyms for different are distinct, non-uniform, differing, dissimilar, unusual, uncommon. I prefer to believe, and my heart very clearly tells me that my daughter is uncommon, not defective. . . . I guess I had been working under the misconception that you like me, did not put much stock in such labeling, and in fact, avoided such frightening limiting notions as lenses through which to view children. (Drais, 1996, p. 1)

The phrases "severely retarded" and "profoundly retarded" evoke powerful images about human potential and the moral worth of people to whom these terms are applied. "To be called retarded is to have one's moral worth and human value called into question" (Bogdan & Taylor, 1982, p. 14). These people are thought of and referred to as "vegetables" and "subhuman." The following description was used to describe people so classified. "They have eyes, but they see not; ears but they hear not; they have no consciousness of pleasure or pain; in fact their mental state is one of entire negation"(Bogdan & Taylor, 1982. P. 15). These labels act as a self -fulfilling prophecy and the lives of these people become structured based upon society's interpretation of mental retardation and the stereotyped reactions that the concept produces. Assumptions based upon the inability of this group of people to learn results in our decision not to teach them. If they are subhuman we can deprive them of their rights. "If they are a separate category of human being, we can separate and ignore them" (Bogdan & Taylor, 1982, p. 16).

Revisiting the past provides a foundation on which we are able to re-conceptualize what mental retardation meant to different societies during different periods of history. It is here we can begin to comprehend our actions and reactions to parents and their children with disabilities. "Deeply rooted attitudes, ingrained and reinforced by tradition, and institutional and social structures and practice, are not changed except over a long period of time" (Sarason & Doris, 1979, p. 357).

Up until the late 1950's and early 1960's most children who were labeled severely or profoundly retarded were denied access to public schools (Goodman & Bond, 1993;

Ferguson, Ferguson & Bogdan, 1987). According to Lusthaus and Lusthaus (1996), the last two decades have been a time of exploration into ways of achieving effective practices in inclusive education. The experiences over recent years have brought the realization of the importance of building relationships between teachers and parents as a key component to student success. Parental involvement in special education is popular today and many authors talk about the importance of and ways to foster parents' involvement in their children's educational programs (Epstein, 1995; Kozloff, 1994; Ysseldyke, Algozzine & Thurlow, 1992; Nietupski, Krayewski, Ostercamp, Sensor & Opham, 1988; Biklen, 1985; Schulz, 1985; Roos, 1985).

The full inclusion of students with disabilities requires an effective working relationship between home and school. This relationship is fostered when school personnel have knowledge of parents' objectives for the child and when parents have knowledge of what the objectives of the school are for the child. If full inclusion is to succeed, then it is necessary to "gather the people involved to develop a process for continually adapting the curriculum and the class routine" (Bunch, 1991, p. 80). While all parents are a valuable resource to teachers, their involvement becomes especially important in the case of students with disabilities.

According to Ferguson and Ferguson (1987) the assertion by special educators that parents are crucial to special education programs may be supported in theory but not in practice. "Special education professionals, in too many cases, reveal their opinions of parents only when pressed in the privacy of the teachers' lounge: I love parents; it's all these mothers and fathers who cause all the problems" (p.347). While the Individual

Educational Plan (IEP) provided parents with the legal right to have a decision-making voice in the development of the child's educational program. Both the quality and the extent of this participation has been and continues to be questioned.

Origin of The Study Topic

The Researcher: A Personal Journey

I am now in my mid-forties. A white middle-class male born on an island off Canada's east coast, the youngest of four children. My Father died when I was four years old leaving my 15 year old brother, two sisters aged 17 and 18 years old, and mother to care for each other. I remember that we took in boarders to help meet the financial needs of the family. These boarders were all young female teachers who taught at the local school.

After about four years of being a widow, my mother remarried and I went to live with her and her new husband and his family. My brothers and sisters had moved on by this time making their own way in life. My new step-family included three children, only one of whom was still living at home, a male about three years my senior. We became close as a family and my adolescence was marked with the usual mischief and carefree ways of childhood.

It was during my elementary years in school that I was to have my first encounter with people who had mental disabilities. They were not in my school nor were they children. They were grown men. At the time I did not consider them to be men, nor did they act or live like men. Or at least, what I thought men lived like. They wore ragged clothes that were many sizes too big for them and they wore knee high rubber boots on their feet, regardless of the season.

My friends and I would walk to school by way of the railway tracks. On this particular route we would pass by two houses. In one of those houses lived a female classmate of mine. In the other house, a small bungalow, lived a family who I knew by name only. The children who lived there went to a different school system. In addition to the family living in this small bungalow, there also lived "three dummies" (locally applied term for people who could not speak). But not only could they not speak, there were other peculiarities that separated "them" from "us." They did not live with the rest of the family on the main floor part of the house, but in the basement. This basement consisted simply of an earth floor and four walls constructed of loosely fitting boards. One could use such a place to store items or materials that were of little value or importance.

Of the "three dummies," I knew only one by name, Ted. He seemed to be the smartest of the three. I inferred this from his actions, as his behavior seemed to be less childlike than the other two. I guess these men may have been in their late 20s and early 30s. They would run back and forth along the banks of the railway tracks, dragging tin cans tied to a piece of rope behind them, yelling and screaming -- things I thought crazy people did. It may have been their way of expressing themselves through song perhaps, but to me they were noises that enhanced our fear of them and distanced us from them. As young boys, our response to this phenomenon was to throw rocks at them as they passed by. Being clever ourselves, we were sure to keep our distance from the "three dummies" who we considered less than human, and surely less than men. Although they were similar in stature to that of a man, we felt their actions and the clothes they wore to be less indicative of how men acted or dressed. We perceived them as the "other," and we were not like them. As I reminisce, I wonder how and why these men were allowed to live like that. Who were responsible for their care? Were social services available? Did the way these young men lived in some way reflect society's view of disability? This was my first experience with people with disabilities. An experience in which I take no pride.

I remember as a teenager working hard both at school and at work. I attained my first job shortly before I turned fifteen. My step-brother was working in one of the local supermarkets where he was able to gain me employment. I worked part-time, Thursday and Friday evening from 5 pm to 9 pm and on Saturdays from 9 am to 5 pm. During the summer holidays, I would work 40 to 50 hours a week. I was making 70 cents per hour. That wasn't very much even back in 1968. But I had my own income and a sense of independence. I managed to go to school and work part-time during three years of high school. It was during these years while working at this local supermarket that I had my next encounter with someone who had a disability -- a very short, round-shaped young woman with a bald head and glasses. She would come into the store always accompanied by another person. I know now that she had Down's Syndrome. Today she is a friend of mind. At that time, we found her to be very funny looking and unknown to her, the object of our cruel comments.

My next exposure to disabilities came in 1976 when I met my partner's brother. He has Down's Syndrome and is now 39 years old. As I reflect, I now see this encounter with Peter and his sister was the turning point in my life and the reason I chose the type of work I do today. Prior to meeting Peter and my future partner, I had drifted through about half the work toward my undergraduate degree in education and had not yet established any serious career goals. I had moved from job to job both at home and in other locations within Canada and occasionally returned to university to do a few courses and enjoy life. Over the next three years I became better acquainted with my future brother-in law and his sister, my present wife. She convinced me to finish my education degree, and from there I went on to complete a diploma in special education. This was accomplished in 1979 -- the year we were married.

In the early 1980s, I became a volunteer in a local association for the mentally retarded. Here I had some exposure to parents of children and youth with disabilities, as the volunteer board consisted mainly of professionals from various service agencies. I eventually became president of the local association, and then became a representative on the provincial board. In this capacity I met many parents and I listened to their stories, both within board meetings and at provincial and national conferences for community living. My involvement with the associations eventually led me to issues ranging from mainstreaming/integration, to employment issues affecting people with disabilities. With government assistance, we were instrumental in establishing an employment agency in my hometown with a mandate to seek paid employment for our clients with disabilities. In 1989, we were instrumental in producing a video that presented individuals with disabilities in employment situations within the community. This video has been distributed by the Roeher Institute in Canada and I believe also in Europe. From the video I remember the smiles on the faces of these young people at their new work sites and the excitement of their parents as they talked about their sons and daughters, who for the first time were being paid an hourly wage for their labour.

In 1980, students who had been previously segregated in separate educational facilities were integrated into segregated classes in the local schools. I had started my first year teaching with four students in a segregated class. The next three years saw me teaching in a general special education class with 12 students. Again we were segregated, but with some integration into certain classes within the mainstream. The rest of my experience has been with students who were labeled "trainable mentally retarded." My work eventually led me to experience three summer institutes in integrated education at McGill University in Montreal (1987-1988), the Roeher Institute in Toronto (1987) , and Acadia University in Nova Scotia (1989). This was another turning point in my life and part of its impact is witnessed by my return to university at this time to finish the graduate work I started at McGill in 1987. I was fortunate enough at that time to live on the same floor with Norman Kunc. For those who do not know Norman, they may know his book <u>Ready, Willing and Disabled</u> (1985). Those three weeks living, eating and drinking with Norman put a new perspective on disability for me. Others who had a great impact on my life over those three years were: Judith Snow, Marsha Forest, Evelyn Lusthaus, Doug Biklen, Herb Lovet, Dianne Ferguson and Margie Brown, some of whom were self-advocates, educators, and others were both parent and educators.

Here I am after 18 years of living and working with people who have always existed on the fringe of society, who for the most part were never really accepted as equal players, except within a small minority of supporters. Throughout my teaching years, I have been able to rely on the support from the parents of my students. From my years at the summer institutes on integrated education and my work on community living boards, all those stories from parents about their constant struggles must have awakened something in me. I have had very good working relationships with the parents of my students. Their expert advice about their children's abilities, likes and dislikes, has made implementing school programs for their children so much easier. When I didn't know what to do in the way of programming for their children, I called home and sought the advice of their parents!

My teaching experience with students who wear the education label of "trainable mentally retarded" has allowed me over the last 18 years to get to know so many wonderful students. I owe a debt of gratitude to the students I have worked with over the years. They have helped me realize the error in my teaching methods and because of this, I feel I have become a better teacher. They could not tell me with words that I was wrong in my approach, but told me with their cold stern stare or with their outbursts of behavior. They were my students, and I say "my" because the rest of the school had long ago disowned them. To their parents, I owe a debt of gratitude for sharing their knowledge, skill and experience about their children. In my search to understand the students with whom I work, I have also come to gain a greater understanding of myself.

This research topic was conceived many years ago in my search for ways to try and make education meaningful for all my students. Although I did not recognize it until now, I feel the only ones I had to reach out to for support were the parents of my students.

Purpose of The Study

The purpose of this study is to gain insight and understanding into how parents of students, who are mentally handicapped, experience the IEP process in our schools.

Definition of Terms

Individual Educational Plan (IEP). The term individual educational plan (IEP) used in this study refers to a written plan developed by an educational team and consisting of long and short term goals that reflect and meet the assessed needs and abilities of the student.

Individual Educational Plan (IEP) Process. Within this study I refer to the Individual Educational Plan (IEP) Process as meaning and involving more than the Individual Educational Plan meeting. The process includes the following: how the child is referred to the IEP team; the IEP development meeting itself; the implementation of the plan; the monitoring of the plan; and the review and revision of the plan.

IEP Team. The IEP team is a term used to refer to the group of professionals and parents who have knowledge and are deemed necessary to contributing to the overall development of the student's program.

IEP Meeting. The IEP meeting refers to the actual conference or conferences where the plan is developed by the team.

The Implementation of the IEP. The implementation of the IEP pertains to the areas of responsibility assigned to the various team members who ensure that the plan is carried out.

Monitoring of the Plan. The monitoring of the plan relates to progress checks by the person responsibility for a particular set of objectives in the plan.

Review and Revision of the Plan. The review and revision of the plan refers to the meetings where the team comes together to discuss the student's progress and make any changes deemed necessary by the team.

Disabilities. Throughout this study I refer to students with disabilities. For the purposes of this study, when I refer to people with disabilities, I mean people who have been identified with one or more of the following medical labels: moderate, severe or profound mental retardation, severe or profound cerebral palsy, legally blind, fetal alcohol effects, non-verbal, attention deficit hyperactivity disorder (ADHD), seizure disorder and multiple handicaps.

Inclusive Education or Inclusion. The term inclusive education or inclusion implies full membership in all aspects of the school system. Segregation is not practiced within that environment.

Significance of The Study

I see the significance of this study relating to four areas. First, this study contributes to the literature that now exists in the area of parental involvement in the development of educational plans for their children. It extends the current literature by focusing on parent-professional involvement in the full IEP process rather than primarily on the IEP meeting.

Secondly, this research contributes to the knowledge of professionals working in the field. A greater understanding of how parents view and feel about their role in the IEP process may allow professionals to reconceptualize their thinking and take appropriate action.

Thirdly, the research can add to the understanding of parents and parent advocates about the IEP process and the role they can play in cooperation with school personnel to improve the process.

Finally, this study could influence policy development regarding IEP requirements at provincial Departments of Education, at the local school boards, or simply within local schools.

Parameters

Qualitative research methods do not allow for generalizations in the sense used by quantitative research where explanations and predictions generalize to other people and settings. "The techniques used in qualitative research are not efficient ways to produce predictive, generalizable statements about how to better control designated outcomes. . . . this type of research does not try to operationalize the world" (Ferguson, Ferguson & Jones, 1988, p. 178). Firestone (1987) points out that "qualitative research is more concerned with understanding (verstehen) the social phenomenon from the actors' perspectives through participation in the life of those actors" (p.16-17). The study findings add one more contribution to our growing understandings of the parent-professional relationships in the IEP process. Understanding can be a start toward improving the lives of students and adults with disabilities in our communities.

The research was conducted using interviews with parents of four families as participants. The small sample allows the researcher to collect the kind of data Bogdan and Biklen (1992) call "rich description" (p. 2), and what Geertz (1973) termed "thick description" (p.3). Ferguson et al. (1988) defined thick description as "a multilayered account that relishes complexity, recognizes nuance, and strives for understanding over prediction" (p. 178). Glesne and Peshkin (1992) point out that, "In the numbers game, depth is traded for breath. For in-depth understanding you should repeatedly spend extended periods with a few respondents and observation sites" (p.27).

Finally, parents will be sharing personal information with the researcher. To help facilitate a smooth transition into the study, participants were recruited from families known to the researcher and/or members of the supervisory committee. This was intended to foster the development of a trusting environment within which the research was conducted.

Organization of The Study

The study is organized into six chapters followed by references and appendices.

Chapter 1. Introduction: This chapter includes a brief introduction to the study, followed by the origin of the study topic and the purpose for the study. This is followed by a definition of the terms and the expected significance of the study. The chapter concludes with a discussion of the parameters and the organization of the study outlined.

Chapter 2: Review of the Literature: This chapter establishes the background for the study by reviewing the literature on societal views of disabilities and parental involvement in the IEP process.

<u>Chapter 3: Methodology</u>: This chapter presents an explanation of the research paradigm, the method for selection of participants, description of the participants, procedures to collect the data, and the methods used to analyze the data.

<u>Chapter 4: The Parents' Perceptions</u>: This chapter presents a reconstruction of parents' perceptions of the IEP process from their comments and the stories they told during the interviews.

<u>Chapter 5: Discussion</u>: Findings derived from the data analysis are presented and discussed in this chapter.

<u>Chapter 6: Conclusion</u>: The final chapter summarizes the study, presents conclusions, and offers recommendations for educational practices to improve the IEP process, and suggests future research studies.

CHAPTER TWO

Literature Review

Creation of The "Other"

If one wishes to understand the term holy water, one should not study the properties of the water but rather the assumptions and beliefs of the people who use it. That is, holy water derives its meaning from those who attribute a special essence to it.

Similarly, the meaning of the term *mental retardation* depends on those who use it to describe the cognitive states of other people. As some have argued, mental retardation is a social construction or a concept which exists in the minds of the "*judges*" rather than in the minds of the "*judged.*" A mentally retarded person is one who has been labeled as such according to rather arbitrarily and applied criteria.

Retardate, and other such clinical labels, suggests generalizations, about the nature of men and women to whom that term has been applied. We assume that the mentally retarded possess common characteristics that allow them to be unambiguously distinguished from all others. We

> explain their behavior by special theories. It is as though humanity can be divided into two groups, the "normal' and the "retarded." (Bogdan & Taylor, 1976, p. 47)

The misconceptions and prejudices about people with mental handicaps are so pervasive in American society that no one can escape their effects. In a society that values intelligence, physical attractiveness and self-sufficiency, those people with mental handicaps become particularly vulnerable as they tend not to possess these attributes. Valuing such attributes in our society has taught us to perceive people with mental retardation ". . . as devalued people and perhaps as the most inferior group of people in society" (Dudley, 1983, p. 8). Edgerton (1967) speculated that ". . . no other stigma is as basic as mental retardation in the sense that a person so labeled is thought to be so completely lacking in basic competence" (p. 207). Bernstein (1970) felt that identifying a person under the label of mental retardation "raises a fundamental question about the extent of his *humanness* " (p.77).

Allen and Allen (1995) use the following quote to illustrate how social interpretation of mental retardation has changed over time.

> In less complex, less intellectually centered societies, the mentally retarded would have no trouble in attaining and retaining a quality of realizable ambitions. Some may even be capable of gaining superiority by virtue of assets other than those measured by the intelligence test. They could make successful peasants, hunters, fisherman, tribal dancers. They can, in our own society, achieve proficiency as farm hands, factory workers, miners,

> waitresses . . . their principal shortcoming is a greater or lesser degree of inability to comply with the intellectual requirements of their society. In other respects they may be as mature or immature, stable or unstable, secure or insecure, placid or moody, aggressive or submissive as any other member of the human species. Their 'deficiency' is an ethnologically determined phenomena relative to the local standards, relative to the educational postulates, vocational ambitions, and family expectancies. They are "subcultural" in our society but may not be even that in a different, less sophisticated setting. (Allen & Allen, 1995, p. 158)

Goffman (1967) said, "The normal and the stigmatized are not persons but rather perspectives. These are generated in social situations during mixed contacts by virtue of the unrealized norms that are likely to play upon the encounter" (p. 138).

For Biklen and Duchan (1994), mental retardation, like marriage, is a socially constructed concept. It is framed within particular cultural settings through perspectives created within that culture. ". . . mental retardation does not exist as fact separate from interpretation, but that it is a concept constructed to account for selected events, behaviors, or phenomena" (p.173). It is not a trait like hair or eye color that is possessed by a person but rather a result of social perceptions that can vary over time and from culture to culture (Bogdan, 1980).

Biklen and Duchan (1994) support their claim by referring to two opposing views of retardation: the normative view, which uses normal children and adults as a way to understand those who are labeled retarded, and a competence view that views the behavior of those people labeled retarded as different from but not inferior to those who are labeled normal.

These opposing views are based in different theoretical frameworks. The first regards research as experimentation that uncovers objective truths about retardation. Researchers try to discover factors that identify behavior of people identified as retarded. The other researcher views retardation as subjective interpretation, that is, dependent upon the point of view of the individual. This interpretative research is carried out in the tradition of ethnography or symbolic interaction. Here, researchers are interested in how meaning is given to retardation by members of a cultural group.

These opposing views of mental retardation are also based in two interpretations of reality and truth. In this first view, the positivist view, researchers see the events of the world as understood through objective truth, free from experimenter bias (Biklen & Duchan, 1994). Retardation is conceptualized as a diagnostic category determined through observable symptoms that deviate from the norm and legitimized by intelligence tests. The development of the intelligence test by Binet and Simon in 1905, and later revised in the United States (Anastasi 1988), helped to separate ". . . the identification of mental retardation from the social interactions that had defined it" (Allen & Allen, 1995, p. 159). Mental retardation was now based on empirical evidence and could be identified as objective truth.

In the second view of reality and truth, the events of the world are dependent upon the experiences of the person engaged in them and that truth is " highly complex" and subjective. Biklen and Duchan (1994) see this "experienced" view of the truth as a phenomenological view of truth. "Experience-based researchers see retardation as socially constructed and as varying depending on who is viewing it and the circumstances of the viewing"(p.177). Reality is viewed as complex and socially constructed. "Knowledge is perspectival, dependent on the viewpoint and values of the investigator" (Kvale, 1996, p. 42). Unlike the positivist objective view, researchers working within this view of reality as experienced phenomena realize the importance of viewing themselves as "within" the discourse and not "outside" of it (Biklen & Duchan, 1994).

Rhodes (1995) suggests that we have conceptualized people with disabilities as the "other" and this view originates in a "distorted modernist view that encourages us to distance ourselves from one another"(p.458). Shakespeare (1994) had this to say:

> . . . The idea of otherness is complicated, but certain themes are common: the treatment of the other as more like an object, something to be managed and possessed, and as dangerous, wild, threatening. At the same time, the other becomes an entity whose very separateness inspires curiosity, invites inquiring knowledge. The other is to be veiled and unveiled. (p. 290)

Liberatory pedagogy is a postmodern view of the world that is oriented to change instead of accepting things the way they are (Rhodes, 1995). The orientation of liberatory pedagogy is toward transforming knowledge as opposed to the simple transmission of knowledge and its reality context. In the modernist view, knowledge defines who we are and who we are not. Defining ourselves through knowledge separates us from others by using knowledge to determine who we are.

Rhodes (1995) uses special education to illustrate how modernists use knowledge to define and separate. In this context "... knowledge separates 'them' from 'us' to create 'others' that are not ourselves. We use the reductionist psychological knowledge to spoil 'their' identity and distant them from ourselves"(p. 458). Special education has served to establish separate school communities that establishes "them" and "us" (Sarason, 1979; Kozloff, 1994). Dudley (1983) uses the metaphor of a wall and two worlds to discuss the separation of "them" from "us" (p.27-30). Goffman (1963) expressed this point of view in his explanation of how a child may first experience stigma. He explains that a child with disabilities may be protected in the first years of his life from the realities of stigma by his family, by where he lived and by type of stigma -- until his first day of public school. This becomes the time of stigma learning. Depending on the type of disability the child may be sent

> ... to a special school for persons of his kind, and the more abruptly he will have to face the view which the public at large takes of him. He will be told that he will have an easier time of it among 'his own' and thus learn that the own, he thought he possessed was the wrong one, and that this lesser own is really his. (p.33)

Mental retardation is not a physical property that can be seen or touched. It is a concept that serves two purposes; the segregation of a group of people; and justification for social action in regard to those who are segregated. This separation does not have to be a physical separation but "conceptualized in such a manner to justify special attention and action" (Sarason & Doris, 1979, p. 11).

In creating the "other" throughout time we have also learned to fear those we have created as "other." Rhodes (1994) uses the ethnic cleansing in Bosnia and Nazis Germany as examples of our desire to separate or wipe out the "spoiled image" we have created in our minds. Our occupation to wipe out the "spoiled image" has a long history as evidenced by Plato's view that: ". . . the offspring of the inferior or of the better when they chance to be deformed, will be put away in some mysterious, unknown place . . ." (Blatt & Kaplan, 1966, p.46).

Historical Perspective

Looking In The Rear View mirror

> Society's attitude toward persons with disabilities has always been complex, fashioned by the prevailing culture, religion, government, and economic conditions of a particular period. The care and training of exceptional individuals has followed historical trends, rather than creating them. (Winzer, 1993, p. 4)

Ferguson and Ferguson (1987) stated that "one way of understanding parents of disabled children is to know the story of their past and current struggles" (p. 353). Speaking to the importance of an historical perspective Sarason and Doris (1979) state " . . . if we want to understand the concept of mental retardation and those who are called mentally retarded, we have to understand ourselves and our society in historical terms" (p. x).

Throughout history people who were different because of mental retardation have been ". . . a source of wonderment, misunderstanding, fear, sorrow, amusement, and superstition"(NIMR, 1981, p.1). Most died at an early age because they were outcasts of society and unable to care for themselves (Malaka, 1993). Prior to the 19th century, treatment of people labeled mentally retarded consisted of neglect, ridicule and torture (Anastasi, 1988). Historical role perceptions of people with mental retardation could be classified under the following categories: a) less than human (Steer, 1983; NIMR, 1981), ". . . particularly apt to be unconsciously perceived or even unconsciously labeled as subhuman, as animal-like, or even vegetables or . . . waste products . . . waste materials" (Lusthaus, 1991, p.29); b) menace to society (Steer, 1983; NIMR, 1981; Ferguson & Ferguson 1987); c) sick (Steer, 1983); d) burdens of charity (Steer,1983; NIMR, 1981); e) holy innocents or eternal children, (Steer, 1983; NIMR, 1981); f) developing persons (NIMR, 1981). This last view expresses an optimistic view of handicapped individuals. Other role perceptions of people with mental retardation include "fool," "freak," or "entertainer;" however these perceptions have had less influence on our attitudes today (NIMR, 1981; Bogdan, 1988).

These labels although completely inaccurate have left their impression, and their legacy is still felt today. The following view was taken in the 1960's about children with Down's syndrome.

> There are thousands of children on this earth who should never have been born. Their lives are blank. They do not play; they do not read; they do not grow; they do not live or love . . . There is a difference between a man and a brute . . . we should refrain from respirating "monsters." (Lusthaus, 1994, p.29)

The 19th century witnessed a development of interest in the humane treatment for people labeled mentally retarded (NIMR, 1981; Anastasi, 1988). Our current ideology which emphasizes the developmental potential of people with mental handicaps with a focus on education, treatment and training to help them become an integral part of the mainstream of society, is consistent with the views of early researchers. Society was about to reconstruct mental retardation.

The work of Jean Marc Itard with Victor, "the wild boy," and Johann Jacob Guggenbuhl, who in 1840 established the first teaching and treatment center for children labeled mentally retarded in Switzerland, as well as the work by Edouard Onesimus Seguin and Samuel Howe, helped to provide educational and training services for children who were mentally retarded (Lusthaus, 1991). These early efforts to improve the lives of children with mental retardation through the establishment of residential centers provides a basis to help us comprehend ". . . the tragedy which was about to occur in the field of mental retardation"(NIMR, 1981, p. 7).

Attitudes that had once supported the developmental potential of individuals with mental retardation were to change drastically. This change in attitude was in part due to a number of compounding factors particularly related to these early residential centers. First, some of these early schools were just outright failures. Secondly, students with more severe handicaps required a longer stay and learned less. Thirdly, residents had no place to go after training; and finally, the objectives of these early schools were misunderstood by many who expected complete and rapid cures in large numbers. Developmental attitudes degenerated into pity and charity. The name "school" soon disappeared from these residential centers to be replaced by "asylum" (NIMR, 1981). The 19th century gave rise to the institutional service model that is still with us today (Ferguson & Ferguson, 1987).

We now have the beginnings of a protective model of service that initially was based in benevolent care. Unfortunately, this model "bore the seeds of dangerous trends: isolation, enlargement and economization"(NIMR, 1981, p.9). People with mental retardation were moved out of society for their own good as expressed in the writing from the late 1800s.

> Here and there scattered over the country, may be villages of the simple, made up of the warped, twisted, and incorrigible, happily contributing to their own and the support of those more lowly -- cities of refuge in truth, havens in which all shall live contentedly, no longer misunderstood nor taxed with abstractions beyond their mental moral capacity. (NIMR, 1981, p.10)

Rural locations were often selected for these asylums so gardening and farming could be carried out in an effort to be self-supporting. The term "funny farm" was to be later coined in reference to these institutions for people labeled mentally retarded and mentally disordered (NIMR, 1981). At the end of the 19th century the humanitarian beliefs that had established these first institutional settings began to change. ". . . public and professional concerns had shifted from a desire to protect the retarded against society, to a determination to protect society against the retarded" (Edgerton, 1967, p.208).

The turn of the century saw the development of a new concept toward people with mental retardation where people were seen as a "menace to society." Lusthaus and Lusthaus (1992) say that "the turn of the century was perhaps the darkest times in the history of how North American society has treated people with disabilities"(p.96). The eugenics movement to a large degree was influenced by Charles Darwin and his book "Origin of Species" (Pfeiffer, 1994, p.489). Eugenics was defined by Sir Frances Galton as "the science which deals with all influences that improve the inborn qualities of a race" (NIMR, 1982, p.11). Mental retardation now became much more than a personal or family problem. It was recognized as a threat to society. "Retarded children and adults thus became living threats to the well being of society . . . a "menace" to their family, neighbors, community and country" (NIMR, 1981, p.32). Eugenicists promoted the myth that someone with mental retardation "was a degenerate form of man whose very existence lowered the quality of the human race and posed a direct threat to the future of the species" (Lusthaus & Lusthaus, 1992, p. 97). These attitudes eventually led to the segregation into large institutions and the sterilization of people with mental retardation (Pfeiffer, 1994). According to Lusthaus (1991) "The ultimate effect of this trend was dehumanization of mentally retarded persons on a vast scale, the nature and extend of which may never be known" (p. 35).

The attitudes expressed toward people with mental retardation were not only coming from scientists but were echoed by politicians, institutional officials and leaders of charitable organizations. "Feeblemindedness, they warned was a major peril to society: it was the cause of society's problems: crime, delinquency, pauperism, prostitution, and immorality" (Lusthaus & Lusthaus, 1992, p. 97). Parents during this period were likely to believe that having a retarded child was a major disaster, and the genetic potential for mental retardation, a crime against society. Such publicized studies as R.L. Dugdale's (1877) The Jukes: A case study in Crime, Pauperism, Disease and Heredity, and Henry Goddard's (1912) The Kallikak Family: A study in the heredity of feeblemindedness (Pfeiffer, 1994) and Feeble-mindedness: Its Causes and Consequences (1914) (Sarason & Doris, 1979) helped shape societal attitude of the time. "These 'scientific' studies ...were enough to strike terror into the hearts of any family even remotely associated with 'degeneracies,' of which mental retardation was considered the worst" (NIMR, 1981, p. 32).

The first half of the 20th century can be seen as a time of great frustration and isolation for parents and their children with mental retardation. During this period up to World War II, large institutions became the norm (NIMR, 1981) and educators, psychologists and social workers all used a medical model to treat a "sick society." Parents were convinced that the professionals knew what was best for their children (Ferguson & Ferguson, 1987). This belief can still be found today as in this comment by a parent to her daughter's teacher; "I know you'll do the best for Carol. I trust you" (Baskwill, 1989, p.1).

This was a time when children were separated from children, and parents isolated from other families because of the stigma associated with mental retardation (NIMR, 1981). When people are seen as mentally retarded, people close to them are seen as being negatively labeled also (Lipsky & Gartner, 1987). Courtesy stigma (Goffman, 1963) or the spread of stigma from the child to the parent "introduces a significant barrier into parent's relationships with others" (Berstein, 1970, p.78). Parents can be excluded from activities, refused services, or made not to feel welcomed (Ferguson & Ferguson, 1987, p. 371). Parents can often be seen as being responsible for the disorder and incapable of handling it (Turnbull & Turnbull, 1988; Bernstein, 1970; Akerly, 1985; Warren, 1985). The situation is further complicated because "by definition, of course, we believe the person with a stigma is not quite human"(Goffman, 1963, p.5). Parents were usually told to place their child in an institution at birth (Bernstein, 1970; Turnbull & Turnbull, 1988; Gorham, 1975) or tell people it had died (NIMR,1981; Avis, 1985).

The institutional movement dominated the field of mental retardation from the 1920s through to the 1980s (NIMR,1981). Today residential institutions still play a major role in the lives of many people with mental disabilities. The dehumanization of people labeled mentally retarded in institutional settings was explored as early as the last century, when Dorothea Dix, in the middle of the 19th century, outlined the inhumane conditions in the state's institutions to the Massachusetts legislature. A century later dehumanizing conditions were exposed by Burton Blatt (1966). The following quote serves to express his horror at what he saw; "There is a hell on earth, and in America there is a special inferno. We were visitors there during Christmas, 1965" (p. v). A decade later Blatt was to reveal that little had changed except in a "superficially esthetic way" (Sarason & Doris, 1979, p. 417). Shields (1997) also relates witnessing dehumanizing accounts of feeding practices used with children by some attendants during her time as a volunteer worker in a Canadian institution.

According to Sarason and Doris (1979) the disreputable history of the institution can be explained

> by the fact that mental retardation has never been a "thing" but a conceptual invention bearing the imprint of society's structure, traditions, values, and prejudices. If that imprint does not seem to give priority to institutionalization, to the tendency to segregate, we will be only deluding ourselves if we believe that an opposing tendency supported by near and long-term social history has been extinguished. (p. 417)

Attitudes that have been developed over long periods of time are not easily changed.

The historical involvement of professionals with parents seems to be characterized by a number of emerging themes. First, parents were seen as the cause of their child's problem or at least worsened it. Secondly, parents were gradually relieved of their responsibility of parenting because they were seen as being incapable of handling their children (Ferguson & Ferguson, 1987). Policies and practices of institutions and hospitals did little to reinforce positive influences of parents on their children. In fact the opposite was more the case as these facilities seemed to reinforce a view that parents were not a good influence on their children (Avis, 1985).

A New Era

The next reconstruction of perceptions of people with mental retardation came during the 1950's and the 1960's. Social scientists, human rights activists, parents and educators demanded fundamental changes to improve the lives of people with mental retardation (Lusthaus & Lusthaus, 1992). Our description and explanation of people we have seen labeled mentally retarded has been influenced by time, place and society. Throughout history, society's reaction to mental retardation has been based on what it has perceived to be "right or wrong, appropriate or inappropriate." Time does influence what action society believes to be the right course toward those who are different. We have only to look to people who are homosexual, the elderly, alcoholics or women to see the evidence of this. The concept of mental retardation has undergone significant change, and there is no reason to believe that this process will not continue. (Sarason & Doris, 1979, p. 13).

In the 1950s parents began to organize and form support groups in both North America and around the world. Parents formed strong local, regional and national associations. In the United States, the National Association for Retarded Children (NARC) was formed and in Canada, the Canadian Association for the Mentally Retarded (CAMR) was established. These early associations at first dealt with providing information, support for parents and in some cases operating schools and day programs (Lusthaus & Lusthaus, 1992; Ferguson & Ferguson, 1987). The rise of the parent movement may be seen as the single most important development in the field of mental retardation. No other actions have produced more change in society's attitude toward people with mental retardation. The efforts of these parent organizations were also responsible for altering the direction of service development for people with mental retardation (NIMR, 1981). During this period, mental retardation became a topic of public discussion based more on moral-humane rather than legal-constitutional grounds.

Since parents started the first schools for their children in the 1950's, we have moved through an evolution with respect to the principles of normalization (WolfensBerger, 1986), integration (Forest, 1984; Ferguson & Brown, 1992), mainstreaming (Berres & Knoblock, 1987; Biklen, 1985), and inclusive education (Stainback & Stainback, 1992; Little, 1992). (See appendix A for discussion of terms).

To understand society's present position with respect to parents and the education of their children who have severe or profound mental retardation, we need to examine the particular pattern of events that led to the changes we see in present policies and attitudes about the education of students with disabilities. The civil rights movement began to eliminate racial discrimination but soon spread to the rights of other oppressed groups in society. One of the most significant racial discrimination cases which resulted in racial desegregation of the schools was Brown v. Board of Education of Topeka in 1954, which had its origins in the efforts of the civil rights movement (Biklen, 1987). Other legal victories followed such as; PARC (Pennsylvania Association for Retarded Children v. Commonwealth), 1972; and Mills v. D.C. Board of Education, 1972, which first established the mandate for schools in some states to serve children with handicapping conditions (Biklen, 1985), and provided a basis for the Education for All Handicapped Children Act (EHA) also known as Public Law 94-142 in 1975 (Biklen, 1987).

In the 1960s, a number of forces combined to further strengthen the fight for a better life for people with disabilities. In 1962 the Kennedy family's personal and political interest in mental retardation provided much support to these volunteer organizations. The President's Panel on Mental Retardation was established and released its report to the President: A Proposed Program for National Action to Combat

Mental Retardation. This document encompassed the hopes and aspirations of parents and set them into service goals and public action (NIMR, 1981). Also during this decade, the inhumane conditions of residential institutions were being exposed (Blatt, 1966) and social scientists were directing their attention to the treatment of people with disabilities. The effects of social stigma (Goffman, 1963) and exclusion from the community (Lusthaus & Lusthaus, 1992) were topics of discussion. The civil rights movement helped to establish education and services as a right as opposed to charity (NIMR, 1981; Lusthaus & Lusthaus, 1992). In 1968 the principle of normalization was introduced to North America and provided an alternate philosophy to social segregation. Wolfensberger taught this principle throughout North America explaining "that normalization involves using culturally valued means to give people the opportunity to play socially valued roles in society" (Lusthaus & Lusthaus, 1992, p. 99).

There is no doubt that many changes have improved the lives of families and their children with mental disabilities over the second half of this century. Laws have given access to better services and education. The Canadian Charter of Rights and Freedoms contain three sections that particulary apply to issues related to disability. Brown (1996) cites particular issues related to discrimination where these sections of the Charter have been used to support court cases. It is unfortunate, that society's attitudes with respect to people with disabilities have required the use of the Charter of Rights, in both federal and provincial court cases.

Brown (1996) states that overall most Canadians are at least familiar with general principles of equality rights for people with disabilities, and for the most part equality rights are supported by the Canadian public. But, support in theory does not necessarily translate into support in practice.

> In the past 25 years there have been many examples of situations when someone, or some group, would say "of course people with intellectual disabilities should live in the community the same as everyone else . . . but not on my street, or not in my restaurant, or not in my child's classroom, or not on board the school bus, not as my employee, and so on." (Brown, 1996, p.11)

The change in society's attitude and social policy was headed by a dedicated minority supported by political pressure and the backing of the courts. Litigation as a means of accessing inclusive schooling for students with disabilities has played a major role in the United States and to a lesser degree in Canada (Winzer, 1993; Smith, 1993; Crealock, 1996). Opposition to these changes came from schools, state agencies and institutions who were being told their values were wrong and evil. When viewed from this perspective, we should not be surprised and we need look no further to understand why opposition to the newly secured rights for people with disabilities did not dissolve (Sarason & Doris, 1979).

Individualized Educational Planning

Origin of The IEP

The need for educational planning has been of concern to educators and parents for a long time as indicated by the following quotation.

> In 1951 William Cruickshank wrote that parents of handicapped children need help from people who can be honest with them and give them guidance and understanding, as they attempt to meet the needs of these children who are deaf or may never walk. Carefully planned educational experiences are a requisite to the school systems' effort to meet the needs of deviating children. (Turnbull, Strickland, & Goldstein, 1978, p. 414)

The carefully planned educational experiences referred to by Cruickshank were mandated in the United States through the passage in 1975 of the Education for All Handicapped Children Act (EHA or P.L. 94-142). In Canada provisions of P. L. 94-142 have had an impact on educational practice. Some provinces have introduced legislation to effect change, while other provinces and territories have provided direction in school acts, leaving local school boards the role of developing policies and procedures to guide their provision of services for students with disabilities (Andrews & Lupart, 1993). One of the six principles in P. L. 94-142 stipulated that the education provided to each child with a handicap must be "appropriate" to the "individual". This appropriateness to each individual under federal law required teachers and other school personnel ". . . to prepare explicit plans (Individualized Educational Plans or IEPs) for the individualized education of each child" (Reynolds, 1981, p. 105). These plans changed parental participation in the educational decision-making process with respect to their children's future in that parents were now given the right and the mandate to participate in various ways in their child's education. The Office of Special Education in the United States Department of Education presented an interpretation of parental participation in the IEP:

> The parents of each handicapped child are expected to be equal participants,

> along with school personnel in developing, reviewing, and revising the child's IEP. This is an active role in which the parents (a) participate in the discussion about the child's need for special education and related services, and (b) join with other participants in deciding what services the agency will provide to the child. (Turnbull & Turnbull, 1986, p. 226)

Winzer (1993) reports that classroom teachers have complained that IEPs are time consuming. Because so much time is spent on meeting legal requirements of giving tests and filling out forms, time is taken away from actual teaching. Winzer cites one study where teachers on the average spend 11 hours formulating an IEP. Plans for a child with a hearing impairment take the longest. Students who are labeled trainable mentally retarded, the least (Winzer, 1993).

Ferguson and Ferguson (1987) have stated that "Real involvement with parents cannot be legislated" (p .347). Turnbull et al. (1978) saw the development and implementation of the IEP as a new frontier for parent-professional partnerships related to educational decision-making. They recognize the fact that such a relationship is based in law. Whether such shared decision-making results in an appropriate plan for a child's education, will largely depend on how both groups adapt to their new roles and responsibilities (Ferguson & Ferguson, 1987; Turnbull and Turnbull ,1986).

Parent Involvement and The IEP

The EHA (1975) and the most recent revision by U.S. congress in 1990 called the Individuals with Disabilities Education Act (IDEA) brought about significant changes in educational programs for students with disabilities. The IEP process provides the means for parents and professionals to work together in developing educational priorities for students with disabilities in a forum based on equal decision making and individual rights. "The importance of the IEP in directing, documenting, and facilitating collaboration of a student's education cannot be minimized or ignored" (Smith & Brownell, 1995, p. 1). Smith (1990) reviewed the IEP literature from 1975 to 1989 and concluded that "evaluations of individualized education programs (IEPs) over the past decade have pointed to an inoperative and questionable document" (p. 6). He further points out that in light of such findings, little has been done to change the current situation.

Parental involvement in the IEP meeting has been researched in a number of areas. One area of research has been in professionals perception of the parents' role (Gilliam & Coleman, 1981; Gilliam, 1979). Both of these studies report that professionals ranked parental roles low in importance of contribution and influence in the IEP meeting. Lipsky (1985) addressed professional biases in relationships with parents and reported the following comment. "We cannot assume that families have the intelligence, values, education, motivation or intent to enable them as a unit to proceed as cooperative members of the rehabilitation team" (p. 615). A survey of professional members of school planning teams, by Yoshida, Fenton, Kaufman, & Maxwell (1978), revealed that a majority felt that parental participation should consist mainly of gathering and presenting information relevant to the case as opposed to contributing to educational planning.

Another area of research on parental involvement in the IEP meeting has been in the parents' actual role within the conference (Goldstein, Strickland, Turnbull & Curry, 1980). This study revealed a model of parental participation as "passive participant". It is worth noting that these observations involved 14 IEP conferences. Eleven of these observations involved students being considered for special education for the first time, who were labeled either mildly mentally retarded or learning disabled, and who were in grades two through six. During these meetings teachers reviewed an already written IEP with parents, who were passive participants and solely recipients of teacher comments during the meeting. Penney and Wilgosh (1995) report that "... obtaining a parents' signature on the individual educational program (IEP) is frequently the outstanding purpose of a parent meeting" (p. 3). The National Committee for Citizens in education surveyed 2300 parents and over half reported that " IEPs were completed before the meeting and without their participation" (Witt, Miller, Mcintyre & Smith, 1984, p. 28). Similar findings are reported by Turnbull and Turnbull, 1986).

Goldstein et al. (1980) also revealed that parents were satisfied with the IEP conference. The researchers state this was an unanticipated finding in light of the actual parent involvement in the conference. They relate an example where a parent walked a mile and a half in below freezing weather to attend her child's conference that lasted only six minutes. On the follow-up questionnaire, the mother gave the highest rating on all items "indicating a highly favorable reaction to the conference" (p. 284). The reason for this response is not easily discernable, but there are an number of possible answers. It could have been due to a lack of knowledge on the part of the parent as to the purpose of the conference. The parent may have viewed the conference as an increase in communication over what had been experienced in the past and a sense of relief to know that the conference had not been to report her child was in "trouble". The parent may have also felt pleased about the extra help the child was receiving (Goldstein, Strickland, Turnbull & Curry, 1980).

Research has also reviewed the parent's perception of their role in the IEP conference (Lusthaus, Lusthaus & Gibbs, 1981). Results of this study indicated that parents most often find themselves in the role of giving and receiving of information. Biklen (1987) reported that parents often feel frustrated at the IEP meeting and at times are intimidated by the process (Gilliam, 1979). The following experience will help illustrate this point.

> When I walked into the room there were about twelve people sitting around a table. No one even stood up and greeted me. The only person I knew was Sean's teacher and she didn't even smile. No one introduced me to anyone. Everyone had stacks of papers sitting in front of them. And everyone looked so serious. I felt like I was on trial. I really felt frightened. I was afraid I was going to cry. This was not what I had expected at all. I'm not sure what I had expected, but I certainly did not think I was going to be frightened. I was so eager to get out of there I agreed to do anything they said. It was awful. (Biklen, 1987, p.26)

A study by Vaughn et al. (1988) involving 26 initial placement conferences for children referred for possible learning disabilities showed similarities between their research and that of Goldstein et al. (1980). Vaughn et al. (1988) stated that over the last ten years "... despite differences in samples and geographical locations ... parent participation at the IEP conference continues to remain at the same low level, despite numerous suggestions and programs for parent advocacy training" (p. 87).

An explanation for understanding this finding by Vaughn et al. (1988) may be found in Skrtic's (1991) perspective on two organizational configurations -- the professional bureaucracy and the adhocracy.

> The difference between the two configurations is that, faced with a problem, the adhocracy "engages in creative effort to find a novel solution: the professional bureaucracy pigeonholes it into a known contingency to which it can apply a standard program." (Skrtic, 1991, p.184)

The requirements of the EHA, parent participation in the IEP conferences being one, assumes an adhocratic value orientation where problem-solving and interdisciplinary teams collaborate to develop personalized programs (Skrtic, 1991). This adhocratic orientation is in opposition to the value orientation of the professional bureaucracy where "individual professionals work alone to perfect standard programs. Culturally, this value conflict produces resistence in the form of political clashes, which undermine the ideal of collaboration . . ." (Skrtic, 1991, p.185).

The passage of P. L. 94-142 provided a means through which the role of parents in the educational decision-making process could be re-conceptualized as participant and partner. This law ". . . the mainstreaming legislation, like the Supreme Court of 1954 desegregation decision which preceded it, gave concrete form not only to constitutional principles but to particular values" (Sarason & Doris, 1979, p. 9). Present research indicates that while the intent of the law remains, this change has not taken place (Vaughn, Bos, Harrell, & Lasky, 1988). Referring to the EHA, Skrtic (1991) states that:

> Schools appear to be complying with its procedural requirements because of the adoption of practices that, although they may be well intended and in some respects actually may result in positive outcomes, serve largely to

> symbolize (e.g., IEP's and resource rooms) and ceremonialize (e.g., IEP staffings and mainstreaming) compliance with the letter of the law rather than conformance with its spirit. (p.188)

The Parents' Dilemma

Professional attitudes toward parents with children who have disabilities do not seem to be conducive to equity within the IEP process (Biklen, 1989; Gent & Mulhauser, 1988; Gartner & Lipsky, 1987; Lipsky & Gartner, 1987; Biklen, 1985; Schulz, 1985; Roos, 1985; Steer, 1983; Gorham, 1975). Kirby (in Steer, 1983) indicates that parents have reported that their children were seen as burdens by the school district and they were told that they should be glad that their children were receiving any services. School personnel, especially principals, communicate that children with disabilities "do not deserve the same kinds of experience and services in the school that so called typical children receive" (p.3). Gorham (1975) states that parents of handicapped children have learned to live with past experiences and current dilemmas. Because of this, "we are unduly grateful to principals or school directors for merely accepting our children in their programs. The spectre of 24 hours a day, 7 days a week care at home, with the state institution as an alternative has made us too humbly thankful" (p. 522).

In cases where parents are seeking inclusive educational placements for their children, the experiences with school personnel and the type of action taken can be quite varied. Erwin and Soodak (1995) provide an example where a parent attended a meeting with an interdisciplinary team and was told that inclusive placements did not exist. The parent sought legal help. She received an impartial hearing and the request for inclusive placement was granted. Another parent comments on the complexities of legal negotiations:

> You have to be real tough. And at the same time you have to be real nice. Its almost a passive aggressive thing. During mediation you have to be real nice because you have to be able to work with them after that and you don't want to work with people who hate your guts. (Erwin & Soodak, 1995, p.142)

Penney and Wilgosh (1995) report that many parents of children with a disability believe that educational opportunities are a direct result of advocacy for their children.

Part of the explanation for the variety of scenarios that may be encountered when school personnel and parents come together to talk about the education of their children with disabilities may be found in the words of Sarason and Doris (1979):

> We stress the fact that it has been the courts through which these social changes have been brought about and not through a changed public consciousness. . . . What has been inculcated over the decades into the minds of people does not become transformed by legislative fiat. (p. 9)

Conclusion

There is a paucity of literature with respect to the perceptions of the IEP process held by parents of children who have moderate, severe or profound disabilities, particularly cognitive disabilities. The literature cited in this review refer primarily to students with mild learning disabilities. The studies themselves reflect the actual IEP meeting and not the IEP process. Parental reactions may be different when considered in light of the total IEP process, the level of severity of students' disabilities and the nature of the services required (Nietupski et al., 1988). When students require services from the school, such as inclusive education, the relationship between parent and school may require a reconceptualization of the structures of our schools (Skrtic, 1991) and value system (Rogers & FreiBerg, 1994).

CHAPTER THREE

Methodology

This is a qualitative research study and methods consistent with this approach will be used to collect the data about parents' perceptions of the IEP process. Qualitative research is an "umbrella term to refer to several research strategies that share certain characteristics. The data collected has been termed soft, that is rich in description . . . and is not easily handled by numbers" (Bogdan & Biklen, 1992, p.2). Qualitative methods will "...provide rich and descriptive data derived from the study participants' own frames of reference" (Erwin & Soodak, 1995, p. 137). This research is not about trying to prove a particular hypotheses or test a set of variables. Its purpose is to come to understand how others experience a particular phenomenon. "Qualitative data take the form of narrative rather than numbers" (Biklen & Moseley, 1988. p. 156).

Qualitative research may refer to both the methods used to collect and analyze the data and the set of beliefs and assumptions about epistemology and the kinds of questions we can ask within that world view. The interpretivist paradigm is used to focus upon "insider perspectives" (Ferguson & Halle, 1995, p. 1). The understanding pursued is "a kind of empathic process whereby one tries to approximate the perspective of others" (Ferguson, Ferguson & Taylor, 1992, p. 6). Heshusius (1994) called this search for knowing and understanding a "participatory mode of consciousness" (p.15) which encompasses "a state of merging . . . where one forgets self and becomes embedded in what one wants to understand" (p.19). Within interpretive research, the theoretical perspective of symbolic interactionism (Blumer, 1969) will provide the orientation for the study. The basic assumption is that people create shared meanings through their interactions and those meanings become their reality.

Participant Choice

The study involved four parents from the Maritime region of Eastern Canada who had experienced the IEP process in the public school system. The study participants were identified through two means. Three of the four parents were selected through the help of a key person known to both the author and the participants. This key person was knowledgeable about the situations of the participants and their experiences within the public school systems. These relationships were developed through their affiliation in an advocacy organization, The Canadian Association for Community Living. The involvement of these participants would insure information-rich experiences from which one could learn a great deal about issues of central importance to the purpose of this research. Initially, only three participants were identified to participate in this study. The fourth participant, also a member of the advocacy organization and friend of one of the original three participants, was included after asking to be accepted in the study. In addition, the help of this key person, whom the parents in this study both trusted and respected, facilitated the establishment of a relationship of trust between the author and participants. The fact that the fourth participant family were close friends of one of the original three participants and that they requested to be included in the study, indicated a level of trust and a willingness to share their experiences with the author.

The criteria used in the selection of participants for this study was in keeping with the purpose of the study. First, the participants had to have experience in the IEP process in the public school system. The reason for their involvement in this process then, being their child's disability and subsequent need for individualized programming.

Secondly, the participants had to have children who were now in different levels of the school system. Initially, only three of the four levels, elementary, junior high and high school were represented. The inclusion of the fourth parent provided representation from the primary level and so provided current information across all school levels. This representation across all levels provided information from parents who had experienced the IEP process over a period, at one end as short as 7 months, to a span of 11 years on the other end. In addition to being able to see how parents now experience the IEP process in each of their respective levels, three of the participants were able to compare their experience in the IEP process across placements with different school personnel.

Sources of Data

All participants were parents of children on an IEP. Their children ranged in age from 6 to 19 years and were currently placed in inclusive environments within the public school system. One of the participants was a single father. In two of three cases, both parents participated in the study, while only the mother participated in the remaining family. All fathers worked outside the home, and all mothers worked at home.

At the time of this study all parents were actively involved as members of their local Association for Community Living and supported inclusive educational placements for their children. Only one parent in the study was not a member of the local Association for Community Living and inclusive placements were not an available option when his daughter first started school.

Time

The data for this study was collected over a six day period between the 6th and the 11th of April, 1997. Four semi-structured in-depth open ended interviews (e.g., Bogdan & Biklen, 1992; Stainback & Stainback, 1989; Glesne & Peshkin, 1992) were carried out, one with each participant family at their home, and each lasting between 60 and 90 minutes. Additional follow-up interviews were arranged with each participant and lasted between 40 and 60 minutes.

Procedures

Given that parents' perception of the IEP process was the primary interest, in-depth semi-structured open ended interviews were used to gather information across participants. This provided an informal forum for parents to describe their experiences in the IEP process with school personnel. Kvale (1996) states, "Interviews are conversations where the outcome is a coproduction of the interviewer and the subject" (p.xvii). He further explains that, ". . . an interview is literally an ***inter view*** (bold italics in original quote), an inter change of views between two persons about a theme of mutual interest" (p.2).

During qualitative research, themes and questions usually emerge in the process of the research as was the case in this study. An initial set of 13 guiding questions (see Appendix B) was used to assist the conversation and provide the author with consistency across interviews. Flexibility was maintained throughout the conversation by changing the order of questions, modifying questions or asking follow-up questions based on the content of the conversation. The initial questions provided a starting point for the conversations by giving parents the opportunity to tell about their child. Parents readily did so and this allowed the author insight into the world of the parent and child prior to entering public school. Once parents started talking about their experiences before school, they began reflecting on their experiences upon entering school and continued up to their present situations with school. During the conversations, parents were specifically asked to talk about (a) their initial contact with the school, (b) what was their involvement in the development of the IEP, (c) how they experienced IEP meetings, and (d) what their part was in the on-going evaluation of their child's plan.

I contacted each participant by telephone and arranged a meeting time at their convenience. I explained the purpose of the study, that I would require an initial meeting with them and then a follow-up meeting to be arranged at the conclusion of our first meeting. The author personally interviewed all participants in their home. Notes were written regarding participants and the actual interviews. After each interview I listened to each audio-tape a number of times prior to the follow-up meeting. This allowed me to identify points of clarification as well as subsequent pertinent questions generated from the interview itself. In addition to the notes, I wrote down comments that the participants made either before or after the interviews with respect to the focus of the study.

Each interview began with a brief introduction by the author where the purpose of the study was reiterated. Confidentiality and permission to tape-record the conversation were also addressed. Three of four interviews were scheduled outside school hours and the author was able to meet the child requiring the IEP.

Interviews began by using open-ended questions and parents were encouraged to speak freely about their experiences, feelings, and perceptions of their involvement with school personnel during the IEP process. At the end of the interview a time and place were arranged for the follow-up meeting.

Analysis of Data

In qualitative research, analysis is inductive. Taylor (1988) states that, "Concepts, insights, and understandings are developed from data, rather than being formulated a priori" (p.175). The analysis of qualitative data begins with the identification of key themes and patterns. This involved looking through the interview transcripts and field notes to increase my understanding of them. Coffee and Atkinson (1996) point out that coding and retrieving conceptualized as an analytic strategy implies three kinds of operational processes: "(a) noticing relevant phenomena, (b) collecting examples of those phenomena, and (c) analyzing those phenomena to find commonalities, differences, patterns and structures" (p.29). According to Bogdan and Biklen (1992) "Analysis involves working with data, organizing them, breaking them into manageable units, synthesizing them, searching for patterns, discovering what is important and what is to be learned and deciding what to tell others" (p.153). This organizing, managing, and retrieving the most meaningful pieces of data is accomplished by assigning "words and phrases" (Bogdan & Biklen, 1992, p.166), or "tags and labels" (Coffee & Atkinson, 1996, p. 26) to patterns and topics identified in the data. These words and phrases, or tags and labels, are coding categories. A set of coding categories was developed following the steps outlined by Bogdan and Biklen (1992).

All interviews were audio-taped and transcribed verbatim by the author. These transcripts along with the author's field notes and observations from the interviews served as the data for this study. The author began by typing the interviews and leaving two inch margins to provide space for the author's comments and open coding. Open coding is the "process of breaking down, examining, comparing, conceptualizing, and categorizing data" (Strauss & Corbin, 1990, p.61). Each line of the transcripts were also numbered. After each audio-taped interview was transcribed, the transcripts were read while listening to the tapes. This provided a check to verify the accuracy of the transcribed interviews. Both the initial transcribing and verification check of audio-tape to transcript accuracy increased the author's familiarity with the data.

A preliminary list of 56 coding categories was developed and assigned numbers. These numbers were then assigned to 'units of data' (Bogdan & Biklen, 1992) as the transcripts were read. These 'units of data' were either paragraphs, sentences or sequences of paragraphs that describe the particular topic represented by the coding category. The first attempt to code the data using the preliminary list of coding categories was referred to by Biklen and Bogdan (1992) as, ". . . really a test to discover the workability of the categories you have created. The coding categories can be modified, new categories can be developed, and old ones discarded during the test" (p.176). Coffee and Atkinson (1996) point out that codes are tools we use to organize our data. "They can be expanded, changed or scrapped altogether as our ideas develop through repeated interactions with the data" (p.32). The point is not to come up with the right coding system (Bogdan & Biklen, (1992) but to recognize the set of codes as, ". . . links between particular segments of data and the categories we want to use in order to conceptualize those segments" (Coffee & Atkinson, 1996, p.45).

Analysis is a continuous process and can be seen as a process of data simplification or reduction (Bogdan & Biklen, 1992; Coffee & Atkinson, 1996). The on-going analysis resulted in the 56 codes being redefined or merged with other categories to identify emerging themes. For example, a major theme "barriers to the IEP process" emerged from parents descriptions of their experiences with school personnel in trying to get an IEP for their children. Topics identified within the theme (e.g., professionals' view of the child, professional decision-making, and language) were merged into one category (i.e., attitudes: valuing the child) to improve the organization and presentation of the data. Miles and Huberman (1994) state that, "The organizing part will entail some system for categorizing the various chunks, so that the researcher can quickly find, pull out the segments relating to a particular research question, hypothesis, construct or theme (p.57). In developing some of the final categories I used actual words supplied by the participants to help identify themes that reflected their views more clearly. For example, the coding categories, ownership and professionalism were generated from the conversations with the participants and became part of the theme 'barriers to the IEP process'.

Each participant received through e-mail, a rough draft copy of their own story as presented in chapter 4. Prior to the e-mail I telephoned each participant and explained that I wished them to read my version of their story and make any changes to the story that they felt were necessary. Two of the participants rephrased statements or provided additional information for further clarification and understanding of their statements. The other two participants reported no changes were indicated. Once these changes were made all participants were satisfied that their stories were accurately presented.

Confidentially

The identities of all participants in this study are confidential. The names of all the participants, family members, friends, school related personnel, institutions and communities have been changed. The only name in the study that has not been changed was the Association for Community Living (ACL). Because this a national organization with provincial, territorial and local affiliations throughout the country, the author felt that association with this organization would not contribute in any significant manner to the identity of the participants in this study. Each participant was asked to sign a consent form (see Appendix C) prior to their participation in the study. Copies of this form were retained by both the author and the participants. All copies of the audio tapes and transcripts made of the interviews will be destroyed upon completion of the study.

CHAPTER FOUR

Parents' Perceptions

This chapter presents a reconstruction of the parents' perceptions of the IEP plan process. This reconstruction is developed from the parents' comments and stories they told over the course of the interview process. The stories are presented in the order in which they were completed by the author.

Bill's Story

Bill is a single parent with sole custody of Gina, his nineteen-year-old daughter. Gina has a mental disability. Bill explains that Gina was born with part of her brain missing and has faced many medical issues in the first few years of her life. He points out that he views his daughter's disability as a condition which has caused her to be delayed. He states, "That's the way I see it. It's a delay."

Presently, Bill is an active member in the local Association for Community Living (ACL), a support group for people with mental disabilities. The membership of these associations include people from various backgrounds, including parents and self-advocates, who come together to advocate for and on behalf of people with mental disabilities.

Gina and her father have encountered many educators and support personnel over the past 16 years who have provided Gina with educational programs in both segregated and inclusive environments. Their first involvement with education outside the home for Gina began when Gina entered preschool.

Preschool Years

Bill's involvement in Gina's educational program began with her first placement in preschool. At three years of age Gina entered an integrated [children with and without disabilities] preschool program run by the local Association for Community Living. At that time Bill felt that this preschool did not provide Gina with adequate programming. He explains:

> Gina was getting ill at preschool a lot. They would leave her by a window -- open in the middle of winter and leave her on the floor unattended. To me there wasn't any real teaching going on and they were more focused on higher -- developing the kids with higher skills than Gina at the time, because Gina never walked until she was four.

Bill's need to change his daughter's situation at the preschool placed him in a confrontational situation between himself and the director of the preschool. He explains what happened:

> It was a difference between the director of the program and myself and how we saw things to go for Gina, and to the point where I was told to drop Gina off and pick Gina up and not to come in and view any more. I

> challenged -- I challenged them to the point where -- drop her off and pick her up -- that's it. And of course that doesn't go well with me.

Bill felt this to be an unsuccessful placement for Gina and he decided to remove her from the program. He decided to place her in another preschool which was operated by a relative of Gina's mother. He states, "We took Gina out of there, and moved her into quote, 'a normal daycare'. . . in the neighborhood preschool in which Gina was the only challenged individual with about 20 kids in it, and it was dynamite." Bill had an optimistic view of the program that Gina was receiving at this preschool. He wanted Gina to be with and included in what the other children were doing. He describes his feelings around her new program:

> Gina flourished. I was just blown away with it all. Gina was included in everything. That's what I wanted. The other kids were learning like numbers and colors, and well Gina wasn't doing that, but she was included in it and that meant a lot.

This was Bill's first experience with inclusion. He was not directly involved in the planning and implementation of Gina's program, but he liked what he saw happening for his daughter. Gina's inclusion in activities with the other children was important to Bill. Her inclusion with the other children and his access to come and go at the preschool were important to him. He states:

> How much she got out of it, I'm unsure at that time. But I could drop in at anytime and Gina was right there at what was ever going on. She was in the thick of it. The other kids helped Gina. That was my first taste of it

all.

Bill experienced two pre-schools. Although both schools were integrated environments, there was a difference in the kind and extent of the involvement that Gina received at each school. Bill feels that the community living preschool ignored his daughter's needs and his intervention to help correct this put him in direct conflict with the director of the school. He explains his feelings about that particular preschool, "How did I view it? I had a lot of anger. That's about all. I had anger at these people." Bill explains what he feels caused the problem he had with the preschool, "I think they lost sight of what it was all about. It was more of 'I'm in charge and I'm the big wheel and you do this or otherwise.'"

Bill felt that at the second preschool, the director's attitude of openness and inclusion helped his daughter flourish. Unlike the previous placement, this new pre-school not only included Gina in the activities with the other children, but became a place where Bill was free to drop in and observe. Commenting on the attitude of the director toward Gina's position at this preschool, Bill noted that "[director named] believed that Gina belonged that way, included in what all the other kids around were doing." Regarding this attitude of inclusion as it related to the community living preschool, he stated, "The words were spoken the same, but the actions were different, and that's the problems that I had."

Public School

Gina entered public school at the age five. When Bill approached his neighbourhood school to register Gina for primary, he was told by the principal that the school had nothing to offer Gina in the way of a program and suggested a class placement in another system. Bill describes the circumstances around this placement in a neighbouring school board:

> That was a segregated program. Our family lived out in [Timperton] and Gina was taxied to [Saxony] which is about a 45 minute drive. It was out of here -- away from her peers. Other kids in the neighbourhood all went just down the road a mile and Gina was taxied.

Bill explains that inclusion was not a practice in this school system at the time and that segregated classes were the norm.

Bill's initial contact at Gina's first primary school was with the Special Education teacher of the segregated class where Gina would be placed. Bill's only contact at this time and for the three years that Gina attended the segregated class would be with this teacher. Other than regular parent-teacher evenings scheduled for all students, Bill did not have any additional meetings to plan Gina's program or have other involvement with her program at that time. Bill remembers Gina's three years in the segregated class. He comments, "That went well. Gina was learning things. Gina was happy there." Bill was to later qualify those statements by saying, "I was not active like that then [referring to his involvement in ACL]. That's all I knew at the time -- segregation."

During these years Bill remembers having input into Gina's program and follow-up. He states,

> We always had follow-up. We'd have meetings, not like the ones I have

> today with the school. We have them when parent-teacher meetings were: This is what we're doing. This is what we're working on. Can you guys do this at home?

The road to inclusion

It was due to family circumstances, that at the age of ten, Gina was placed in foster care. While in foster care Gina entered into her next school placement, an integrated pilot project at a local elementary school. Bill expressed his feelings about this placement:

> Things went well. That was my second taste of an integrated class. The school put on sign language courses to teach the teachers and her fellow students. I went to them, the principal was there. Like they really put out to the whole school because it was a pilot project -- put out -- dollars were there. But that lasted a year and the foster mom gave Gina up.

Because of circumstances beyond Bill's control, Gina was removed from this placement and placed in an institution. This was an extremely emotional time for Bill. While Gina was living at the institution she attended the local community public school. Bill comments on Gina's segregation at this school and the actions he initiated as a result of the pending closure of the institution:

> I went to the school up there, and it was just -- they wouldn't even integrate her into gym. Nothing. Just (pause) and the (a long pause), the announcement came from government . . . that the institution was

> closing. So I got right on the bandwagon and Gina [would be] moved into a small option. But during that six months, I arranged with the school system that Gina would be integrated into grade seven.

Bill's initial contact with the school board brought him into direct contact with Mr. Peters, the head of Special Education for this school board. Bill was asked what he wanted for Gina. He stated, "I want Gina in grade seven, totally integrated with her peers. He [Mr. Peters] said, 'Okay'. I get off the phone and I figure, well this is happening." Bill was soon to find out that things were not going to happen so easily.

At this time, both Bill and his ex-wife had joint custody of Gina and within half an hour of Bill's conversation with Mr. Peters, Bill's ex-wife called saying that she had just been talking to Mr. Peters and that he wanted Gina segregated and that would be the best thing for Gina. Bill recalls,

> A half hour later -- I went ballistic. I had a talk with Mr. Peters about a week later. It wasn't a pretty talk. I told him what I thought of him. To put a parent against a parent to get what they want, is wrong.

Bill's decision to place Gina in an inclusive environment was eventually achieved. He states, ". . . Gina was integrated. . . . She was full time." He also recalls, "That was the start of the fight with the [district] school board."

"It's a value system."

Gina entered her new school in January and would be the first student with a mental disability to attend that junior high school. During the remainder of that school year, from January to June, Bill had monthly meetings with the principal, class teacher, and the mainstream support teacher. Bill remembers these meetings as being times of adjustment for school personnel and decided to remain in the background when it came to programming for Gina for the remainder of the grade seven year.

During that time of adjustment Bill particularly remembers Gina's homeroom teacher. He refers to her as being a good teacher. He recalls that she took it upon herself to take a night course on inclusion. Bill was later to find out that not all teachers at the school took the same interest in professional development with respect to inclusion. Bill recalls part of a conversation he had with Gina's homeroom teacher in which she expresses her feelings about the reaction from her colleagues regarding her decision to take an evening course on inclusion: "She said, you know I have done this and my peers of teachers think I am a fool for doing this. She said, I am so heart broken." Bill states his feeling with respect to the attitude expressed by these teachers toward Gina's homeroom teacher.

> I honestly feel in my heart of hearts that when educated people -- teachers -- I should say teacher, because teachers have their own agenda -- they don't want to teach people that are challenged and when someone comes along with them that does, they really do, they crap all over them. I know they are burdened with all this other work. But what they don't realize is that Gina can teach them, Gina can challenge them and get them to experience things that they never else would.
>
> That's a belief I have, not all teachers, but I'd say 95% of teachers

> don't want to teach challenged children. That they don't think they are going to learn and be productive in society. So why bother. Let's put them in sheltered workshops etc., etc., etc., and let them go swimming and bowling.

Bill expresses his opinion about the attitudes of some teachers toward students with disabilities. He states, "If you don't believe that the child should be taught, then you don't teach them. It's a value system." He notes that this belief has been formed through his relationship and experience in dealing with the education system. He states:

> Yes. Yes. You have some that put a lot into it and I have run across a couple of those. But that's all I can say is a couple, and it's like a rainbow in the storm when you meet them. It really is. It just makes everything that much easier and you see Gina learning something, actually learning. It's something.

"The TA was running the show."

Bill relates that grades seven and eight were not good years for him and Gina. In fact grade eight and nine proved to be particulary difficult when it came to communication between the home and school. Initially, the relationship between Bill and the principal was cordial, but eventually deteriorated when Bill became more vocal in his attempts to resolve issues surrounding Gina at the school. Innocent conversations with Gina's circle of friends became Bill's source of information with respect to Gina and what was happening at school. He explains:

> She had a great circle of friends through grade eight and nine. Gina would have parties at the house and sleep-overs. They'd go to movies. Like outside the school it was working. Her peers and they [members of the circle] would say things to me. I'd bump into them when we were shopping and they would just blurt out things innocently.

Some of the feedback Bill received from the students would prompt him to question the principal why certain things were happening. Bill states, "Of course I'd ask a question of the principal. Why is this going on? It got to the point in grade nine with that principal that I wouldn't even talk to him anymore." Bill describes how the relationship gradually deteriorated over time. He states:

> I'd go in and talk to him [Mr. Baker, principal] in his office about the issues and he'd reassure me and away I'd go. A month later we'd be still there in the same situation. The principal and I were just batting heads with each other -- over things around Gina. Her being out of the classroom.

Over this period of time as the relationship between Bill and Mr. Baker was deteriorating, relations with the TA (teaching assistant), the person who worked with Gina during the school day also became strained. Bill referred to this particular TA in junior high as "the nightmare one." Bill gives his opinion on how the attitude of a TA toward students with challenging needs, with whom they work, can impact a student's program. He states, "If you don't have a TA that believes that the child is going to learn -- all you are going to do is walk the hall."

Bill believes that the deteriorating relationship between Mr. Baker and himself was somehow linked to the personal friendship Mr. Baker had with the TA and her husband. He explains:

> We brought in a new TA. The new TA loved to challenge me -- grade eight started going bad and that was on the TA. The TA and I couldn't see eye to eye. I didn't realize until grade nine graduation why. Things fell off with the principal and I , and after Gina's graduation I discovered that the TA and the principal were like this. Best of friends. I found out that day that the TA's husband was the principal of a school just down the road. So there was a nice little clique going around.

One of Bill's concerns with respect to the TA revolved around the level of personal care Gina was receiving from the TA. He describes the situation this way:

> . . . The TA would send Gina home if Gina voided in her pants. One of the problems I had with that was, Gina never voided [in her clothes], only there. Well come to discover, Gina wasn't pulling down her pants far enough and the TA wasn't going in and making sure it was happening. Gina would be sent home.

The issues Bill raised with respect to the TA in the performance of her responsibilities to Gina were not confined exclusively to the personal care Gina was receiving. He explains,

> Not only that, Gina would sit on the floor in the front foyer waiting for the taxi to come pick her up -- wet, while all the other kids were changing

> classes -- watching. This was done a lot, and like -- I could never get them to see that.

Bill had concerns with the TA around another issue as well. "The complaints that would come home. Gina is grabbing at her." Bill had his own explanation as to why Gina was grabbing at the TA. It was quite different from what school personnel believed to be the cause of this behavior. Bill explains:

> When Gina gets frustrated, and I mean she really -- doesn't really want to do anything and she doesn't. I shouldn't say she doesn't, [but] very seldom she does it around the house. She'll just grab at you. "This is not what I want to do. I don't want no part of this." And everyday in the [home-school communication] book: "Gina is grabbing at me." They were blaming it on Gina going to see wrestling. She just sits there and laughs at it. That's got nothing to do with it. But they would not hear of that. They thought Gina was very aggressive and should be in a "behavior class".

In addition to these concerns Bill had another issue with respect to this particular TA. He states, "The TA was running the show. This TA, she told the teachers what to do, she thought she was the guru of education." Bill also described her at team meetings: "Like in the meeting, this woman would just almost take it over." Such behavior on the part of the TA eventually led Bill to question her presence at these meetings.

> We had a couple of meetings with the principal, TA, mainstream support [teacher] and her homeroom [teacher]. After a couple [meetings], I asked the question: I said "What's the TA doing here? The TA is supposed to

take direction from the teacher. She doesn't need to be in this meeting."

Bill recalls that other teachers were aware of the conflict that was taking place. He states, "But they believed it was me." Bill recalls that at one planning meeting these issues were openly discussed. He says, "At one meeting it was -- when I said I don't want her back. I said she is detrimental to Gina's education." Bill received no support for his position with respect to the TA, not even from the mainstream support teacher. He explains, "When push came to shove she went quiet on me and I was left there. I know now that she's not one I would trust again. Not the way I did."

Bill describes his working relationship with the mainstream support teacher. He explains,

> I'd talk to the mainstream support. Her and I get along quite well. But we would only have meetings away from the school, not in the school. She would keep me fairly quiet. I'm working on this Bill. Yes, I understand the TA.

Bill was feeling hurt and angry about the lack of support he experienced during this meeting. He comments, "Hurt ? -- I came home from it (pause) anger!" Later Bill spoke with some of his friends and together they decided to take action. They wrote a letter to the superintendent of schools and the Minister of Education. "But that fell on deaf ears."

Because of his actions, Bill felt that both the teachers and the principal had now labeled him "as one who would rock the boat and you cannot satisfy." Bill acknowledges that he never actually heard them state this for him to hear. Rather it was a feeling he experienced as a result of their attitude toward him at subsequent meetings.

Bill was not happy with the outcomes from his meetings with school personnel or the outcomes with respect to programming for Gina in grades seven, eight and nine. Bill had more input now than he had when Gina was in the segregated class during her primary years: "More, but I pushed myself on them. They didn't want it . No, they didn't want me there." He presents his perception of those years:

> I wasn't happy, but I understood there was some growing pains for the school because Gina was the first challenged student that they ever had. Gina was blazing a trail. They kept hanging their hat on this thing. So it had allowed me -- it gave me more time to give to them because of it. We are searching for this. We are searching for that.
>
> They gave me the MAPS [Multi-Action Planning System] session. So I came out of that with great hopes. They wanted computers, so I got Gina a laptop with intellikeys and all that stuff, and like I kept plugging stuff in, but nothing was coming back.

The MAPS (see Forest & Pearpoint, 1992) presentation of which Bill spoke is separate from the IEP meeting, but the information gained at such a session can be used in the development of the IEP.

"... the battle for the spring."

This meeting took place in the spring at the end of grade eight. This meeting was requested by Bill at the suggestion of a friend and university professor. This meeting was attended by: the principal, all Gina's class teachers, the mainstream support teacher, students and staff personnel who worked with Gina at home. Bill felt that school personnel were not receptive to this meeting from the outset. He explains:

> Oh yeah, yeah (laughing). But it was a game and I didn't realize it at that time. It's funny when you got to push them into a corner to accept something, they accept it, they make it look like they are hugs and kisses -- but meanwhile they are still going there own way. Oh yeah, I asked for a follow-up in grade nine of MAPS.

The follow-up to the MAPS session was to take place at the beginning of grade nine. Bill had tried to get the MAPS session during the fall term.

> When I approached them in grade nine for the follow-up, they just dragged their feet. . . . Just having meetings - - saying it hard to get the teachers together. The mainstream support [teacher] at the time was hard to get the facilitator -- her time and their time coordinated -- and then we got into other battles, like in January, and MAPS just got put so far on the back burner.

In January Bill's attention was redirected by a new issue: which high school would Gina attend? Bill was not part of any transition plan for Gina in preparation for her move from the junior high to the senior high school. School and school board officials took it upon themselves to decide where Gina would attend high school. Bill explains:

> They gave a package to all students. Gina didn't get that. Of course I

> make a phone call. "Where's Gina's?" "Well Gina is going to Central High." "No Gina ain't going to Central High. That's a segregated program." "No it isn't." "Yes it is." I said, "Gina is going to Lakeside High." "Well there's no support down there." I said "that's not my problem, people. That's your problem, but Gina is going to be mainstreamed with her neighbourhood kids/peers down at Lakeside High." I finally got the papers home of what high school Gina would like to go to, and I had dialogued with them there. Like that was the battle for the spring!

Bill saw the junior high years pass with little resolved in relation to the development of a program plan for Gina. Bill refers to Gina's final report card from the school to help formulate his perception of those years in junior high. He recalls:

> Gina's report card for grade nine -- her final report card -- I didn't open it. It was given to us on graduation day and I wasn't going to spoil the day, because I knew what was inside of it. I waited to about the middle of July and I opened it one Saturday afternoon. Each teacher said different things, but they all used certain terminologies that were all identical that put Gina down. It angered me a great deal that one person wrote all this stuff about her and the school supported her.

Bill expresses the feelings and the emotions he had toward this report:

> It hurt me a great deal. It was very degrading. It just tore my heart out. Then it made me laugh that these professional teachers are so small.

> Because it wasn't – to me it wasn't to get back at Gina, because Gina will never read the letter. It was to get me.

<u>"I will not be bullied by you."</u>

Bill assumed a more proactive role in Gina's program at the high school level. Prior to the beginning of the new school year Bill had initial contact with the guidance counselor at the high school. Bill and the guidance counselor discussed Gina's schedule and addressed some of Gina's needs for the coming year.

> We talked about Gina's schedule. We talked about what I saw, she was very open. I talked about the circle of friends, and because they had peer helpers' signs all over the guidance office, and that Gina would need that, and you know if we could plug that in that would be great.

Bill relates his impressions of that meeting:

> I spent an afternoon with the guidance counselor two weeks prior to school opening that year for grade 10 and to me everything was just hunky-dory. But I could see it was just emotion. I think she patronized me. That's the best way to put it.

Bill did not feel that their meeting and the information that the guidance counselor received from him contributed to producing an IEP for Gina, because of how he was already perceived by personnel at the high school.

> I think she [Ms. Pick, guidance counselor] had quite the candid conversation with the principal [Mr. Apple], but they already had their

> minds made up because Gina was in their school. My reputation preceded me. That's what I feel and it was all negative.

Bill knew the principal prior to Gina's entering the high school and explains that relationship:

> I worked in the area for the [public service] corporation and I used to see him all the time. We'd stop and have a quick little chat. But he never knew I had a challenged child. To me we were friends before I went there. But that's not the way it turned out.

Bill's first formal meeting with Mr. Apple was an attempt to open a parent-principal relationship. "I met with the principal and I said, listen I know a lot of things are being said about myself as a parent. But I would like to start off with a clean slate." The principal's response was, "Oh yes, Mr. Brown." This would be the last contact with school officials until the scheduled parent-teacher night two months later in the first term. Bill was not asked to be involved in any planning meetings nor to share any responsibility as part of a planning team to develop a program for Gina. There was no IEP process that involved the parent in any manner. The parent-teacher night would be Bill's first meeting with Gina's teachers and the first evaluation of Gina's program. He describes the events of that evening:

> I went around parent-teacher night and this is the first parent-teacher night at the high school. I went around and met the teachers and it amazed me. They had everybody's file here, but Gina's is over there. "Gina is pleasant to teach. She's this, she's that." But what's she learning in your class?

> "Ah umm, communication. We can't communicate with Gina", and all this stuff coming up.

After meeting the teachers that night, Bill went to see Mr. Apple, the principal. He recalls that meeting:

> So I went in and saw the principal. I say, "where's the IEP?" He said, "Mr. Brown, we have nine terms here, do not get upset with the first term." So him and I get into a dialogue. It came from his mouth, "I will not be bullied by you."

Bill's reaction to Mr. Apple's statement prompted a similar response. He states, "I will not be bullied by you." After this confrontation with the principal, Bill was promised that things would be in place for the second term.

"They haven't got time."

Bill waited until the start of the second term in January before contacting the school again. But over the course of the first term Bill had concerns with respect to Gina being out of the classroom. He explains, "But I was hearing from the TA and Gina's peers in grade ten about Gina being out of the class, going for walks out and around, and not being in the classroom, and all that stuff." Bill was in telephone contact with the mainstream support teacher around this issue. He states, "The mainstream support and I had a couple of conversations on the phone. But I don't buy into his garbage. So he stops calling."

His dissatisfaction with the school's progress in developing an IEP for Gina prompted Bill to direct action. He explains,

> Second term started in January. I made the call. I said "where are things at?" and then I started pushing. I brought an advocate into the meeting. I brought a lawyer into the meeting, and they introduced themselves.

This meeting took place in February and also included Mr. Apple the principal, the mainstream support teacher, and the supervisor of student support services. Bill had his agenda of what he wanted accomplished at this meeting. He states:

> Gina being out of class, going for walks out and around and not being in the classroom and all that stuff -- I got that corrected. I wanted the teachers to teach. The principal said "they don't have time to teach Gina." I wanted an adapted program. "They just don't have time because of all the changes." Lunch was an issue. The TA would not support Gina at lunch. They would not let the -- ah students that would support Gina -- but they wouldn't let that happen.

An IEP had been developed prior to this meeting by the mainstream support teacher and was presented to Bill the night prior to the meeting. Bill had no participation in the document and was to review it for approval at the meeting the next day. He recalls:

> He had to have her IEP done before that meeting. Ah, and it shows up here on my door the night before. I brought that up, I said, "how can I prepare myself for a meeting when I don't see the IEP till the night before?"

Bill did not have any participation into the development this document. During this February meeting, Bill remembers the mainstream support teacher as giving excuses for the lack of program planning for Gina. "His biggest complaint is Gina cannot communicate. Gina does not like her computer, and all Gina wants to do is pull on people. So she should not be, you know, in classrooms." Bill had a very specific opinion of this teacher's ability. He states:

> He's the most useless . . . . Oh, this guy is a piece of work. This guy is some piece of work. When I'm at a meeting I don't even look at him. Like I don't know what he is getting paid for, but it is not to help people with mental challenges. No it's not!

At this meeting the issue of the mainstream support teacher not providing support to the TA or the classroom teachers was also addressed. Bill felt that the principal always came out on the side of the mainstream support teacher on issues related to Gina's programming at these meetings. He explains:

> The TA told me that they wouldn't see him for weeks on end and the principal always went to bat for him. This last IEP he gave us the other month, a month ago, there was a couple [components] that weren't even filled out. And Marlena [parent advocate] asked him -- "Oh it must have been oversight," and the principal accepts this shit. Like Marlena just goes at him. Me, I just sit there, I can't even talk to the man.

February was the first meeting Bill had with school personnel to discuss Gina's program and none of her teachers were present at that meeting. Bill states, "None of her regular class teachers attended any of these meetings. Not even her homeroom." Bill relates that Mr. Apple told him that these teachers could not attend these meetings because of their heavy workload. Bill states, "They haven't got time. They haven't got time. They haven't got time. . . . They've got a heavy workload and they haven't got time for this."

Bill explains that the absence of Gina's class teachers at any of these meetings was a result of the position taken by the principal after Bill had met with Gina's teachers at the parent-teacher night last Fall. He states, ". . . the principal has made it very clear that *he* will deal with me, and that's that." Bill explains, "For me to go and ask questions of the teacher and want things -- that's no. I'd go through him."

Bill outlines the present pattern of communication between the home and school:

> Well now what we, yeah, I don't go to parent-teacher meetings. I just with Marlena [parent advocate] and other supports that I bring in and we have meetings with the principal with the mainstream support and sometimes the guidance counselor, sometimes the computer experts are there and everything is documented.

Bill explains his position on how he viewed things to work at the school with respect to providing Gina with an adapted program. He explains:

> I wanted Gina to have an adapted program, and that the teacher own Gina; that the teacher utilize the TA to assist her in getting material, and to use the mainstream support person -- who that's what his job is -- to help the TA find those materials, adapt those materials. I was told by the principal that "the teacher doesn't have time to do this."

"<u>. . . the hugs and kisses . . .</u>"

During the February meeting an agreement was reached that would see the school bring in someone from the school board who could assist in adapting a program for Gina. Bill states, "They sold this guy to us." Bill would also bring his own support to the meeting. He explains, "They wanted to bring this person, and I said, 'well I might want to bring someone' and that's when I asked Marlena [parent advocate] to come." It was agreed that the next meeting would be held in May. Three months would pass before Bill and the school personnel would meet to discuss adapting a program for Gina.

Bill was still pursuing an adapted program for Gina, and in addition to his regular advocate for the May meeting, Bill also had the assistance of a university professor [Dr. English] to help school personnel in adapting a program for Gina. The principal had brought in someone from board office to help adapt Gina's program on computer. Bill describes the meeting: ". . . it was hugs -- you wouldn't believe the hugs and kisses at this meeting -- because their guru agreed with Dr. English. This is what I want, that's progress." Bill explains this progress in terms of the mutual agreement between the professor and the board specialist on what were Gina's needs. He states, "They just took over the meeting. Gina needs this, Gina needs that. You wouldn't believe it. The principal and the mainstream support -- just in disbelief." Bill remembers that all parties at the table that day agreed to go outside the school system for assistance. He explains:

> It was agreed by us and by all at the table, even their big guru -- the computer guru that the principal brought in -- that we go to St. Elsewhere University to see if one of their master's students could take this up. If

> that was unavailable then we'd go to -- the principal wanted their school people to do it -- if that was unavailable then we would approach Hillman University. The principal got back to us in September. The St. Elsewhere University was unable to do it.

"... all you are going to do is walk the halls."

A year had passed and Gina was still without an adapted program. However, this changed over the next five months and Gina's program took a different course. The hiring of a new TA in September of the following school year, Gina's grade 11 year, would radically alter the relationship between home and school. This new TA was a licensed teacher who was unable to find a position as a teacher within the school board. The working relationship with this TA was quite unlike the working relationship that Bill had with the TA in the junior high. This TA, Tara, had a different attitude with respect to Gina and what she needed. Bill explains:

> Tara went in there to teach Gina -- well, to be the teacher's aide. Right off the bat Tara and I just hit it off. Her philosophy is the same as mine. Gina needs to learn. We need to adapt the program. She told me she never saw the mainstream support [Mr. Edgar]. She had done all the examining -- Gina would write the exams with the other kids. Things with the principal, with the other students, with the teachers -- was all going great, okay, outside these little glitches of getting the adapted computer program in, which I was working on.

Bill had a lot of respect for Tara. He explains, "To me the positives that happened in grade 11 to this point are because of the TA." Bill describes the relationships between Peggy the home support person, whom Bill refers to as his team leader, Tara this new TA, and Gina, as being quite close. He describes the relationship:

> So Tara -- my team leader [Peggy] here at the house and her were like this [locks two forefingers], and Gina. She'd come here after school, she'd come here for parties. Gina has gone over there. She took Gina out for one of her assignments for science. There's a beaver dam -- her and her husband came here on Sunday afternoon, took Gina out to view a beaver dam and put together the project. Her and Peggy clicked. They were both college graduates. This is a teacher who believes in Gina and they both have the same values. Gina should be educated. If you don't have a TA that believes that the child's going to learn, all you are going to do is walk the halls.

The relationship between Peggy the home support person and the previous TA was not as amicable. Bill explains that there have been various times when his home support person was asked to go into the school and help teach the TA something that they were working on at home. He explains:

> At different times Peggy has gone into the school at their request and my agreement to teach the TA something and nothing positive comes out. They blame everything that's going on on Peggy. They went in to teach some hypercard. It just so happened that day the computer wasn't right up

> to snap. So there was some growing pains there for about an hour and all they did at the next meeting was crap on that. Just crap, crap, crap. We try to -- and this is the good thing about the TA that just left -- we tried to adapt her program on hypercard. Gina utilizes computer here 90% of the time here on her homework. At school she won't even go near it. Peggy gives them suggestions. Peggy is somewhat like me when it comes to Gina's education. Peggy will push the envelop. Peggy will make suggestions to the TA, the TA of last year who was uneducated, I don't even think she had grade nine, would run to the principal and constantly complain about Peggy and her expectations.

Bill recalls the following issue that was brought to his attention at this meeting:

> That Peggy is telling me things at home that are not so at school -- to the point to where we all agreed that if there's anything that the principal needs to talk to home about, or one of the teachers, to call me directly or to call Marlena [parent advocate].

Bill explains his course of action with respect to Peggy, his home support person and her involvement with the school:

> And this year they even went over that boundary and they started crapping on her again, and I said, "well wait a minute, you guys are not supposed to be talking to Peggy anymore." And I caught them in it. I said, "well, don't blame Peggy, Peggy doesn't come home and lie to me." I said, "you guys know the process. You're suppose to call me." So they

> had to back off on that one, to the point where they wanted to hire Peggy to support Gina at lunch, and I said, "no you're not doing that. You guys want home, home [sic]. Home's home. Peggy drops her off. You put the homework in her book. Peggy helps at home and that's that.

"... very loud and clearly ... they don't value Gina."

Bill acknowledges that the relations with the school personnel are back to where they were prior to the hiring of Tara as the TA at the beginning of grade eleven. He states, "So we're back to the stage where it's just home's home and school's school. Where to me, they should be working together. That's where the other TA worked."

During January of grade 11, Tara told Bill that she was pregnant and that she would be leaving in February. Bill turned to his parent advocate Marlena at this point, and she advised him to call the principal Mr. Apple and find out what was taking place. Bill explains,

> She [Marlena] said, "well you'd better call the principal and find out what in the hell is going on." I called the principal. They hadn't even started looking. So you'd better get your act together. So what's Gina supposed to do."

A meeting was arranged and Bill and Marlena met with Mr. Apple to discuss the hiring of a new TA.

> So right away we had an emergency meeting at the school. I and they agreed that they would start looking for someone. Her due date was the

> last day of February. The last week of February -- still no TA -- no hiring. They promised crossover cause Gina had sign [language] and all this.

It was necessary for Bill's home support person Peggy to cover at the school until the school was able to hire a new TA. Bill made it clear that they would pay her wage while she worked with Gina at the school. He states, "I forced them into paying her wage because I'm not going to pay it."

A new TA was hired in March, and Bill and his parent advocate met again with the school personnel. In addition to Bill and Marlena, the meeting was attended by the principal Mr. Apple, another computer expert, and the mainstream support teacher Mr. Edgar. Bill describes the meeting:

> The principal started going on, "We got a great TA" -- da dit, da dit, da dit. I said, "Wait a minute. I want you to know how I feel." I said, "First of all you said this and this back in January, and it didn't happen, and to me it just goes right back to the beginning of grade 10, where you guys really don't value teaching Gina." I said, "All you guys do is hang your hat on communication. Have you yet brought in someone to teach sign language to you." I said, "Gees, I can bring in my people to do it. But you don't want them in here." I said, "I've offered you and offered you and offered you, and here we are back at square one again." This computer expert, who's brought in, that the principal said is going to adapt all the programs, I turned to her -- no the principal turned to her -- "Well this is so and so and she's going to do this."

> Well she goes on her spiel of what she's all about, and at the end of it, I said, "Can you adapt the programs?" She said, "No I can't." I looked at the principal and I said, "Well I guess it's time to go to Hillman University. He said, "Oh no, they can't do that" -- da dit, da dit, da dit. Marlena just went back to her notes and said, "Listen, you said if you can't do it then we're allowed to approach Hillman University." We caught them with their pants down again.

Bill felt that he should have been asked to sit in on the interview for the new TA . He states, "And that five people interviewed her and all that crap. Wait a minute, nobody asked me to go to the interview." The principal called Bill the night they finally hired a new TA and let him know that she was a dietician and was very educated. Bill's explains his reaction to this information and the circumstances around this call:

> As long as the teacher, you know, gives her direction, then that's great. So I hung up the phone, and I just sat there and went, like what's the dietician got to do with it all. One of my complains last year was that the TA was uneducated and that's the way I was putting it at the meeting. So when the recent TA was hired this point was emphasized by the principal.

Bill expresses his feelings about the schools handling of this situation:

> No. No. To me it wasn't a gross oversight. It was a matter of when all that finally went down, after all the promises that were made, that there would be someone there to do crossover with Tara and Gina, to learn some of Gina's sign language, some of her needs, and how best to support her in

> the classroom. When it came down that she went on her exact due date, that she told them that she was going, and they hadn't anybody interviewed – what that told me very loud and clearly is, they don't value Gina. I made that very clear at the meeting.

Bill related that their response to his observation that they didn't value Gina was, "Oh, they just said they're very busy. This is the fastest they've ever acted and we just went back to the notes of the previous meeting that they promised that this would be in place." Bill related that two months had passed between the time the TA had announced her leaving until the new TA was put in place.

The previous year, during one of the meetings with Bill and his support people, school personnel had suggested that it was difficult for them to accommodate Gina's needs at that school and that she would be better provided for at another school. He recalls, "'Gina needs this and the other thing and the best place for Gina [another school] to get everything she needs.' They put a positive swing on it. 'This is all for Gina, really it isn't?'" Bill viewed the placement class that they referred to as being a segregated classroom. Bill felt that "This is not what Gina needs. This is what they need. It's not confrontational. It's not. They do this with a very positive swing to it and they're all sitting on one side of the table going yeah, yeah, yeah."

Bill described the seating arrangement during these meetings:

> Well the first meeting, like I'm pretty good at that. The first meeting they tried to sit all on one side, but they had a couple of chairs in between and I know better than that. So Marlena sat between one and I sat between the

> others. You know, like I don't play this. That's confrontational right there. But that's what they want. They want the power on the one side and us on the other begging. I don't play that game. Marlena and I and if someone else is with us and we have brought other people into it, we just sit around the table, and we try to get there first so they got no choice but to sit along side one of us.

"She's changing attitudes. I don't think so."

Bill's experience with the IEP process has provided him the opportunity reflect on what he would do differently if he had to relive it again. He states,

> I'd have the MAPS with great follow-up. That's the way I'd have done it. That we all focus on Gina and her day. That we all hold each other accountable and stop this power struggle -- and it's a power struggle.

Bill's perception of those in power in our schools is "This is my castle, my school."

Bill shared these thoughts on the type of school he thought a child with challenging needs should attend. He states:

> Well there's some schools in this city that the philosophy and the support -- the support is there -- maybe not the dollars yet. But they're very creative. There are some of us who believe that Gina's peers help teach Gina 'cause she has a thirst for reason. That Gina is valuable. She can learn. She can be a productive member of society, and that us as her teachers, myself included there, if she's not learning something, it's not

> because she doesn't want to -- it's to me -- we're doing something wrong. Let's try something different instead of saying she can't. Let's find if yes she can, but where? Unless it's a physical reason why she can't -- that's the only reason I want to hear it -- it's physical. I don't believe Gina will ever be an astronaut. Don't get me wrong with that. But they're things that Gina can do that will fulfill her life to be a productive member of society. I think we have an obligation to provide that to her -- that opportunity.

Bill's attempts through the years to have an appropriate IEP process established to support Gina's schooling has at times caused him to worry about possible negative repercussions for Gina. He states, "I used to. But now, like grade 11 is almost over. She only got a year left. They can't do any more damage. They really can't." Bill is hoping that Gina's last year in school will be better. His reason for this hope lies in the situation with the present principal. Bill explains his optimism "He retires in June and I can't wait. I hope grade twelve is going to be better."

Bill comments on the role of the TA. He states, "The TA should not be velcroed to the student." He explains:

> The reason is that the student becomes dependant on this TA. They [student] must be taught by the teacher. This is very important not just for the student, but for his/her peers. A teacher must teach all students in the classroom. If a student is tied to a TA, then the TA is doing the teaching. This is wrong. A TA should never support a student for anymore than two

> years. What I think would be nice is one year. If a student has a TA for more than one or two years, they [TAs] don't push them [students], they make choices for them and they don't even know it, and they would argue that isn't so with them. People with special needs are not stupid. They can get people to do all the work if we don't put safeguards around such issues.

Bill also addresses the need for TA's to be qualified to work with students, that they be certified for the positions they occupy. He states:

> In a perfect world the educators would see that the TAs need skills to support students in the classroom. They would have to be certified for elementary/junior high/high school and be upgraded every two years. With this in place you would get a better TA with many skills to help the teacher teach the student in the classroom, and the TA would stay at that level.

Bill ends with these reflections on the past and a look to the future. He states:

> It's been suggested to leave Gina there for another year, another grade twelve, which will make Gina 21 when she leaves school, and I know I'm legally allowed to do that. But I can't leave her there for another year. I can't wait to say good-bye to the education system. Yes, a lot of people tell me that Gina is blazing trails for the kids to follow. She's changing attitudes. I don't think so. I really don't. She'll graduate with her peers and that's the end of it. That's enough for me. I'm going to take a break

but then I'm going back fighting with other families. Yes, I am going to go back. I think the school board needs someone that is slightly removed to rattle the cage.

Beverley's and Robert's Story

Beverley and Robert have two children, a son and a daughter. Their daughter, Molly, has a number of challenging needs. Before I relate the story of Molly and her parents' experiences in the education system, Beverley explains the circumstances around Molly's needs and describes her strengths:

> Molly has Cerebral Palsy which challenges her physically, visually [legally blind] and intellectually. So she's basically fully dependent on others. She has some seizures and she has a gastrostomy now, as of last summer -- summer before. But she is extremely bright and she's extremely healthy. She communicates with no problem. She knows exactly what she wants and how she's going to get it. You just have to know her well to be able to pick up on what she's asking for.

To see that her needs were met from birth, both parents have been involved with professionals from various disciplines to deal with issues related to health, family support and education. Their story is reconstructed from their experiences in the education system as parents of a child with disabilities.

Institution to Special School

Molly was four when she entered the institution. The decision to place Molly in an institution was a difficult one for both Beverley and Robert:

> We were living in [province] at the time. We moved to [province] in 89 and because of the lack of supports that were offered to us as a family at

> that point in time, Molly went into the [institution named]. It was a very difficult decision for us even though she was home with us every weekend and I volunteered at her school setting during the week and Robert used to stop in and see her on his way home from work. It was still an incredible difficult time for her because there certainly wasn't enough support for her to develop the way we felt it was necessary for her. So that was really an ongoing battle. It was very difficult.

Beverley describes their relationship with the institution as being "not very good." Both Beverley and Robert expected to be involved in Molly's care. They were expecting to have much more input than the institution may have been accustomed to receiving.

> So we arrived with a whole lot of expectations and I don't think they ever had a parent input, like we expected to have. As soon as your child would go into care, then everything is provided. We didn't want them to provide for Molly. We still wanted to provide and they had a very difficult time with that when I said I still want to buy her all her clothes.

There were also other issues at the institution that were not very comforting to both Beverley and Robert. They had concerns about her educational program. Beverley explains that, "There was a teacher there available. But she (Molly) saw him a couple of times a week and it was nothing major. You know there wasn't really any -- a lot of things going on." Another concern centered around the level of staffing at the institution. She remembers that,

> Staff was always too low to how many kids were there. Staff duties took

> priority over what the kids needed to have done. Her food, it was just a very difficult time. I think the kids were basically fed, bathed, dressed and ignored most of the time.

Beverley also made reference to the physical environment. She states that, "When we arrived it was still ward sleeping and the big steel cribs and that." Finally, there was an abuse situation that involved Molly. Beverley recalls that, "Molly received second degree burns. Molly never went back to the training center after that."

". . . like going home."

When Molly was five and six and living at the institution, she attended a special segregated facility for students with special needs. While things Beverley described things as "not very good" at the institution, the situation at the special school was different.

> It was wonderful. I learned a lot. I volunteered one full day when she went and so I would arrive and basically be her care-giver that day and support person and teacher. It was really a good learning experience because of what they had under one roof. I was quite convinced that she shouldn't leave -- that she had everything that she should have -- there under one roof.

In her reflections on Molly's attendance at this school Beverley states that,

> I guess in hindsight, I wish she had never went. I don't think there is anything they offer at [school named] that can't be offered within the

> public school system. It's just we need to learn to be a little bit more creative and innovative in what we do.

The kind of relationship that existed between the staff at the special school an Beverley and Robert during the two years Molly attended this school can best be understood from Beverley's comments.

> It was great. I mean there were certainly some things that needed to be addressed here and there. She actually just went back for an assessment and it was like going home. It was wonderful just to see the people and everybody was really excited.

Beverley recalls their participation in the planning of Molly's program during the two years she spent at this school.

> Yes, probably. Yeah we were. Now it was new to us. School was new to us of course, when your child first starts school. So, I think we were probably finding our way the first year. But we were very involved and we quite appreciated the support we received and I really felt that I learned a lot, the time that we spent there.

Transitional Planning

Because of school policy, Molly was only permitted two years attendance at this school. Beverley explains that, "Of course at that time they did the two year placements and when that two years came to a close we had to make the decision." This policy required Beverley and Robert to begin transitional planning for Molly's entry into the public school system well in advance of her leaving the special school. "We started planning almost a year in advance. So I think it would have been October. Then the following September she was going to be entering the public school system." The transitional planning process for Molly was in place. Administrative personnel from the outgoing facility, two members from the school board, and her parents were to develop this plan.

Beverley and Robert were informed at the time that Molly could have a choice of placements within the public system and provisions were made to facilitate the process.

> We were told that Molly could go into a segregated setting -- a particular school -- or she could be fully integrated into our neighbourhood school. They took us to see the two school environments and we chose that she should go to our neighbourhood school. We didn't want her to be segregated. We did that and once we made that decision, the principal and the two primary teachers came over to meet Molly a couple of times. Then Molly came over to the school a couple of times with one of the workers from [special school] I thought that was good, that this planning that we were doing to have a sense of what needed to be done.

Although a transition team and a plan were in place, Beverley was to later question its effectiveness. "I am not exactly sure what good it did." Her statement was in response to the displacement of support personnel (teacher assistants) during the first month of school and subsequent impact and disruption for Molly, her parents and the school. Beverley explains the circumstances around this situation.

> Then came September and we started school and it was probably the worst experience in my life. The first month of school she went through four teacher assistants because of union things. People bumping people and that kind of stuff going on. Molly is certainly much more tolerant, has much more patience since she has been fully integrated. But at that time and when she's not happy in a situation she just yells and you know cause that's how she communicates. She's either happy or she's pissed off. It was very difficult for everybody and my big thing was I wanted everything to work out because my concern was for the other children as well. You know if things aren't going -- if Molly is not supported well then the other class, the kids are going to suffer because of it and we didn't want that to happen.

Primary - Basically a write-off!

Molly was not the first child with disabilities at her new school, but as Beverley explains: "She was probably the first child with as many needs as she has. So, that it probably was their first experience with someone in a chair who was fully dependent." Both Beverley and Robert are members of the local Association for Community Living. Because of their affiliation with this support network they were aware of certain "best practices" that would provide them input into Molly's program. In particular, they would first want to approve her individual educational plan.

> We made it clear from the start that we had to approve everything in

> regards to what they were doing with her and because I had the wonderful opportunity of knowing Erin [pseudonym for parent advocate] before and being involved in a very dynamite family support group. We came together over a lot of issues around the closing of the children's training centres. This little parent group had been together for awhile and we really learned a lot from each other and from people that were involved.

The first IEP meeting to discuss Molly's program took place early that fall. "It would have been October, September or October. That's something we generally try to push for that will happen right away, as soon as possible." The parents had input into the development of the IEP, but as Beverley explains, " . . . I am not sure how knowledgeable we were at that time." A number of support personnel also provided input into Molly's IEP: An itinerant from her special school, a speech therapist and a physiotherapist had put together their programs for the school to follow. In addition the school would develop their program. As Beverley put it, "Everybody was involved in that first meeting."

It was during this initial IEP meeting that Beverly would first encounter an attitude that questioned the full time placement of her daughter in the primary class. Molly's class teacher addressed the issue of Molly's apparent tiredness in the afternoon and sought options outside the classroom. Beverley recalls that time and makes her intention clear as to where she wanted Molly to be during the afternoon class.

> Now of course the teacher's attitude at that time was, "Wouldn't there be another place that Molly could go in the afternoon because she seems to

> get so tired at that time." I said, "Well not that I know of because every other"-- she was seven at the time -- "every other seven year old as far as I know, goes to school. So I don't think so." So there are a lot of little things like that to work out.

Although both Beverley and Robert felt that they had input into Molly's IEP, Beverley felt uncertain about its outcomes. "I'm not sure exactly what was being followed." Also both were not experienced enough to know at that point, what if anything, was missing from the IEP. When the IEP was finally written, Beverley felt that it looked okay, but sensed that there was something wrong. "When I first saw the IEP, even though we discussed it, all of us . . . I knew there was something missing." Beverley had previously referred to their inexperience with school when she talked about Molly's entering the special segregated school. "School was new to us of course when your child first starts school. So I think we were probably finding our way the first year." This inexperience was still evident when Molly entered primary, but it was quickly disappearing. "The goals seemed to be appropriate. But there was no means of getting there."

Beverly also saw that the attitude of school personnel toward Molly's placement was for social as opposed to academic reasons. ". . . you know the big thing was, she's here socially, right? You really don't want her to. . . ." This attitude became evident during their first IEP meeting with the school as Robert explains:

> I mean when we sat down at her first IEP in primary and half way through the meeting, the principal at the time said, "Oh, so you mean she's not just

> there socially. You want here to do academics too."

Through the help of their support network, both Beverley and Robert began to understand how Molly could participate beyond just a social level in the primary class.

> So I called Erin and I said, "Something's missing but I can't pinpoint it." Erin said, "I'll come up." I said, "Oh no, you're too busy." But she did. She came up the next night and actually sat down with Robert and I. She put the pieces of the puzzle together for us and helped us to understand what could be accomplished. It was us having a better sense of what could be done for math for Molly. What could be done for the different subject areas. So once that happened it really helped me understand things much more.

Beverley felt that the school personnel really didn't know what to do with respect to educational programming for Molly. Beverley describes what she observed during one of her volunteer sessions in Molly's class during her first term in primary. She states:

> They really didn't really know what they were doing with her, and it wasn't until -- it was probably December when it actually hit me and I was at the school so much that they finally gave me a job to do. I was spending so much time at the school they gave me some specific things that I could do because I was driving the teacher crazy I think. Because I wanted to be helpful more than anything, if they needed me, so that their job would be easier - that was always my intent.
>
> But it wasn't until, it was early December and I was in the classroom and

> the teacher assistant and myself -- the kids were going to do a craft and this was kind of like a revelation when this happened this day. Molly is over here and of course all the kids are over here and I waited for the TA to take Molly over to the group of kids to glue on this cotton for their Santas. She didn't, so I brought Molly over to my circle of kids who I was helping and so we did that and I put some cotton on Molly's hand. . . . it took maybe ten minutes. Next thing they were going over to reading circle. In a very loud voice the teacher said to the TA, "Are you and Molly coming over to reading circle now?" The response was, "Oh no, Molly now has to do her sensory." And I thought, oh my God, if Molly would have glued on her cotton, that would have been her sensory stuff and it wouldn't have been any big "baa hoo" and she wouldn't have to miss reading circle. So that was like -- it just kind of went -- oh my God!

Beverley's vivid recall of this particular experience four years ago and the exact conversation related to this incident in the classroom help emphasize the impact it had on her. It also helps to demonstrate her ability to see how Molly's individual program can be adapted to regular classroom activities. A second incident occurred later that day,

> Then as I was leaving the classroom that day the teacher took me aside to tell me that she knew I would understand that Molly would not be able to be involved in the Christmas concert that year because they would not be able to get her wheelchair on the stage.

These two incidents with the classroom teacher in addition to her earlier suggestion to segregate Molly in the afternoon would prompt Beverley to review the experience of Molly's first four months in school and prepare for some specific action to improve the situation. She explains:

> I guess the two things came so close together I couldn't respond to this woman and I basically left the school. The principal wasn't in that day or I would have spoke to him because he actually was a really good guy and I did appreciate his support. But he wasn't in and by the time I got home I was no longer pissed off. I was angry and I phoned the school board and I talked to the sub-system Supervisor of Special Services, who I talked to a lot actually that first year and basically said, "Melanie I don't care how they get her on the stage I expect her to be part of the concert and if they're singing one song -- they're primary and so it's no big deal."

Beverley's actions in this situation resulted in prompt response from the principal. "So I got a call from the principal saying, 'Beverley it was a misunderstanding.'" Beverley felt that was not the case. "I thought no way because of the way she told me." Molly was eventually included in the Christmas concert.

> So she was included but again it was a big "baa hoo." How are we going to do it? Well there were three stairs. I could have taken her up myself at that point in time and I said that I would. However, I don't feel it was my role.

Robert's interpretation of this incident is expressed in his following comment: "They turned a mole hill into a mountain quite quickly."

Beverley had some very definite opinions about that first year in public school. She classified the year this way: "The first year was basically a write-off." Although this was Beverley's impression of the year for Molly, there were positive developments. A MAPS (Multi - Action Planning System) session was conducted in January.

MAPS

> Because of what happened at Christmas time with the incident I told you about, we had a MAPS in January that first year. Well, we basically went through the six steps. Except they didn't do the last step. Step number seven, which was plan a day in the life of Molly. I though that was the most important step because then it would at least give the teacher a sense of -- these are the things I can do. The school board said, "No, that's not our job. We don't tell the teacher how to do their job. It's up to the teacher to plan the day." It was a really disappointing process because they didn't.

It is interesting that the school board personnel's perception of step seven in the Maps process was seen as telling the classroom teacher how to do their job. While Beverley's perception of the exclusion of step seven was: "I still felt , well there's the teacher, she still doesn't know what to do with Molly in the class. It was very frustrating." However, Beverley did see some good come from the MAPS process.

> The maps, although it probably wasn't conducted exactly the way it should have been as far as how to plan a day for Molly, I think it at least gave

> everybody involved a better sense of what our expectations were for Molly at school.

Robert felt that it was beneficial. He explains:

> It asked some questions in terms of what we think about Molly and her future in particular. It's not often that we get an opportunity to think past tomorrow for her or for your family for that matter because of her. Yeah, it was beneficial. I think in particular it opened a lot of eyes to the school people about Molly and about where -- how Molly fit into our family and the importance of that.

Robert believes that it was the MAPS process that gave them a better perspective on the IEPs that were developed for Molly. "I think it wasn't until we had the MAPS session that we really had any confidence or comfort in the IEPs that were being drawn up." Beverley states, "I think it probably gave everybody a better idea of the expectations for Molly in regards to how we wanted her to be included, which was fully included."

The MAPS session was initiated by school board personnel. However, in preparation for it, Beverley and Robert conducted some preliminary work themselves. Their affiliation with a support network allowed access to a resource person and advocate who supplied an orientation to what MAPS encompassed. Beverley explained the circumstances surrounding the initiation of the MAPS session and their knowledge and expectations about the process. Although the MAPS session was suggested by personnel from the school board, both Beverley and Robert expressed some concerns:

> It was her [Melanie, Supervisor of Student Services] suggestion that we

> have a MAPS session but there was no information, she didn't provide any information to us as a family or the school as to what a MAPS was. So we contacted Erin [parent advocate]. Erin actually came up and the whole group of us [parent support group] went through the MAPS session. We watched videos and had some written information, actual texts and that as to what the steps were so we could prepare ourselves a little bit. I gave the information to the principal -- some of the written information, saying this is what the MAPS is. I then found out that there was nothing that was provided to him at that time. Just to give him an idea beforehand.

First Grade -- "It Was a Good Year. A Really Good Year!"

The first year was felt to be mostly a write-off for Molly but her second year was different. Beverley would take a more active role in the development of Molly's program. This involvement would come at the invitation of the class teacher.

> So come second year -- grade one -- she had a fabulous teacher who welcomed me into her class and said let's work together. "What do you want to do? Can you do some stuff for me? Like do some tactile stuff." I spent basically that whole year, much to Erin's chagrin, helping to develop the curriculum for Molly.

Beverley would see herself spend most of that year involved in developing materials for Molly's program. While Beverley was pleased to have a teacher that openly welcomed her support, she was still not sure whether Molly's program would be adapted.

> Because even though I had a receptive teacher, I still wasn't sure that some of the materials would be adapted in the class. So I began doing some books and writing some books and developing some things and that kind of stuff -- all tactile stuff.

Beverley was pleased with the how things went for herself and Molly in grade one. The grade one teacher's welcoming attitude and her openness to accept help from Beverley made grade one a more enjoyable place to be in comparison to primary. She recalls, " It was a good year. It was a really good year."

Grade Two -- "A Really Frustrating Year!"

During grade two and three most of the communication regarding Molly and her program came from the resource teacher.

> The last two years we had -- the resource teacher was -- she just actually retired so I think it was probably a good thing. She was a very negative person. Every thing about Molly was negative and whatever, she had to say or write or whatever, was always done in a negative tone.

Interestingly, Beverley noted that it was the resource teacher who had the least direct contact with Molly, yet was always present and was the most vocal person at the planning meetings regarding Molly's program. Beverley explains why she believed that this was the case. "I think she was probably put in that role. That she's the one that's going to, you know chair the meeting. That kind of thing." Surprisingly, Molly's classroom teachers who saw her continually on a daily basis seemed to have the least to say at these meetings. Beverley describes the mood and atmosphere at these meetings:

> Just really frustrating and really disappointing. Just because you know I would arrive with all this stuff and some articles and my books I created and say these are some things I have done. I am willing to help you know. Please. You know I've always said that. Whatever I can do to help the classroom stuff. Let me know. The teacher barely said anything -- this teacher.

Beverley felt that grade two had been a really disappointing year and that this was directly related to the teacher's reluctance to include Molly as one of the class and her silence at meetings.

> The teacher was just a woman who didn't talk to you and didn't share. I don't think I even went to parent-teacher interviews. Robert went that year because I was so frustrated with her because she didn't take part: she didn't accept ownership of Molly as one of her students and I felt that -- I guess it was just, I don't know, a really frustrating year.

Beverley feels that this teacher's lack of accepting Molly as one of her students was evident to them during their meetings. She explains that, "Yes because she didn't participate. Like she didn't open her mouth at meetings. It was the resource teacher or the principal that spoke."

It was not only at these meetings that Beverley found Molly's grade two teacher with little to say: "I mean the teacher wouldn't even talk to me. She'd see me on the playground and she'd turn her head and walk the other away." Beverley made her concerns about this lack of relationship with Molly's teacher known to the principal. "Now of course when I talked to the principal about it, she'd say, 'It's just her personality. That's the way she is.' I thought, what's she doing teaching, you know."

But even under these circumstances Beverley felt that Molly's needs were being addressed, "The only saving grace was at this time we had a most excellent TA and she was dynamite and I knew that Molly's needs were being met even though the teacher had this major attitude." Beverley concluded her recall of Molly's grade two experience as: ". . . a really frustrating year." Robert's perception was similar:

> It was a typical case of one step forward and two steps back. Just when we thought in grade one that we made some progress and we were relatively pleased, we had some more work to do and some lobbying to do and that was largely unsuccessful in trying to get those teachers turned, in those two successive years.

It is interesting to note that Molly's grade two teacher was teaching at the school when Molly was in grade one and would have had opportunity to know Molly and her parents before she became Molly's teacher.

Grade Three - "Gang Bang"

Beverley's experience with Molly's grade three program was as she put it, "Last year was a little better." Beverley explains that a number of conditions existed to allow Molly's needs to be met. However she continued to have concerns about the teacher's genuine acceptance of Molly in the class.

> They had a very creative teacher in grade three. But again, like she wasn't that interested. I mean it's evident. You know when someone's interested in your child and when they're not. But again we had the same TA for three years, from grade one, two and three. So she knew Molly well and I knew that her needs were being met as well because of the other three professionals in her life -- physio, speech and itinerant. So we got a lot of technical aids and different things through them. So her basic program was being carried out and I knew that she was basically being included in the classroom for pretty much everything.

Throughout these years Beverley has always offered her assistance to the classroom teacher, both in class assistance and outside by transporting Molly to class field trips, so that she wouldn't miss out on these activities. "I felt that we worked really hard and we had done as much as we can to offer to do whatever. Let me know when you want me. You know." The same level of support provided by Molly's parents to facilitate her present placement may have been lacking on the part of school personnel. Beverley describes a meeting they had with school personnel to discuss supporting Molly in her program. She identifies the personnel:

> It would have been the TA, the principal, I don't even think the teacher showed up last year -- the resource, Robert and I. There were two TAs there because one TA had a medical background. So she was able to have this medical input.

Robert supplies the following correction to Beverley's statement and illustrates the classroom teacher's lack of input into the meeting:

> I think the teacher was there. I just don't think she was vocal at all. I think when a question was asked -- I mean you'd be looking at the teacher asking a question and the response would come from either the principal or the resource teacher or the TA.

Beverley continues to explain why she felt it was a very negative meeting.

> We were at this meeting last year and it was really really negative and there were some health concerns that people were concerned about and that kind of thing. . . . Well, our thing is we want Molly's quality of life to be the best that it can be in every respect. Well right away the resource teacher, "Well it can't be because she is not doing well. She's unhappy and this and that" and then the nursing person said, "I'm sure she's going to dehydrate." Because she has a lot of bowel problems which we were attempting to sort out.
>
> We were working diligently with her pediatrician during this time and trying to figure out what was going on. She was having some seizures and med changes during that time. You know you kind of have to give time for some of this stuff to work through because it just doesn't change overnight. But it was a gang bang as far as Robert and I sitting there. We always tell other parents never go to a meeting by yourself for God sakes. You know we thought we had exceeded that point. We went and I think you know, I don't think we'll ever go to a meeting again by

> ourselves. That type of meeting anyway. But it was just negative. That is Molly's fault. You know we can't do enough for her. She's having too many seizures.

Beverley relates who was voicing the concerns. "The resource led it off, but I'm sure it was because of the input from the two TA's. She was having a bit of gagging problem which ended up all being directly related to her constipation." A solution was presented by the resource teacher. Beverley explains,

> The other thing that was referred to actually at this meeting was, the resource teacher said, "You know there's a [segregated] school over in [place and school named] . . . . I know there is a lot of G-tube kids that go over there."

Beverley comments on how feeding Molly is perceived by the teacher as a serious problem requiring to be solved by placing Molly in a segregated school. "Now Molly eats all her meals. All her stuff is pureed, but she just gets two supplements. Two cans of supplement a day basically through her G-tube and that's it. So basically she's eating everything else." For Beverley this was not seen as a problem of any magnitude.
The content of the meeting had a strong emotional impact on Beverley as did the principal's interpretation of the nature of the meeting.

> I barely made it to the front doors and I was in tears by the time I reached it and I don't usually get to that point anymore. I just get pissed off and then work it out. The principal was following behind us and poor [principal named] saying, "Now that was positive wasn't it?" When she

> reached me I said, "I'm sorry, I can't even talk to you about it right now."

Following this meeting Beverley and Robert received a written report on Molly as part of the IEP process. Beverley particularly took issue with the language of the report and describes her response:

> Shortly after that we received like an annual little update on Molly. It was the most negative thing I have ever seen in my life and it sat for two weeks before I could do anything with it, and they needed it because -- or they needed us to sign it and send it back, because that's the deal. Like they don't do anything without our signature on it. Finally sat down to go over it and I basically had to change things -- like the wording was very inappropriate. I went through the whole thing and I changed it. I changed all the wording. You know . . . "because Molly is confined to a wheelchair, she can't participate at this time." So I went through the whole thing and changed it.
>
> We wrote a letter and sent it to the school board and said we have been dealing with this long enough. This is shit. We shouldn't have to be dealing with it. It's your responsibility. [The principal named] was very disappointed with us because we had to take it outside the school. The report came back. It was all nice and tidy and it was much more positive.

To deal with the issues surrounding Molly's medical needs at school, Beverley and Robert called her pediatrician. It was arranged for Molly to spend from a Monday to Friday on a care-by-parent unit at the children's hospital, after which time a case conference was arranged with school personnel. Members from the school consisted of the principal, the TA , resource teacher and a person from the school board. Molly's classroom teacher was not present at this conference. Beverley describes her view of the parent-professional relationship as portrayed during the case conference:

> So Molly's pediatrician was there. Her neurologist dropped in to let them [school personnel] know that unless her face is turning blue and she's having a seizure in the last ten minutes, they don't have to worry about it. But the interesting thing was that all the information that they asked and was given back to them was no different than the information that we [parents] had given them. . . . You know they had to hear it from the professional. They didn't believe us -- which was really interesting.

In general Beverley and Robert had specific reflections with respect to their interactions with some professionals in the education field. Beverley, in her conversations with Molly's grade four teacher, described their interactions as being on the same level.

> Well, we just talk to each other like regular folks, not me talking to someone who is up here; who is in an authoritative position. Which in some years that's the way I felt with some of the teachers who might be a little bit older than myself. I think -- felt that they knew what they were doing. They didn't need to ask me anything. I think there are ways that at times parents are kind of regulated to feel very small. I think I kind of felt that way a number of times in regards to other teachers not being able to

communicate.

Beverley explains what she meant by feeling small. "Just that what I had to say about Molly wasn't taken seriously." Robert added: "That they knew it all and you didn't know anything. That kind of feeling." Beverley further adds to Robert's perspective.

> The information that we attempted to give to the school in regards to Molly -seizures, bowel movements and how to G-tube her -- was never good enough. They needed to hear it from the professionals. They needed a nurse to come in and do a big demonstration of how to tube feed Molly. I went in and I did it and offered to do it again. But no, they had a nurse go in and do it. Those types of things. There are even some questions around the TA who seems to be -- have still a lot of questions about feeding her. When we went to [school named], that was one of her things. She wanted some feeding tips, which somewhat ticks me off because I am her mother and we have been feeding her for 12 years and I think we are doing a pretty good job. Thank you very much! I offer, but I don't want to - ah, I don't want to get into their space.

Robert felt that this particular issue around the tube feeding scenario should not have been a big deal. Nor should it have gone as far or on as long as it did.

> I guess what's probably frustrating is that we see so many people in the medical profession on Molly's behalf in relation to her concerns, and the common phrase used with us, and I'm sure with ever other parent, is "you know your child best." So when someone says we as parents can't come

> in and show them something related to our daughter, that we do day in and day out, it tends to be a bit of a kick in the ass.

Robert felt that the issue of feeding Molly through her tube while at school should have been a chance to problem solve. But as he explains,

> The thinking was, you know, so regimented that there had to be a policy before we can do this. And it was -- "I'm not sure we can do this" -- rather than this is an opportunity or a challenge. Let's rise to the occasion -- you know. It was always friction.

Beverley attributes the situation to being "just attitude."

Beverley brings things into perspective by relating to her son's school experiences. He is labelled normal and as she describes,

> He kind of just slides right through the school system year by year. How easy it is for him. So there is a lot of you know -- shit -- that we have to deal with that we don't have to deal with with him.

Robert agrees with Beverley's perception of their problems with school personnel when he states, "There are a lot of road blocks and many of them are mental roadblocks." It is also her son's experiences in school that Beverley draws upon to help her put things into perspective with respect to Molly's education.

> They weren't tracking her progress whatsoever. They kept telling me that they don't do that for kids. They don't track progress. I didn't realize exactly what I meant and I didn't realize what was missing until my son started school. In primary, when I had my first teacher interview, she got

> all his work from the very beginning of school until here. I thought, Jesus Christ. That is what is missing with Molly. I can see his progress in front of me. So I kept going back to them and saying, "You know we're not tracking her progress" and they kept telling me -- they just didn't understand what I meant.

Beverley felt that to a certain extent there was some discussion through the IEP process as to what goals or objectives had been achieved. But not in a way that it would be beneficial to the teacher who would be teaching Molly the following year. There wasn't any indication as to whether something was working or not working and why continue with something, if it's not working. "We need to track that kind of stuff so there is something on paper for next year's teacher, so it's not redundant." Beverley was able to engage the assistance of a relative to help her develop a graphing system. Every week there would be three days on which Molly's responses would be scored and graphed. At month's end, one would be able to see how she was responding in all her activities.

Beverley remembers the resistance to her plan. She says it was ". . . like horrendous to get them to accept this. Well it was too much work. Nobody had time to do it." Beverley felt that this resistence came from both the classroom and resource teachers. "Yeah, but you know it would have been resource I would have to be dealing with too, and the big change [graphing system for evaluating progress] -- not receptive from her point of view either." Beverley was forced to go to the school board to get this implemented. Because one of the school board support personnel had training in the area of integrated education, Beverley felt that this person would at least understand where she was going with this concept.

> I went through school board for this. Melanie, who was our sub-system supervisor, did the [graduate study in inclusive education]. . . . knew exactly what we were talking about. I mean my point all along was that Molly needed to have meaningful participation that was relevant to what the class was doing at every given moment. So I went back to Melanie and I said I needed support in this and they [school personnel] took it on reluctantly.

Changing Attitudes

Both Beverley and Robert were becoming aware of the importance of positive relationships with school personnel, especially the principal. "Ever year I guess we gain a little bit more knowledge as we go." This is evidenced by Beverley's comment with respect to the departure of their principal at the end of grade one. It was this principal to whom Beverley referred as being a "really good guy" and whose support she appreciated. Beverley felt that it was important to establish a good relationship with the principal.

> Then our principal changed part way through and we got a new principal-- I think at the end of her grade one. We kind of had to start all over again with the principal. Which you know it's crucial to build a relationship with the principal because of course, it's their school and blah blah blah. . . . So we probably spent grade two kind of getting to know this new principal [Sheila] that had come onboard, who really

> hadn't even though she wanted to be helpful, she really had no idea what to do. So it really has taken us a long time to get Sheila to where we feel she's at least helpful now.

Beverley and Robert were able to recall the process that led to their current relationship with the principal and how she came to play a supportive role in Molly's life. This developed through participation in a lifestyle planning team established for Molly. The local support group for the Association for Community Living, to which both Beverley and Robert belong, provided guidance in the selection of the membership for this team, i.e.; profession of the members of this team, the reason for their selection, and the purpose of the team.

Beverley and Robert both explain the circumstances surrounding the new support they received from the principal, after her participation as a member of this team. They speak for themselves.

Robert:

> Her principal -- we have now, for I guess this is the third year. It started out slow and we took a lot of effort to educate her and get her on side. One of the most beneficial things that we did, was establish a lifestyle planning committee for Molly which included a number of people from various walks of life who we had dealings with; education, recreation, family friend/advocate, itinerant teacher, social worker, Molly's pediatrician.

Beverley:

It was a group of individuals who had a stake in her life. We met once a month in our home. The itinerant teacher from [special school], her physiotherapist, her pediatrician came when she could, the principal from the school, someone from community care, our social worker and we came together -- a park and rec -- a wonderful integrated park and rec in [city named]. All these people would come to this and help us identify what our needs were.

Robert:

The criteria for, or we required, people who had the ability to make decisions, so that's why we didn't ask the TA or the teacher -- but those who had the authority to make decisions, so that we wouldn't prolong processes, and for the purpose of having other people involved, and take ownership of some of the issues, and help us in directing some concerns, and finding solutions to some concerns, without totally burdening us with some of those. There were probably two or three major concerns at the time surrounding Molly: education was one of them; transportation and respite, I guess.

We would meet roughly once a month, or every six weeks, in our own home, so it was on our own turf. At one stage we divided. We named a couple of other smaller committees; transportation committee and a respite committee. Then there were two or three people on each of those. Beverley on one of them and I sat on the other.

Beverley:

> We always took notes so that we did up minutes and we sent minutes out to everybody. These were the issues that were discussed. But the other important thing was that it was significant to have other people help us identify *for other people*, that certain things were important, so that the principal was also hearing this from other people and not just us.

Robert:

> There were actually times when we would have concerns but we would (pause) say there was an education concern, but we would get someone else to ask the question on the committee rather than it come from us, so that there wasn't a constant sort of head butting with the education system.

Beverley:

> She [Sheila] was very defensive at first. Very defensive at times when we had concerns about school. Specific concerns about a certain issue. But it certainly helped I think to have other people hear us, as that [acted as] a buffer, and turned it into a discussion, so that there was another perspective that she could perhaps look at.

Whatever else this committee had accomplished, Beverley felt it had at least accomplished this: "I really think with the principal's involvement on this, she finally began to have a better understanding of what life was like and what the issues were at home and what we were striving to do for Molly." Robert viewed it like this: "It wasn't really until last summer, I guess it was, or summer of '96, or actually, the spring of '96, when we actually noticed that she joined the team." Beverley and Robert used a number of indicators to determine that in fact the principal had become a support to them and Molly.

> We had repeatedly asked as each school year was coming to a close, two basic questions; 1) Would Molly's TA be coming back the following September. 2) Could Molly hook up with her new teacher for the following year before the current year ended? Try as we might and promises were made and never carried through in previous years. This was a request that we made probably three years running.

It was at the end of the lifestyle planning committee's second year of existence when things began to turn around for Beverley and Robert. They explain:

> The tell tale sign or the breakthrough was when the principal agreed to introduce or at least identify who the next year's teacher would be for us. We received a phone call late in June before the end of the school year last year, Sheila asking if we'd like to do some transition and meet the new teacher who'd be coming to the school, so that -- there would be a new TA and new teacher arriving at the school.

The principal asked that Beverley call her later in the summer to find out who she had hired. When Beverley called, the principal wanted Beverley to know why she had hired this particular teacher. "I called her in July and she said, 'I want you to know who I hired. I want you to know why I hired him' She specifically hired this new teacher with Molly in mind, asked specific questions in regard to integration and all that kind of stuff." Beverley and Robert gave the impression that it was because of this principal's involvement with the lifestyle planning team that she had a greater understanding of Molly's needs and the parents' concerns.

". . . one of the less stressful years . . ."

There were a number of developments that made grade four a very different year from all the other years Molly spent in public school. The catalyst for this development was the commitment of Beverley and Robert to see that Molly was provided with services and resources that she required to meet her needs in the school system. Through their actions they secured the support of the school principal who, upon seeing and understanding the needs of Molly and her family, began to prepare her school to meet these needs. Because of her new insights, the principal was able to hire a teacher whom she felt would best serve the needs of all children in the classroom, including Molly.

Beverley's comments affirmed the principal's choice for the new grade four teacher. "He's wonderful. Like he's wonderful." Beverley proceeded to elaborate on her comment:

> Even when we sat down to do her IPPs, because they're called IPPs this year. But even some of the language from her previous IEPs, he picked up on and said, "Why do we have to keep saying -- you know -- So she can be included with the class." He said, "That's a given." He said, "I expect her

> to be included with the class." So he has been great and it has been one of the less stressful years that I have ever had in many ways and I'm doing less as far as curriculum adaptation.

Other aspects related to the IEP process such as the meeting itself began to take a different focus. Beverley explains, "The teacher basically took over. He's the one that basically chaired the meetings. When we'd go to a parent-teacher interview this year, it's him and him alone. It has made a world of difference." The IEP this year, as Robert explains, was drawn up by the new resource teacher in "harmony" with the teacher. How parental input into the IEP process occurred at this time is explained by Robert:

> We got together, all of us basically to sit down and review. I guess all of us agree on specific things such as communication as being one of the major objectives for Molly or goals in her life. So, if IEPs don't change drastically it's just a matter of maybe some of the objectives and activities and it was basically, teacher and resource teacher who worked together initially and then we came together to discuss this.

Robert feels that for the first time the development of the IEP has proceeded as it was supposed to proceed. ". . . it was with the teacher doing the lion's share of, a) the work on it and b) the communication about the work that went into it." Robert describes how he recalls the flow of meetings prior to this year.

> Previous to that it was a case of the principal speaking for the teacher or the resource teacher speaking for the teacher. We were quite refreshingly surprised. It was a faster meeting. It was not as frustrating or perhaps even

acrimonious as some of the last ones had been.

Both Beverley and Robert had their opinions as to why things were different.

> Probably because of the ownership issue, I think was probably why we would go to these meetings without great expectations, and perhaps a fair bit of stress about them because we didn't think anything was going to transpire, and we thought we would probably lock horns again and not get very far.
>
> The previous resource teacher also was very negative -- very negative in her approach -- always focusing on the negative; rather than on the positive -- on what Molly can do -- and what her strengths and abilities are. She always focused on what she can't do -- what she's missing out on. You know they can't meet her needs and this is why -- because it's her fault. That frustrates me to no end right from the beginning.

Beverley believes as does Robert that the big difference in the flow of these recent meetings is that the teacher took the responsibility for Molly's program, that the teacher has more creativity and works well with the resource teacher. "He seeks out opportunities to integrate and adapt the programs to meet Molly's needs." It is obvious from the following conversation that he feels there is a good working relationship between home and school.

> But he is really keen. You know, he's not afraid to ask, and you know, it's just nice to have -- like we're on the same level. When I have a conversation with him, it's "Call me anytime. Okay." I will, and you

> know, "Do you want to come in for this or come in for Art next week." You know he'll just call and say "We're going on a class trip. Can you transport Molly that day?" And it's just really nice where we haven't had that for a long time.

Robert goes on to describe other attributes of this new teacher that helps to foster this new relationship. "He's very open to suggestions too. I think in a lot of cases in years previous, we would make suggestions and nothing would ever happen to them." Robert felt that there were particular reasons why there was never any action taken on their suggestions. "I think that was a reluctance to embrace Molly, to educate themselves about children with needs." Robert suggests steps that could have been taken by the school to accomplish this task.

> You know they could have done something as simple as calling other schools with children with similar needs to Molly's. Schools that were respected for their integration or even their segregation programs and found ways to make her become more a part of the classroom. I think it's a willingness actually.

Beverley and Robert also feel that this year, for the first time, they have a teacher who has shown interest in Molly and who is supported by the principal. They refer to a two day assessment of Molly at the segregated special school. Beverley and Robert explain what they felt was so important about this.

> What happened though is that the teacher went for one full day and the TA was there for two days. So that he had a sense to see some of the different

> things that can be developed for her and that. We never had a teacher show any interest.

Beverley and Robert felt that this positive attitude by this teacher toward Molly and her inclusion in his class had impact on others who attended the meetings.

> I would think so. Sheila for instance grabbed me into her office one day when I happened to be in and just talked about how well Molly is doing this year. "She's had a fantastic year this year at school and you seem to be much more calmer." I said, "Well Sheila" I said "you know (pause)." Well we had a bit of a talk about how the negativity affected us as her parents and in turn affected Molly.

Robert also explained the principal's role in Molly's teacher attending her assessment for that one day: "She went to bat for us in making this happen through the school board; because of course there's an expense involved by having to replace that teacher for the day."

Beverley feels that this year has been "a much more positive sort of year and they [school personnel] have gone the extra step." One of the concerns first addressed when Molly entered public school was her being tired in the afternoon. At that point in time, the suggestion was made that there might be some other place beside the classroom that Molly could be at these times. "They seem to be much more willing now to take the extra effort and figure out how she can stay in the classroom." Beverley explains how Molly's perceived tiredness is now approached in a different manner.

> I think they're learning that if Molly falls asleep, it's because she's bored.

> So we've found out how Molly can have earphone inserts to be able to listen to things. Because in grade four they're doing things that could be much more quieter. So we need to figure out how we can include Molly with something similar to what the rest of the kids are doing. Like if they are doing silent reading or whatever, then she's doing some. She has earphones for the computer in her class, so she can being doing some of that work while they're doing silent stuff and that. So there seems to be -- they're much more keen to explore new things this year.

Beverley's explanation about what seems to make the difference from year to year with respect to it being a positive or negative experience for them and Molly, was "teacher attitudes. That's it." Who plays the most important role when it comes to having a positive attitude and including Molly as a full member of the class, was clear in Beverley's mind.

> The teacher, because my problem in previous years when the teachers weren't really involved in her life (pause) -- that I knew that the TA and Molly could go merrily on their way, and even though they were getting work done, specific work done, she wasn't necessarily being included with the class and the rest of the kids knew that. So if you don't have a teacher who recognizes a child as part of their class, then the other kids pick up on that.

Commenting on how the teacher's attitude toward the child as a full member of the class affects the relationship between the parents and the principal, Beverley described the continuing good relationship with the principal this way, "It's a positive relationship this year especially because there's been nothing that we need to address because we have had a most excellent teacher."

Beverley had specific ideas on how this has impacted on Molly.

> I think Molly knows when she's included and she's not. So I just think having people who do not respond to her -- I mean she depends on her auditory sense, it's her major way of learning and communicating with others. If she doesn't have a teacher, for instance (a teacher), who never speaks to her, never speaks her name -- I think she regresses.

Beverley feels so strongly about this that as the current year in grade four draws to a close her thoughts focus on what next year will bring. "Even though year to year has been different and to be quite honest with you, now that we're coming to the end of this school year, I'm panicking about next school year because I don't know who her teacher will be." This seems to be a major concern for Beverley and Robert as each school year ends and a new year begins. They do not have the same concern with respect to their son.

Learned Experiences

Beverley's and Robert's period of involvement with the education system has been relatively short. Molly was in grade four at the time of this research. However, their experiences with a daughter with challenging needs in that system has provided them with insights and understanding as to how the system can help support students with disabilities.

In concluding our conversations, Beverley and Robert had advice to offer, based upon their experiences with the IEP process. This advice was directed toward young families just starting in the education system with a child with challenging needs.

> Well to start planning early. To find out about as much information as you can. This has actually just happened to me. I have just met a young couple who has a five year old who she's torn about whether he should go into a segregated class or an integrated class. I gave her several articles written by parents from different provinces in regard to education. I talked about our experience a little bit and told her that she had to develop a relationship with the principal. That was critical.
>
> That it was important that they learn and understand what the purpose of the IPP is. It's not just to set goals but how to get there. Like what are the means of reaching those goals and I think that's what's missing a lot of times.
>
> What can be done for different subject areas because that's where a lot of teachers are at a loss. When they said "Molly can't do math" and I said "yes she can by tactile way." We can count on her fingers. She can feel the number one. She can hold one thing. She can hold two things. It's understanding that kind of stuff. Because to me that it's so easy. It's so easy to be able to -- having a sense of that kind of stuff.
>
> Then I told her when she finished reading that stuff, then we would sit down and look at a couple of Molly's IPPs and probably never go to a

meeting by herself.

Beverley's and Robert's experience in the IEP process over the years has prompted the following advice to other families.

> I don't know if there's a way to help families learn more before they reach school. To understand again what the purpose of it. . . . I knew it was about setting goals, and even though we were involved in identifying the goals -- what needed to be worked on, communication, what Molly's strengths were -- I found that we weren't always focussing on her best abilities. You know the things she could do well. It was never the question; *How can we do it?* It was; Can we do it? You know maybe we can't.
>
> I think there needs to be more of an interdisciplinary approach within the school somehow. We're working together to solve problems. I don't think that happens enough. I think parents feel alienated, and feel like they're asking for way too much [just by having their child attend school], and I think that's why parents don't get involved at times because they're just happy [grateful] that the school takes them and why interfere [rock the boat].

Responding to various questions, Robert and Beverley had specific advice for both teachers and administrators on how to help facilitate a positive IEP process and to help parents become equal partners in that process. They speak for themselves.

Robert:

Well I guess the main thing is to find out what the parents want before they [school personnel] dictate what is going to happen.

Beverley:

How would they do that? By asking I guess what parents hope for their child so they got a better sense. So I mean, there has to be that component. The other thing is, we as families have to be educated as well. There's a ton of resources out there. Even if it's only reading material to read about what the possibilities are, because there are. Initially I couldn't wrap my head around how Molly could do math -- and how she should -- why she should -- Why we should even bother. But now I understand that, and we have to help other younger families understand those things. And I don't know -- it's about building relationships too.

Robert:

How does the system help parents? I think the system also needs to further educate themselves about the processes of the IEPs, because our experience seems to be that whenever we have an IEP and it's a new year or a new teacher, it's perhaps the first time they have ever been through that process.

It has to come -- it seems that the knowledge of these things, at least in the [city] system is available at the board level but it's not at the trench level. They don't seem to be doing anything from the

> administrative perspective to bridge that gap -- opportunities for professional development perspectives where they address a few issues relating to disabled children.
>
> It would seem to me that they should be putting more emphasis on that, as more and more children are entering into the system, and more and more of those children have multiple or complex needs. Even from the home and school perspective -- I was actively involved for about a year, just attending the meetings. At all our home and school associations it was routine to have a guess speaker at the meeting every month. Never was that guest speaker who was brought in, addressing issues related to the disabled population -- despite the fact that the principal was always there, and asked for input in terms of who the next speaker might be.

Final Comments

Robert and Beverley continue to work to help to improve the quality of life for Molly and at the time of this interview had already pursued establishing a circle of friends around Molly. Robert feels that a MAPS session would be beneficial in further exploring that avenue. They also continue to provide information to school personnel about summer conferences and programs that teach courses on supporting students with disabilities in the regular classroom.

Robert's final comment recognizes the importance of the classroom teacher, such as Molly's grade four teacher, becoming a resource for issues around disabilities in the school. It also recognizes the role hierarchies and relationships play at the grassroots level in the school. ". . . you're talking about a teacher talking to a teacher rather than a resource talking to a teacher or an administrator talking to a teacher. I mean there is nothing like peer interactions to make things happen."

Charlie's and Barb's Story

Jeffery was eight months old, when he came to live with his present guardians, Charlie and Barb Smith. Jeffery is now six years old. Charlie and Barb had already raised two children prior to Jeffery's coming to live with them. They are in the process of adopting Jeffery and are currently awaiting that to be finalized.

Jeffery was jaundiced at birth. He was a colicky baby and at six months old underwent an operation for strabismus and has worn glasses since that time. Barb and Charlie describe Jeffery as a child who would rarely sleep and would go sometimes for three days before eating anything. Even today Barb says, "He's extremely, extremely picky -- what he eats now." She indicates that Jeffery was late walking and was four and a half years old before he was toilet trained in the day and almost five years old before being toilet trained at night. She states that, "He was slow at everything -- speech. Even today, he has a speech difficulty."

Charlie describes Jeffery as, ". . . extremely smart. Even too smart for himself." Charlie had specific concerns related to Jeffery's fascination with fire and water. Charlie describes those concerns around the issue of water.

> If you go to the water, even at his age, he doesn't know how to swim exactly -- he loves the water, he's not scared of it. He will go to the deep end and dive or jump. Whatever, it makes no difference to him, whatsoever.

When Jeffery was three years old, the Smith's felt they should place Jeffery in regular daycare. Barb and Charlie explain their reasons for that decision and what they discovered.

Barb:

> We thought we would put Jeffery in a regular daycare because we heard that all people in the '90's, this is the way to go. You have to have your child advanced and ready. So, we struggled financially to put him in the door and he would not want to stay. He would cry. We noticed that things were wrong.

Charlie:

> We also at that time noticed that there was obviously something wrong. We just didn't know what.

Barb:

> We noticed before, but this was icing on the cake more or less.

Charlie was told by the director of the daycare that Jeffery was spoiled. Barb indicates that she had not been told this, but rather that Jeffery just needed time to adjust. Barb was inclined to agree with what she had been told by the director of the daycare. She states, "With me it was just that he needed to adjust really. I felt that too. She's right. But, then an incident took place. He didn't have an appetite. We thought he had allergies -- it wasn't."

Both Barb and Charlie are very involved in Jeffery's life and were active participants in the gathering of background information that helped Jeffery's pediatrician make a diagnosis. They discovered that Jeffery had been exposed to alcohol while in the womb. Jeffery was around three and a half when he was diagnosed as having Fetal

Alcohol Effects (FAE) and Attention Deficit Hyperactivity Disorder (ADHD). Charlie states, "They feel ADHD comes in place, you know, it's secondary." Barb and Charlie relate their knowledge and feelings with respect to fetal Alcohol Syndrome (FAS) and ADHD.

Charlie:

> FAS is -- 90% of all mental retardation comes from now and the neurons are what's burnt and they don't come back.

Barb:

> If he had ADHD we could have dealt with it because ADHD -- they may outgrow a certain portion of it. I mean they're more adjustable.

Charlie:

> If it would have been drugs, it would have eventually flushed out of his system.

Barb:

> Even crack.

Charlie:

> But, because it's alcohol, what it does, it burns the brain. If you had a Cat Scan or M.R.I, you would see where the blotches or the black spot that's burned. It will never come back. So he has to adapt in other ways.

Barb:

> A lot of children with FAS or FAE cannot go on a lot of drugs such as Ritalin and Cylert. They can have many reactions but with Jeffery, in

> particular, it was a violent reaction. He was on Ritalin twice. It didn't work -- changed from there to Cylert -- that didn't work.

Charlie and Barb provide some insight into their present situation at home with Jeffery.

Barb:

> I find with Jeffery being as hyper as he is, we're constantly thinking of things to do to him -- busy all the time -- we get worn out. Jeffery is never regular in bed, 9-10-11 and 9 is a very good night. Mostly it's 10 and 11o'clock at night and school, he's late for school most mornings.

Charlie:

> If he gets 15 minutes snooze during the day -- 1 o'clock in the morning , 2 o'clock in the morning, before he goes to bed or before he's tired enough, that he is going to finally let it run over and bang keel over.

"... technically it would create segregation."

Charlie and Barb placed Jeffery in a developmental preschool after his medical diagnosis was known. Their decision to do this was based upon their present experience with the regular daycare and upon the advice of a friend, who worked with the local social services. Their choice of a particular developmental center was based on three factors: the use of discipline, the kind of programming offered, and finally, Charlie's feelings about the level of security at the center. Charlie explains his concerns around discipline at one particular developmental preschool.

> Discipline was simple in their school. You go in a time-out room. Well, where's the time-out room? It's this tiny, puny, little cubby, four feet across by two feet wide with a stool inside there, sit on that stool and it's a one way mirror. You don't do that to my kid.

Charlie also had difficulty with the way they structured their programs at the center. He explains:

> You walk into the place and I ask some questions as in -- "Okay, if Jeffery starts in this particular center -- what does he do for his rooms [placement within the program]?" "Oh no, he starts in this room." [Staff response]. I said, "What happens if he progresses from that room and he is ready to move on to the next one." "Oh no, he has got to finish the year in that room." [Staff response]. Okay, because of the age. They went age instead of mentality. I asked the ladies "when do you move him to the next place?" "Well, we don't. It's next year, when we start, he moves on." [Staff response].

Charlie relates his concerns around the level of safety he perceived at this preschool. "Also at the same time your walking down this hall, you don't see anybody, except there's like a little branch you go in where the administration is, so I also had concerns that anybody could walk in and walk back out [without being seen]."

Barb also had concerns with this particular developmental preschool. After visiting the center, her concerns centered more around the feelings she experienced while being there. She explains:

> So we checked the first one out, which we had told you earlier about the institutionalized feeling we had from it . . . . Honestly, the feeling I got from that, it was a brick building, well, so was the other one that we put him in, mind you, but this one was -- a very rainy day when we went there and I cried when I came out.

Charlie also explains why they settled on a particular developmental pre-school.

> The ratio was one in four. One in six the maximum. They're all trained into doing their jobs -- education is there. I wanted one-on-one computer. He had that once a day, one hour a day, one-on-one computer. They are telling you that there is a communication book coming everyday. Anything that was coming forth, or if there was something wrong with Jeffery, they would mention it. If not, then maybe we are going to try this, or give you an example. They did something much different there than the other one. This one took us in the classroom to show us what they were doing. It was an open type concept and we did see that it was not segregated. Which was also my little problem with the other place -- technically it would create a segregation. They were really open. Showed us the entire thing.

Another aspect of this particular pre-school that attracted Charlie and Barb was the use of an extra-sensory stimulation room. Charlie describes the room, "There's fibre optic -- changing colors, the smell, the ocean, the waves. It's a calm down. It's the smell, the eyes, the touch -- you name it." Barb was also impressed by this special feature at the developmental school. She comments, "Yes, it's everything. Oh, it's incredible."

The initial positive impressions Charlie and Barb had about this developmental preschool were also accompanied by their feelings with respect to accessibility to the program and staff at the preschool. Charlie explains that, "Whenever you had a thing -- walk in." Barb describes it much the same. "Yeah, walk in. Like open door." Barb describes how she was also impressed by the physical appearance of the place and how that left her feeling.

> Very bright -- airy, where the other one was so dark. . . . truly when you walked in there, it was bright. It was just bright. It didn't have this institutional feeling that we had in the other one.

Charlie points out that this particular developmental preschool belonged to and was operated by the local Association for Community Living (ACL). He explains, "So it was an inclusive one and it is not a segregated one." It was during this time that Charlie became involved with this association as a member of the executive on the preschool committee. Barb comments that Charlie's volunteering on this board would help keep the preschool open and Jeffery wouldn't lose what he had at this center. Charlie explains how his involvement developed.

> We got involved in the preschool, into their committee and we helped a little bit. One day there was a problem with the executive level -- that if they didn't have a slate of officers -- the preschool closed. Well somebody's got to move. So, I moved in there.

Transitional Planning

Charlie's affiliation with the local ACL provided him with the opportunity to meet the mainstream coordinator for the local school board, who was also a member of the local ACL. Charlie relates that this provided the opportunity to access information needed to prepare themselves for Jeffery's entry into the public school system.

Charlie and Barb both knew what they wanted in a school for Jeffery. They sought the assistance of the director of their preschool in helping find a school. The director recommended a school close to them. Charlie's position on the issue of finding a school was not restricted by distance. He states, "I don't care about the distance. Bring me the best school."

In May while Jeffery was still in preschool, an orientation was arranged at the local school Jeffery would attend. Charlie recalls the comments of a teacher at that school after a 45 minute orientation. "One of the teachers said, 'there's no problem with him. We don't need a teacher assistant.'" Charlie's reaction was, "Whoa! Whoa! This is new. You don't know yet. You just don't know." Also during this time Shirley French, the coordinator of the resource center, cautioned her teachers, ". . . don't be to quick to say something like that." Barb reflects on that comment made by Shirley French at that time, "She was very much on our side there."

Both Charlie and Barb met with the resource teacher at this time. Charlie comments on that meeting.

> We had this meeting with her and then we said, "Well we don't have any problem with this school." It was really open with Shirley. So we

thought, okay. Now we have this in place.

Barb also states, "At the time it was great and we were very happy because this is ideal. It is in our area and we don't -- transportation wouldn't have to be a problem."

To prepare for this move into the public school system in September, Charlie and Barb began initiating plans in January of that year. Charlie explains their action plan. "What we did originally is, we flooded the school board with information because we wanted a teacher assistant." A teacher assistant was finally arranged for Jeffery. Charlie comments on the present situation, "Now they're sure happy there is one."

In June, prior to Jeffery's entering public school, a meeting was held at the preschool. The focus of this meeting was to provide information to parents and guardians about their children with disabilities entering into primary grade in the school system. Also during the month of June, a transitional meeting was held at the elementary school. Accompanying Charlie and Barb to this meeting was an advocate from ACL, Fran Mason. Charlie explains the function of the advocate from ACL. "We had Fran come in and she was taking the minutes and what we didn't think of, she asked." For the first time, public school based personnel were part of a planning meeting centering around Jeffery's needs. The new members of his team would include a speech therapist, occupational therapist, the principal and a resource room coordinator. A classroom teacher was not present at this time because they did not know the specific individual who would fill this position in September.

Charlie explains the purpose of the meeting. "It was for her [Shirley, resource room coordinator] to have an idea of where Jeffery was coming from -- to create his

IEP." Barb felt a little discouraged at this meeting because of the answer she received from the board mainstream coordinator in reference to her question around a teacher assistant for Jeffery. She recalls this conversation:

> I asked her one question. "What will happen if the TA that is for Jeffery is not compatible?" She said, "Well compatible with you or with Jeffery." I said, "Well both." Well the idea is -- it would depend." She didn't tell me, depend upon experience. "The union." she said. I said, "How hard would it be to have someone new if it wasn't working." It would be difficult because they are covered under the union. So she said, "It could be difficult."

During this meeting, it was also agreed to implement a procedure to monitor Jeffery's behavior while he was at school. A daily communication book would be used to report back to the home. This would contain entries from the school each day and carry correspondence from the home back to the school. The information could then be used to report back to Jeffery's doctor, as to how he was progressing. This information could then be used to make necessary adjustments to medication or follow-up treatment measures.

Barb states, "We had communication going back and forth when school began." Charlie explains, ". . . the book is so we can have a perspective to go back to Dr. Chaulk and say -- is there some type of a pattern -- guide of how he is doing. . . . maybe a solution -- structuring something that would work."

"... persona that we should know everything"

Jeffery entered primary in September. His placement was in regular class with an hour an a half a week allotted to resource room. Barb expresses her feelings with respect to Jeffery's placement. "It just hurt me to know that we had to put Jeffery into a learning center [resource room]. You know he wouldn't be going normally into school." Barb expressed her feelings to Shirley French about the placement. "I told her it just hurt me that he would have to follow in there because I felt he would be ostracized by the other kids you know. You know how that can be." It was mid September when Barb asked Shirley about Jeffery's IEP . She recalls that conversation. "September 16 when I asked about the IEP -- 'Gee, I really don't think he needs one.'" She went to Ms. Marks, that's the principal of the school. Ms. Marks said, "Yes, draw one up." Charlie's position on the development of an IEP was, "You're definitely drawing one up." Neither Charlie nor Barb had input into the development of the IEP at this time.

Charlie and Barb recall that they first met with Vickie Park, the classroom teacher, at the first parent/teacher meeting in October. Later that evening, they went downstairs to meet with Shirley, the resource coordinator. At that time she presented them with the finished IEP document. Charlie and Barb both describe the meeting that evening and their feelings with respect to the IEP with which they were presented.

Charlie:

> Shirley sort of said "Well yeah, anything you guys got a problem with?" Well, if I don't know, and there's all those pages, we're supposed to just -- well, what does this mean? I don't have a chance to do it in the meeting

> because I'm concentrating on too many other things.

Barb:

> She brought out the IEP and you're the fellow [Charlie] who looked it over. I figure he knows, he is more in tune than I am with these things. So she brought it out and she asked about it. Charlie made a change he asked for and that was it.

Charlie:

> That included putting the Education Program Assistant [TA] in the middle column [a heading]. That was the only change that we made. It's our first, like it's our first time in the school, and then you know some people had the persona that we should know everything. Well, I don't know everything.

Barb:

> I know nothing and he probably knows less and that's more than I. My youngest is 24. So it's been quite a few years.

Charlie:

> That's how many years ago we were in school. . . .

Charlie also remembered that he informed Shirley, the resource coordinator, for purposes of the IEP, that Jeffery was not on Cylert anymore. He also noted that they had not received a report from Jeffery's occupational therapist. He indicated that they never did get that report.

"Everything was smooth until February. . . ."

The communication book that accompanied Jeffery back and forth to school each day provided a link between home and school. It allowed Barb and Charlie to know how each day was progressing for Jeffery and to have a written account of his behavior for the purpose of providing appropriate programs.. Barb explains:

> Yes, or if he had a bad day, like he was on Ritalin, it didn't work. He went from that two weeks later onto Cylert. This is all recorded in this book. When I go back to the children's hospital, I was able to say, look this is what happened with Jeffery, he busted our windows almost. So this is all that this has been about and it was because it was carried over from preschool.

The daily entries in the communication book were from Alice, the TA, and not Vickie, the classroom teacher, and only occasionally from Shirley, the resource coordinator. Barb did not have a concern with the daily reports coming only from Alice. She explains:

> That was not a problem for me, you see, I felt very comfortable with this person [TA]. She's with Jeffery all those hours and she can pretty much read him. Shirley sees him an hour and a half a week up to that point. I didn't see there was any problem.

In February the relationship between the home and school became strained. Barb describes the events and circumstances surrounding the deterioration of the relationship.

> I can show you a date I looked at the book and I was very down about it..

> February 13 was -- this is not positive. There is not much positive here. Are you telling me he cannot learn or are you telling me something else. It meant that Jeffery was inattentive and not focused.
>
> In February when I wrote this, it's not positive, everything changed. It was written anyway and with that, that changed the whole communication -- everything. I asked for a meeting, and the reason I said, it is because parent-teacher night, 10 minutes is not enough time to go over Jeffery's -- encompass Jeffery's education. We have not seen the IPP since that time you see. Nothing.
>
> When I wrote that, the learning coordinator [Shirley] had been photocopying pages from the book and she decided that she should be reading the book everyday. She should also be writing in the book.

Barb's response to the TA's comments regarding Jeffery's behavior, and her request for a longer meeting to discuss his program, resulted in some procedural change at school with respect to the communication book. Charlie indicated that within a day or two of Barb's comments and request, Vickie, the class teacher, began to initial the entries made by the Alice in the communication book. Barb states, "Which we have never had before . . . . this carried through until the 20th of February. . . . when we went in and had our meeting."

The week after Barb wrote the note, she and Charlie went to the parent-teacher night and had a meeting with the classroom teacher for approximately ten minutes. Barb comments on that evening.

> At that time we did and then we went down with Shirley. Down to the learning center and we still did not have the IPP. . . . at this time we were not too impressed. So we asked when we had the meeting, we asked to have Fran [parent advocate] come in with us.

She explains why they wanted a person from family support of the local ACL to accompany them to their meeting to discuss Jeffery's program.

> We asked her to come back in with us because we felt that something was going on. We weren't sure what was happening and I felt like I couldn't trust them totally at that point. Because I didn't know what I had done that was so wrong. I just asked for a 10 minute -- more than a 10 minute meeting because it wasn't going to encompass what we had to go over.

The request for a longer meeting with Jeffery's classroom teacher Vickie to discuss his program would now also include Shirley, the resource coordinator. Charlie had some very specific thoughts on her presence at this meeting.

> Well I didn't want Shirley. I want to know about the classroom. I don't want to know about the learning center. I want to know about the classroom and the one that's the boss, as far as I'm concerned is the teacher, not the learning center coordinator. She might be the resource of everything, but you don't coordinate the classroom. It's still going to be the teacher, that's the boss.

During the first parent-teacher interview in the fall term, Barb and Charlie met only with Vickie and Alice. They later went down to see Shirley in the learning center.

The upcoming meeting would tentatively include those people plus, at Barb and Charlie's request, the parent advocate Fran, and the principal Ms. Marks. Charlie speaking of the resource coordinator states, "She also wanted to bring her supervisor into the next meeting -- suddenly wants to bring the coordinator of mainstream." Charlie began to speculate on why things were beginning to develop in a particular manner with respect to the upcoming meeting. He states,

> See the whole thing started when Barb requested a meeting to be longer. They already know that I am quite active with the school and I believe in integration and all that stuff. So, maybe they seen something that wasn't there.

Charlie discusses another point that was brought to his attention. He states, "I look at the learning center as a segregation class. I never mentioned anything like that. I never talked about that." Charlie's concern around the learning center was not whether he viewed it as segregation or not. His problem was with the school wanting to increase Jeffery's time in there from one and a half hours a week to five hours a week. He explains,

> The only reason they gave me, it's not because it's going to benefit him in the classroom, it's for him to like coming to school. That's my problem. So, if Jeffery is doing bad in school next year. What does that mean, he goes back for another three hours.

Charlie and Barb explain that just prior to this, they had read a piece in the newspaper about a court decision in an Ontario case where the court had given the School

Boards the right to decide the appropriate program placement for a child with disabilities. Barb states, "Charlie became panicked." Charlie explains,

> When I read this now -- the teacher can decide where my child goes, I start to whoa -- red flag. Then the signature comes in [on the communication book]. Maybe two weeks after I seen this new case reversal and I thought, "oh, they are going to do something to Jeffery." I don't know what. I went on the defensive.

Barb comments, "Now it's blown way out of proportion. It's unbelievable." In addition to this Barb also reflects on the response she later received from the resource coordinator with respect to her note and a request for a longer meeting.

> That's all I meant -- that was all. But, of course I can write very sharp. The learning center coordinator told me -- she said, "You know you can be very sharp with the pencil." I thought, "well if I have a problem, if I don't address it -- I'm not on a professional level like you people." So, I mean I'm not going to use the choice words. I'm just going to tell you this is (pause) -- I want an answer.

The particular entry in the communication book to which Barb had written her response was not atypical from other entries. On the contrary, this type of note about Jeffery being inattentive and unfocused was much the norm. Barb recalls her reasons for writing her response to the TA's observations that particular day.

> They are all typical pretty much, unfocused, inattentive, yep, pretty much -- the odd day. We had many indications, and I was so tired of seeing --

> after looking at this book since November, and seeing that he's off Cylert, and this is the prognosis -- like this is not -- to me I felt down. I felt this is not positive. That was my reaction -- what I wrote.
>
> I just blew. I looked at it all and I thought, this isn't positive, he's primary. Things are going on I'm not told about. Things that are written in the book are contradictory. I mean I want to know about his behavior. I have to take this child to the children's hospital. You know I need the significant things written down, so I can back up and say, "well okay, we haven't had many positive days since he has been off Cylert. Has it been because it takes three months for him to get back down to his self or what?" So that's why the book is carried through.

Barb cites specific examples of behavior that were not recorded in the communication book. She recalls:

> Such as the day he jumped across the table at a little boy and grabbed him by the neck. That was not put in the book. A day out in the schoolyard when one boy held him down and one boy kicked him. That wasn't put in the book either. Then I had a case where he and a little girl got into a little racket, and she hit him in the head, and that was not put in the book.

Barb and Charlie were at the school each day, either volunteering in some capacity, as in Barb's case or just dropping off or picking up Jeffery. They saw the TA everyday and the resource coordinator, maybe every second day. Barb relates that there were things that they had addressed over the last six months, but they were of no great significance. She states, "I felt comfortable." and Chris comments that, "Everything was smooth until February when we requested the meeting."

"You have made me get my hands slapped."

When the meeting finally took place on February 20th, their parent advocate Fran and the supervisor from the board were not in attendance. Charlie's comment summarizes their approach prior to going into the meeting, "We went in and tried to pacify everything." Increasing Jeffery's time from one and a half hours a week to five hours a week in the resource center was discussed. Barb and Charlie each held a different view about this change. They explain:

Barb:

> I felt it would be good for Jeffery to go into the learning center more often than what he was in there already. Because I am up there everyday with him, I see the parents, how they react. I see how Jeffery reacts to the other kids and I felt that, perhaps it would do him good to be in there. Charlie had a problem because Shirley's idea was to make him like school.

Charlie:

> Not that there was a problem learning in the classroom. Just for him to like school.

Barb did not have a problem with that because she felt that Jeffery needed down time and this would be great. They agreed to meet again in one month. Meanwhile, the schedule for Jeffery to come to the learning center was prepared by the resource center coordinator. It was not acceptable to both Barb and Charlie. During the meeting they had agreed to four weeks in the learning center. The resource teacher had drawn up a schedule for 30 school days that would take them up to April 18th . Barb relates the reasons behind the change. "We said we wanted to meet back in one month -- four weeks. Well, she felt that because March break was there and Easter was down the end of March, that she would like to have this go 30 school days." The schedule was revised to reflect the initially agreed upon time and Barb reported that Shirley, the resource coordinator, later wrote apologizing for the misunderstanding.

Barb explains how she and Charlie felt and relates their concerns around this change in the schedule.

> Charlie became irate over that. I became a little distrustful at that point too. Again, because I felt she was playing us somewhere. I went back to see her on Tuesday. We had an hour and a half talk, at which time she told me . . . "Charlie is worried about segregation." I said, "No, Charlie is worried about Jeffery being, down the road, put into a classroom and there's nothing we can do about that. Like we can't make a decision. Like the case in Ontario."

It was also during this same conversation that the resource coordinator Shirley told Barb that her supervisor at the board office did not know why Jeffery was not already seen on a daily basis at the learning center. Barb reported that Shirley wanted her supervisor from the school board to attend the next meeting that was to take place in a month's time, to review the implementation of Jeffery's new schedule. Barb describes her response to having this supervisor present at this meeting.

> I asked her if she had spoken to her superior, why was it important for her superior to come in and tell us what the guidelines were, I am not interested in her, send a paper. I don't need her at the meeting. I don't want her there. I said, "You're going to alienate Charlie, if you try to do this. You're going to alienate Charlie and I don't like her. I don't want her there." I don't like the response I had from her in the daycare meeting we had last May or June.

Barb also relates that during this meeting Shirley questioned the professionalism of Alice, the TA. Barb states, "She went as far to tell me the TA was not professional." Charlie adds, "Or professional enough." Barb indicates that Shirley asked her to promise not to tell. Barb was not sure why she was told this and indicates her confusion and uncertainty as what this all might mean. "Maybe she's waiting for me to come back and tell Alice and Alice go back to her, you see. Then everything is mixed up. The [communication] book's out. I don't know. But I know I didn't do that because that's not my place to do that with her."

The other issue brought up at this meeting was how the communication book could and should be used. That is, who has the authority to write in it and/or sign it, and the potential weight it carries as a legal document. Barb recalls that Shirley made the comment that, "Well you're going for an adoption-- if this was brought out in court -- the TA has certain guidelines she should go by." Barb and Charlie did not realize that the TA should not be signing the book. Barb explains,

> We didn't realize the TA wasn't supposed to do it. She can be held liable. I asked where did this come from? Where was this discussed. I said "you discussed this with [board mainstream supervisor]." She [Shirley] said, "Yes, she is my boss."

Barb and Charlie were not pleased that Shirley and her supervisor had discussed Jeffery's pending adoption. Barb felt that since she wrote the note telling them that things weren't positive and she wanted a longer meeting to discuss Jeffery's program, relations had been on the decline. Charlie's states, ". . . from there it has just gone downhill."

Barb wanted to be sure that their decision to limit Jeffrey's time in the learning center would not interfere with their existing relationship with Shirley. Barb stated, "I hope you're not upset and you know we have a good relationship going here and I don't want to destroy anything." It was at this same time that Shirley indicated to Barb that her supervisor did not know why Charlie didn't already know that the communication book should be signed by the classroom teacher or the resource coordinator, and not by the TA.

Charlie explains where he thought this impression originated.

> Shirley for some type of impression thought that I was the biggest friend to her boss [board mainstream supervisor]. I said, "Well I just know her through the board (ACL)." This person -- supervisor -- said I should have known that the TA can't sign the book. I should have known! I just started school!

Barb adds, "Yes, because Charlie is with ACL, he was supposed to have all the answers."

It was also during this conversation with Shirley that Barb indicated that she and Charlie would like to continue on with the book as previously done. Barb relates Shirley's response, "Well you have made me get my hands slapped. I should have a job description." Barb's reflection on that comment was, "Because it was like our fault that this book has caused this havoc up there. I know it hasn't. It's a personal thing." Barb explains reasons for this assumption on her part.

> She felt that the TA [Alice] and I were friends. The TA is very nice. She lives in the area. I'm going to talk to her. I see her. Her daughter also babysits Jeffery. That caused friction right there. That caused a little bit of friction.

Barb also indicated that the resource coordinator Shirley told her that Alice, the TA presently working with Jeffery, would not be with him next year, that they [school personnel] had made a mistake in placing her with the new students coming in, and that she should have been placed with older students. Shirley related who Jeffery's TA would be for the next school year; in Barb's words, "a very good friend of hers." Charlie comments, "That's only because the [communication] book is so detailed that she [Shirley] doesn't like it." Barb agrees with Charlie's opinion stating: "I'm positive. I'm positive of it. But, I can't say that, can I."

Another point that would surface in the meeting between Barb and the resource coordinator Shirley was the role of the principal Ms. Marks. Barb comments on the situation:

> She told me that I'm to come to her with anything regarding Jeffery. We didn't need the principal at the next meeting because even though the principal is her boss, she's employed through mainstream . . . [board mainstream supervisor] is her employer, and the principal really didn't have any idea about what was going on in the learning center.

Charlie and Barb felt that since up to this time Ms. Marks, the principal, had sat in on only one meeting, and that was in June when they were preparing to bring Jeffery into school in September, perhaps Shirley's opinion was correct. In addition, Barb believed that Shirley was being really nice and that maybe they should look at things again and try to be more trusting of Shirley's advice. Charlie comments, "That was another split [between the two parents] they managed to create."

Since the implementation of Jeffery's new schedule in the learning center, Shirley had been writing in the communication book each day. Barb describes the situation:

> She would write in the book everyday from that point, "He's having a great day in the learning center. He's having a great day in the learning center." Well, all these days for the last month have been great days in the learning center. But up in the classroom, poor old Jeffery is chaotic. He's having one heck of a month.

The resource teacher was now writing in the book daily. But this was not the case for the classroom teacher with whom Jeffery spent most of his day. Barb reported that the classroom teacher wrote in the book "the odd time -- the odd, odd time."

"Where's the outcomes - the objectives?"

The next scheduled meeting for Barb and Charlie with the school involved a discussion of Jeffery's IEP. Two days prior to this meeting Barb and Charlie happened upon Jeffery being disciplined by the classroom teacher. Both were upset with the way in which the teacher handled Jeffery's discipline. That evening Barb wrote a note stating that she did not fully understand what Jeffery had done. Barb expected that the next day, Thursday, when she went to pick Jeffery up, the classroom teacher would fill in the details for her as to what exactly happened. Barb was not told what happened, but as she states, she was told something more interesting by the classroom teacher. The classroom teacher related that,

> You know today-- the principal has a tree downstairs, and she always, if a child does a good deed, they always mention it on the PA and put their name on the tree. Jeffery began to cry and he looked at me and said, "They don't think I'm the goodest."

Earlier that morning Barb had met Jeffery and the TA in the corridor on their way to the library. Barb describes the circumstances around the encounter and what implications it would have for the scheduled meeting the next day.

> When I was walking back through the school on Thursday morning, looking for a mitten, she and Jeffery are walking to the library. I say "hi, what are you doing?" Jeffery's head was down and he was very quiet and I thought that's strange. The TA tells me in the hall, they've decided to take Jeffery out of the classroom when he's having a bad time. Take him

> for a walk. Do something with him.

Barb's reaction after this was to call Fran, the parent advocate, to seek advice on a course of action. Barb recalls the details around this conversation.

> "Did you give them permission for this?" I said, "No I didn't." So she said, "When you go into the meeting you ask them, why was this decided? What's the outcome and what are you looking to accomplish?"

The next day Barb, Charlie and Fran attend the scheduled IPP meeting along with Ms. Marks, Shirley, Vickie the classroom teacher, Alice the TA, and the speech pathologist.

> So Friday, we go in with Fran. We [Barb and Charlie] went in there with different agendas. He was going to discuss what he had to, and I was going in to discuss the method they use for discipline.

Barb describes her interpretation of the principal's attitude and what she believed the principal's thoughts to be during the meeting.

> The principal is there. She's late mind you and she seems like, [sarcastically] "Well gee, you know, I've got to be here, honestly." After Charlie mentioned the IPP . . . my whole feeling about her was, "Gee! What am I [principal] doing here?
>
> When we finished with our first two concerns, she more or less sat in her chair and this nonchalant attitude and her hands up in the air. "What do you want us to do? What do you think?" or something to that effect. I don't have it word for word and at that time I thought, she's a friend to the

> school teacher -- Jeffery's teacher Vickie, who she brought from her old school with her. Shirley tells me she's [Vickie] a very good friend of the principal. But, the principal doesn't know what's going on in the learning center. So I'm thinking, we have this person here acting like an airhead, a teenager and I was really quite irate. I thought "you could handle this with a little bit more seriousness." This is not a PTA meeting where you're worried who's going to get a prize for what -- I mean this is a child's education. I really didn't think that was necessary, that little attitude she had, that little air.
>
> I felt that she was giving us the brush off. Like it's not important that was the attitude I collected from her. It did bother me because like I said to you, I've had two days that I'm quite wound up. I'm ready to go now and I'm thinking, I've put him in this school thinking that this is the school that is going to help Jeffery and this is the outcome.

During the meeting Barb addressed seeing Jeffery in the corridor two days before with the TA -- his being taken out of class when he was misbehaving. Her concern centered around the possibility of Jeffery realizing that, if he doesn't want to stay in the classroom, all he needs to do is act out and he'll get to walk the halls most of the day. Barb states, "Well gee, I can walk the halls and see who's got a basketball out there, whatever." Barb recalls that at this time the TA spoke and indicated that they were presently doing this, taking him from the class if he misbehaves. Barb explains what happened next.

> Fran picked up immediately, [to the TA] "You been doing what?" I said, "well it wasn't discussed," and she [TA] said "well, (long pause)." She was stunned at that time, because she realized that she's going to be in trouble with [Shirley] the learning resource coordinator. I don't know. I'm just assuming at this point.

Barb recalls that at this point Shirley interjected stating that they were going to ask at this meeting to take him out of the classroom, if he misbehaves. Charlie's response to that position was that, "They already did it the day before." Barb continued to question why he was being taken out of the classroom and how much time he was missing in the classroom. Barb comments that Shirley who "can always answer everything," on this occasion "sits down and keeps quiet."

Charlie had come prepared to discuss the IPP at this meeting. Throughout the year, he had been guided by Fran, the parent advocate, to learn how an IPP is developed. He explains:

> Looking at the IPP and I got some stuff that I didn't know at the start of the year. But, when Fran came down, she said, "Well Charlie, how do you gauge this?" Like the last page of the IPP. You can't gauge it. None of that stuff is possible to gauge. So how do you know if he achieved it or did not achieve it? Imagine this would be what you would intend to do. This is the technique. That's your objective, your outcome. If you don't have an outcome, how can I change the technique to make sure that it reflects what we are trying to do? [They say] "Oh well, we know what it

> is." [I say] "No. No. This is the team. When I ask you for a copy of the IPP, it's because I want to see what's written there."

Barb recalls that the school personnel entered the meeting without a copy of the IPP. She describes that situation. "They come in the classroom, by the way, with not one of them carrying the IPP. We did. We had it. They did not have it. They didn't have it!" Barb recalls the response from the resource coordinator, "Oh well, I could go down and get it." Charlie describes what happened next.

> There was some scrambling when the principal came in and said, "Yes, that would be a good idea." Whoosh! One went downstairs to get it and came back."

Barb commented, " So we go over the IPP. Well heaven behold, there's nothing written in the IPP. It doesn't show what he has accomplished." Charlie made reference to Jeffery's five-hour placement in the learning center and how this was not included in his IPP. Charlie describes the principal's input into the meeting at this point.

> "I believe what Charlie is trying to say is, how do we warrant five hours for Jeffery to be in the learning center, if you don't have nothing like that [IPP objectives]."

Charlie continues,

> Nobody at that time would bring the thing [goal], "oh it's for him to like school" because they know I would go right through the roof. Not this time."

Fran, on Charlie and Barb's behalf, asked a number of questions related to Jeffery's placement in the learning center. Barb recalls:

> The principal didn't like it. She kind of -- the hair went up on the back, and Fran asked on our behalf, "Are there any improvements since the last meeting regarding Jeffery in the classroom?" Well of course, no, and if anything, it had deteriorated. Then she went on to ask if he improved in the classroom, could we look at putting him back in, instead of leaving him in the learning center for four and a half hours.

Charlie's concern was also with the issues that were raised by Fran around evaluation of the IEP goals and objectives. He states, "Who's gauging it? What's the setup? What's the mechanism for bring him back?" Charlie states his concerns about the lack of clarity with the IEP objectives and how these were going to be evaluated.

> Where's the outcomes -- the objectives? If you look at the last page, "to complete a task with very little prompting." What type of task are we talking about. "To carry out assigned task with minimal support." Well that's depending on the assigned task. "To use words as a means of problem solving." How do you gauge that? "Appropriate conversation - interaction with his peers." Well that's good, but who gauges that? The principal said, "I understand what Charlie wants instead of the book."
>
> Now let's remember that the book is a little thorn in their side. Okay, I must be the only guy in Townville that has this book written that way. But, that's the way they sure made us feel.

"I didn't think it was our right."

It was decided at the meeting to change the method of reporting on Jeffery each day. The new procedure would involve recording on Jeffery every fifteen minutes. Charlie states, "We got to break this, the IPP and the classroom, in fifteen minute blocks. Then you can use this to make a statistic on when he's bad and what we have to do to change it." Barb and Charlie thought that this was a good idea. The recording would be done in the classroom by the TA. Barb comments, "The teacher doesn't have time as we know." The learning resource coordinator would also do some of the recording when Jeffery was in the learning center.

In addition to this change, Barb and Charlie discovered at this meeting that the Speech Pathologist will be withdrawing her services from Jeffery. Their reaction to this news is expressed in their following comments:

Charlie:

> The speech and hearing is also saying, "I didn't see Jeffery for the last three weeks and I find I can spend more time with somebody else with more need right now." I don't have anything in my book saying he was doing that good. I don't have anything here that he is doing anything.

Barb:

> Nothing saying that she was stopping, either by the way, to give her services to another child.

Charlie:

> At the meeting she proposed that she would come back in September.

> So let's make sure it's in the minutes. September you're re-assessing Jeffery to see how he's doing.

When the meeting was over Barb was uncertain as to what was actually to take place with respect to the IPP. Her comments, "I really don't think that got covered too much. They're going to fill something in, but I have no idea what. I really don't know what our role is." Barb was upset after this meeting and was unable to recall if their role in the IPP was discussed at the meeting. Charlie was able to recall what had taken place. He states, "She's going to tentatively present it to us. A completed draft." Barb comments, "That's what she was supposed to have been doing when we got the last report card." Barb and Charlie would not have input into the development of the draft document. Barb comments on this, "I didn't think it was our right. We don't know what our rights are, we really don't. We don't know."

Up to this point Charlie and Barb had not received a copy of the IPP. He states, "They're writing it. They *are* writing it." Charlie explains what will happen once he is handed the completed draft.

> She's going to present it to me and I'm going to say "I don't like it." What I figure I'll do is, present me the paper and then I'm going to say "in two weeks we'll make an appointment." I'm coming back with Fran after I've had a chance to review it, after she's given me some ideas from what she has seen before, and I might know some other people that had an IPP and then look at it.

Charlie already has an idea of what he is looking for with respect to a program for

Jeffery. He explains his present situation with respect to the IPP.

> Now since then, well we've done some research too and I want the core curriculum. What they teach in the classroom. Next thing I want is the adaptation to make this feasible.

"... how can I make sure that I am getting the best for him."

Although Charlie's experience with the IPP process has been brief, less than a year up to the point of this interview, he was able to provide insights into what he felt could improve the process. His experience with respect to parent involvement in the process prompted the following comments.

> Parent participation not just the teacher. I think I know my child a lot more than they do to start, and they're making the IPP without knowing what my child is like. That would be the first thing I would tell them.

Again based on his experience with the IPP process, Charlie had this to say with respect to attending the meetings with school personnel:

> Also call [local ACL] and have someone come with you. If your child has a problem you shouldn't be going in alone, because it seems you are able to get much further if you have someone with you.

Charlie felt that he, as well as school personnel, should have been better prepared about the development of an IPP. He explains his concerns:

> Some type of guidelines that are standard. It would be a set of guidelines as to what an IPP looks like and go from that model. An individual one, I

> don't mean a standard one for everybody. You would have some type of idea, what it is that you are going to sign. Like they presented me with this thing and I just looked at it. They wanted us to sign it -- that was it. I signed because I didn't know better. Then I got my friend to come and tell me that there's some stuff we should be doing, that we're not. In that case they educated me.
>
> I would say there is a book out there for a child with a disability and what the IPP should look like. I believe anybody with a child with a disability should read that book first. We just received a book today and there's an awful lot of stuff that I wish I could have known. Also, the IPP -- the main thing I would be asking, would be, I would want a review every three months.

Charlie felt that if school personnel were able to address the issues or questions that parents forgot to ask, or did not know to ask, during the IPP process, parents could benefit and the possible confrontations between the home and school could be prevented. He explains,

> Delineating some of the questions you might forget, that they know should be asked and you're able to ask them, and it also doesn't make you look like the bad guy. Especially when you're new to this.

Charlie further explains this point by referring to the incident when Barb wrote the note about things not being positive.

> It's just that we had a great feeling about it [school] and suddenly they

> seem to think that -- we're not against them -- but that we're asking stuff. My wife said that she was talking to another EPA [TA or Education Program Assistant], a friend of the family, and she said that the biggest mistake that we made is, as soon as we mentioned that it wasn't positive feedback we were getting -- canceled the whole deal [home-school relationship].

Charlie also had some advice on what to look for when trying to decide about choosing a particular school for your child. He believes that it is important to be well informed when you go to school. As he explains,

> There were some decisions that were made at the start we thought were right. But, we didn't know better. That's the part, if I don't know better, how can I make sure that I am getting the best for him?

Charlie advises caution and trust when dealing with the school system.

> You have to be cautious. Yes, you have to trust them, but as soon as you see something happening that's affecting your beliefs, that's when I think that you have to really step in and say, "hey we're not playing a game here." My wife is also of the belief that you almost have to have another meeting to see where they're coming from.

Charlie feels that it would be important to know the attitudes and philosophy of the people who will be working with your child and if they are open to parent involvement. He explains:

> I would say go to the school and ask them if you can sit in on a couple of

> classes, just to see how things are happening in there, especially if they have a learning center. Define the learning center. Get a definition of what their meaning is: Is it a school that is totally integrated or do they see it as segregation? Do they have the training needed to be able to carry out the task if the child has a disability? Do they have knowledge on the type of disability that the child has? Are they open to a team concept? Are they open to communication or is it a one way thing? Are they receptive to some of the ideas that a parent might have?

Charlie feels that is important for a parent to be able to talk the classroom teacher on an individual basis. He expresses his concern that a meeting may become dominated by particular individuals making it difficult to get to know the positions of school based personnel on the issues at hand. He explains:

> Is it possible for the parent to talk to the teacher in homeroom and then the learning center, so that you get the real views. Because we were attending meetings and we had at the start -- their version -- both of them [classroom and resource]. Suddenly, we attend some meetings and the teacher is not allowed to speak, because the person that is the learning center coordinator is the one that wants to speak, and the teacher is the one that knows Jeffery, because she is with him the most.

Charlie is of the opinion that his current situation with respect to this would not change until the present learning center coordinator moves on. However, he does acknowledge that a solution to their current situation at the school will require their involvement. He states, "I know it's our own conflict type thing. It's not something somebody else can fix. It's just something we'll have to. Trying to find out what's right I guess."

Charlie and Barb have also been supportive to the school through the passing on of any information they find with respect to FAS and ADHD. But Barb states, "Whether they're reading it or filing it under file 13, I have no idea."

Charlie sums up his current feelings with respect to the IPP. "I wish there was some type of panel set up with what to expect from the IPP -- what it is and what you can expect from it. Because right now I don't know." Barb and Charlie express their current situation with the school personnel. Barb states, "Now it's blown way out of proportion. It's unbelievable and it's only primary." Charlie adds, "It's been a long fight." The interaction Charlie and Barb have had through meetings with school personnel around programming needs for Jeffery has eventually resulted in decreased communication between themselves and the TA. Charlie's comments, "We had an excellent partner, and suddenly now since this meeting, the TA might have sent five sentences to us." This final comment by Barb summarizes her feelings about the present situation at school, "I now feel it's them and us."

May's Story

Donald was 14 years old at the time of this conversation. May informed me that Donald was not born with a disability and explains the circumstances surrounding his disability:

> He was 10 days old. He had a cerebral bleed. It did minimal brain damage, but it wasn't diagnosed until he was 11 months old. Then when he was 15 months old he went into seizure status. We were living out of town at that time, and by the time the ambulance got to us, and got him into the hospital, he was in seizure status for over an hour. That's when his brain damage was done.

May is not sure of Donald's classification, but describes him as having a lot of needs. "He can't feed himself and he doesn't have communication. So all of his personal needs have to be done for him." But she is quick to observe, "He is very alert and aware of his surroundings. In addition to his personal needs, Donald also has side effects from his medication. She states,

> He tends to get side effects to the drugs very easily. His condition is known for very difficult seizures -- unable to control them -- and even now we don't have control of his seizures. He had 4 or 5 seizures before he went to school this morning.

Donald's worst seizures are what May referred to as multi-focal seizures, ". . . in that they involve several areas [of the brain]." She describes the conditions that exist with these seizures:

> He doesn't lose consciousness, but it does involve a lot of different parts of his body and he does vocalizations and moaning with them. His eyes can roll back, his face will contort and he will turn. His position will change and that sort of thing.

"... an integrated placement that would work."

Donald attended a developmental preschool for about three years, after which time he entered the public school system. May believed that an integrated placement would be best for Donald. May met with a special education staff member from the school board to discuss what she was looking for in a placement for Donald. It was determined that he would not be able to attend his neighbourhood school because it was not wheelchair accessible. A school was suggested and the principal and a teacher from that school went to the preschool to observe Donald. May met with the principal and the teacher at the preschool at this time. She describes that encounter:

> In planning for it, we met with one school and the response I got from the principal and the teacher was very negative. It seems like -- "he drools -- who's going to supply the Kleenex -- who's going to do this -- who's going to do that?" You know just any petty, petty little thing they could find for it not to work, not to have him integrated in the classroom.

May would not challenge the attitudes of school personnel at this time. She felt, "... it's not worth it, to start school with that kind of negative attitude. So, I just said to the person from the school board, I said, 'I'm not fighting this.'" Because Donald had to be bussed anyway, May felt that there were other options available to her.

May was promoting an integrated placement for Donald during this period of transition planning around his entry into the public school system. But this position was not shared by all. A team meeting prior to Donald's move into public school did not support May's view of an integrated placement. May states:

> An inter-departmental meeting was held. At the meeting were five members of the school board administration staff, the principal of the school being considered, the director of the preschool Donald was attending, a physiotherapist, an occupational therapist from St. Thomas hospital, and a speech therapist. According to the notes, I was not at the meeting, the comments and attitudes of those at the meeting are reflected in the notes. The only person at the meeting who supported my request for an integrated placement was the person who had met with me previously at my home. The consensus of those at the meeting was that Donald's needs could only be met in a segregated setting. The types of comments made by the principal when I had met him previously were repeated.

May recalls her position around having Donald placed in a segregated class. "I felt that for the most part people were against it and they wanted him put in a segregated class. However, I refused to allow it to take place."

May had not committed herself to a particular school for Donald, and it was at this time that she suggested to the school board staff that "we look at other schools." She explains what she was looking for and her reasons for doing so:

> What I was looking for was an integrated placement that would work. I felt to start off, that was the highest priority. Rather than fight to have a particular school, I wanted a school -- something that would work. So I was looking more at the people who were going to work with him -- they were open and willing to work. I felt if I started with a negative, and I started out by beating my head against a wall, it would never work, and then they would use that as a reason to put him in a segregated class. So my main focus was -- he's going in an integrated classroom and I'm going to find the best placement for him I can -- where it might work. That's what I was looking for.

May would eventually find a school where the attitudes of staff were supportive. ". . . it was a completely different attitude with the staff there. They were completely open to him. So he went to Denson School and I found the staff there were excellent." May met with the principal and the teacher prior to Donald's entering school:

> I met with the principal and the teacher ahead of time, but basically that was it. There wasn't a whole lot of meetings. . . . I think the teacher did go to the pre-school and spent some -- a little bit of time there to meet Donald and to see how they [staff] worked with him within the setting.

During this time May worked mostly with personnel from the school board administration office, whom she knew from previous meetings. Initially, these meetings were concerned with meeting Donald's personal care needs and the hiring of a TA.

When Donald actually entered school he was placed in a grade one class instead of a primary class. This was a move aimed at helping to provide a successful entry into public school. May explains the reasoning behind this move:

> There was one teacher that had taught grade primary and was doing some study with regard to her own education and was following the students through primary to one. So, she was moving from a primary to a grade one class with the same students, and it was felt that because she was already familiar with these students and them with her, it would be easier putting Donald in her class, because these kids weren't new to the school system, they had -- you know -- were a little bit more mature. Donald was a good size child, so he wasn't tiny for the class and they just felt it would ease that situation. So he was actually put in a grade one class.

Donald also spent the following year in grade one. May explains that the decision to have Donald spend a second year in grade one was based upon the following reasons, ". . . to keep him at his own peer level and because again she [classroom teacher] was staying teaching grade one. She was now familiar with him. . . ." May recalls that, "as far as the school is concerned, that went really well." May was pleased with the relationship that existed between the home and school during those two years. She relates that most of her contact during that time was with the TA. And that the TA and the teacher got along well and worked well as a team. May states, "So my communicating with the TA -- it all flowed back and forth."

May recalls the circumstances surrounding the decisions about a grade two placement for Donald and how she felt about those decisions:

His second year in grade one. He was sick quite a bit and again the seizures were out of control. So what would frequently happen is, he would have a major seizure, either before he left for school, maybe on the bus, or when he got to school, first thing in the morning. Then he would end up sleeping for a couple of hours because it just wiped him right out.

As a result, when it came to the end of the year and started planning for grade two, they had a number of reasons why he should not go into grade two in that school system. I was getting this from the school board administration people -- everywhere. A new teacher -- the class was going to have two new teachers, it was going to be split -- they were going to work part-time each.

The class -- the previous teacher -- had built a treehouse in the classroom -- physically there was not enough room for Donald in the classroom unless they tore that down, and then all the other kids couldn't use it. They couldn't leave him in grade one again because there were a number of children coming up from primary who had behavior problems, and there would be a new teacher in grade one again, and that teacher would not be able to handle Donald's needs, plus all the behavior problems. As it turned out -- I was not told this at the time -- but his TA, who was familiar with him, was going on. She was a qualified teacher and was taking a teaching position. So there was going to be a new TA as well.

> I was told things like, if he were in a segregated class, he would get one-on-one, he would get computer, which he wasn't able to get in the integrated class, and a number of other things. I did not approve of this, but because he had spent so much time sick that year and really wasn't gaining a whole lot from the class, I didn't feel I had much to stand on to fight it.

These reasons were revealed to May during a planning meeting. She states, "I was informed of all this stuff at a meeting, but it had all been pre-planned." May was able to recall that the principal, the resource teacher, the teacher assistant, the teacher, and one, if not two, people from the school board administration, were present at this meeting. May relates how she felt at this meeting. "Well, I felt I was being manipulated. But you know they had already come to the decision, what they wanted and they were making it. They were feeding me information to make me go the way they wanted me to go." May went to this meeting alone as was the case for most meetings. "Yes I was alone. Most meetings I have always been alone and that's difficult."

The next year Donald was placed in a segregated class against May's better judgement. She states,

> I was against it in the first place. But to myself, I said I would give them one year to prove me wrong. In my own mind I knew this was the wrong placement for Donald. I wouldn't complain. I wouldn't kick up a stink. Let's see what happens.

Over the period of the following year May was able to drop into Donald's class on a frequent basis. She was not impressed with the level of support Donald was receiving. She felt that the demands placed upon the teacher and supports due to the nature of the students in the class, in contrast to Donald's nature, predisposed him to less attention from the teacher. She comments,

> Donald being a very happy, agreeable non-demanding child in a class of eight other children; some of whom are mobile, some of whom are aggressive, some would get into things - - he was being totally ignored as far as I was concerned."

May went on to elaborate on her observation of Donald's placement in the segregated class:

> He got certain basic things -- like he got his physio. But as far as the computer work -- that was not happening. Most of the times I went in, I found Donald sitting in front of the television, usually without even so much as a toy to stimulate him on his tray, which is something I did complain about.

This was the same type of circumstance May found Donald in when she used the local institution for respite care for two weeks during one particular summer. She explains:

> During the two weeks he was there, Donald started chewing his hands. That is a habit we have never been able to break. When we went to visit Donald, we frequently found him in the hallway, opposite the staff (nursing style) station. All the residents of that wing would be sitting on

> one side of the hall. It was intended that they watch the television, which was suspended from the ceiling above the staff desk, on the other side of the hall. This would be very difficult to do as the hall was only five or six feet wide. There was nothing else for the residents to do. They were given no other games, toys or activities to stimulate them. I found this particularly frustrating because I had told the staff several times that Donald was not to be left in his wheelchair with nothing on his tray for him to play with.

May had no meetings that year to discuss Donald's program. She reveals, "I never got an IEP for him that whole year. Nothing was going on." This was not what the school board had promised when May reluctantly agreed to this placement for Donald. Donald spent two years in the segregated class. May had planned to remove Donald from that setting at the end of the first year, but personal circumstances prohibited her from spending the time she felt was necessary, to have Donald placed in an integrated placement. However, by Christmas of that second year, she made her intentions known to the school board: "So I called the school board administration and told them I wanted Donald out of the segregated classroom." Up to this point May had still not seen an IEP for Donald and raised that issue with them at this time.

It would be some time later before May would receive an IEP for Donald. "I finally in March of that year got an IEP for Donald." May had no input into the IEP and had little confidence in what they presented to her. She explains,

> One of the key things that they had on that IEP was having Donald watch

> TV and be observed. As far as I was concerned, they were just covering their butts because that's all they had been doing with him.

Her reaction to the IEP and the subsequent meeting she arranged with the teacher is described in the following comments:

> The completed IEP was sent home with Donald. I had no input into it's preparation and when I received the IEP, I hit the roof. I made an appointment to meet with Donald's teacher to address my concerns. Prior to going to this meeting I went through the IEP several times and made some jot notes to remind me of all the points I wanted to address. The meeting started and I noticed that the teacher was not taking any notes. Part way through the meeting I asked the teacher, "Are you not going to take any notes on the changes I want." His response was, "Well, I will use yours." Mine will tell him nothing. They were very brief and were only meant to trigger my mind because I knew what I wanted and to make sure that I did not miss anything.
>
> It was another couple of months before I received the revised IEP. It turned out that I had been right. My notes were not sufficient for the teacher to follow to make the changes that I had requested to the IEP.

May believes that the only reason she got the IEP when she did, was because they knew she was angry, and that Donald was being removed from the class. She states,

> I do not think I would have gotten the IEP. Because I did speak to other parents that I knew whose children were in that class and none of them

> were getting IEPs. So, to me it was a terrible setting.

May describes the effect she felt that this two year placement had on Donald. "I saw regression in Donald. Donald became very lethargic, totally paid no attention to what was going on around him. He just totally regressed. He was a different child again."

May insisted that Donald's next placement would be at the local school, the same school his younger brother attended. The change in Donald was so dramatic that it did not go unnoticed by parents, teachers and staff at his new placement.

> Even though the people Donald came into contact with at his new school had not known him before, the changes that took place in him were so obvious that they were aware of them. So much so, that when he finally went into the local school, every week, every month, the teachers, the staff, parents within the school, would come up to me and say he's changed so much.

"Your walking a fine line."

Donald's new placement would have been grade four, but instead school personnel decided on grade five. The move was deemed necessary because the grade four classroom was upstairs, and rather than move the grade four class downstairs, they decided to put Donald in grade five. May's feeling with respect to this decision can be heard in her comment reflecting on that decision: "They decided in their wisdom to put him in grade five."

May felt that Donald responded to being around the active children, but felt that this school was not a good setting for him. She explains why:

> The reason I say it is not a good setting was, there were empty rooms in that school. You had a one-on-one TA, and the teacher had the TA take Donald out of class almost totally. So much so, that at the end of that year -- I was somewhere else -- I met someone who was working as a part-time teacher and who had worked in the school, and she asked me, "Well, what's going to happen to your son's class?" I said, "Well, what do you mean? Why should anything happen?" "Well," she said, "with the cutbacks the segregated classes are being cut out." I said, "My son is not in a segregated class." He had spent so much time in a room by himself with the TA, that people literally thought he was in a separate class.

It would seem that May and the school had different ideas as to what constituted an acceptable program for Donald.

> They thought nothing of taking him out of class time to go for a walk, and she [TA] thought that this was the big thing. She was getting him out, she was taking him to Robbin's Donuts. They were missing the whole point.

As in previous years, May was not included in the planning of Donald's program. She indicates that she was called in and presented with the IEP for her to sign. Her position of being non-confrontational, especially during the first year, prevailed in this situation as well. She explains her dilemma:

> I was presented with a completed document and asked to sign it. I don't recall that I did make changes in that particular year. Again, a new school, a new setting, I was trying not to make any waves. This was the pattern I found myself following. The first year in a new school with new staff, I tended to let them get their feet wet and see how they adjusted to Donald.
>
> I tried not to be too demanding about things. I didn't want to upset the teachers and staff. I was afraid that if I did, it would set up walls and make things worse. You're walking a fine line. How far can I push to getting Donald's needs met without getting the teachers upset?

She continues her reflections on that year:

> So the first year I didn't do a whole lot. He did spend a lot of time in the other room. But he was improving, in that he was around an active bunch of children. So he was being stimulated. He was coming back to his old self -- with the stimulation he was starting to do other things. He was starting to vocalize again -- the sort of things he used to do.

". . . in spite of the system"

Donald's entry into grade six took place without any transitional planning and as May's comments indicate, this was something she experienced regularly: "He went into grade six. There was no planning on the transition or anything. Each year I am never told who his teacher is going to be next year."

In grade six a MAPS was conducted for Donald, at May's request. It would prove not to be a good experience, contrary to the intention of the MAPS. May cannot recall all the people who were at this session, but she does recall that she had a resource/advocate person with her. She recalls the events as they unfolded at that meeting:

> I don't remember who was involved to have a MAPS for him. Actually Sheila [resource/advocate] came down with me for that and it was horrible. The teacher's attitude was, "The only reason I'm on the basement floor -- I'm not with the other grade six's and up near the library is because of Donald." His homeroom teacher [Mrs. Starky] said that!

This was one of four obstacles that May would encounter during this MAPS session. The other three concerned a) Donald's peers being at the session; b) looking at a typical day in Donald's schedule; and c) the development of a circle of friends around Donald. May recalls the circumstances surrounding each of these issues:

> It was my understanding that a couple of his peers would be there. When I arrived for the MAPS, I was told that the teacher [Mrs. Starky] herself decided they were not going to be there, but I was not informed. They, the facilitator [Ms.Dunphy] as well as the teacher [Mrs. Starky], would not allow the MAPS to progress to looking at his daily schedule and what could be done. Well, the facilitator wouldn't do it. She said, "No that's up to the teacher." The [school system] was doing MAPS at the time and not doing that step. I have another friend who a MAPS was done initially for, and that was why I was encouraged to do it, and again, for their MAPS, they did not do that step either. . . . Because what they were being

> told was, it was up to the teacher to plan the student's day. It was not up to us to say how it's going to be done.
>
> One of the things that came up, was that it was felt that a circle of friends should be set up around Donald. His homeroom teacher [Mrs. Starky] was trying to stipulate, that if a circle of friends was being set up around Donald from his classmates, she would have to decide if those classmates were going to *be allowed* to be part of his circle of friends. So I did not pursue a circle of friends for Donald that year at all, because I wasn't getting into this.

May also had concerns as to how the session was handled by the facilitator Ms. Dunphy from the school board office. She explains:

> The fact that it progressed and she [Ms. Dunphy] did not stop the negative statements towards Donald -- the fact that even though I requested some of Donald's peers for their input -- the teacher [Mrs. Starky] determined on her own without consultation, without anyone else, they were not going to come, and yet the facilitator [Ms. Dunphy] did nothing about all of these things from the teacher.

In addition to May's concerns about the teacher and facilitator, she was not impressed by the silence of Angela the TA. She states,

> The TA was there and the MAPS session -- when you're going around with the different questions -- you know -- your dreams -- your fears and that sort of thing -- every time they came to the TA [Angela], the TA had

> absolutely nothing to say.

May not only had to deal with an attitude on the part of the teacher [Mrs. Starky], but also on the part of the TA [Angela]. She recalls:

> A conversation that the TA he had most of the year, that year, was relayed back to me. Her comment as a TA working with a child supposedly in an integrated setting was, "I don't know why he's here. He's not going to learn anything anyway. He should be in a segregated class."

The MAPS should have been a positive experience giving greater insights into Donald's strengths and needs -- how his life might look with proper supports and how it could look without these supports, and what his parents wanted for him. May's dream may have turned into the nightmare that day. "I was extremely angry even before I left the MAPS session. I was just furious. I just couldn't believe things that were being said and the way the whole thing was being handled." May could not answer why Mrs. Starky, Donald's teacher, wanted to be able to decide who would be included as his circle of friends. May continues with a description of an action taken by Mrs. Starky that year with respect to Donald's seating arrangement in her class.

> There was a lot of things with that teacher. She would put the students in the homeroom -- the desks would be in a horseshoe shape, so she could be basically in the center. Donald was stuck in the back corner, despite of being told, at my insistence, by the principal to move him in several times. It got to the point that the principal would go down and physically move him in, but she would always put him back.

May referred to Mrs. Starky, Donald's grade six teacher, as, "The teacher who was segregating him." May also explains the circumstances surrounding a skating party with Donald's class:

> I would drive Donald to the skating rink. That was no problem. I even told them I would stay and go skating with him. They were shocked that I was going to take him. This was both the teacher and the TA. "You're going to put him in the ice?" "Yes he loves it." He'd go skating all the time.
>
> I went and I took Donald skating and some of his classmates asked, mostly students from other classes, could they push Donald on the ice. I said sure. I always let them -- they had to be supervised so they didn't do crazy things. One of his classmates asked and he actually pushed Donald twice, and I thought nothing of it until I got back to school [after the skating session].
>
> Their teacher was out sick that day. The substitute teacher approached me because he felt he was in a position and didn't know what to do about it. He had received instructions that morning, over the phone from the homeroom teacher, that Donald's classmates were to be told, that they were not allowed to push Donald in his wheelchair, on the ice. He had relayed that message to the students. One of the students obviously disobeyed him and he wasn't sure what to do about it, because he disagreed with the instructions. He felt they were wrong, but he didn't

> know what to do about the fact, that the student had disobeyed him.

May summarized the situation in grade six with respect to the attitudes that Donald had to face. "You had a teacher who segregated him and a TA who doesn't believe he should be there."

After the incident at skating was made known to May, she became upset and went to see the principal. It was here that the blame for all her problems regarding Donald was placed directly at her feet. She explains:

> I was told by the principal that the reason I had so many problems, was because it was my own fault, that I complained about everything -- that all the problems that Donald had were my own making and that sort of thing -- that I never had anything good to say." In response to this encounter May wrote the supervisor at the school board.

The actions of Donald's classroom teacher are in stark contrast to those of the substitute teacher. May explains:

> He turned out -- he was very good. He actually substituted for Donald's class earlier that year, and it was the first time I had got something home from school that the other kids had done, working with Donald. There was that much of a difference between the way he worked with the class and allowed Donald to be part of the class than the other teacher. It was the first time.

Donald's brief experience with inclusion was obviously a pleasing experience for May. Her next comment expressed her feelings about Donald's experience in the public school system up to grade six: "Anyway, he managed to get through in spite of the system and not because of it." May was determined that Donald would be moving from that school and into junior high the next school year, despite suggestions that Donald remain at that same school the coming year. She describes her position on that suggestion:

> At one point I was talking to the principal and I was talking about planning for Donald for going into junior high. After his previous comments and that -- the principal had the nerve to say to me, that someone suggested that Donald stay here next year. I said, "I'm telling you right now, he's not." I came home. I called the school board administration and I spoke to Diane [Supervisor of Student Services] and I said, "Donald -- just so you know; I don't care who says it, who thinks it -- Donald is not staying in that school next year. Donald is going to junior High."

". . . to discuss the focus of his IEP"

Prior to Donald's entry into grade seven, May had a meeting with the principals from the elementary and junior high schools, Junior High resource teacher, and speech and physiotherapists to discuss Donald's move to junior high. One of the things that May had been trying to achieve over the years, was more peer involvement, or peer teaching with Donald. She saw that this could be accomplished by pulling back the TA and getting the teachers to plan, so that there is peer teaching. She broached this issue at the meeting:

> I have had no success with that at all. . . . talking about the need for teacher assistant -- the junior high school principal said, "Well, he will need a full-

> time." The elementary school principal said, "Well, no, you're going to need a full-time plus, because you have to cover your lunch hour." So at that point I interjected and said, "Why can't Donald be left in the classroom with the teacher while the TA takes the lunch hour." That's as far as I was able to get. That has been done over the years. . . . Which was a money saving thing for the system.

May did not feel very confident that this scheduling had been of benefit to Donald over the years. She explains, "I think what happens a lot of times is, depending on which class he's in and who his teacher is each year -- a lot of times it means he just sits there." She felt that

> For the most part, there was nothing directed by the teacher, as far as peer activities for Donald during the times when the TA was not there. As far as pulling back the TA, however, there's no -- very little in most classes now -- peer interactions or anything like that. He's just sitting there.

Donald's entry into junior high prompted May to change her approach of allowing them to get their feet wet with respect to Donald, as she had in past years. The reason for this change was necessitated by the structure of junior high with respect to teacher assignments. May contacted Mr. Kane, the principal of the junior high,

> So I did speak to him and I did ask that at the beginning of the year, that I be able to have a meeting with the teachers to discuss the focus of his IEP. This is the first time I have ever done that because this year he was going to have different teachers for every subject, and I wanted to talk to them."

May met with the class teachers, the resource teacher, and Mr. Kane the principal at the start of grade seven to express her concerns and explain what she was looking for in his IEP. She explains:

> Basically, what I wanted and I explained to them was -- before you get started on this and go down the road and spend hours developing something that is not acceptable, let me tell you what I think, so we don't have to re-write it. You're not committed to this because you spent so much time on it. So we did have some conversation. They worked on it. I asked the principal several times when it was going to be finalized.

This was the only meeting May would have with the group until she was presented with the IEP in completed form. She had no other input other than the initial meeting. She recalls, "I think it was May of that year I finally got it. There were a number of changes and things I didn't like in it." May had particular concerns with the language used in the document and some of the objectives that had been established for Donald.

> I had my notes of things. Most of it was just wording. A lot of it was negative. Just the phrasing of things in a negative way, instead of in a positive way. For instance, Donald would get excited and vocalize. And they were talking about trying to stop the vocalizations, and one of the things I put in was, that Donald would be given something to distract him, or an activity. A lot of it was just negative phrasing. Although there were some things that were very specific. For example, I requested the pulling

> out of the TA. Some of the teachers would allow, and had written in his IEP, for periods of time anywhere from 30 seconds to two minutes. My comment was, "but there are times when the TA is gone for lunch for an hour and Donald is alone, why do you have to restrict it like this?"

When May began to question their [school personnel] work that had been done on the IEP, she felt the atmosphere of the meeting began to change. She comments, "The resource teacher immediately got very upset and jumped on me and said, 'I hope you realize that this IEP was planned in conjunction with [two school board personnel] and whoever else was involved from administration at the time.'" She felt the position taken by the resource teacher, Ms. Parsons, changed the mood of the meeting. May explains how she interpreted the mood of the meeting after the comments made by Ms. Parsons. "So as soon as the resource teacher started this, the hostility started building and you could feel it from all the teachers, because they felt I had no right to question what they had done."

May does acknowledge that some of the "stuff" in the IEP was not inappropriate. The meeting "calmed off" finally when the member of the school board administration, who had been part of the development of the IEP, arrived and agreed with May on the things she had requested.

The end of grade seven came and went without the completion of an IEP for Donald. "It's the end of the year -- the IEP isn't done. He's had no programming basically, other than his physio -- you know that comes from his physiotherapist and the speech therapist all year."

"<u>. . . through the whole year without an IEP.</u>"

In grade eight May received an IEP for Donald. This time May adopted a new approach to getting an IEP completed for Donald. She enlisted the support of Diane, the school board Supervisor of Student Services, in helping her get an IEP developed for Donald that year. May describes why this particular person was contacted: "I found her very good to work with. I had dealt with her regarding issues in the past and found her to be very supportive. . . . She's very committed to integration, to the exchange of information." May recalls the details around their first meeting to develop the IEP.

> I called Diane, who would be the person in charge from school administration, and we set up meetings. It was the resource teacher, Diane and myself. At the first meeting we brainstormed about ideas where to go and things to do with Donald. It was taking the grade eight curriculum and we had asked the teachers to give some main subject matters that they would be covering. For example, in science they were going to be studying the classification of animals, in social studies they were going to be covering weather.
>
> So what we did is, we looked at how many of these can we take, a few of them for the year and cross them over. For example, if they were studying animals and weather and the English class they're studying poetry, can we have poetry on animals and weather? The resource teacher had a concern about the perceived amount of work that was involved. Diane eased her concerns by relating that the three of them would be

> involved in this endeavor.

May explains the next step in the process:

> We are all going to go out and collect what we can find and we will come back for our next meeting and try putting it together. What we will do is put together a sample module to present to the teachers, as a guide for them to do the IEP.

This may have worked quite well at the time, except that Ms. Parsons, the resource teacher, did not show up at the next meeting because she had scheduled something else. She was later questioned about her absence by Mr. Kane the principal and Diane, who felt that she should have been there because this was a planning meeting, and it was her responsibility to be there. May and Diane proceeded with the development of the module without the resource teacher present. May explains their rationale behind the development of the concepts in this sample unit:

> For example, if we were discussing animals, animals would be irrelevant to Donald unless you focus on things that he had been exposed to. We decided -- well we have a dog, there are cats in the neighbourhood, birds when he is outside, and he has taken horseback riding -- so those are animals that are common to work with. We could relate that to his math in dealing with numbers 1-4, in saying like four paws, one nose -- this kind of thing and interrelate them again with poetry and English.
>
> In social studies we decided his aspect would be the home and school not the country. There was mention of dealing with historic

> figures, and I said, "that would mean nothing to Donald, so let's deal with current figures. At least if he watches the news on TV, he might see them there." That part was actually in the final IEP.

A third meeting was scheduled and Diane brought the sample module. Ms. Parsons, the resource teacher, was also able to attend this meeting after missing the second meeting. Because Ms. Parsons or Diane had not followed up with each other with respect to what had taken place at that second meeting, an embarrassing and unnecessary conflict ensued. May explains:

> The resource teacher came to this third meeting with reams of stuff on
>
> animals,
>
> poetry and different things. After saying she didn't have time to do the work, for some reason she went ahead and did this whole ream of stuff. She had animals from Africa. Donald doesn't know anything about animals from Africa. He doesn't know anything about Africa. Animals, sea animals -- whole raft of stuff that was totally inappropriate -- and then got very upset because she said, "I spent hundreds of hours doing this" -- but she had been told not to do it."

May felt that it was almost like Ms. Parson's actions were deliberately trying to set up road blocks. However, May's also questioned Ms. Parson's ability to provide support to teachers and to Donald.

> I did not feel during the two years that she was resource teacher, that she was giving any appropriate guidance with regard to the IEP, and what was

> appropriate for Donald. I don't think she understood, or even knew herself, what was appropriate for Donald.

May also relates that during grade seven and eight, she and the resource teacher had talked about the resource teacher being able to arrange various things, but they were never done. May explains:

> When we talked about things like the circle of friends, things being done like books being made up -- large books -- large pictures being done -- and she could arrange it -- none of this was ever done -- nothing. Finally, at the end of grade eight around April, I finally get his IEP. So, in effect he [Donald] went through the whole year without an IEP.

The TA -- Grade Seven and Eight

The teacher assistant, Terry, was the one who probably worked more closely with Donald during the school day. It was more closely than May liked because it served to relieve a teacher from assuming any interaction or planning with Donald, if they so desired -- something that May had been trying to change for years without any success. May did not approve of Donald's TA during these two years and thought that ". . . as far as any programming with Donald -- it was a write-off."

May describes her experiences with respect to her interactions with the Terry over aspects of Donald's program.

> . . . a lot of issues had come up with regard to the fact that this TA he had in junior high was not doing the work, I felt he should be doing. Donald

> had surgery during grade eight. Because of that surgery he had his hamstring lengthened and part of his physio program had to be cut. After a few months, when he had recovered, and I had spoken to the doctor, and I had spoken to the physiotherapist, I went into the school and spoke to the TA. I told him it's time to start doing the whole program again. His response was, "Well, I'm doing the whole program." "No, we cut part of it out three months ago." "Well, what part?" So I started explaining to him. He had no idea what I was talking about.

May recalls that she had personally told Terry, and that he did not remember the exercises she had described to him. When she asked him for the written copy of the physio program, neither the TA nor Mr. Kane, the principal, was able to find a copy of the program. May took her copy from home, copied it, and gave it to them. She recalls,

> They were only doing a small portion of his physio program. When I gave him a copy and showed him the physio program and showed him the exercises I wanted reinstated, his response was, "I never did those."

May also had to deal with issues surrounding the TA not taking Donald to class. She states,

> For example, you'd have to get him down the stairs to get him to the workshop. So if it was only a one class thing, the TA decided on his own not to take Donald. So it was something I had to address because the TA did not have the right to make that decision.

May felt toward the end of grade eight that this particular TA was not doing the work with Donald that she felt should be done. She wrote and complained to the school board saying that she felt "... it is in Donald's best interests that he have a new teacher assistant for the next year." She was successful in her effort and Donald had a new TA in grade nine.

"They were thinking curriculum related."

May received Donald's IEP in grade nine at the beginning of that year. She states, "I think by October." There were improvements over the previous year, but she felt that there were still a few concerns with the IEP. May states:

> In Donald's grade eight IEP there were items which were repeated in each individual subject. In an effort to simplify this document, I retyped it. I listed those items which were not specific to any subject into a general category, as goals for Donald, that would apply to all classes. At the beginning of grade nine, I gave the revised IEP to the principal, to be used as a guide in setting his grade nine IEP. This year, finally, I got his IEP at the beginning of the year.

The IEP for grade nine was developed with May's involvement. The grade nine IEP was a carry over from grade eight. She recalls, "I think what we did is -- because his one from last year in grade eight was so late in the year, and it finally gotten to a point where we sort of liked it, we decided basically to go with it." There were changes with respect to subject matter. May explains:

> I asked that the grade nine teachers be consulted because the material

> being taught was going to change from grade eight to grade nine. The topics dealt with in his grade eight IEP were relevant to what was being taught in grade eight, but might not be relevant to material covered in grade nine. The teachers felt that yes, the topics covered in the grade eight IEP could fit within the guidelines of the grade nine curriculum. Because of this, it was decided that the subject related portions of Donald's grade eight IEP, would be kept for grade nine and the general goals that I had outlined, would be included.

May recalls that the teachers were having a difficult time in understanding what she wanted for Donald. May wanted Donald's in-class activities related to the curriculum at that time.

> . . . if they were in math class, he should be doing something related to math. The teachers were having a hard time understanding. They were thinking curriculum related -- well we're doing higher fractions -- how am I going to relate that to Donald? They were not simplifying it enough. . . . we're saying, well, just subject related is all we're doing.

These issues were addressed at a meeting with Mr. Kane the principal, Kathleen O'Dell the new resource teacher, and May. It was at this meeting that they clarified their position for the class teachers as to what they meant by subject related.

> This is how we came up with rewording it. So we're not saying that he has to do fractions. All we're saying is, if you are studying math, he should be studying something to do with math. Okay, so that's all we're

> saying when we're saying subject related.

Donald would be doing a parallel curriculum in each class. A few minor changes were made at this time to Donald's IEP and presented to May.

May spoke of Ms. O'Dell, the new resource teacher in grade nine, as being "very good." She explains what she meant:

> When I talk to her, she seems to have a much better understanding and we are in more agreement on the direction for Donald's IEP. She seems to have much more background in program adapting to meet the level of someone of Donald's needs -- how to adapt -- and that programs meet his needs -- much easier to work with -- much more open to suggestions.

May relates that there has not been a whole lot of communication between herself and Ms. O'Dell. But whenever she has gone to speak to her on some issue that needed to be addressed, May found her to be "very open in accepting me and in giving me her feelings back with regard to both good and her frustrations in dealing with the system."

"It's like they're afraid to acknowledge they don't know."

May gave her perception of the relationship with teachers over the years as far as planning with respect to Donald's program.

> With the teachers -- I have told them -- if there is something that you are planning in the school, maybe I have something regarding it at home that would be relevant for Donald. Over the years, at different times, I have sent supplies in. I have bought supplies for the school for Donald. Some

> of them have been lost on me. I have made things. But for the most part, the teachers don't even take me up on the offer or even call.

May related one instance during grade seven where Donald's science teacher had called about a lab they would be doing on dissecting worms and his concern about Donald's involvement, because Donald would mouth things. May's solution to this was to provide a bag of gummy worm candies. She explains, "I took them in to the teacher and I said, "Here, I know the kids are doing worms. You can give this to Donald," and I said, "you can give them all one." May recalls that other than this, she never gets calls from teachers. "Nothing. It's like they're afraid to acknowledge they don't know. If they don't admit it, or don't confront it, and it's never dealt with, and they get through the year, -- and it's gone."

". . . based on progress made on his IEP."

May had requested that the teachers do a baseline evaluation on Donald, at the beginning of grade nine, based on his IEP, and then evaluations could be done periodically throughout the year to see what progress had been made. She states, "I know that it has not been done, and I know that the teachers have not been doing any sort of evaluation." May knows this to be the situation because she gets daily reports from the TA. She states, "Something else I had to insist on and fight for." May acknowledges that it's not the role of the TA to be giving reports as to Donald's progress. "It is not their responsibility." But, as she explains, "I can't get the teachers to do it."

May explains her concerns around the issue of ownership of Donald and his IEP:

> The first TA [Terry] really was not mature enough to handle what was happening, in that, because the teachers were not taking ownership of Donald and ownership of the direction of his IEP. Nothing was coming down from the teachers and this person did not have the ability to do it on his own -- which they shouldn't have done. But as a result there was nothing. This year we're very fortunate in that the TA [Carl] does have the ability to do things on his own. He has worked and done programming with Donald on the computer and different things and is much more alert and competent and has therefore done a lot of things for Donald on his own and made progression on things. But, he still is doing it on his own and that is a concern because if anything happens, it's all going to fall on the TA and technically it shouldn't.
>
> It's the responsibility of the teacher and that is a battle I have yet to win. Getting the teachers to realize they are the ones who are supposed to -- they are responsible for Donald's programming, and they are the ones responsible to guide the TA -- to give direction to the TA. The TA is not supposed to plan and set-up and implement all these things.

Communication between teachers and parent seems to be an area of concern for May. She states:

> Never, even now I don't. I get feedback, notes from the teacher assistant on each class. Classes that the teacher assistant is not there, I don't get a note on that class. Anytime the TA is away, be it lunchtime or out sick, I

get no communication from the school.

May has asked the teacher for correspondence on these classes. She comments, "Yes, I have gone to [Mr. Kane] the principal and [Ms. O'Dell] the resource teacher and everything and asked. Some years I have had better success than others, to the point, that the teachers will at least initial the comments made by the TA." May indicated that the same situation persists this year. She states, "I'm getting nothing again, if the TA is not there. At one point, I did go in and cause an issue about it. For a few weeks the teachers did initial it, but then it stopped again."

There were concerns centering around when Donald's evaluation could be done and these were brought up by Mr. Kane at a meeting. May provided the following solution: "One example I gave him was, if the students are writing a test in math or something, then that period could be used for doing some evaluation on Donald's IEP." May is confident that this has not been done and wonders how they can write his report card. She relates her position with respect to the present, and past, report cards:

> I will no longer accept report cards from teachers telling me that Donald knows his name; Donald smiles at me when I call him. That is not acceptable. His report card this year is to be based on progress made on his IEP and I will accept nothing else.

Donald stayed home for the week during the first term examinations at the school. May did receive evaluations from each of the subject areas afterwards. She felt that these evaluations should have been done at the beginning of the term and used as baselines. May is uncertain about what to expect in the second term report. She comments, "We're coming up now for the mid-term report for the second term. I am waiting to see what's going to happen there."

The issue of appropriate programming has been one of the major obstacles that May has had to deal with throughout Donald's schooling. It has been such a concern to her that she was able to state that, "Attitudes at junior high, as far as acceptance of Donald being there are good. It's the programming that is lacking."

"... someone they know nothing about.."

May's greatest concern about the IEP process centered around Donald's exposure to the junior high system. She felt that his various subject teachers had not done their job with respect to any programming for Donald. She states,

> My attitude was -- here it is, it's the end of April, this is the second year in a row that the teachers have not done their job. They couldn't -- they didn't have anything to do it with. No programming has been done for Donald.

May's following comments help to explain what she feels to be the problem with the level of programming at the junior high level.

> A teacher is only involved with Donald usually for one year. They go in and they talk about doing up an IEP about someone they know nothing about, and they refuse to involve and ask questions of the parent, who has known the child all his or her life. It's stupid.

At the time of this interview Donald was in grade nine and May wanted him placed back in grade eight for the coming year. May felt, that at the end of grade eight, they had at least made some progress in the development of an IEP. May also indicates that that year was "the year that I felt I had the most involvement into the planning of his IEP. . . ." Her contribution to the IEP process and her effectiveness as a resource person has been demonstrated through her ability to adapt material to the curriculum in the development of a sample module. May expressed her views on the involvement of parents in the IEP process:

> I think you have two problems. 1) You have teachers who are in the system and are resistant to change, and 2) you have parents who up until the last few years have had their kids, for the most part, in segregated classes and have just handed over responsibility carte blanche. I know a friend who's a teacher and who has battled with parents, when she's had special needs student in her class, to get them in to take part in meetings to plan for things. Unfortunately, with some people you have resistance on both sides -- both the teaching staff and the home. I honestly don't know the answer, but what I find very frustrating is that those of us who want to be involved are still being blocked out by the school.
>
> I don't know how you can change the parents who don't want to be involved, who say take him, he's yours. You deal with it. Historically, many parents have looked at school as a babysitting service and have not wanted to become involved in the IEP process. I don't know what can be done about that. But, I really wish something could be done about the

teachers' reluctance to talk and even get to know the parents.

Since May had volunteered at the school, there were opportunities for teachers to discuss issues around Donald. But May related that most of the time they would simply say, "Hi." This point about teachers' reluctance to talk and even get to know parents left May feeling somewhat perplexed. She explains:

> Knowing that there were so many things that weren't being done and when I went to see the principal, he would tell me, "Well the teachers don't feel that they know how to do this, or they know what they should be doing." I couldn't understand it. You know they're telling the principal that when it comes to adapting programs to meet Donald's needs, following his IEP, that they don't know what they should be doing. I have agreed and told them, you know if you have any questions, call me. Contact me if there's anything I can do.

May feels that the organizational structure of our Junior High schools complicates the matter. She explains:

> I think in Junior High level it becomes really an issue because of the fact that they have so many different teachers. They're only teaching the child one subject. They may see him three times a week, which is actually another reason for me wanting to put Donald back in grade eight. Two years ago at this school, they started with the middle school program for grade seven's, in which two teachers team to teach two classes. So that you only have two teachers teaching the core subjects to those two classes,

> so there are fewer teachers. Next year they're supposed to start it in grade eight. My feeling is that hopefully, if I put Donald back in grade eight, I only have two teachers to deal with instead of five and that will facilitate the teachers in getting to know Donald better -- getting more involved with his IEP and better knowing each other. There's only one teacher that I know that Donald has right now and I only know him because it's the music teacher who's been very good with Donald through seven, eight and nine.

May describes this specific music teacher as being the best with Donald with respect to including him in his class. She explains,

> It just happens that he has a personality and an ability and he works well with Donald. He doesn't exclude Donald. He doesn't ignore Donald. He does stuff. So he's the only teacher that I really know this year at all.

Outside this specific teacher there has been no teacher, since the first couple of years of school, with whom May has been able to establish a good working relationship. She explains what she believes to be the reason for this good relationship during those first few years:

> I think it was a good team between the whole school -- it was a good team. There was positive from the principal, positive from the resource teacher, and a good qualified TA who actually had her teaching degree and worked well with the teacher. So it was much more open. I think everybody just felt more comfortable. The main teacher in the room acknowledged she

> had no experience and that. But, she had support from her principal and her resource teacher with regard to planning and programming. So much so, that the resource teacher and the principal each day, on their own, to allow the TA's break time, the principal and the resource teacher were the ones who went in and substituted for the TA. That's how positive and involved they were. So I think the whole positive attitude from the top down played a large part in it.

". . . less apt to do it, if you have a witness."

May's experience with the IEP process enabled her to provide the following advice to other parents or guardians of children with disabilities on finding a school in which to register their children. May felt that the attitude of the principal with respect to special needs students would be important.

> The first thing you would do is to go and talk to the principal and find out, because the principal has such an influence over the rest of the school, to find out basically what his or her attitudes are with regard to the special needs student.

May states the importance of this attitude, "That's going to basically set the tone for whatever is going to happen." The involvement that you will have in your child's program plan will depend upon you. "It's going to be up to you to request the meetings and you're going to have to fight for the involvement you want."

May also provided particular advice with respect to the IEP meetings.

> Don't go alone. Most people I know have gone to most of them alone. Sometimes it's been okay. Sometimes it hasn't. Anybody else I talked to, I've always told them to take somebody . . . even if that person only takes notes. Because when you leave the meeting you can focus on what's going on at the moment. You can't remember at the end of the meeting and you can't remember the details. So it's better to have someone, even if that person does nothing else but take notes for you to refer back to -- what's been decided -- what's been agreed upon at the end of it. So that you have something concrete and it's going to be up to you to follow up on those agreements and make sure these are done. Because my experience is when you're at the meeting, they don't get followed up on.

May suggests taking someone knowledgeable about the IEP process if possible, but if that is not possible, just the presence of another person with you may prevent you from being intimidated at these meetings.

> If you know someone who's involved in the system and can help you that's good. But, most people don't, so even if it's just a friend, a neighbour -- someone. Just the fact that there's someone else there will sometimes make the people at the meetings sit back and be more careful in how they treat you. Almost like there's a witness there.

In the past May has experienced situations at meetings with school personnel where she has felt that she has been mistreated, and that the knowledge she has about her son was undermined. She explains:

> I haven't run into it bad. I have know other people who have. But for example, the time when the principal said, "Well, you know it's my fault. I never have anything good to say. All I have is negative stuff." I don't think he would ever have had said that in front of a witness. So I have experienced it -- not as bad as I know other people have. But, basically being made to feel that you don't know anything. You know, "we're the teachers -- we're the professionals -- we're trained in this -- we know what we're doing -- and you're just going to have to do what we want"-- kind of attitude. I find they're much less blatant, if they're going to do it, they're less blatant about it if you have another person there. Not all of them are going to do it. But, if they do, I think they will be less apt to do it, if you have a witness.

Professional development

In efforts to try and help school personnel become more knowledgeable, May has, over the years, taken it on herself to inform them about any summer programs or courses directed at curriculum adaptation and IEP writing. But she relates that any attempts at this have proven to be ineffective.

> When I am aware of training programs, like summer programs in program adapting and IEP . . . I've taken the pamphlets into the school and left them in the teachers room . . . given it to the principal . . . to see if any teachers would follow up on them. I have never heard that any of them

> have.

The information that May has this year pertaining to training in program adaptation will be given directly to the resource teacher. May explains her reasons for this move:

> Actually, this time I was planning on taking it directly to the resource teacher, as I say because I feel she would be open to it. Not because I think she needs it, but to encourage -- going up to talk to her about what's going to happen to Donald next year, because as I said, my plan is that he will go back to grade eight and he will not progress into high school at this point in time. So, therefore looking at that end and saying, okay he's going to have eight and nine here again, let's get some of our teachers going.

In some way May's next statement seems an appropriate point at which to conclude her reflections on the IEP process. She states, "It's not just for Donald though, there are other special needs students in the school. I know that, so no matter what grade level they're in -- in some way it's going to benefit the school system."

CHAPTER FIVE

Findings

This chapter presents the findings obtained from one semi-structured interview and one follow-up interview with parents of each of four families who participated in this study. The results of the analysis are discussed in terms of the following two major themes that emerged: (a) barriers to the IEP process, and (b) facilitators of IEP process. Each major theme was comprised of categories, each of which contained a number of sub-categories.

The experiences of the parents in this study do not necessarily represent the experiences of all parents who seek out IEPs for their child, nevertheless, commonalities among their experiences can contribute to research literature and our professional understanding.

Barriers to the IEP Process

Attitudes

In their quest to obtain an IEP for their child, parents often felt they ran into a "wall of attitudes" or "mental roadblocks." Various synonyms for "wall" include bastion, barricade, divider and fortification. For roadblocks various synonyms include blockade, barrier and obstruction. The metaphors describe attitudes where school personnel saw disability and deficits first which prevented them from seeing the child behind the disability.

Valuing the child. The negative attitudes parents perceived the school personnel held translated into actions that devalued the student as a person who has dignity in his/her own right. The following examples support this position: As one parent noted,

> Well, come to discover, Gina wasn't pulling her pants down far enough, and the teaching assistant wasn't going in making sure it was happening. So Gina would be sent home, and not only that, Gina would sit out in the front foyer, waiting for the taxi to come pick her up -- wet -- while all the other kids were changing classes -- watching. This done a lot, and like I could never get them to see that.

We need only place ourselves in the position of this 17 year old girl to imagine the indignity and embarrassment of such an experience. Another parent's report serves to illustrate how this attitude of devaluing the child is evident in a placement decision.

> They had a number of reasons why he should not go into grade two in that school system. The class -- the previous teacher had built a treehouse in the classroom. Physically there was not room for Donald in the classroom unless they tore that down and then all the other kids couldn't use it.

We do much to devalue a person's worth when we prize the presence of an inanimate object over that of her/his inclusion or place within the group. One can only speculate, if this reason would have been used to exclude Donald, if his disability had been of a physical nature only. These actions speak loudly to attitudes that devalue the worth of the person. Such attitudes are damaging to all children, alienate the parents and compromise the IEP process.

Language. Negative attitudes were also apparent to the parents in the written language used in the writing of IEPs and evaluations of the children. Parents often felt that things were phrased in a negative way and inappropriately worded, focusing more on what the child can't do, highlighting the deficits, instead of their assets. Some people may interpret a person's disability as so encompassing and debilitating, that they see the person as incapable of doing anything. In general, society has always been dominated by a view of disability that taught us to see disability as inability. Beverley's description of Molly's resource teacher during grade two and three as being a very negative person serves to illustrate a deficit first perception.

> Everything about Molly was negative and whatever she had to say or write, or whatever, was always done in a negative tone. Molly is *confined to a wheelchair and can't participate* at this time.

In this author's experience, it was common practice for teachers to write IEPs highlighting a student's deficits and then trying to develop programs around those deficits. Later training for teachers promoted developing programs from a list of needs that were identified based on a student's strengths. Teachers were now trained to look for a student's assets, build on their strengths, not their deficits.

A deficit first perception used in writing student evaluations, can send messages that we may, or may not, intend to relay. When Gina's teachers used a deficit first perception to write her grade nine evaluation, her father related what he felt was the real message behind this evaluation.

> It was given to us on graduation day and I wasn't going to spoil the day, because I knew what was inside of it. I waited until the middle of July, and I opened it one Saturday afternoon. Each teacher said different things, but they all used certain terminologies that were all identical that put *Gina down*. It angered me a great deal that one person wrote all this stuff about her and the school supported her. It hurt me a great deal. It was *very degrading*. But it tore my heart out and then it made me laugh that these people -- these professional teachers are so small. Because to me, it wasn't to get back at Gina because she will never read the letter.

These examples of negative language interfere with the IEP process in the following ways: First, negative language keeps the focus of programing on remediating deficits instead of building on student strengths, and limits access to opportunities that might otherwise be available. Secondly, regardless of the context, no parent wants to have their child talked about in language that diminishes their child's worth. Therefore, such language serves to establish a barrier which alienates the parents as partners in the IEP process.

Resistance to problem solving. Negative attitudes were also evident through the actions of school personnel toward the student in the classroom, and in their approach to problem solving. One parent felt that the way his daughter's needs were addressed was indicative of a system where his daughter was not valued. This attitude of devaluing the child precluded an atmosphere of creative problem solving.

> If you don't believe that the child should be taught, then you don't teach them. It's a value system. There are some of us who believe that Gina' s peers help teach Gina because she has a thirst of reason. That Gina is valuable. She can learn. She can be a productive member of society. That us as her teacher, myself included there, if she's not learning something, it's not because she doesn't want to. It's to me, we're doing something wrong. Let's try something different instead of saying she can't, let's find if yes, but where.

Another parent, Robert described the school's approach to problem solving around his daughter's needs, as always a source of friction. Instead of rising to the occasion and an opportunity to challenge, "They turned a mole hill into a mountain quite quickly." Still another parent, May relates her experience with the principal and teacher at a school she approached, about her son's very first placement.

> The response I got from the principal and the teacher was very negative. "It seems like he drools. Who's going to supply the Kleenex? Who's going to do this? Who's going to do that?" You know just any petty, petty [sic] little thing they could find for it not to work -- not to have him integrated, in the classroom.

The feelings and experiences described by these parents about the approach to problem solving by school personnel, may not say as much about their ability to problem solve, as it does about their willingness to at least try. This lack of willingness to try may send strong messages to parents about the diminished importance of their child in the eyes of school personnel and serve to create barriers to the IEP process.

Child as cause of the problem. In some situations negative attitudes focused on the student as the cause of the problem. "The teacher's attitude was 'the only reason I'm on the basement floor -- I'm not with the other grade six's and up near the library is because of Donald.'" These attitudes toward the student were also present in the school's approach to problem solving.

> The previous resource teacher also was very negative -- very negative in her approach. Always focusing on the negative rather than on the positive, on what Molly can do, and what her strengths and abilities are. She always focused on what she can't do. What she's missing out on. You know they can't meet her needs and this is why. Because it's her fault. That frustrates me to no end right from the beginning.

When the attitude of school personnel was such that the student was seen as the problem, recommended solutions focused on the exclusion of the student, rather than their inclusion. One parent [whose daughter was nonverbal] explained how school personnel interpreted his daughter's behavior as inappropriate, and recommended placement in a class for students with behavior problems. While the parent explained his daughter's behavior as a means of communication.

> When Gina gets frustrated, she'll just grab at you. "This is not what I want to do. I don't want any part of this." Everyday in the book [home-school communication book] -- "Gina is grabbing at me." They were blaming it

> on Gina going to see the wrestling. That got nothing to do with it. But they would not hear of that. They thought Gina was very aggressive and should be in a behavior class.

When the student is seen as the cause of the problem, the proposed solutions recommend taking some action directly against the student, such as removing him/her from the class, or from the school as in Gina's case. The same approach is used in the following scenario. The following suggestion was offered as a solution to Molly's apparent tiredness, and subsequent sleeping in the afternoons. "Now of course the teacher's attitude at that time was, 'Wouldn't there be another place that Molly could go in the afternoon because she seems to get so tired?'"

This same problem, with the same student is addressed in another school year, by a different teacher, with a different attitude and approach. The attitude of Molly's new teacher did not question her placement in his class. Her mother explains about working with the classroom teacher, "Even when we sat down to do her IPPs [same as IEP], 'Why do we have to keep saying -- so she can be included with the class. That's a given. I expect her to be included with the class.'"

Solutions to the problem were now redirected from taking action directly against Molly, to taking action, or making adaptations, to the environment. When a contrary view, seeing the environment (not the student) as the problem, solutions were focused outside the student, and on the present inclusive environment. This new focus facilitated the IEP process through collaboration between parents and school personnel. A parent explained her feelings about this new perspective:

> It's a much more positive sort of year and they've gone the extra step. I think we're learning, that if Molly falls asleep, it's because she's bored. So we've figured out how Molly can have earphone inserts, to be able to listen to things, because in grade four they're doing things that could be much more quieter. So we need to figure out how we can include Molly with something similar to what the rest of the kids are doing. Like if they're doing silent reading or whatever, then she's doing some, she has earphones for the computer in the class. So she can be doing some work while they're doing silent stuff and that. So there seems to be -- they're much more keen to explore new things this year.

When school personnel focus on the student as being the cause of the problem, it does little in the way of creating an atmosphere of cooperation and collaboration between the home and school, essential to the IEP process. We only need think of our own children and our experiences with the school system to understand that to any degree.

Limited expectations. Some parents in this study also indicated that attitudes of limited expectations for their child would impact directly upon the type of program their child would receive. One parent reported knowledge of a comment made by a teaching assistant regarding her son, that reflects this concern. "I don't know why he's here. He is not going to learn anything anyway. He should be in a segregated class." This next parent's comment reflects how important he felt attitudes were in programming to meet the needs of his child. "If you don't have a TA [teaching assistant] that believes that the child's going to learn, all you are going to do is walk the halls."

When we limit expectations for our children to their present level of functioning, we deprive them of the opportunity of reaching their full potential. There is no difference, in this respect, for children with or without disabilities. In this author's experience in working with students with disabilities, expectations are very much related to the kind of program that will be implemented with a student -- whether we will attempt to challenge them or not. If we believe them incapable of learning, then they are often assigned busy work or may just sit and do nothing at all.

Rejection of the child. Parents also described experiences that demonstrated subtle rejection of their children in the classroom.

> The desks were put in a horseshoe shape, so she [teacher] could basically be in the center. Donald was stuck in the back corner, despite being told at my insistence, by the principal, to move him in several times. It got to the point, that the principal would go down and physically move him in, but she would put him back.

Our actions speak louder than our words. This teacher was undoubtably sending a strong message to the other students in her class, about how she felt about Donald, and people with disabilities in general.

In addition to rejection within the classroom, there was exclusion from class activities.

> The teacher took me aside to tell me, that she knew I would understand, that Molly would not be able to be involved in the Christmas concert that year, because they would not be able to get her wheelchair on the stage.

> There were three stairs. I could have taken her up myself.

Both these experiences, although different in the degree of rejection, send strong messages to parents about their child's acceptance and inclusion. In this author's experience, the kind of relationship that will develop between the home and school, will in large part, be contingent upon the acceptance or rejection of the child by school personnel. A limited view of the student undermines his/her potential and often translates directly into an IEP with limited expectations.

Cooperation and teamwork. Positive attitudes that accepted the children and welcomed them into the school and classroom, produced an atmosphere of cooperation and collaboration between the home and school. One parent referred to teachers with such positive attitudes as being "like a rainbow in the storm." This parent explained that when you meet teachers with positive attitudes, "It makes everything just that much easier and you see Gina learning something -- actually learning -- it's something."
Another parent found this positive outlook in her son's first school, but has not since experienced it in any of his other placements. She explained the benefits of positive attitudes at her son's school:

> I think it was a good team between the whole school. There was positive from the principal, positive from the resource teacher, a good qualified teaching assistant, who actually had her teaching degree and worked well with the teacher. The main teacher in the room, acknowledged she had no experience, but she had good support from her principal and her resource teacher, with regard to planning and programming. So much so that the

> resource teacher and the principal each day, on their own, to allow the teaching assistant's breaktime, the principal and the resource teacher were the ones, who went in and substituted for the teaching assistant. That's how positive and involved they were, so I think that the whole positive attitude from the top down played a large part in it.

Unfortunately, these parents experienced few occasions in their children's schools where such positive outlooks and team dynamics were present. The negative attitudes parents perceived from school personnel precluded an atmosphere of cooperation and collaboration. These attitudes served as barriers, hindering the development of the IEP and excluding the parents' involvement in its development.

The comments of this parent serves to capsulize what parents had to say about what they experienced, felt about the IEP process and where the problem might originate.

> I found that we weren't always focusing on her best abilities. You know the things she could do well. It was never the question, How can we do it? It was, Can we do it? You know, maybe we can't. I think there needs to be more of an interdisciplinary approach within the school somehow. We're working together to solve problems. I don't think that happens enough. I think parents feel alienated, and feel like they're asking for way too much, and I think, that's why parents don't get involved at times, because they're just happy that the school takes them, and why interfere.

Trust and Respect

When any parent sends their child off to school there is a certain trust that teachers will do what is required for their child. This trust remains in place unless it is disturbed by some action that results in a breach of that trust. The respect that accompanied that trust, also begins to deteriorate. I feel that the findings in this study indicate that parents felt they experienced a breach of this trust, and subsequent loss of respect for school personnel.

Placement decisions. The IEP process began when parents met with school personnel to discuss a placement for their child. All parents in this study wanted integrated placements and hoped their child would be welcomed by the teacher, included as a member of the class, and have an IEP developed. These are the same things any parent would expect from their child's teacher. Nevertheless, each year their child's placement became a concern for these parents. This concern was realized by either of two conditions: first, schools would sometimes challenge the student's current integrated placement, and want her/him moved to a different school, where the necessary supports -- considered as segregated placement by parents -- were in place.

> "It's hard for Gina here. There's only a resource teacher here for half a day. Gina needs this and the other thing and the best place for Gina to get everything she needs is at Ridgewood High and Frank Hick's class."
>
> Frank Hicks is a teacher in a segregated classroom. This is not what Gina needs. This is what *they* need.

Parents in this study reported that when school personnel questioned the inclusive placements of their children, they did so by trying to convince the parents that other (segregated) placements would better meet their child's needs. The parents felt that the motive for the change was in the best interest of the school and not the child. "You know they had already come to the decision, what they wanted, and they were feeding me the information to make me go the way they wanted me to go." Parents were mistrusting of school personnel when it came to the school's attempt to move their children into segregated settings.

Secondly, parents became apprehensive over the uncertainty of how next year's teacher would receive their children. Parents were never, or rarely informed, who the child's teacher would be for the coming school year. This was an obvious concern for parents that went unaddressed by school personnel. One parent relates how she felt about never being informed about next year's teacher:

> . . . now that we are coming to the end of this school year, I am panicking about next year, because I do not know who her teacher will be. We had repeatedly asked, as each school year was coming to a close, that -- two basic questions: "Would Molly's teaching assistant be coming back the following September? Could Molly hook up with her new teacher for the following year, before the current school year ended?" Try as we might and promises were made and never carried through in previous years. This was a request that we made probably three years running.

Mistrust of school personnel became critical for the parents of one child, who felt that the school had complete control over where their child should be placed. These parents became very concerned, when an Ontario supreme court decision, gave school boards the power to determine a student's most suitable placement. "Charlie is worried about Jeffery being down the road, put into a [segregated] classroom and there's nothing we can do about that. Like we can't make a decision."

The concerns expressed by the parents in this study, with respect to their children's placement and teachers, on the one hand, indicate a sense of mistrust for the school system and, on the other hand, an insensitivity to their needs. It would be difficult to have respect for someone you feel you cannot trust.

Balanced partnerships. A common characteristic shared by the participants in this study, was their choice to be involved in the development of their children's educational plans. Parents were quite willing and capable of contributing to the IEP process, but were denied access to any form of partnership with the school. Typically, the only role assigned to the parents by the school, was providing their signature to an IEP document, that parents had insisted be developed in the first place.

Parents acknowledged their inexperience with IEPs, but actively sought participation in their child's program. This participation usually came at the parent's insistence. "We made it clear from the start that we had to approve everything in regards to what they were doing with her." At other times, parents became persistent in their request that school personnel develop an IEP, and when necessary parents sought help outside the school. "I pushed myself on them." Parents were also consistent in their resolve that an IEP be completed for their child. One parent stated how he felt about having an IEP for his child, "You're definitely drawing one up." Parents became very interested in trying to help teachers develop an IEP.

> With the teachers -- I have told them -- if there is something that you are planning in the school, maybe I have something regarding it at home, that would be relevant for Donald. I have sent supplies in. I have bought supplies. I have made things. But, for the most part, the teachers don't even take me up on the offer or even call.

In most cases, to insure that an IEP would be developed, parents literally developed the IEPs themselves.

> I spent basically that whole year, much to Erin's [friend/advocate] chagrin, helping to develop the curriculum for Molly. Because even though I had a receptive teacher, I still wasn't sure that some of the materials would be adapted in the class. So I began doing some books and writing some books and developing some things and that kind of stuff, all tactile stuff.

During parent-teacher interviews, parents described situations where teachers had the principal and/or resource teacher with them. At these meetings the teacher barely participated during the interview. Special Services personnel, or the principal, would have the most input at meetings, even though they would have the least amount of direct contact with the student during the school day. This lack of input by classroom teachers, either attending or participating in these meetings, was a major concern and common experience for all parents.

Parents were mistrustful of school personnel even when they felt that their ideas and suggestions were being well received.

> I spent an afternoon with the guidance counselor two weeks prior to school opening that year for grade ten and to me everything was hunky-dory. But I could see it was just emotion. I think she patronized me, that's the best way to put it.

With few exceptions, parents in this study reported that they never felt part of any team or an equal partner in the IEP process. Based on their past experiences in dealing with school system personnel, all the parents were in agreement, that an advocate should attend meetings with them. This point was emphasized by all parents, especially when it came to meeting with school personnel around issues related to program planning for their child.

Communication. In addition to their resolve for an IEP, parents were supportive in working with the school and helping develop these programs. They made themselves accessible where possible by spending time volunteering at the school their child attended. But school personnel did not use this easy access to parents to include them in the development of an IEP or in dealing with issues related to their child.

> I felt like I couldn't trust them totally at that point because I didn't know what I had done that was so wrong. I just asked for a 10 minute -- more than a 10 minute meeting because it wasn't going to encompass what we had to go over.

Parents found this distancing among teachers to be unsettling and were perplexed by its occurrence. "I really wish something could be done about the teachers' reluctance to talk and even get to know the parents." This silence and distancing on the part of teachers became difficult to deal with. "I mean the teacher wouldn't even talk to me. She would see me on the playground and she'd turn and walk the other way." Other parents experienced similar situations where opportunities were available for teachers to communicate with them, but teachers did not use these occasions to have any form of communication with the parents. "Things are going on I'm not told about. Things that are written in the [communication] book are contradictory. Like we would see the teacher assistant everyday. We see the [resource teacher] maybe every second day." This silencing and distancing may be even more problematic for parents at the junior and senior high school levels, because of subject teaching and the greater number of teachers involved with the students.

A perceived failure to carry through on promises, develop programs, or share information with parents about what was happening with their child, created mistrust and a lack of respect for school personnel.

> . . . the mainstream support, who is the most useless person I have ever met in my life. When I'm at a meeting I don't even look at him. I don't know what he is getting paid for, but it's not to help people with mental handicaps.

The parents in this study, had many opportunities to experience situations, that would leave them with feelings of mistrust and lacking respect for the school personnel.

Professionalism

When we think of professionals, we tend to think of a specific group of individuals who possess certain expertise that is not readily available to all of us. The knowledge shared within the group is closely (secretively) managed and dispensed by those who are already members of the (exclusive) group (i.e. medical schools, law schools, etc.). This seems to be very much like Skrtic's bureaucratic model already discussed. A certain status is attributed to those within the group, by others outside the group, who do not have ready access to this knowledge. When members do not readily share this knowledge with those outside the group, a hierarchical relationship is established, precluding an equal partnership, and maintaining a professional/client relationship, with its underpinnings of power and control (Skrtic, 1991).

The IEP process requires that both school personnel and parents work together, and see each other as equal and contributing members in a partnership. The professional/client relationship is not a framework that is conducive to the IEP process.

<u>Privileged status.</u> Parents felt that professionalism as they experienced it, acted as a barrier and helped to distance them from the educational process. Parents often felt that they were made to feel like they didn't know anything. "You know, we're the teachers, we're the professionals. We're trained in this. We know what we're doing and you're just going to have to do what we want kind of attitude." Another parent expressed her concern about being made to feel small. "Just what I had to say about Molly wasn't taken seriously or that they knew it all and you didn't know anything." Robert felt that school personnel undermined the knowledge they had to share about their daughter.

> But the interesting thing was that all this information that they asked for and got back to them [from the hospital case conference] was no different

> than the information that we had given them. But it wasn't -- you know they had to hear it from the professional. They didn't believe us. So when someone says we as parents can't come in and show them something related to our daughter, that we do day in and day out, it tends to be a bit of a kick in the ass.

Parents often encountered school personnel who did not acknowledge their inexperience in writing objectives for the child. Parents felt that this translated into inadequate programing for their child. Parents reported that school personnel rarely sought parents for their assistance, and resisted the expertise from outside the school system that was made available to them, through the efforts of parents. One parent felt that, "Universities -- parents are not seen as a resource." Parents were usually never included in development of the IEP, nor did schools accept resources offered from outside the school system. Parents were frustrated and couldn't understand why school personnel took such a position.

> They go in and they talk about doing up an IEP about someone they know nothing about, and they refuse to involve and ask questions of the parent, who has known the child all his or her life. It's stupid.
>
> I said, "all you guys [school] do is hang your hat on communication. Have you yet brought in someone to teach sign language to you? I can bring in my people to do it, but you don't want them in here. I've offered you, and offered you, and offered you, and here we are back at square one."

<u>Exclusive club.</u> This stand alone attitude complicated the IEP process through the

development of poorly constructed objectives that parents felt were not meeting the needs of their child. One parent uses an example to illustrate how restrictive school personnel were in writing objectives. She wanted teachers to have more interaction with her son. "Some of the teachers would allow [peer interaction] and had written that in his IEP for periods of 30 seconds to two minutes." Another parent describes her impressions of the IEP review meeting she attended, "We go over the IEP. There's nothing written in the IEP. It doesn't show what he has accomplished." Parents were tired of receiving evaluations that told them nothing about what their child was doing, or the progress they were making. They wanted to be able to pinpoint what was, or was not, working and have something that the following year's teacher could continue. Parents wanted more from evaluations than they had been previously accustomed to receiving.

> I will no longer accept report cards from teachers, telling me that Donald knows his name. Donald smiles at me when I call him.
>
> Gina is pleasant to teach. She's this, she's that. But what's she learning in your class?
>
> They were not tracking her progress whatsoever. They kept telling me they don't do this. I didn't realize exactly what I meant, and I didn't realize what was missing, until my son started school. In primary, when I had my first teacher interview, she got out all his work from the very beginning of school til here. I thought, "... this is what is missing with Molly. I can see his progress in front of me." She [parent's sister] helped me develop a graphing system for Molly -- three days a week at school.

> This was like horrendous to get them to accept this. It was too much work. Nobody had time to do it.
>
> Like the last page of the IPP, you can't gauge it. None of that stuff is possible to gauge. So, how do you know if he has achieved it, or did not achieve it? But you know that, if you have what you intend to do, this is the technique, that's your objective, your outcome. If I don't have the outcome, how can I change the technique, to make sure that it reflects what we're trying to do?

The frustrations of parents around appropriate programming for their child prompted them to take action to improve these programs or in some cases, to develop the program. Experiences such as those described with the IEPs and the IEP process, prompted parents to become educated about developing and adapting program plans for their children and demand membership in the exclusive club.

<u>Parent as problem.</u> When parents tried to ameliorate this situation, they were sometimes blamed for their child's problems, and were told so by school personnel.

> I was told by the principal -- that the reason I had so many problems, was because it was my own fault -- that I complained about everything -- that all the problems that Donald had, were my own making and that sort of thing. That I never had anything good to say.

The cause of problems for school personnel has now shifted from the child to the parent. Another parent was told by her son's resource teacher that it was her (parent's) fault that she (resource teacher) had been disciplined by her supervisor. "You have made me get my hands slapped." Sometimes, parents were not directly told that they were the cause of their child's problems. One parent explains that at IEP meetings with school personnel he felt that their attitudes toward him expressed a certain sentiment. He describes how he felt, "I was labeled as one who rocks the boat and you cannot satisfy."

Power struggle. Parents had similar perceptions of how their desire to help and become involved in their child's program, had deteriorated into an issue about power and control. Parents felt that the professional stance taken by school personnel, precluded a cooperative and collaborative involvement in the IEP process. One parent characterized his relationship with the schools, as a "power struggle". He felt this needed to stop. He believed that they should all hold each other accountable and get back to the real issue, which was his daughter's education.

All parents related similar experiences, recognizing power and control, as an issue with which they were forced to contend. "You're walking a fine line. How far can I push to getting Donald's needs met without getting the teachers upset." Other parents used such expressions as, "them and us," and "on our own turf," which speak to a division of roles, and the power and control that directs the relationship between home and school. With the power and control resting only on one side, this reinforces a vision where parents see themselves as "outsiders." This division is evident in Bill's comments about his perception of where things stand between him and the school. "So we're back to that stage where it's just -- home's home and school's school."

In a rare occurrence in this study, a parent's description of how she related to one of her daughter's teachers, illustrates the effect on the communication process when power and control struggles are absent.

> Well we just talk to each other like regular folks -- not me talking to someone who is up here -- who is an authoritative position. Which in some years -- that's the way I felt with some of the teachers -- who might be a little bit older than myself. I think, I kind of felt, that they knew what they were doing. They didn't need to ask me anything. I think there are ways, that at times, parents are kind of regulated to feel very small. I think, I kind of felt that way a number of times, in regards to other teachers -- not being able to communicate.

Parents were sometimes offered a choice of an integrated or segregated placement for their child. Despite the availability of integrated options, there were occasions when school personnel wanted the student placed in a school or class considered by parents to be a segregated placement. Parents were being told that these placements would better meet their child's needs. Sometimes parents felt they were being manipulated into accepting the school or school board's decision:

> I was informed of all this stuff at a meeting, but it had been pre-planned. I felt, I was being manipulated. But you know they had already come to the decision, what they wanted and they were making it. They were feeding me the information to make me go, the way they wanted me to go.

Another parent described this manipulation as an attack upon them and their child, "It was a gang bang, as far as Robert and me sitting there. It was just negative." Sometimes parents held their position and insisted on an integrated placement for their child, despite what the school wanted:

> "Well Gina is going to Central High." " No Gina isn't going to Central . That's a segregated program." "No it isn't." "Yes it is." I said, "Gina is going to Lakeside High. Gina is going to be mainstreamed with her neighbourhood kids -- peers down at Lakeside High."

This confrontation around the issue of placement, clearly illustrates a power struggle between the parent and school official.

There were other occasions, when parents yielded to pressure, against their better judgement. They knew that the placement the school had chosen, in their mind, was not the best one for their child.

> I did not approve of this, but because he had spent so much time sick that year, and really wasn't gaining a whole lot from the class, I didn't feel I had much to stand on to fight it. I was against it in the first place. But to myself, I said, "I would give them one year to prove me wrong. I wouldn't complain. I wouldn't kick up a stink."

The issue for parents was never about gaining control over their child's program. One parent expressed her position, "I wanted just to be helpful more than anything, if they needed me so that their job would be easier. That was always my intent." For these parents, their involvement in their child's life at school was a natural extension to their involvement at home. Parents were understanding of the school's position with respect to programing for their child, and expected that school personnel would need time to get to know their child in order to prepare an IEP. "She was probably the first child, with as many needs, as she has. So, that it probably was their first experience with someone in a chair, who was fully dependant." Another parent also expressed a similar understanding.

> I wasn't happy, but I understood there was some growing pains for the school because Gina was the first challenged student that they ever had. Gina was blazing a trail. They kept hanging their hat on this thing. So it had allowed me -- it gave me more time to give them because of it.

These parents were knowledgeable of the fact that school personnel, in order to develop an IEP for their child, would need time to get to know him/her. This parent, like the others, knew that developing IEPs required that school personnel get to know their child. However, she expresses a concern that was also relayed by another parent -- that school personnel would use some form of retribution against her and her son, if she became too demanding.

> Again a new school, a new setting. I was trying not to make any waves. This was the pattern, I found myself following. The first year in a new school, with a new staff. I tended to let them get their feet wet and see how they adjusted to Donald. I tried not to be to demanding about things. I didn't want to upset the teachers and staff. I was afraid if I did, it would set up walls and make things worse.

Ownership

Historically, Special Education has assumed ownership of 'special students'. In segregated classrooms, ownership was never an issue. This same thinking, on the part of both Special Services personnel and teachers in inclusive environments, became a significant factor which jeopardized ownership of the child and her/his IEP by the classroom teacher.

In the experiences of all parents, who cumulatively had dealings with 30 or more teachers, there was only one exception, where the classroom teacher actually assumed responsibility for the child's program. In all other experiences, the primary responsibility for the child's program was assumed by the Special Services personnel in that school. In one case, where the mainstream support teacher was only half-time, the school tried to have the student moved to another school where full-time Special Services personnel were in place.

Policy to practice. What are the implications for policy development at the school board level, when major stakeholders are not included? Simply saying that a school board has a policy of full inclusion, does not mean that automatically the attitudes or necessary skills are present in each school, or teacher's classroom, to implement such policy. The student's placement in an integrated class, did not mean that this placement went unchallenged by the school or the classroom teacher. Where ownership was questioned, the writing of the IEP became the responsibility of the learning resource or mainstream support personnel in the school. In such environments, the implementation of the program by default went to the teaching assistant.

It seemed that when the classroom teacher assumed responsibility for the student's program and included him/her as a member of the class (only one parent experienced this happening) other aspects of the IEP process began to fall into place. Parents explained that the flow of the IEP planning meetings changed from the principal or resource teacher speaking for the classroom teacher to the classroom teacher actually chairing the meetings. The parents felt they were equal partners in the meeting and the meetings were faster and less acrimonious. Parents were invited by the class teacher to actively participate in class activities with their child. They describe the development of the IEP that year as being drawn up in "harmony" with the resource teacher. This particular parent felt that these changes were due to the classroom teacher doing, as he expressed it, ". . . the lion's share of the work on it and the communication that went into it."

Whose job is it anyhow? The ownership issue, or responsibility for the student's program, and the perceived amount of work involved in the development of IEPs, was a major concern for teachers. A parent reported the comments of one resource teacher, "Well who's going to do all of this? I have this and this to do. I can't be expected to do all of this." A parent recalls her daughter's classroom teacher's comment, with respect to the parent's request that they track her daughter's progress, "Well it was too much work. Nobody had time to do it." Another parent was told by one principal that the teachers don't have time to be responsible for his daughter's program. In light of these attitudes, teaching assistants were often targeted to assume the duties that the teachers were to busy to handle. For the parents of one child, the following explanation sheds light on the relative importance of ownership.

> Probably because of the ownership issue. I think was probably why we would go to these meetings without great expectations, and perhaps a fair bit of stress about them, because we didn't think anything was going to

> transpire, and we thought we would probably lock horns again, and not get very far.

When there was no clear acceptance of ownership it becomes increasing difficult to have the task completed because everybody does not see it, as being their responsibility. Therefore, nobody completes it. In the absence of any ownership and subsequent development of an IEP, the child may be subject to the following program described by Donald's mother.

> He spent so much time in a room by himself with the teaching assistant, that people literally thought he was in a separate class. They thought nothing of taking him out of class to go for a walk, and she thought that this was the big thing. She was getting him out. She was taking him to Robbins' Donuts. They were missing the whole point.

In one case, a teaching assistant who was a trained teacher, actually carried out the adaptations and implementation of the child's program. Like the teacher, the attitude of the teaching assistant toward the child facilitated or complicated the IEP process.

> Tara [teacher assistant] went in there to teach Gina. Well to be the teacher's aid. Right off the bat, Tara and I just hit it off. Her philosophy is the same as mine. Gina needs to learn. We need to adapt the program. She told me she never saw the mainstream support. She had done all the examining. Gina would write the exams with the other kids. Things with the principal, the other students, with the teachers was all going great, outside these little glitches of getting the adapted computer program.

In this particular example, the TA virtually took ownership of Gina's program. For this particular parent, it was the first time in a number of years that he felt his daughter was actually learning something. While board policy indicates that classroom teachers are responsible for the development and implementation of programs for all students in the class, every example in this study, except one, appears to be contrary to board policy as ownership was typically delegated to the TA. The exception was in the case of Molly's grade four teacher who accepted Molly into his class and took ownership of her program.

Parents were not content with the teaching assistants doing the work of the teachers. One parent stayed away from parent-teacher interviews one year because of this. "I was so frustrated with her because she didn't take-accept ownership of Molly, as one of her students. I felt that -- I guess it was just -- I don't know, a really frustrating year for me."

Another parent expressed concerns about the teaching assistant doing the teacher's job and the implications of that practice.

> He is still doing it on his own, and that is a concern because if anything happens, its going to fall on the teaching assistant, and technically it shouldn't. It's the responsibility of the teacher, and that's a battle I have yet to win. Getting the teachers to realize they are the ones who are responsibility for Donald's program, and they are the ones responsible to guide the teacher assistant, to give direction to the teacher assistant. The teacher assistant is not supposed to plan and set-up and implement all these things.

As mentioned previously in these findings, there was only one instance, from all the data provided by these parents, which collectively represents about 25 years experience in the system, where a parent described the classroom teacher as taking ownership of the child and his IEP.

<u>Elementary and secondary school differences</u>. One parent reported that the issue of ownership becomes even more complicated in the junior high school because students have so many different teachers. "They're only teaching the child one subject. They may see him three times a week." The fewer number of teachers that their child has, will increase the amount of contact between their child, the teacher and parent.

> . . . I only have two teachers to deal with, instead of five, and that will facilitate the teachers getting to know Donald better, getting more involved with his IEP, and better knowing each other.

In primary and elementary school students were exposed to a classroom teacher who taught most of their program. Two students in this study entered junior and one into senior high school, where they were introduced to subject teaching and consequently a greater number of teachers for each grade level. While the IEP process seemed to mirror the primary and elementary experiences, it is not clear from this study that ownership and the IEP process became more complicated as students moved into junior and senior high school. What is clear, is that parents would certainly encounter more difficulty in the IEP process, if the pattern of relationships experienced at the primary and elementary levels continued on into the junior high and high school levels, simply because of the number of teachers with whom a parent would have to interact.

Keystone of the IEP process. It appears that negative attitudes of the classroom teacher precluded ownership, whereas, positive attitudes facilitated teachers accepting ownership and was reflected in the teacher's commitment to problem solving and working closely with school personnel and parents. When parents experienced positive attitudes from school personnel, they usually described those individuals as creative, not afraid to ask questions and willing to reveal their vulnerability, and as being open to suggestions. Parents in this study seem to consider the positive attitudes of teachers in the IEP process as being more important than the teacher's actual skill levels in writing, adapting and implementing programs.

All parents hoped that teachers would include their children as part of the class and accept ownership or responsibility for their child's program.

> I wanted Gina to have an adapted program and that the teacher own Gina. That the teacher utilize the teaching assistant to assist her in getting materials and to use the mainstream support person, whose job it is to help the teaching assistant find those materials -- adapt those materials.

The inclusion and acceptance of the student by the classroom teacher signify ownership of the child's program and membership in the class.

> He's wonderful. Even when we sat down to do her IPPs, because their called IPPs this year -- but even some of the language from her previous IEPs, he picked up on and said, "Why do we have to keep saying -- so she can be included with the class." He said, "That's a given." He said, "I expect her to be include with the class." So he has been great, and it has

> been one of the less stressful years, that I have ever had in many years, and I'm doing less as far as curriculum adaption.

Unfortunately, parents experienced few occasions throughout their children's school histories where such teacher attitudes were evident. The opposite of this situation was more the general rule for the parents in this study. It was not evident from this study, whether a teacher's positive attitude promotes acceptance of ownership, or whether the reverse is true. However, both seem to be present or absent together. When present, parents were welcomed into the IEP process and reported that they felt they were equal and contributing members of a team. When absent, as in most cases within this study, the results for parents were the reverse, they were not welcomed into the process, nor did they feel like equal, contributing members, or part of a team. They were placed in a position that necessitated them to seek alternate means to get an IEP for their child. This in turn placed them into a conflict situation with the school system.

Facilitators of the IEP Process

Some things can be seen as both facilitators or barriers in the IEP process. Part of that interpretation depends upon the position taken by the respective participants in the process. In this section, I will speak about things normally seen as facilitators of the IEP process, but recognize their potential influence as a barrier.

Parents' Early Strategies

Parents used a number of strategies to try and overcome the barriers they faced in securing an IEP for their child. These strategies varied with the degree of difficulty parents encountered from school personnel. They were evident from the time of initial contact with school personnel and continued throughout the child's school placements.

Trusting Basic senses. Some parents focused on finding a placement for their child where the attitudes of staff would be open and accepting. Participants in this study acknowledge the attitude of the principal and the classroom teacher as an important factor in determining how the IEP process would unfold. They hoped this would ensure an easy transition into their child's new placement and avoid confrontation around supporting the needs of their children from the very beginning.

> What I was looking for was an integrated placement that would work. I felt to start off, that was the highest priority. Rather than fight to have a particular school, I wanted a school -- something that would work. So, I was looking more at the people who were going to work with him. They were open and willing to work.

When it came to finding a placement for their child, parents were initially more concerned with the attitudinal milieu of the staff at the school, than the staff's ability to develop IEPs and adapt programs. They were also concerned that the necessary supports be in place for their child.

> My big thing was, I wanted everything to work out, because my concern was for the other children, as well. You know if things aren't going -- if Molly is not supported well, then the other kids are going to suffer because of it, and we didn't want that to happen.

Parents expressed a concern that, if their children were seen as being a disruption to classroom routine, then school personnel could use this as an excuse to recommend them being removed to some other (segregated) environment. It has been the experience of this author, that children with challenging needs in integrated settings were more often like parolees on probation. Any breach of behavior could warrant their removal from society (integrated classroom) and placement back in the institution (segregated classroom). These same standards were not always applied to the other students without challenging needs within the class. Their placement was considered permanent, and required a much more serious offense than at times being disruptive to other students, to be permanently removed.

Wait and see. Other parents gave schools time to adjust to their child, before seeking the IEP, and only when schools were not forthcoming with the IEP, did they then become more insistent, and seek assistance from outside the school. Parents were aware that the schools needed time to adjust to their children and allowed for a period of orientation where school personnel could have time to get to know the student, before developing an appropriate program for him/her.

How can we help. Parents also became volunteers in their child's school, thus providing opportunity for direct daily communication with teachers. Parents were interested in knowing about what was happening with their children. It also provided them the opportunity to learn more about the school their children attended. Parents intended this strategy (volunteering) to facilitate the IEP process, however as already discussed, teachers did not use this proximity to parents to include them in programing to meet the needs of their child.

Parents Accessing Expertise and Support

The parents in this study were not content to drop their children at school and have no other involvement in that aspect of their lives. When early strategies on the part of parents failed to accomplish their goal of having school based personnel develop an appropriate IEP for the child, they sought the help of others.

Writing letters. Parents sometimes wrote government ministers and supervisors of special services at the school board administration level. Sometimes these people at the board were identified by parents as an ally. "I found her very good to work. I had dealt with her regarding issues in the past and found her to be very supportive. . . . She's very committed to integration, to the exchange of information." Throughout this study, parents have reported focusing on the attitudinal orientation of individuals toward integration as a key component, when seeking support.

These actions taken by parents in an attempt to have their rights, and the rights of their children respected (IEP and parent participation), served to draw attention to the issues. In the parents' perspective, these actions were sometimes seen as futile, but at other times were instrumental in assuring that someone was accountable for the lack of action by school personnel, and ultimately services received by their children were improved by such action.

Becoming advocates. Because parents were active members of their local ACL (Association for Community Living), they were in a unique position that provided them access to an advocacy support network. A major area of advocacy provided to the parents came in the form of someone to accompany them to IEP meetings. This became such an important part of the advocacy role that parents were always quick to point out that you should never attend an IEP meeting alone -- "to make sure that you always had someone with you."

Parents had a number of reasons why it was important to have someone with them at meetings. One of these reasons included someone to take notes.

> I've always told them to take somebody . . . even if that person only takes notes. Because when you leave the meeting, you can focus on what's going on at the moment. -- what's been decided -- what's been agreed upon at the end of it. So that you have something concrete, and it's going to be up to you to follow up on those agreements and make sure these are done. Because my experience, is when you're at the meeting, they don't get followed up on.

Parents also saw the presence of another person at the meeting with them, as a protection against intimidation.

> Just the fact that there's someone else there will sometimes make the people at the meetings sit back and be more careful in how they treat you. Almost like there's a witness there.

Other reasons given by parents for having an advocate with them at these meetings included, getting issues addressed that the parent felt needed attention, and asking pertinent questions that the parents didn't think of asking. Parents were also aware that even the seating of personnel at these meetings was important.

> The first meeting they tried to sit all on one side, but [this time] they had a

> couple of chairs in between and I know better than that. So Marlena sat between one and I sat between the others. You know, like I don't play this. That's confrontational right there.

By becoming involved in their children's education, these parents were learning more sophisticated strategies. This was being accomplished by gaining more knowledge (educational) through affiliation with other parents (ACL) and professionals. In light of this study, the changing role of parents, from novice to expert (in advocacy and education), could be reasonably argued from either a facilitator or barrier position.

Learning professional knowledge. Because parents wanted their children's inclusive placement to become more than a social club (this too was questionable with the amount of reported time spent out of class), and because school personnel failed to provide IEPs, or provided poorly constructed IEPs, parents took it upon themselves to become knowledgeable about IEPs.

Three of the four families in this study had a MAPS session conducted for their children. Unfortunately, the MAPS was not implemented as it was originally designed. In each case, step seven, planning of a day in the life of the child, was left out of the process. Parents were upset over this as they recognized the implications of this move. By eliminating the critical final step in the MAPS planning process, this would severely restrict the classroom teacher in his/her ability in completing the development of the IEP.

> I though that was the most important step, because then it would at least give the teacher a sense of – these are the things I can do. The school board said, "no, that's not our [planning team] job. We don't tell the

> teacher how to do their job. It's up to the teacher to plan the day." It was a really disappointing process because they didn't and I still felt -- well there's the teacher -- she still doesn't know what to do with Molly in class. It was very frustrating.

Parents felt that step seven in the MAPS process was so important that it should be allowed to proceed. "We argued with her [school board facilitator] about that, and we could not make her understand how important it was that we should do it."

Parents also questioned the behavior of the classroom teacher at a MAPS session.

> I was extremely angry even before I left that MAPS session. I was just furious. I just couldn't believe things that were being said, and the way the whole thing was being handled. The other things, like the comments the teacher would make, during the process of the MAPS -- I found upsetting. "Was it a case of the facilitator not picking up on it or simply not being well enough trained?"

The parents' observations with respect to the actions of school personnel at the MAPS session seem to indicate that parents were better prepared and had a greater understanding of the MAPS process than the school personnel themselves. Parents indicated they had initial preparation before attending the session. This was arranged through their support group and not provided through the school board. One parent actually helped the school principal prepare by supplying print material about the MAPS process.

The parents of one child, on the advice of their support network, established a lifestyle planning committee around their daughter. This committee consisted of an interdisciplinary team of people, each of whom was involved in some aspect of the child's life; education, recreation, family friend/advocate, itinerant teacher, social worker and pediatrician. The principal of their daughter's school was involved as a team member. The criteria the parents used for selection to this committee employed a unique strategy.

> The criteria for -- or we required -- people who had the abilities to make decisions, so that's why we didn't ask, the TA or the teacher, but those who had the authority to make decisions, so that we wouldn't prolong processes.

In addition, their purpose was to create an opportunity for other people involved in their daughter's life to take ownership of some of the issues, thus relieving some of this burden from the parents. Their unique way of accomplishing this eventually led to the principal's support in transitional planning for their daughter.

> The other important thing, was that it was significant to have other people help us identify, for other people, that certain things were important, so that the principal was also hearing this from other people and not just us. There were actually times when we would have concerns but we would -- say there was an education concern -- but we would get someone else to ask the question on the committee -- rather than it come from us -- so that there wasn't a constant sort of head butting, with the education system. The difference in getting parent issues addressed by professionals, or not

addressed, may be found in making the issue not only the concern of parents, but also others who empathize with the parent's position.

> She [principal] was very defensive at first. Very defensive at times, when we had concerns about school -- specific concerns about a certain issue, whatever. But it certainly helped I think, to have other people hear us, as that buffer, and to turn it into a discussion, so that there was another perspective, that she could perhaps look at and that.

Such strategies proved to be effective and was evidenced when the principal "joined the team." The parents felt that proof of this happening occurred when the principal agreed to introduce, or at least identify for them, who Molly's teacher would be for the coming year.

> We received a phone call in June, before the end of the school year, last year. Sheila, asking if we'd like to do some transition and meet the new teacher, who'd be coming to the school. There would be a new TA and new teacher, arriving at the school. She specifically hired this teacher with Molly in mind, asked specific questions in regard to integration, and all of that kind of stuff. Then she and I connected in the summer.

Both MAPS and the lifestyle planning committee are examples of valuable educational practices. Their intend is to remove barriers between parents and teachers and to improve the IEP process. The irony in this is that these educational practices can become potential barriers, if school personnel resist accepting, what is seen as professional knowledge, from perceived non-professionals (i.e., shooting the messenger).

Parents also used their support network to become knowledgeable about writing, evaluating IEPs and adapting programs. Parents had little knowledge about IEPs, when their children first began school. But their persistence to have a program for their child necessitated their self education about the process. "Well we've done some research too and I want the core curriculum -- what they teach in the classroom. Next thing I want, is the adaptation for Jeffery to make this feasible."

The education of parents about the IEP process was accomplished through the utilization of expertise from people in their support network.

> I brought the IEP home and although it looked okay, I knew there was something missing. But again I am not sure how knowledgeable we were at the time. The goals seemed appropriate, but there was no means of getting there. So I called Erin [friend/advocate]. She put the pieces of the puzzle together for us, and helped us to understand, what could be accomplished.

The education of parents about the IEP process eventually enabled them to spot poorly written IEPs, and to question their effectiveness, in meeting the needs of their child. This became obvious to parents, to the point where parents began to actually rewrite the IEP, provide suggestions on how to adapt activities in the classroom, and develop examples of adapted curricula.

Teachers' Professional Development

The need for teachers' professional development through in-service is seen as an ongoing concern for provincial Departments of Education and individual school boards around the implementation of new curriculum and teaching strategies (i.e., cooperative learning, team teaching, etc.).

School board initiated. What was obvious by its very absence in the experiences of these parents, was any indication that professional development for their children's teachers was being provided to any degree by the school board around the issues of inclusion and program adaptations. Parents may simply not have known what was taking place at school, with respect to professional development around inclusion. This view may be highly speculative, however, in light of the time parents spent at their child's school volunteering, or in trying to have IEPs developed for their children. It would seem unreasonable to think that school personnel knowing the parent's interest in helping with their child's program, would not take every opportunity to inform parents of any professional development directed toward implementing an appropriate program for their child. Whether there was professional development or not, is not clearly evident from the study. What is evident from the study was the need for such professional development.

> Well teachers don't feel they know how to do this, or they know what they should be doing. . . . You know they're telling the principal that when it comes to adapting programs to meet Donald's needs, following his IEP, that they don't know what they should be doing.

Individual teacher initiated. Parents described only one example where a child's teacher took it upon herself to learn more about inclusion. In this particular instance, the teacher was ridiculed by her peers for her action. "She said, 'you know I have done this and my peers think I am a fool, for doing this.'"

Parent initiated. Parents also became promoters of professional development for teachers of their children and their children's school. They used two approaches to try and prepare school personnel with current information and programs to better prepare them to work with their children. One way parents attempted this was through providing literature about their children's disability to their school. One parent questioned if the material they were sending into the school was actually used, "Whether they're reading it or filing it under file 13. I have no idea." Another parent passed on information to the school regarding special training programs.

> I have also taken into the schools, when I am aware of training programs, like summer programs in program adapting, and IEPs and that kind of stuff. I've taken pamphlets into the school and left them in the teachers' room, to see if any of the teachers would follow up on them. I have never heard that any of them have.

Teachers' Professional Accountability

Teachers have a responsibility to the students they have in their classrooms. They are entrusted to deliver a program of studies and evaluate the students' progress in these studies. In the hierarchical structure of our educational system, administrative personnel in schools and at school board levels are all accountable for the actions of their subordinates. Where accountability happens the IEP process is facilitated, and in its absence it becomes a barrier.

Individual teacher. There was only one example, in all the years represented by the data in this study, where parents described a classroom teacher fulfilling his/her obligation to their children, where the teacher accepted ownership for their child's program and the responsibility for the development of the IEP. There were many situations, where classroom teachers or resource teachers simply failed to come to IEP meetings, and parents felt that no accountability was required by the supervisor for their actions.

Administrative supervision. There were few examples where teacher accountability came under close scrutiny by administrative supervisors. Teachers were not taken to task for their obvious breach of responsibility. Parents often felt that teachers were supported in their actions by their supervisors. "The principal said they don't have time to teach Gina." At other times, if supervisors did not support the actions of teachers, they appeared to do nothing to question them.

> The fact that it progressed and she [Ms. Dunphy] did not stop the negative statements towards Donald -- the fact that even though, I requested some of Donald's peers for their input -- the teacher [Mrs. Starky] determined on her own without consultation, without anyone else, they were not going to come, and yet the facilitator [Ms. Dunphy] did nothing about all of these things from the teacher.

In one instance, a resource teacher's absence at an IEP meeting was questioned. "Yes and that did eventually come up at another meeting, with the principal and Diane and her, because Diane thought that she should have been there."

Policy implementation. The children of parents in this study were all attending schools where inclusive education and required IEPs were school board policy. With this policy in place, there was very little evidence of any application of its practice. In light of the present findings, we might consider if school system personnel would be held accountable if they did not follow policy, as in the case of implementing a new science or math curriculum. The one example in this study where policy was followed by Molly's teacher, her parents and the principal expressed great satisfaction with the parent and school communication and interactions and with Molly's progress that year. But unfortunately for the majority of Molly's education or the other students referred to in this study, board policy was not practiced to this degree or in fact at all.

Relationship to the Literature

Attitudinal Barriers

There were many occasions when parents in this study felt that they could not trust and respect school personnel. This trust and respect was, to a large extent, contingent on teachers' attitudes toward the child; what they did, or did not do, and how they did it. Schulz (1985) refers to personal experience to relate how lack of respect for her son, shown by the teacher resulted in her subsequent lack of respect for that teacher.

> When asked what she would be doing in the fall, she replied, "Oh, I'll be teaching a bunch of nuts over at Fifth Avenue School." My son was one of those "nuts." It was not a good year for him. His teacher had no respect for him; she expected very little from her students and got exactly

> that. How could I respect her? (p.8)

Shulz continued by saying that when her son found a teacher who expected him to learn, she felt that her son learned more in that one year, than all other years combined. She saw this teacher, as valuing her son as a person who could learn, and as accepting responsibility. In addition, she felt that this teacher also valued her as a parent and assured her that everything was under control in the classroom. Schulz (1985) believes that, "Respect for the child is, of course the essential bond between the parent and the professional" (p. 7). The experience of Schulz is consistent with the experience of parents in this study when they encountered teachers, or teaching assistants, with similar attitudes toward their child.

Turnbull and Turnbull (1986) see trust and respect, as being essential to the emergence of effective and meaningful communication among parents and professionals. Meaningful and productive communication is seriously compromised in the absence of a trusting and respectful relationship. Sarason (1995) states:

> . . . it is also obvious -- to say that the assets of parents cannot be perceived and realized by educators unless the relationship between the two parties bears the stamp of respect and trust. And when those features are absent you have the situation where people talk, if they talk at all, past and not with each other. (p.50)

Turnbull et al (1986) further emphasize that such a relationship can also have an affect on the child, "When teachers and parents find themselves in adversarial roles, distrusting each other, children suffer" (p.116). Communication and respect are crucial to any effective parent-teacher relationship and are often lacking in parent-teacher confrontations (Schulz ,1985, p.5). Parents and teachers often fail to recognize that there is a lack of communication and respect. They must first become aware of the nature of the problem before they can remedy it. "Awareness, therefore, seems to be the starting point" (p.8).

Turnbull and Turnbull (1986) state, "When family-professional relationships become problematic, there often is a tendency to place the blame on one or the other party, to define the problem as existing in either the professional or the family." (p.118). This is a position that was consistent with the findings of this study. For example, one principal told a parent that she was the cause of all her son's problems. In other examples, parents blamed friendships between school principals, teachers or support personnel, as the reason for a lack of accountability in programming for their children.

The following two factors are identified by Schulz (1985) as being detrimental to the parent-teacher relationship and are supported by the findings. First, she states that, "There has been a reluctance on the part of school to admit that they need help." (p.5) This was evident in the resistence of school board personnel to complete step seven in the MAPS process. Secondly, there is "... the reluctance on the part of the teacher to accept the abilities of the parent" (p.5). This is seen when parents were asked to sign IEP documents when they were rarely completed, but were not included in the process of developing, implementing, monitoring, or evaluating the program. Biklen (1985) reported the comments of a parent expressing the same sentiments:

I really do believe that parents know their kids better than the teacher. If

> the goal of education, particularly with special kids, is to get them into the world and function. Leaving parents out, I think you are missing a whole lot in the program. (p.150)

Sarason (1995) speaks of the "political principle" as justification for parental involvement in decisions which affect them, or their children. According to Sarason:

> . . . among the most effective barriers in accepting and acting in accordance with that principle were our ways of defining the assets and deficits of people, barriers as strong between the different layers of school hierarchy as they are between that hierarchy and parent-community groups. One of those barriers, of course, is in the form of rigid boundaries professionals erect to ensure that "outsiders" (who may be other kinds of professionals) remain outsiders. (p.7)

Sarason (1995) further points out another barrier being a failure to see the other person as having assets and being capable of contributing to the process. This position is not based in considerations of power alone. He states, "There is more to it than that, and the 'more' is that people are seen as having nothing to contribute in the way of ideas or knowledge or experience" (p.40). Remarkably similar to statements from parents in this study, the following statement by Schulz (1985) supports Sarason's position, and serves to capture the essence and extent of practices, which devalue parents' knowledge and contribution.

> There have been so many times I wanted to say, I have a son who is retarded. I taught him to walk, to use the bathroom, to feed himself, to say his first words, to interact with the family. I know my son; I can help you

> to know him and to teach him. (p.5)

Power Structures

The literature has described the role of parents in IEP meetings as one of "passive participant" (Goldstein et al. 1980), giving and receiving of information as opposed to educational planning (Yoshida et al. 1978), and where the signing of a completed IEP document is frequently the purpose of an IEP meeting (Penny & Wilgosh, 1995; Witt et al., 1984; Turnbull & Turnbull, 1986). This was the same purpose parents experienced, in this study, when they attended IEP meetings. Van Reusen (1994) reported a study that examined parental involvement in the placement/IEP process ten years after P.L.94-142, which ". . . characterized the conference as one of decision telling, not decision making" (p. 469). Parents in this study, reported few instances where they considered themselves to be part of the decision making process. They were in most instances part of the decision telling process.

Sarason (1995) states, "It is unrealistic to expect that a profession will without external pressure, be motivated to take the initiative to include outsiders in its customary decision-making ways" (p. 24). The major obstacle to parent involvement seems to stem from a relationship between the two sides that centers around "power and turf, a situation conducive to nonproductive struggle" (Sarason, 1995, p. 55). The education system disempowers families by keeping them at the periphery.

> They [parents] provide information, approve plans, receive reports, and attend parent-teacher meetings. Yet, little is done in the typical program to

> equip families with the skills and opportunities to collaborate with staff on assessment, planning, teaching, and program evaluation. (Kozloff, 1994, p.126)

The findings indicate that these same roles discussed here were experienced by parents in this study. What must be noted is that these roles were experienced, in the first place, only after parents themselves became the impetus for the development of these plans. All parents were kept on the periphery and would have remained there, powerless, except for their persistence to have educators provide an appropriate program for their children.

Turnbull and Turnbull (1986) report a number of barriers identified by parents as contributing to their expected role of passive participant in IEP conferences. Three are particularly relevant to this study:

1. A lack of understanding of the school system, that is, lack of knowledge about what are their rights pertaining to special education and IEPs. Findings in the study reveal that initially, parents were unsure of their rights and lacked knowledge about developing and evaluating IEPs. When forced to become advocates for their child, parents begin to acquire the knowledge and skill to develop appropriate objectives and evaluation procedures.

2. Parents reported a sense of feeling inferior to school personnel. They experienced this feeling because of a sense of diminished power in decision making (Turnbull and Turnbull, 1986). Sarason (1995) reports that in his experience where power struggles became an issue, it was not because that was the initial "purpose of the participants to make power so central but rather in some way to improve the substance

and quality of the educational experience" (p.28). Findings support the positions of both Turnbull and Turnbull (1986) and Sarason (1995). Parents reported having little input into their children's program. It was their intent to be helpful to the school system, not to engage in a power struggle with them. Parents felt that school personnel made the decisions without their input and parents either went along with the decisions, or challenged them.

3. Parents also reported feeling intimidated by the large numbers of professionals at meetings (Turnbull and Turnbull, 1986; Biklen, 1987; and Gilliam, 1979).) This intimidation probably has more to do with the professional's communication style than the actual numbers of professionals at meetings (Turnbull and Turnbull, 1986.) Findings in this study are consistent with Turnbull's interpretation of the professional's communication style -- any sense of intimidation felt by the parents seemed to be more related to how the school personnel talked about the child and interacted with the parent, as opposed to the number of professionals present at any meeting.

Parents' ability to contribute more in conferences when an advocate was with them is borne out in the literature (Turnbull and Turnbull, 1986). This study helps us understand the nature of the advocacy support and the outcomes it can produce. All the parents in the study related feeling more relaxed and being able to concentrate more on the issues at hand. This enabled them to keep track and later follow-up on what was agreed to at the meeting. Parents in this study were emphatic about having the presence of an advocate at the meeting. They repeatedly stressed the advice that one should never go to an IEP meeting alone.

Turnbull and Turnbull (1986) identified a number of attitudinal barriers sometimes held by professionals that inhibit parent-professional relationships:

1. Through a sense of unequal power distribution parents are made to feel vulnerable when asking for help. A position acknowledged by Gorham (1975).

2. Professionals distance themselves from parents and parents describe this distancing as being accompanied by a lack of empathy on the part of the professional.

3. Parents are sometimes viewed as less observant, less perceptive, and less intelligent. Parents feel that professionals find their opinions and impressions as unimportant.

4. Professionals find parents to be "pushy" and "resistant" (p. 126).

These attitudinal barriers identified as sometimes being held by professionals, were also identified in school personnel by parents in this study. Parents felt that school personnel sometimes made them feel inferior.

> Well, we just talk to each other like regular folks, not me talking to someone who is up here; who is in an authoritative position. Which in some years that's the way I felt with some of the teachers who might be a little bit older than myself.

Parents also felt that school personnel had little empathy for their situation. When parents were trying to document their child's pattern of behavior, and were relying in part, on the reports from school personnel, they omitted aggressive outbursts of behavior, by Jeffery while at school. "At the same time the reason for the book is so that we can have a perspective, to go back to Dr. Chaulk and say is there some type of a pattern guide of how he is doing."

All the parents in this study felt that school personnel either ignored or undermined the knowledge they had to share about their children. "You know they had to hear it from the professional. They didn't believe us -- which was really interesting." Parents in the study also reported that they believed school personnel found them difficult to deal with. One parent reported feeling like school personnel had labeled him "as one who would rock the boat and you cannot satisfy." Another reported, "I was told . . . that all the problems that Donald had were my own making and that sort of thing . . . ." Parents presence in the IEP process was certainly not welcomed and school personnel made sure they knew it.

Implementation of the IEP

Hermary and Rempel (1994) see a need for more research in parental involvement in the implementation, evaluation, and modifications of the IEP. Little (1992) reported because a program has been written does not necessarily mean that it is being implemented. He states:

> With the program on paper it remains to be seen if it becomes a program in action. Evidence from numerous site visits, direct interviews, and correspondence, indicates the existence across the country of "discrepancy scores, or a lack of correspondence between stated aims and actual practice," the difference between intention and action. (p.39)

Findings indicate that parents in this study experienced this discrepancy addressed by

Little, and because they were forced to play a sophisticated advocacy role, they wanted to be better informed about development and evaluation of the IEPs.

Penny and Wilgosh (1995) reported that parents believe that the educational opportunities available to their children are a direct result of parental advocacy. In this study, it was only when parents became advocates for their children, that school personnel at least attempted to better address or improve educational opportunities for the child, in the form of qualified personnel and programs.

Collaboration: structures and practices. Rhodes (1995) states that special education has served to create separate school communities establishing "them" and "us". Many authors have addressed the inefficiencies of a dual system of education -- "special" and "regular"(Stainback & Stainback, 1984; Biklen, 1985; Lipsky & Gartner, 1987). In the last hundred years or so, we have been successful in creating a dual system of education. Initially, a system of specialized education was developed to serve the needs of children who were considered "exceptional" or "special."

The intended purpose of special education then and now has not changed. Special education was designed to be part of the system of general education but it developed into a system on its own. What was originally conceived to help students with special needs may be the very thing that has now become a liability for those students, for whom the concept of special education was designed to help (Stainback & Stainback, 1987, p. 35; Little 1992, p. 11). Ferguson and Asch (1989) state:

> A "cult of expertise" seems to gather devotees equally from among the ranks of educators, doctors, therapists, and professionals of all levels and

> degrees. Parent narratives repeatedly describe the power struggles around the most valuable cultural commodity: specialized knowledge. The negative version of this is to devalue the worth of knowledge that parents have about their own children. Concerns are dismissed. Requests are patronized. Reports of home behavior are distrusted. Certainly, this is not true for all parent - professional relations, but it seems endemic to special education with its historic association with a clinical model that has little room for "amateurs." The positive version of this is to overvalue the knowledge of the experts. This leads to educators and others persistently defining problems of child and parents so as to acquire "specialists" for their comprehension, not to mention their solution. (p.123)

The findings suggest that this dual system of education provided the foundation, and the long-standing attitudes and beliefs about the role of special education teachers, generated the legitimacy for ownership of the child's program by special education personnel. In their contact with all schools, parents either dealt with the principal, or special education personnel (resource or mainstream support). Special education personnel assumed responsibility for developing the IEP and were the most vocal at meetings with parents, classroom teachers' involvement was characterized as mostly non-existent.

Skrtic (1991) believes that to program effectively to meet the needs of students with challenging needs is beyond the "paradigms of practice" of any single profession, and requires an interdisciplinary approach. The degree of interdependency and the availability of essential personnel "depends in large measure on the local history of special education services, which reflects values embedded in political cultures at the state, local, and school organization levels" (p. 186). Skrtic (1991) uses the term "adhocracy" to describe the kind of system necessary to implement the requirements of the EHA (The Education for All Handicapped Children Act). The adhocracy is a problem-solving organizational structure characterized by innovation and geared to creating new programs. Biklen (1989) point out that the "creative" style of problem solving left open by the IEP to help students develop skills and build competence, often only leads to detailed plans for "remediating inability rather than acquiring ability in different ways" (p. 45). Skrtic (1991) maintains because the requirements of the EHA are adhocratic --

> A problem solving organization in which interdisciplinary teams of professionals collaborate to invent new personalized programs -- they contradict the value orientation of the professional bureaucracy in every way, given that it is a performance organization in which individual professionals work alone to perfect standard programs. Culturally, this value conflict produces resistence in the form of political clashes, which undermine the ideal of collaboration . . . . (p.185)

All parents in this study, indicated a need for a team approach in programming to meet the needs of their children. "I think there needs to be more of an interdisciplinary approach within the school somehow. We're working together to solve problems." While parents were in agreement as to the need of this kind of approach in the schools, there was little evidence to suggest that this is actually happening.

Sarason and Doris (1979) also comment on the typical non-collaboration orientation of professionals: "... teaching is a lonely profession. It is not the loneliness of solitude but a feeling compounded of isolation, frustration, and the pressure to appear competent to handle any and all problems" (p.407). More recently, Sarason (1995) further points out that the training characteristic of professionals "... makes clear that there are boundaries of responsibility into which 'outsiders' should not be permitted to intrude" and that 'outsiders' may be other kinds of professionals as well (p. 23). Findings in this study provide an often repeated example during the MAPS process which included parents and other professionals. School board supervisors consistently refused to allow the MAPS team to become involved in comprehensive program planning with the classroom teacher for the student with a disability, thereby reinforcing the model of isolated teacher.

Berres and Knoblock (1987) use the placement of students in appropriate and least restrictive environments to expand on the point made by Skrtic. They explain that the delivery of services by special education personnel in one school district, may differ from that of another district. These differences may be based upon the life experiences of one group of planners, as compared to those/the experiences, of another group of planners. Experiences and subsequent beliefs about program delivery become the measure to interpret how best to deliver the service. The result of this interpretation among districts can result in two students of similar abilities, one being segregated in one district while the other is having a program based on full inclusion in another district. Biklen (1985) referred to this scenario as the "developmental twin" argument. These differences are explained more by the individual differences between teachers and not between school to school or district to district. Evidence from the study supports this position. Molly's grade four teacher supported full inclusion and accepted ownership of her program. Molly was fully included and the parents reported feeling like equal and contributing members of the IEP process.

Sarason (1995) supporting positions by Berres and Knoblock. (1987) and Biklen (1985) states:

> I have known schools (not school systems) where the political principle informs relationships among school personnel and between them and parent-community individuals. But in every case, respect for the principle was not a matter of formal policy of the school system but rather of an unusual and refreshing array of people for whom the principle was, so to speak, second nature. (p.34)

Findings show that when classroom teachers took ownership of a student's program and worked collaboratively with other teachers and welcomed parent involvement, this behavior was specific to individuals within that system and not reflective of the system in which they worked. Sarason and Doris (1979) maintain that the development of an IEP requires a harmonious relationship among school personnel. Such a relationship can only exist when a person makes a contribution and at the same time feels that their needs are being acknowledged and met. "Such an ambience cannot be legislated and it is no secret that it is only rarely found in our schools" (p.389).

The successful inclusion of students requires a special education staff to be committed to collaborative practice in general education classrooms (Clearing House on Disabilities and Gifted Education). This position is also supported by Berres and Knoblock (1987) and Little (1992) who states that, "the consultative-collaborative model is the true mainstreaming model" (p.15). Commenting on schools which practice inclusion in her Canadian study, Dyson (1994) notes the following:

> Far from protecting themselves from the challenge of student diversity, [collaborative schools] use such challenges to problematise and reconstruct their taken-for-granted practices . . . they organize themselves into fluid problem-solving teams in which teachers with different 'specialisms' collaborate to find novel solutions to novel problems. Under these conditions, exceptional students provide an opportunity for the school to learn about the limitations of current practice and to create the new technical knowledge that is needed in order to 'include' all students. (p.55)

The findings support the position on the value of a collaborative approach among school personnel, but there is little evidence of flexible attitudes or structures to allow this kind of creative problem solving or collaboration. In one example where collaboration among teachers and parent involvement was valued, both teachers were new to the school with the classroom teacher only having a few years teaching experience. In addition, this class teacher was hired based on the principal's interview assessment of this teacher's attitude toward being able to meet the needs of children in inclusive environments. In the other example, the principal was also involved as a contributing member of this team. Villa and Thousand (1990) characterize the principal as the one in a position to:

> . . . deliberately or accidentally shape the organizational structure of a school and the values of school community; and these structures and values may facilitate or thwart the school's capacity to meet the needs of all students in general education environments. (p. 201)

Therefore, it is important that the principal understand the needs of students with disabilities. "A program cannot succeed where the principal is opposed, or negatively disposed to mainstreaming" (Biklen ,1985, p.30). Findings support the position of Villa and Thousand (1990) and Biklen (1985) and the importance of the principal in shaping the direction of services to meet the needs of children with disabilities in general education. When the principal was supportive, parents reported more positive experiences with the school. However, considering the number of school years (25 plus), represented in this study, such positive examples were very few indeed.

Fullan (1992) makes the point that principals should focus upon building collaborative work cultures, rather than imposing their individual visions upon staff. Hargreaves (1994) summarizes Fullan's point, ". . . when educational visions are grounded in the leader's personal and prior vision, they can become not visions that illuminate, but visions that blind" (p. 232). The process in developing collaborative work cultures requires skills such as being careful not to impose one's values, and the ability to encourage others to share their values and concerns. A leader must be capable of managing conflict and problem solving, while at the same time being seen as capable of giving direction and being open or approachable (Fullan, 1992). When parents in this study, described a team process working well in program planning for their children, they described situations where the principal was part of a collaborative team. They saw this as necessary if the principal was to be able to play a key leadership role, in the operation of the school.

System Resistance to Change

Most of the important changes that have taken place in the schools over the last 30 years have not come as a result of local initiative but have been unplanned and the result of external forces such as the courts (Tyack, 1990). Henson (1995) sees schools as particularly resistant to change because of the fundamental nature of the organization. Fullan and Stiegelbauer (in Henson, 1995) explain this fundamental nature of schools:

> On the one hand schools are expected to engage in continuous renewal, and change expectations are constantly swirling around, on the other hand, the way teachers are trained, the way schools are organized, the way the hierarchy operates, and the way political decision makers treat educators result in a system that is more likely to retain the status quo. (p.244)

The teacher and educational change. Changing the way organizations operate requires a change in the behavior of the people in those organizations. "It is a well-documented fact that teachers have historically avoided involvement in the organization in which they work" (Henson ,1995, p.245). The importance of the role of the teacher, when it comes to bringing about change within the school has been addressed by Henson.

Henson's position is supported in the findings of this study as parents explained how the IEP process was facilitated, when the classroom teacher accepted ownership and responsibility for their children's program. When parents in this study, spoke positively about classroom teachers, they also remarked that these teachers were involved in some aspect of continuing their education while teaching.

Henson (1995) reported that teachers seem to be more open to change when it is seen as coming from peers as opposed to being handed down from central office. However, this is contrary to the evidence from this study that indicates that when a teacher took interest in pursuing evening classes on inclusion, she was ridiculed by her peers for doing so. This contradiction may be explained more in light of the attitudes of school system personnel toward the change being sought (inclusion), than in the source (origin) of the change (classroom teacher).

Skrtic's (1991) position on what he calls "acculturation" of programs may help in understanding the different roles assumed by teachers and how these roles come to reflect who assumes ownership of a student's program. Skrtic explains that after teachers leave their pre-service professional education programs, they enter into the school's subculture with it own way of doing things.

> . . . upon entry into school organizations, during the student teaching internship, and later as employees, teachers are inculcated into an existing institutionalized subculture of practicing teachers, with its own set of norms, customs, and conventions. (P.176)

This author's own experience in graduate education programs support Skrtic's position on "acculturation." When I found myself alone, without allies, the only advocate among my colleagues for inclusive education, I gradually found it more difficult to maintain my goals to integrate students into the regular classroom. My commitment to what I felt was right, placed me in confrontational situations with both administrators and fellow teachers. As years went by, the head butting with colleagues/system forced me to compromise -- settling for partial integration. Findings in this study also indicate that teachers who take an interest in professional development around disability issues may be ostracized by their colleagues for doing so.

Little (1992) uses the term "paradigm paralysis" in general education as a problem inherent in achieving inclusive education, describing this as " admitting that it is easier to go on doing things the way we have always done them (self-preservation vs self-renewal)" (p.40). In relation to the inefficiency of narrowly framed categorical programs, ". . . first we deny the evidence and when we can no longer deny it, we ignore and usually repress it, and we keep doing that which makes us feel comfortable with our ideology" (Wolfensberger , 1986, p.10). This is clearly evident in how teachers are prepared for their profession. Parents in this study commented many times that they felt things would change for the best for them and their children when certain teachers or principals retired. "He retires in June and I can't wait. I hope grade twelve is going to be better."

Sarason (1995) points out that preparatory programs prepare teachers ". . . to organize classrooms, teach subject matter and complete a curriculum. Teachers learn to teach subject matter, not children with diverse personality and learning styles" (p.154).

Skrtic (1991) maintains that teachers learn to teach by modeling those already in the system, who got their methods from others before them, and so on. Standard programs are passed on from generation to generation within an institutionalized context. Skrtic points out, that the difficulty with this practice stems from an assumption that rarely occurs -- that the standard programs used by teachers are continually modernized and updated. He sees the failed attempts at innovation over the last three decades as realization of this assumption. "In most schools, the methods of instruction and the curriculum itself are much as they were earlier in this century" (p.176).

This position is supported by Henson (1995) who maintains that there are three common perspectives on how change occurs in organizations:

1. There is the technical view that change comes about from increased knowledge and technical assistance in the form of new programs.

2. The power and influence exerted by individuals and groups. The focus is political behavior where attention is directed at the innovation as well as the context of the organization.

3. There is the cultural perspective which looks at shared values, beliefs, and norms of the organization and emphasizes the importance of organizational context.

Henson (1995) states:

> After more than ten years of attempted reform, educators and the general public are recognizing the limitations of the first two approaches. Second wave change efforts are inquiring about ways in which culture produces barriers that prevent change. (p.259)

Negative attitudes. In looking at special education practices, Gartner & Lipsky,

(1987) maintain that educators have focused on the disability and neglected the person. In their view, the attitude toward disability is far more encompassing than any physical condition. "It is the attitudinal milieu more than the individual's physical condition that influences societies response to persons with disabilities" (p. 70). Berres and Knoblock (1987) make the assumption that the success or failure of integrating students who are moderately and severely handicapped depends upon the attitudes and problem solving skills of educators. These authors believe that such attitudes about handicaps are as important, if not more important, in the integration of students, than the actual skill levels of students being integrated. A position supported by Rogers & FreiBerg (1994):

> The facilitation of learning rests not upon the teaching skills of the learner, scholarly knowledge of the field, curricular planning, audiovisual aids, programmed learning, lectures and presenting, abundance of books, though each may be at one time or another used as an important resource. No, the facilitation of learning rests upon certain attitudinal qualities that exist in the personal relationships between the facilitator and the learner. (p.153)

Edington and Koehler (1985) report that, "Most studies show that teachers, like the general public, have negative views of both handicapped students and mainstreaming." The lack of knowledge about disabilities, experience with handicapped students, and training and teaching these students are also major contributors of these attitudes (Edington & Koehler, 1985; Canning, 1994).

Experience changes attitude. Biklen (1985) reports that research suggests that prejudiced attitudes toward disability can be changed through the planned "personal interaction between those who traditionally give stigma and those who are its recipients" (p.9). Findings support Biklen's position as illustrated by the change noted in the principal after her involvement the life style planning committee. Biklen's research is also confirmed by the author's own experiences with teachers, who changed their negative attitudes toward students with disabilities once these teachers became more familiar with the students.

Research changes attitudes. Henson (1995) also notes that teacher involvement in research makes them more aware. But when teachers are not involved in ongoing research, he believes that, ". . . as teachers, we gather to ourselves that which confirms our deepest underlying prejudices and attitudes" (p. 251). Research can help teachers to become open to their "own experience and the experience of others, putting aside dogmatic arguments and preconceived opinions" (p.251). Recent studies demonstrate that good teachers are not a product of their knowledge or methods. But what makes good teachers is:

> . . . the beliefs teachers hold about students, themselves, their goals, their purposes, and the teaching task. No matter how promising a strategy for reform, if it is not incorporated into the teachers' personal belief systems, it will be unlikely to affect behavior in the desired direction (Combs, 1988, p. 39).

Research affects change. Henson (1995) reporting on an analysis of the benefits teachers received after being involved with research, found that teachers derive the most benefits when they are involved at the highest level. "This type of involvement occurs only when teachers identify a problem that is important to them" (p. 253). This position is supported by my own experiences and interests which have led me into my present field of research. My own personal experience in continuing with further professional development was a result of my conflict between his beliefs about integration and what was the prevailing educational practice at the time.

Findings indicate that parents were aware of the benefits of professional development in the field of disabilities. Their attempts to encourage teachers to take advantage of the research literature (provided by parents) or attend summer programs on inclusive educational practices were, for the most part, ignored. The reasons for teachers ignoring the input of parents into the area of their professional development are not clear from this study. On the one hand, if teachers described by parents in this study, experienced no conflict with their value system and their present practices, then there was little motivation for them to begin their professional development in the area of inclusion. On the other hand, if teachers were experiencing dissonance between their values and their practice, and were open to learning, it is possible that the necessary encouragement and/or support for professional development in inclusive practices was insufficient or absent from teacher colleagues, school administrators, school board, or the provincial Department of Education.

Summary

The findings of this study were consistent with the literature on these characteristics: the attitudinal barriers identified in parent/professional relationships; issues of power and control; perceived role of the parent as "passive participant" at IEP meetings; the role of parent advocates; the need for interdisciplinary teams within schools; special education and the issue of ownership; the effect attitude has on relationship with parents of students' with disabilities; the role of the principal and teacher in educational change; and system resistance to change. There was only one major discrepancy identified between the literature and the findings. This was with respect to teachers being more receptive to change, when it is seen as coming from other teachers, as opposed to be handed down from district office. Finally, there were no findings reported in the study, that were not addressed, in some aspect of the literature.

CHAPTER SIX

Conclusions

In the United States the 1975 (EHA) legislation mandated the right for parents, to be included, in the development of their children's IEP. This legislation has also impacted educational practice in Canada by influencing provincial legislative changes, policy changes emanating from provincial school acts and at local school board levels. Sarason (1995) explains that the problem with the 1975 legislation, is that it failed to recognize predictable problems, or the steps that should be taken to overcome such problems, that would be associated with legislation, that most educators neither strived for or endorsed. He states:

> It is one thing to mandate practices; it is quite another thing to recognize what was going to happen when the culture of every school in the country was going to be altered in ways strange to its members. (p. 36)

Sarason (1995), Sarason & Doris (1979) and Skrtic (1991) identified the problem as one of institutional change. Sarason (1995) states, ". . . the governance structure of our schools has to be changed, if we stand any chance at all of preventing a further deterioration, in the quality of the experience of children and educators" (p.7). Sarason &

Doris (1979) state, "Between enactment of the law and practices consistent with it is the whole, poorly understood problem of how to effect institutional change" (p. 391). Skrtic (1991) states, "From an organizational perspective, the basic problem with the EHA, is that it attempts to force an adhocratic value orientation on a professional bureaucracy by treating it as if it were a machine bureaucracy" (p. 184). Skrtic's point was that the interdisciplinary team and problem solving approach necessitated by the requirements of the EHA are thwarted. This inhibiting of an interdisciplinary team and problem solving approach is accomplished through specific programs and "a comprehensive system of personal development" (p. 185), which assumes that there are known procedures for educating children with disabilities and that this knowledge just needs to be distributed. Sarason and Doris (1979) explain that this provision by law for "in-service training for school personnel to enable them to cope with the consequences of increased mainstreaming is explicit recognition that what is at issue is changing the attitudes of school personnel" (p 379).

Skrtic (1991) continues to explain that once teachers acquire these new practices and training procedures for educating children with disabilities, they will simply change how they have normally performed their work which for both classroom and special education teachers has traditionally been in isolation. He states:

> Change in a professional bureaucracy requires change in what each professional does because each professional does the entire job individually and personally with his own clients. But because school organizations are managed and governed as if they were machine

> bureaucracies, attempts to change them typically follow the rational-technical approach which assumes that additions to or changes in the existing formalization will result in changes in the way the work gets done. (p.166)

In this study, parental involvement in the IEP process, with one exception, has not been at the invitation of the educational agency. Parents were not welcomed with open arms into the decision-making process of the educational establishment. Schools did not work with parents in their attempts to secure an IEP and appropriate programing for their child. Because of this, parents frequently found themselves seeking assistance from outside the school. They were literally "outsiders" looking in.

In order for this to change, educators must become aware of the barriers that are presently at work which inhibit them from working collaboratively with parents. In addition, they must become aware of not only the barriers, but become cognizant of the significance and implications of a collaborative relationship for all parties concerned -- child, parent and educators.

Parents in this study were members of their local ACL support network and so had access to advocates who helped them to become knowledgeable about the IEP process. Sarason and Doris (1979) believe that as professionals, the "disease of professionalism" is to define the needs of people such that they require highly educated professionals. They believe that, "The problems of schools have not been and will not be solved by reliance solely on professionals. . . . One has to believe that there are diverse types of people who can be helpful in the classroom even though they have no professional credentials" (p.406). These authors believe that it becomes necessary for school officials to begin to conceptualize their roles differently. They see the new role of school personnel "... as resource locators and coordinators, constantly scanning school and community in order to match the needs in a mutually productive manner" (p.407).

The obstacles faced by parents that prohibited a collaborative partnership with professionals in the education of their child, positioned parents as "outsiders." The roles of parent and school personnel were played out against the backdrop of the IEP process using a number of categories which included attitudes toward disability/inclusion, trust and respect, professionalism, and ownership. Throughout the IEP process, parents used a number of strategies to facilitate the development of an IEP for their child/children. These strategies involved: finding schools where attitudes were supportive, volunteering at the school, gaining support of key people from both within and outside the school, establishing circles of friends, a MAPS sessions, and promoting professional development.

Parents were required to negotiate in a system where attitudinal barriers became the single greatest obstacle facing them in attaining an IEP for their child -- a greater obstacle than the inexperience of school personnel in developing IEPs, or the ability levels of their children. The findings further suggest that these attitudes are specific to individuals, rather than characteristic of any particular school or school board. In light of the findings, we might consider that attitudes, both positive and negative, displayed by school personnel toward students with mental disabilities and their parents, as being the most influential factor affecting the IEP process.

According to Sarason & Doris (1979) our conceptions of handicapped people as being different, requiring different theories of human behavior and educational practices, were learned and morally justified "... by growing up in a society in which these conceptions and moral precepts were seen as valid, right and proper" (p.391). More specifically they state:

> ... school personnel are graduates of our colleges and universities. It is here that they learn that there are at least two types of human beings and if you chose to work with one of them you render yourself legally and conceptually incompetent to work with the others. ... what we see in our public schools is a mirror image of what exists in colleges and universities. One of the clearest implications of Public Law 94-142 is that the gulf between the special and the regular education has to be bridged, and yet the law requires no change in our college and university training centers. School personnel must change in attitude, thinking, and practice, at the same time our training centers educate school personnel in the traditions of the most restrictive alternative. (p.391)

If attitudes are in fact the greatest obstacle to the IEP process and inclusion in general, then our commitment to a system that values people becomes our greatest challenge. Rogers et al. (1994) believe that we can facilitate the needs of the student with the help of teachers whose attitudes reflect a "realness" or "genuineness," where teachers show themselves outside their roles, or the facade of teacher, and meet the student on a person-to- person basis, where the person is valued, "prizing her feelings, her opinion, her person" (p.156). This can further be accomplished through "empathic understanding" where there is no analysis or judgement made, only understanding from their own point of view. The authors maintain that, "The attitude of standing in the other's shoes, of viewing the world through the student's eyes, is almost unheard of in the classroom" (p.158). The same can be said for parents in parent-teacher relationships.

The challenge requires that we focus our efforts upon changing the attitude of those within the educational structure. To change an attitude of a particular individual requires the replacement of old values with a newly acquired set of values. In this case, the newly acquired set of values is the belief in and a commitment to parental involvement in educational decisions that affect their children. We must begin to build a system where these values can be successfully embedded. Combs (1988) points out that people-oriented institutions change slowly, the way people do. It is through the development of beliefs, attitudes, values and goals that individuals begin to confront local problems and work toward solutions that will bring about effective change.

Educational reform is full of examples where innovations failed to achieve the specified goal or were dropped because of a failure to gain support of those who are actually charged with implementing the change (Lamb-Zodrow, 1987; Combs, 1988). People must be aware of their present beliefs and be open to seeing the need to alter those beliefs. In their Canadian study, Bunch et al. (1997) report that the attitudes held by most educators are positive toward including students with disabilities into their classrooms.

> . . . educators in both traditionally and inclusively structured systems felt inclusive practice possible, beneficial, and appropriate if supports were in

> place. Furthermore . . . teachers meant by support . . . that which calls for increased funding, such as additional educational assistants, and that which does not require additional expenditure, such as empathetic support by administrators. (p.2)

If this empathy from administrators translates into administrators having a vision of what can be for students with disabilities, then there could be far reaching implications for the inclusion of these students into classrooms around the country. Parents identified the philosophy of the principal as a key factor in directing the course of how a school will respond to the needs of students with disabilities. Hegarty (1990) talks about the importance of a visionary leader and that one's vision more than any single factor sets the course for both individuals and groups. To illustrate the point, Hegarty uses the 1961 announcement made by John F. Kennedy, that the United States would send a man to the moon and back. When both media and Kennedy's own personal advisors pointed out that he had no answers to how this would be done, JFK responded, "Now that the vision is in place, the answers will be found" (p.119). We must take that same visionary attitude into our schools, not only for the sake of children with disabilities, but for all children. Skrtic (1991) used the National Aeronautical Space Administration (NASA) during the 1960s as an example of an adhocratic configuration, "premised on collaboration and mutual adjustment, respectively" (p.183), that found the answers of which JFK spoke.

Positive and negative attitudes determined the kind of relationship that was eventually established between the home and school during the IEP process. Positive attitudes displayed by school personnel viewed the problem as external to the child and sought solutions to include, not exclude, the child from the class. Negative attitudes served as a barrier that denied ownership of the child's program by the classroom teacher. Ownership, by default, then became the responsibility of the teaching assistant. In some cases, ownership was never seen as being the classroom teachers' responsibility. This responsibility was assumed by the Special Education personnel in that particular school. However, ownership by the Special Education personnel became a barrier to the classroom teachers' accepting ownership of the student and their program.

Sarason (1995) comments that:

> Generally speaking, parental involvement can claim no victories, unless shadow boxing is a victory. There is far more compelling evidence, again from our urban areas, that parental involvement has been productive of conflict, not of a problem-solving process. (p.13)

Sarason and Doris (1979) state, "Institutions, prejudice, and tradition do not quickly change. They adjust to impacts, changing their overt stance but prepared to reassert themselves" (p.414). We may not be able to change the system by ourselves, but we can change what we think and do. If systems are to change, those who are directly involved in that system must change first. Henson (1995) states that, "Teachers in particular, hold the key to the success or failure of reaffirming the schools" (p.16).

Because teachers are on the front lines, they play a key role in how the game will be played. The following quote from Gartner and Lipsky (1987) puts into perspective what is really at issue. They state:

> We can, whenever and wherever we choose successfully teach all children

> whose schooling is of interest to us. We already know more than we need in order to do this. Whether we do it must finally depend on how we feel about the fact that we haven't done it so far." (p.309)

The IEP process is problematic for schools where the culture of that school identifies a person's worth on a diminishing assets model, where one's value is determined by the lack of identified deficits. The experiences of parents in this study reflect this model. To devalue the child is to devalue the parent. To change we must first have a vision where we conceptualize our schools as communities that value our uniqueness and celebrate our differences, where parents are recognized as valued and contributing partners with educators in the decision-making process around educational placements and practices.

The reform movement in education has lead to renewed interest in how decisions are made in education. Such interest combined with the interest in effective schools has shifted support to on-site management by principals and teams for direction in how funds are spent, staff development and personnel selection. Such change will hopefully bring a school closer together through a sense of shared responsibility and authority (Berreth, 1998). Changing the governance or the organizational structures of our schools requires a change in the people who work there. It is essential that all those personnel involved in the implementation of the change have the opportunity to participate in the process of change (Combs, 1988; Reisberg & Wolf, 1986; and Harme-Neitupski et al., 1989).

The inclusion of parents as partners in the educational process must come from the recognition by teachers that parents are a resource that they have previously overlooked. This requires that teachers change how they have previously done things. Teachers' involvement in research may help them re-evaluate their belief systems, which may be one way to help facilitate this change.

It is only through evaluation of how we have previously done things, that we can ever feel the necessity to change them. All parties involved in the development of the IEP must be viewed as equals, as valued contributors, and as welcome in the IEP process.

Recommendations

The insights and understandings gained from the participants in the current study warrant a number of recommendations directed toward teacher preparation programs and practices. These recommendations are aimed at policy development and implementation at a number of levels of responsibility.

University

1. The following recommendation concerns the structure of university departments where teacher education programs typically divide the education department into general and special education. It is recommended that universities now offering either diploma or undergraduate degrees in the field of Special Education drop these designations, so that course materials would be integrated into one teacher preparatory program, a requirement for all future teachers. Students would graduate from their respective institutions with a degree in education which would reflect the knowledge and skills required by current

teaching.

2. Administrators and faculty in university education departments liaise with individuals and community support groups for people with disabilities and people with disabilities themselves. This liaison would have as its objective, involving these individuals and groups as community resources for teacher preparation programs.

3. Universities hire professors in Education Faculties who are qualified to teach graduate and undergraduate courses for teachers covering topics like adapting curricula and instructional strategies to meet a wide range of diversity in the classroom.

4. Universities make such courses a degree requirement for all teachers.

Provincial Departments of Education

5. It is recommended that provincial Departments of Education include all services to students under one general department eliminating any reference to a special system of education.

6. Provincial departments of education provide additional incentives for teachers' professional development through education courses at universities recognized for their exemplary programs in meeting the diverse needs of all students in the classroom.

7. Provincial departments of education collaborate with universities to ensure courses on meeting diverse learning needs of students are accessible to teachers

outside major centers.

8. Provincial ministers of education promote and foster consultation and involvement of parents and front line teachers in policy development that directly impacts teachers, parents and their children.

School Boards

9. It is recommended that school boards provide frequent and on-going professional development on identifying and developing liaison with community resources.

10. School boards eliminate any designation or reference to special education services within their structures. Responsibilities for student services should be shared among board personnel based on school levels, thus avoiding labeling any particular individual as a special services supervisor or coordinator.

11. School boards should house a well-equipped lending library with current information relevant to working in environments with students who have diverse needs.

12. Selection criteria for applicants for school principal positions include working as part of an interdisciplinary team.

Schools

13. It is recommended that schools should establish collaborative problem-solving teams consisting of teacher volunteers who problem-solve around

individual and group learning needs.

14. Schools who have teachers allocated as support personnel be designated and recognized as working with all students in the school, rather than working only with students identified as having challenging needs.

15. Schools seek out other schools having exemplary practices of collaborative parent involvement in education decision making and placement for their children and take steps to learn from them.

16. Teachers and principals become volunteers in local community support groups for people with disabilities.

17. Where a choice of placement for a student with disabilities exists because of two or more classes at the same grade level, the attitude of the classroom teacher toward students with disabilities should be a consideration in that placement.

18. Schools initiate support networks, like 'circle of friends' or 'special friends' and having planning strategies such as MAPS, as an integral part of programming for students with challenging needs.

Constraints of the Present Study

The present study can be viewed as a first step in a process to better understand the IEP process. It involved interviews with parents, and therefore presents only their perceptions of the IEP process. There are many people involved in the IEP process whose perceptions are not presented in this study. They include but are not limited to the following: principals, resource room teachers, classroom teachers, teacher assistants

(TAs), the student, and others outside the school who would have a direct or indirect role to play in the development of an IEP for the student. Undoubtedly, the perceptions of these individuals would add to those of the parents and go far in providing more understanding of the IEP process.

The interviews allowed the author to spend between three and four hours with each of the participating families. Parents were interviewed in their home environments and the author was not provided the opportunity to observe parents actually engaged in the IEP process with school personnel or other individuals relevant to the IEP process. The use of participant observation, which ranges across a continuum from the author's role as one of mostly observing to one of mostly participation, allows for the use of interview questions generated directly from the behavior of participants. The development of interview questions connected to the behavior of the participants in natural settings can allow the author to better interpret the answers of the participants.

Further Research

Parents identified the attitude of both teachers and principals as a key factor in the issue of ownership, development of appropriate programs for their children and subsequent parents' participation in the development of those programs. Therefore, further research is warranted into the role that attitudes of school personnel play in the IEP process. How are these attitudes developed? How are they maintained? How can they be changed? In addition, research needs to look at the role of these attitudes as they relate to the issue of ownership across school levels i.e., primary/elementary and junior high/senior high.

The current research also identified the inexperience (for whatever reasons) of teachers in developing appropriate objectives and consequently appropriate programs for students with challenging needs as a problem. Further research needs to be conducted into the preparation of classroom teachers in working with students with challenging needs and their parents. Are teachers entering the profession better prepared? More willing to risk collaboration with parents? More welcoming to all students? And if so, why, or why not? What is the relationship between teacher involvement in continuing studies and willingness and ability to involve parents in the IEP process? What is the nature of a well established collaborative work culture and how is it developed? Such questions emanating from the parents' comments suggest that additional research into the role of organizational structure and culture of inclusive schools with respect to the IEP process deserves further attention.

This study also saw advocacy play a major role for parents in the IEP process. Although not entirely clear from this study, parents who are educated in educational practice may be seen as a threat to educators, thus complicating the parent-teacher relationship. Therefore, there is a need for research into the process of building collaborative relationships among and between advocacy/parent groups and educators responsible for implementing those practices.

In light of the constraints of the present study, further research is also needed into the perceptions of those other than parents who are involved in the IEP process. In addition, the constraints of the study also indicate the need for further research into the actual IEP meetings themselves through a combination of interviewing and direct observation. The use of both methods will allow for an even greater depth of understanding than is permitted through the use of interviewing alone.

Epilogue

The parents have revealed their stories and as Peshkin (1993) points out, "The assumption behind the story of any particular life is that there is something worth learning" (p.25). Wolfe (1985) states:

> One hopes that one's case will touch others. But how to connect? Not by calculation, I think not by assumption that . . . I have discovered a "universal condition of consciousness. One may merely know that no one is alone and hope that a singular story, as every true story is singular, will in the magic way of some things apply, connect, resonate, touch a magic chord" (p.72).

I trust this quote from Hersey and Blanchard (1997) will serve as a final tribute to the stories of the parents presented in this paper.

> Many of our most crucial problems are not in the world of things, but in the world of people. Our greatest failure as human beings has been the inability to secure cooperation and understanding with others. (p.1)

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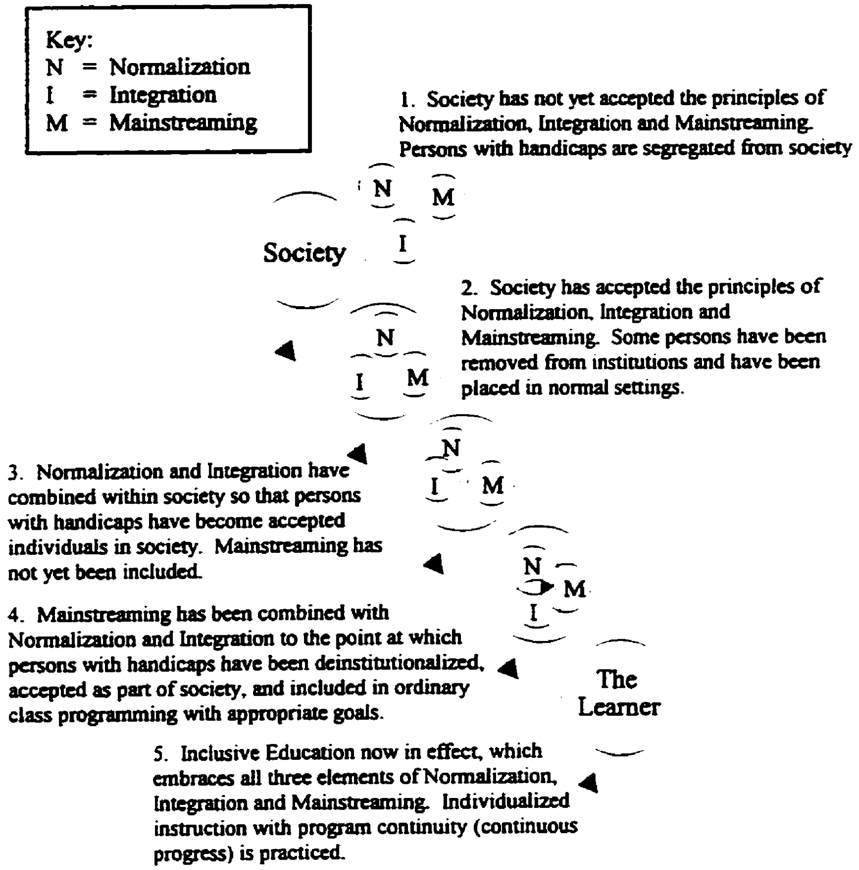
Appendix A

The Evolution of the Principles of Normalization, Integration, Mainstreaming, and Inclusive Education



Key:
N = Normalization
I = Integration
M = Mainstreaming

1. Society has not yet accepted the principles of Normalization, Integration and Mainstreaming. Persons with handicaps are segregated from society

2. Society has accepted the principles of Normalization, Integration and Mainstreaming. Some persons have been removed from institutions and have been placed in normal settings.

3. Normalization and Integration have combined within society so that persons with handicaps have become accepted individuals in society. Mainstreaming has not yet been included.

4. Mainstreaming has been combined with Normalization and Integration to the point at which persons with handicaps have been deinstitutionalized, accepted as part of society, and included in ordinary class programming with appropriate goals.

5. Inclusive Education now in effect, which embraces all three elements of Normalization, Integration and Mainstreaming. Individualized instruction with program continuity (continuous progress) is practiced.

Exceptionality Education Canada, 1992, Vol. 2, Nos. 1&2

Appendix B

Guiding Questions

1. Demographic information of both the parents and their child: occupation of parents, age, age of child, type of disability, type of school, class placement.

2. Tell me about your child? Likes? Dislikes? Strengths?

3. Tell me about the years preceding public school? (Institution; transition planning; parent/professional relationships).

4. Explain the circumstances around your first contact with the school? Who did you work with? How do you feel you were received by the school?

5. Tell me how the decision for your child's present class placement was arrived at?

6. Tell me about your experiences in the IEP meetings?

7. Tell me about the development of the individual educational plan for your child?

8. How was what was important for your child to learn decided?

9. How were you involved in putting these objectives into practice?

10. What is your part in the on-going evaluation of the plan?

11. Tell me about the meetings that you had with the team to review your child's progress?

12. If you could change anything about your experience with the IEP process, what would it be?

13. What advice would you give to someone who was to move into the area and had a child with mental disability who was about to start school?

Appendix C

Interview Consent Form

I am a graduate student at Acadia University working on my master of special education thesis. The purpose of my study is to gain insight and understanding into how parents of students who are labeled trainable mentally handicapped by our schools experience the IEP process.

As part of this study, I would appreciate the opportunity to interview you. If you would agree, I would request your permission to tape record the interviews, and make a transcript of these recordings. In addition to the interviews and transcripts, please be aware that:

1. All personal identifying characteristics will be removed from the transcript and anonymity will be guaranteed to the greatest extent possible.

2. If direct quotations from this interview are used in the written report of my thesis, you will be given the opportunity to read those quotations to ensure: (a) that you have been quoted accurately, (b) that you have not been quoted out of context, and (c) that no personal identifying characteristics have been inadvertently included.

3. All tapes and transcripts made of the interviews will be destroyed upon completion of their use.

I AGREE TO PARTICIPATE IN THIS INTERVIEW, AND TO HAVE A VERBATIM TRANSCRIPTION MADE OF THE INTERVIEW. I HAVE READ AND UNDERSTOOD CONDITIONS 1, 2, AND 3 OUTLINED ABOVE.

____

(Signature of interviewee)

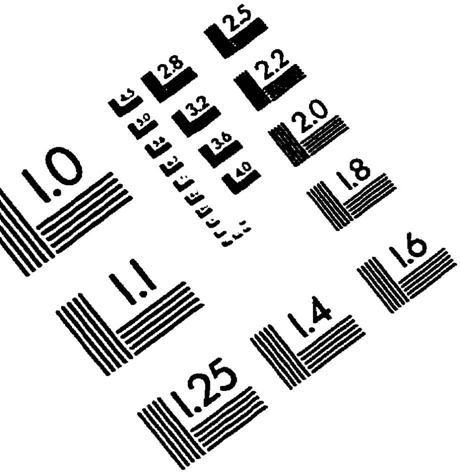
____

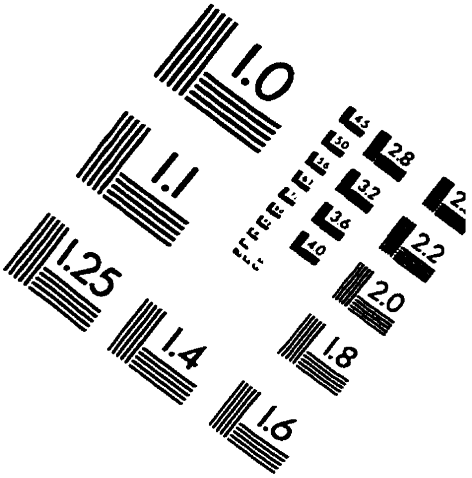
(Signature of interviewer)

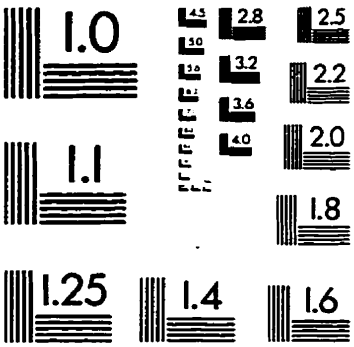
____

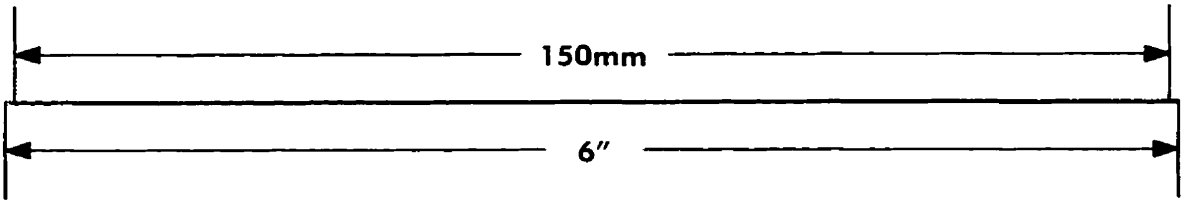
(date)

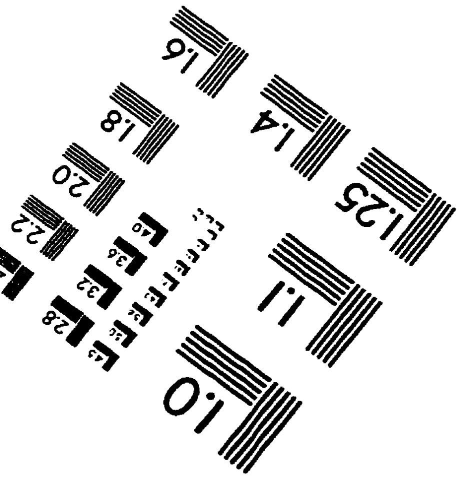
IMAGE EVALUATION TEST TARGET (QA-3)

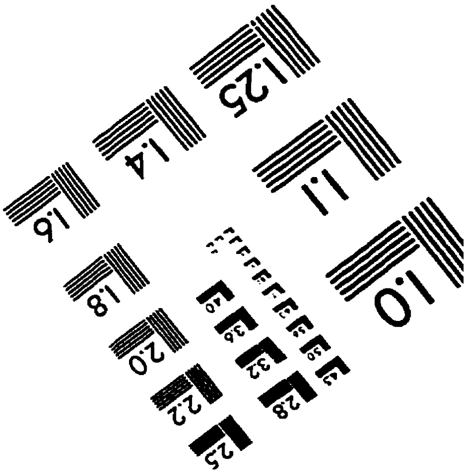












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