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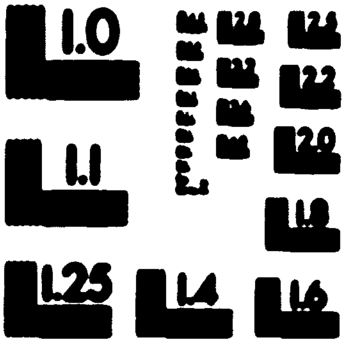

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UNIVERSITY OF ALBERTA

A STRUGGLE TO BE HEARD: PARENTS' VIEWS OF DECISION-MAKING FOR CHILDREN WITH SPECIAL NEEDS

by

Douglas W. Fleming

A Thesis

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF
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DEPARTMENT OF EDUCATIONAL ADMINISTRATION

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ABSTRACT

The primary purpose of this study was to provide information for school based and school system administrators to consider when they are working with parents and making decisions about children with special needs.

A qualitative approach using a multi-case study scheme was employed. Data were collected between April and December, 1992, through the use of semi-structured, in-depth interviews with parents of children with special needs, more specifically those children with severe to profound needs and those with learning disabilities.

Fourteen themes emerged from the analysis of the parent interviews of the children who have severe to profound special needs. These included: taking control very early in the child's life, on becoming "expert" in knowing your child, the kinds of emotions parent experience, and the fact that parents seem to be in a "constant battle" to have their views heard and respected. As a result, parents were expecting to have input into decisions regarding their children, and they have developed strategies to help them deal with professionals. In an effort to become a member of the team working with their children, the parents expressed concerns regarding the additional stress on other family members, the difficulty overcoming labels, the need for open communication,

and the fact that they needed a support network [illegible] them as they struggled to be included.

The parents of the children with learning disabilities expressed many of the same concerns that the parents of the more severely disabled experienced. There were however two striking differences between the two groups of parents. The parents of the children with severe to profound needs did everything in their power to have their children included while the parents of children with learning disabilities were more intent on having the child assessed, monitoring his or her progress and doing whatever they needed to do to make sure the child's individual needs were being met. If disagreements arose between the parents and the school, the parents were not hesitant to seek a redress of their grievances through an appeal mechanism which included a ministerial review or even the courts.

Both groups of parents were adamant that they knew their children best, and they were going to become involved in their children's education.

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To the Board of Trustees of the Westlock School Division, and their Superintendent, Mr. Sig Schmold, I am most grateful for the opportunity to complete this research during my sabattical leave.

Finally, I would like to express my appreciation to the parents whose children have been presented with challenging special education needs, for their encouragement and for what they have taught me about their struggle. You will continue to be my inspiration.

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Chapter 1

OVERVIEW AND PURPOSES OF THE STUDY

> In reality, professionals do not have the right, or even the information, to make major decisions for handicapped (or any other) children. Decision making is both the right and the responsibility of the parents. The role of the professional is to provide information and advice so that important decisions can be as informed as possible. Moreover, the professional role also includes helping families to implement decisions once they are made. (Paul, 1981, p. 157)

The parent-professional partnership in education needs to be redefined. Lipsky (1989) summarized the relationship by maintaining that "while sometimes viewed by professionals in negative ways, parents have been increasingly recognized as playing a substantial role in the effective education of their children, in both general and special education" (p. 159). She expanded this notion and suggested that "parent involvement in the education of students is essential, especially for students with disabilities" (p. 159).

Lipsky (1989) summarized the problem succinctly when she suggested that:

> despite their importance, validated research studies of parental involvement in special education have been few and limited. Most studies focus on a particular activity, such as participation in the individualised education program (IEP) conference, or the number of contacts between parent and teacher. In practice, there is little professional recognition of: 1) the nature of parental involvement and how it changes over the course of the child's life; 2) the differing understandings of disability and their meaning for the nature of parent involvement; and 3) the potential range of parental roles that depend upon parent's conditions, interests and desires. (p. 159)

Turnbull and Turnbull (1982) conceptualized the role of parents as being that of "decision-makers, advocates and protectors, and teachers" (p. 116). In today's educational environment, parents are expecting to have input into decisions regarding the education of their children. However, as Rich (1988) noted:

> Until very recently parent involvement has been the forgotten factor in discussions of students' and the nation's school success. When parent involvement is discussed, it is as if the topic is too big, too discouraging, too hot, and too open to interpretation for policy makers to tackle. (p. 90)

This issue has been known for several years as Gallagher, Beckman, and Cross (1983) found that there was a shortage of knowledge and understanding on the part of professionals about families and children with special needs. The authors called for research which would focus on the family as the unit of study and suggested that a "family" focus should be a prerequisite for all persons in the helping professions.

The Government of the Province of Alberta requires that school boards provide services to students who have been identified as requiring special education services. As a result, the School Act 1990, Section 28(1) required that school boards "shall provide to each of its resident students, an education program that is consistent with the requirements of this Act" (p. 22). Further, Section 29(2) stated that "a student who is determined by a board to be in need of a special education program is entitled to have access to a special education program provided in accordance with Section 28" (p. 23). (See Appendix "A").

The new Alberta School Act, section 29(3) also recognized the importance of parents in the decision-making process when it specified that "before a board places a student in a special education program, it shall (a) consult with the parent of that student" (p. 23).

In addition to enshrining in legislation the rights of a student with special needs to have access to a program, the School Act also made provisions for parents to challenge the decisions of school administrators and school boards. Section 104(1) entitled parents to a ministerial review of any administrative decision by specifying that "if a board makes a decision on an appeal to it or otherwise with respect to (a) the placement of a student in a special education program, . . . the parent of a student affected by the decision . . . may request in writing that the Minister review the decision of the board" (p. 52).

As a result of the legislation, Alberta Education created a new secretariat called the Appeals and Student Attendance Secretariat. One of its functions is to investigate and review school board decisions which are being challenged by parents of students with special needs. As of January 6, 1992, a total of 75 parents had requested that the minister review a school board decision affecting their child with special needs.

Furthermore, the increased number of parental requests for ministerial reviews was, in part, a result of the work of the Learning Disabilities Association of Alberta. During the 1992-93 school year, this association, in conjunction with the Law Reform

Society of Alberta, developed a document entitled The Appeal Process and sponsored at least seven workshops for parents on the appeal process.

Statement of the Problem

The research problem that served as the basis for this study was the following: How do parents view their involvement in the process of making decisions about placement and programming for their children with special needs?

Research Questions

In order to address the foregoing problem and provide a perspective on the process, the views of parents from two different advocacy groups were sought relative to the following seven questions:

1. What processes do school boards in Alberta use to involve parents in educational decision-making for their children with special needs?
2. What are the parents' views of the processes?
3. Do parents desire more input into decision-making?
4. What is the process of dispute resolution when the board and the parent disagree over placement and/or programming issues?
5. How is the disagreement resolved?
6. How are the children's rights to "due process" protected in school board policy?
7. Where and how do parents obtain advice, assistance, or support with regard to decisions related to school programs for children with special needs?

Significance of the Study

The proposed study has both practical and theoretical significance. The results of this study should be of interest to school boards, central office, and school-based administrators who are responsible for special education programs in their school jurisdictions, and/or their individual schools. For example, superintendents and principals will be better informed about parents of children with special needs and their desire to be involved in decisions regarding their child's placement and programming. Superintendents will also become aware of the networks of support some parents build and the importance of advocacy groups in informing parents of their rights. Parents may become aware of effective ways to become involved in their children's education without having to adopt an adversarial position.

In terms of theoretical considerations, the results of the study will add to the body of knowledge and to the theorizing on parental involvement in special education decision-making. This study, in turn, will have implications for how to involve parents throughout the development of programs in the school.

Definition of Terms

The following terms and concepts used in the study are defined below in order to provide consistency in meaning throughout the study.

(a) special education student - a student who has been identified as requiring access to a special education program based on the child's social, physical, intellectual, or behavioral needs, or a combination of these factors, as defined by the Alberta School Act, Section 29 article 2.

(b) children with special needs - this study is restricted to two groups of children: those with severe to profound handicaps and those children with specific learning disabilities.

(c) integration - is a process of educating exceptional students within the framework of regular education, a model in which all children are permitted to live, grow, and learn with their peers.

(d) "parents as partners" is a phrase used to describe an alliance between the parents of a special needs child and the various professionals with whom they will deal. It is the best way to ensure that a student with special needs receives the appropriate education that he/she is entitled to by law.

(e) individual education program (I.E.P.) - this is sometimes referred to as an IPP or individual program plan. It is a detailed written plan which has been devised to identify and plan for the student's special needs. It should include statements of long-term goals, short-term instructional objectives, and specific services to be provided. It should describe how these objectives are to be achieved. It should also describe how the objectives will be monitored and evaluated so that one can determine if the stated goals and objectives are being achieved.

(f) educational decision-making - is a series of processes in the education of the child where the parents expect to have input including participating in the development of the individualized education plan (I.E.P.), granting or withholding consent to special education evaluation and placement, and by having access to and ensuring the confidentiality of their involvement in educational decision-making.

Delimitations

The study was delimited to the province of Alberta, Canada. It was designed to cover the views and perceptions of selected parents from two provincial advocacy groups, namely the Learning Disabilities Association of Alberta, and the Gateway Association for Community Living. A select group of 10 families, which included 14 parents, from 10 different school boards in the province of Alberta, was interviewed to allow them to share their stories with regard to their involvement in educational decision-making.

Limitations

Some limitations have already been placed on the study. The accuracy of the findings is limited to the information obtained through the analysis of the perceptions of those parents interviewed. It is possible that some of the most effective school systems and their policies regarding parent involvement may not have been identified in the sample selected.

When working with volunteer parent advocacy groups, their family and organisational priorities may have taken precedence over the researcher's need to complete the study.

Another limitation was that parents who belong to any kind of support or advocacy group have developed a certain orientation or bias toward issues dealing with their children, and the researcher must recognize that bias when working with parents from the two different advocacy organizations selected.

As an educator and an administrator, the researcher had to constantly be aware of his own personal biases toward parents who are advocating for services for their children with special needs.

Organization of the Thesis

Chapter 1 of this thesis presents an overview of parental involvement in educational decisions affecting children with special needs.

Chapter 2 is a summary of the literature on parental involvement specifically in the area of educational decision making for special needs children.

Chapter 3 describes the research methodology used for the study. The description includes the procedures and techniques used for obtaining and analyzing the data.

The analysis of the data is presented in Chapters 4 to 6. The views and concerns of parents of children with severe to profound needs are presented in Chapter 4. Similarly, the views and concerns of parents of children with learning disabilities are discussed in Chapter 5. Chapter 6 is a compilation of the common themes which emerged during the analysis of the data from both groups of parents.

The last chapter, Chapter 7, reports the conclusions drawn from the analysis of the data and the educational implications of the research problem for both administrators and parents as they begin to develop a partnership to deal with the issues.

Chapter 2

REVIEW OF RELATED LITERATURE

A perspective for this study is provided through a review of the related literature. It quickly becomes obvious that the issue of the parent's role in the placement of children with special education needs is not well researched. Myles and Simpson (1990) found "the attitudes and perceptions of parents of children who will be most directly affected . . . including parents of children with learning disabilities (LD) have received minimal attention" (p. 234). A number of researchers including Simpson and Fiedler (1989), Stancic (1984), and particularly Heller & Schilit (1987) as cited by Myles and Simpson (1990) concluded, "the potential significance of this lack of attention is profound" (p.234).

The nature of parental involvement particularly as it related to children with special needs will be discussed in this chapter. Current legislation in both the United States and Canada will be considered, and five of the most recent cases on parental involvement in education decision-making are reported. The review will highlight the findings of several studies on parental involvement, outline eight approaches to parental involvement in the school as well as discuss some strategies for decision-making. Finally the development of the parent-professional partnership as a special relationship concludes the chapter.

Current Legislation in the United States

The development of legislation regarding the involvement of parents in educational issues has evolved over time in both the United States and Canada. In the United States, particularly because of the principles of PL 94-142, the Education of All Handicapped Children Act, "the rights of parents and guardians of handicapped children are protected, as well as the rights of children" (Turnbull & Strickland, 1981, p. 231). The purpose of PL 94-142 was:

> To guarantee a free appropriate public education to all handicapped children. But many of you may not yet be fully aware of the important role which you, the parent, have to play in helping your child derive the maximum benefit from the law - an educational program designed and delivered to meet your child's needs. P.L. 94-142 gives you the right to actively participate in the process of developing an educational plan for your child. You can have a voice in determining your child's educational career by becoming your child's advocate. (Cutler, 1981, p. 2)

The development of legislation prior to 1975 included Section 504 of the Rehabilitation Act, 1973, which prohibited government agencies that receive federal financial assistance from discriminating against those persons who would otherwise qualify as handicapped persons.

Similarly, the Federal Education Rights and Privacy Act, also called the "Buckley-Pell" amendments, granted parents access to their children's school records and enabled parents to require that schools treat these records confidentially.

In addition to the Buckley-Pell amendments, the bill PL 89-313, which granted federal funds to states for the education of institutionalised handicapped children, and several bills under the Social Security Act, were pieces of legislation designed for the education and habilitation of handicapped children.

There were also a number of state laws which affected handicapped children and their families. These laws included state right-to-education statutes as well as other laws regarding guardianship, removal of parent rights, abuse and neglect of children, etc.

With that background information, the most important aspects of PL 94-142 will now be discussed briefly. Turnbull and Strickland (1981), outlined the provisions contained in PL 94-142, which provided federal funds to state and local educational agencies for the education of handicapped children. There was a stipulation that these agencies must adhere to six basic principles with respect to educating such children:

1) zero reject - agencies may not exclude any handicapped children from a free education,
2) nondiscriminatory evaluation - required that all handicapped children be evaluated in a fair way,
3) individualized education - each child must be provided an education appropriate to his/her needs,
4) placement in the "least restrictive environment" enabled handicapped children to be placed with their nonhandicapped peers,
5) procedural due process - ensured that parents and children are treated fairly, and

6) parental participation - allowed parents to participate in their child's education. (pp. 207-214)

According to Turnbull and Strickland (1981), the legislation entitled parents "to participate in their child's education in several ways, foremost by attending the IEP conference" (p. 213). Parents also had the right to grant or withhold consent to a special education evaluation or placement by initiating a due process hearing and by having access to and ensuring confidentiality of their child's records.

The U.S. legislation also required that the state education agency must establish a procedure for consulting with persons involved in or concerned about education of handicapped children including the parents or guardians.

It was interesting to note that the state must make public the special education plan, hold hearings on the plan, and generally consult with parents of handicapped children. The state is also required to treat as public records, information about its programs for handicapped children. The state's application for federal and state special education money must be made available to anyone who wishes to view it.

Under the "Buckley-Pell" amendments, a student's records are accessible to parents but are also confidential and may not be made available to other agencies without parental consent. Parents have a right to inspect and review all education files pertaining to their child, which must be made available within 45 days of the request. Parents are also entitled to an interpretation of the records by a member of the local education agency. Parents can request that the records be amended and if the local education agency refuses to amend, parents have the right to a due process hearing based on that refusal. Parents are also entitled to a copy of the records for their files.

By U.S. laws, parents have a right to have their child's records treated as confidential. Each local education agency must appoint a person to ensure that personally identifiable information is treated confidentially. Employees who work with confidential information must be trained regarding state and local policies, and updated rosters of employees who handle this information must be made available for public inspection.

The "Buckley-Pell" amendments ensure that parental permission has been obtained before releasing any personally identifiable information to any other agency. The state and local agency must inform parents when the personally identifiable information is no longer needed for education services. With parental permission, the information must be destroyed. The only information which can be retained on file is the student's name, address, phone number, grade, attendance records, classes attended, grade level and year completed.

> Clearly the Buckley-Pell amendments make it possible for the schools and the parents to cooperate, to share responsibility, and to hold each other accountable for the child's education. At the heart of this law is the belief that a parent-professional alliance is the best way to assure a handicapped child a free appropriate public education. (Turnbull & Strickland, 1981, p. 215)

The parent-professional relationship in the United States is demanded and closely monitored through legislation.

The Canadian Experience

Education in Canada is a provincial responsibility and hence there is no federal legislation equivalent to the American bill PL 94-142. Each province and territory has education legislation and related policies, guidelines and procedures. In several provinces, namely Manitoba, New Brunswick, Newfoundland, Nova Scotia, Quebec, and Saskatchewan, mandatory legislation guarantees access for handicapped children to special education services. British Columbia, Prince Edward Island, and both territories have permissive laws which allow for the option of providing special education services to handicapped children but school boards have no legal obligation to do so.

In Alberta, school boards are required to provide an education for each of their resident students including those who are handicapped. For children who are so identified by the school district, it is the district's responsibility to provide appropriate education programs.

Martin (1991), in an article comparing recent legislation in British Columbia, Alberta and Quebec, concluded:

> Despite all the aspirations and the rhetoric to the contrary, the policy implied in current legislative provisions in British Columbia and Alberta seems to be primarily an affirmation of the value of parental participation with no intention to revise the power structure to give parents a say in educational decision making. With respect to this policy, the law may be described as "symbolic legislation." (p. 81)

On the other hand, Martin (1991) viewed the legislation in Quebec as significantly more progressive when she stated:

> The law in Quebec provides for a systematic shift in the balance of power required to effect real parental participation. The provisions have effectively restructured the power relationships among the board, the school administrators, and parents, in favor of parents. Change seems to have been radical in Quebec, when compared with the "reforms" in British Columbia and Alberta. It seems clear that policy-makers in Quebec have attempted to recognise the primary responsibility of parents for the education of their children, and then to force them to get involved both at school and school board levels. (p. 83)

In Canada, the Canadian Charter of Rights and Freedoms (1985) applies to all provincial school legislation by ensuring through Section 15(1) that all individuals are "equal before and under the law" and have the "right to the equal protection of the law without discrimination".

In an effort to maximize special education services across Canada, and as a result of an increased rise of parent advocacy groups and demands for special education services, the Council of Ministers of Education (1989) concluded, in their report entitled Special Education Information Sharing Project, that "all children, regardless of exceptionalities, are first of all children and benefit from regular association with other children within their communities" (p. 23).

In Canada, without the federal legislation mandating a minimum standard of service, the treatment of handicapped children and their parents seems fragmented and disjointed.

Legal Approaches to Decision-Making

While it was not the prime focus for the thesis, it should be noted that a number of parents have attempted to ensure their rights as parents to be involved, or their child's right to an appropriate education, through the route of litigation. In that this study involved members of two different interest groups, the researcher decided to review the role of the judiciary in policy-making as it relates to parents of children with special needs or the interest group to which they belong.

Dolmage (1990), in a study of interest groups, the courts, and educational policy, highlighted several important issues:

1) Interest groups are currently active players in the educational policy arena in Canada.
2) Interest groups have become more active players in the Canadian educational policy arena in the last decade.
3) In the past decade, Canadian educational interest groups have become more willing to employ confrontationalist tactics than they were in the past.
4) Canadian educational interest groups have become more litigious in the past decade.
5) Publicity-focussed protests, presentation of briefs to public bodies, confrontation with politicians and government officials, and regular and informal contact with decision-makers are all tactics employed by interest groups <u>before</u> they appeal to the courts.
6) The Canadian judiciary is assuming a more prominent role in influencing the development of educational policy.
7) Judicial interpretation of sections 2, 7, 8, 15, 23, and 29 of the Canadian Charter of Rights and Freedoms will have a significant impact on educational policy-making.

In an earlier article on the impact of the Charter on educational decision-making, MacKay (1988) concluded:

> A greater access for parents and others to educational decision-making is another post-Charter result. Some educators already provide this, but not all. It is helpful for educators to listen to parents, not always to believe them or to do what they say, but to listen to them. It is desirable for educators to listen to student's views, too, and it can be instructive for them to listen to legal views before making decisions about educational policy. The Charter will provide a vehicle for parents and others to ask for a hearing and, in the Charter world of education, educators will have to allow this. The rather select group of educational policy-makers will be opened up to a number of new voices. (p. 148)

Within this legal framework, let us examine the results of some of the legal decisions which have been rendered by the courts with respect to children with special needs.

One of the first cases involved Shelley Carriere, a physically handicapped child who was forbidden from attending her home school by the County of Lamont in 1978. The Carriere parents sued their rural school board for not providing suitable educational services for their daughter. The case went to the Supreme Court of Alberta which ruled that school boards have the responsibility to ensure that suitable programs are available for "all children with special education needs who do not fit into a regular classroom" (Edmonton Journal, August 12, 1978). In this particular case, the court ordered that the school board either place the child in one of their own classrooms or enrol her in another school system at their expense.

In Bales v. Board of Education, School District No. 23, Central Okanagan School Trustees, 1984, the court emphasized that fair procedure in an education context need not be a full blown court process. In this case, the school officials decided to place a mentally disabled child in a segregated school but the parents wanted their child to be placed in a special education class offered by the local school. The parents failed to demonstrate that the school's placement was unreasonable.

In Yarmaloy v. Banff School District No. 102, 1985, the court was more receptive to the parents' arguments regarding the lack of fair procedure although the judge did not reverse the school's decision for a segregated placement. However, he did order that the school authorities conduct a hearing which allowed for proper parental input prior to deciding the child's special education placement.

In 1989, the New Brunswick Court of Appeal in Robichaud v. School Board No. 39, 1985 set aside the injunction granted by the lower court that had the effect of requiring a school board to integrate an exceptional child into a regular grade 8 class. The lower court had ruled in favor of integration; the Court of Appeal overruled that decision and supported the school board's position that integration was not appropriate for the child.

The case of Elwood v. Halifax County-Bedford District School Board, 1987, was a landmark decision for educational rights of disabled children in Canada. It was also the first case which addressed a number of Charter issues. But equally as important, it addressed the issue of parental involvement in education decision- making. MacKay (1987) noted "another significant feature of the Elwood case and the agreement which resolved it is a recognition of the rights of parents in the educational process" (p. 111). The case "not only obtained the placement that they (the parents) wanted for Luke but also guaranteed a role for the parents in the designing of his program" (p. 111).

Baldwin (1991) in discussing parental control in special education in three provinces, namely British Columbia, Nova Scotia, and Ontario, concluded, "In none of the three jurisdictions discussed do exceptional students have an absolute statutory right to be educated at the neighborhood school, nor are they even guaranteed access to the public educational system" (p. 231). Baldwin noted that once a child gains access to a school system, he or she must be "sufficiently accommodated" in British Columbia, "adequately accommodated" in Ontario, or "be capable of benefitting" from a program in Nova Scotia.

According to Baldwin (1991), "the school authorities maintain the prerogative to set program and curriculum and thereby, for all intents and purposes, determine the parameters of 'sufficient instruction'" (p. 231).

> The conclusion to be reached from a review of the three provinces' legislation is that the legislation, regardless of province or the elaborateness of it, provides that the government and the school board maintain the balance of power, respecting educational decision-making. Parents have no statutory authority to legally influence the special education programs for their children. (Baldwin, 1991, p. 231)

With respect to human rights legislation, Baldwin (1991) also concluded, "It presently appears that a legislative human rights approach to influencing the placement and programming of exceptional children will meet with limited success" (p. 235). At this point, the only circumstance in which a human rights tribunal may consider intervening would be "where the exceptional student is denied a particular service such as access to public school, travel on a school bus, or physical amenities such as an elevator" (p. 235). While these denials are not within the realm of education, the element of a complete denial or restriction of publicly available services may constitute a violation of a human right. "Once the denial of service is established the burden falls onto the school board to reasonably accommodate or show undue hardship" (p. 235).

The only other avenue where parents could influence the service delivery for their child would be through an educational malpractice suit. While this may be an avenue to pursue in the United States, the author concluded:

> Using the courts as a means of gaining damages for improper instruction or, more importantly to compel the equitable remedy of mandamus to order a school board to provide a particular education based on a claim of the board failing its statutory duty, is a closed door. (Baldwin, 1991, p.239)

Parker (1992), in a study of educational malpractice litigation in the United States, recognized the judiciary's unwillingness to recognise the tort of educational malpractice. He disagreed with the previous author by suggesting:

> The failure of schools to achieve educational objectives has reached epidemic proportions. Not only are many individuals deprived of the learning they so desperately need, but society as a whole is beset with social problems each time an improperly trained youth is passed into the mainstream. Available procedures do not adequately deal with the problems created by incompetent teaching, nor do they provide adequate relief to wrongfully injured

> individuals. Therefore, recognition of the tort of educational malpractice is consistent with common law tradition of providing a remedy to a person who has been harmed by the conduct of another. (p. 187)

As editors for the Edulaw School Newsletter, Doctor and Kennedy (1993) reiterated Baldwin's view:

> There have been no successful Canadian suits to date and a recent American decision of the Federal Court of Appeal outlined why such suits are not likely to succeed.
>
> 1. There was no satisfactory standard of care by which to evaluate an educator, particularly considering the different but acceptable theories and scientific methods of academic training;
> 2. There were inherent uncertainities about the cause and nature of damages given that such factors as student's attitude, motivation, temperament, past experience and home environment play an immeasurable role in learning;
> 3. As a matter of public policy, recognition would result in a flood of litigation against schools given the large scale of educational services rendered; and
> 4. It threatened to embroil the courts in overseeing day-to-day operations of schools. (p. 21)

With respect to the issue of integration of an exceptional pupil into a regular classroom, Baldwin cited the Robichaud case. The New Brunswick Court of Appeal ruled that the parents of Nathalie had not met the burden of proving that Nathalie would be harmed in a segregated setting, and concluded: "We are of the opinion that the preparation of a plan for exceptional pupils is not a question of law and does not fall within the courts' jurisdiction" (Baldwin, 1991, p. 244).

With respect to the needs of a learning disabled child, Baldwin cited the Antonsen case. Here the parents sought to have the school board fund a segregated class placement where their child could receive a particular method of instruction which required a segregated placement rather than a regular classroom placement. The Court as cited by Baldwin, ruled with deference to the School Board by stating:

> The Act and Regulations must therefore be interpreted with regard for the fact that responsibility for planning and operating the school system is intended to rest with the elected trustees. A narrow constriction of their statutory authority could defeat that legislative intention. (p. 235)

Some parents have attempted to influence the service delivery system for children with special needs through the Charter of Rights and Freedoms. In his analysis, Baldwin concluded:

> The parents of the exceptional child will bear the burden of persuading the court that a practice of the school board is offensive to Charter guarantees. Potential infringements of the Charter in relation to service delivery for special students occur under the following sections:
>
> 2. Everyone has the following fundamental freedoms:
>
>   (d) freedom of association.
>
> 7. Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.
>
> 15.(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on . . . mental or physical disability. (p. 250)

Baldwin (1991) concluded his lengthy discussion:

> It is evident that the Charter does not easily provide parents of exceptional children with legal means to challenge the discretion of school authorities. Difficulties with presenting solid empirical evidence to establish an infringement of Charter guarantees and the present reluctance of the courts to use the Charter as a positive instrument to order affirmative programs result in judicial deference to school board discretion. (p. 257)

Finally, as Baldwin remarked:

> It is essential to restore confidence in public education. This review of educational decision-making in relation to special education clearly shows that parents have little reason to be confident in a system they have no control over. Opening special education up to scrutiny in the courts and holding teachers liable for neglect may go some distance to remedy the confidence problem. (p. 260)

To conclude this discussion on legal approaches to decision-making, Doctor and Kennedy (1992), summarized some very interesting implications and applications for school personnel:

1. Administrative tribunals have proliferated in many areas of endeavour including education and there has been an increasing number of tribunal decisions the courts are asked to scrutinise.

2. The extent of judicial interference in educational decision-making is determined in large part by the wording of the legislation. Where students are entitled to an 'appropriate' or 'sufficient' special education program, the courts are invited to engage in substantive review of the program. Where legislation mandates special education services, the courts are more willing to examine and pronounce upon the level of services provided.

3. Legislation determines to some extent whether a board will be challenged under human rights legislation or under administrative law principles.

4. In provinces where the legislation specifically allows a board to contract with another board for the provision of educational programs or services, care should be taken to ensure that constitutionally protected separate school rights are not violated.

5. Human rights legislation superimposes upon school legislation the duty to treat students equally in

providing educational services and accommodation.

6. Courts are usually more restrained in ordering specific programs and services than are human rights tribunals.
7. It remains to be seen whether and in what circumstances program or lack of service will infringe one of the Charter rights.
8. School boards avoid litigation at their peril. By acquiescing to demands supported by mere opinions of human rights commissions and by refusing to appeal decisions of human rights tribunals, school boards are committing themselves to a level of services which may not be required of them by law and which they may not be able to afford. (p. 62-63)

It was within this context that we began to study this issue of parental involvement in decision-making for children with special needs.

Current Research on Parent Preferences for Involvement

Turnbull and Turnbull (1986) summarized some of the latest research studies regarding parental involvement. Winton and Turnbull (1981), in a study of 31 mothers of preschool children with mild or moderate disabilities, found that:

> 100% of the parents favored informal contact with teachers and 65% chose this activity as the most preferred. Parents preferred this contact with the teachers to be frequent and that the information shared between the parent and professional would be exchanged on a 'give and take' basis. (p. 139)

According to these researchers, "the informal contact was rated substantially higher than the more formal and active roles of volunteering, participating in counseling or training sessions, and serving on policy boards" (p. 139).

Turnbull, Winton, Blacher, and Salkind (1983), cited by Turnbull and Turnbull (1986), surveyed 100 parents regarding their perspectives on their child's kindergarten program, found the two most important characteristics of kindergarten programs were "informal and frequent communication with teachers and the opportunity to relax each day with the parent knowing that their child's educational needs were being met" (p. 139).

Ammer and Littleton (1983), also cited by Turnbull and Turnbull (1986), surveyed 217 parents of exceptional children and found that 87% of the parents were not involved in their local school program. In this particular study, most parents (69%) preferred regular communication via letters from the school. The next most preferred contact with the school included school conferences (51%), telephone calls (45%), and home visits (19%).

Turnbull and Turnbull (1986), also cited a study by Nocutt and Wiegerink (1983), who tried to determine the actual nature of parental involvement in early education programs. They found most parents to be involved in more passive activities such as receiving information and services. These results were similar to those found in a study conducted by Lusthaus, Lusthaus, and Gibbs (1981) who found that most parents were involved to the extent of giving and receiving information. The second most typical type of involvement was "no involvement", while the role of decision-making was third. In this particular study, where parents were also asked to specify what roles they would like to assume, parents continually wanted to receive and give information in areas like discipline, class placement, evaluation, instructional grouping, transportation, and special resources. "Parents consistently indicated that they would like to exert actual decisional control pertaining to medical services, types of records maintained on the child, and transfers to other schools" (p. 140).

In summary, Turnbull and Turnbull (1986) concluded that "most parents generally prefer informal and frequent communication with their child's educational programs" (p. 140). Goldstein, Strickland, Turnbull, and Curry (1980) and Lynch and Stein (1982) found similar parental preferences for participating in individualized educational program (IEP) conferences. As a result, Turnbull and Winton (1984) concluded "despite current policy requirements for formal and active participation by parents, a more passive role appears to be the dominant practice" (p. 140).

Perhaps at this time, there is a need to re-evaluate parental involvement policy and practices as Turnbull and Turnbull (1986) suggested when they cited Lynch and Stein (1982):

> Perhaps the next step for educators is to review the definition of active participation as it relates to parent involvement. Can "active" involvement be operationalized to fit all parents, or is active involvement an individually defined phenomenon that varies from parent to parent and family to family? Could the same model of individualization for education program be expanded to provide some individualization for the family? Instead of measuring and judging parental involvement by the numbers and kinds of comments made at the planning meeting, it may be time to assess the families' present involvement, ask them to describe their level of involvement, and mutually develop goals and objectives that will allow them to participate as actively as they choose. (p. 62)

Early Intervention Programs

Parental involvement in early intervention programs has been advocated for one or more of the following reasons:

1) parents had an obligation to be involved because they were ultimately responsible for their child's welfare;
2) involved parents provided better political support and advocacy;
3) early intervention programs which involved parents resulted in greater benefits for children;
4) parental involvement resulted in benefits for the parents and family members;
5) by involving parents, the same outcomes could be achieved at less cost; and
6) the benefits of early intervention were maintained better if parents were involved. (White, Taylor, & Moss, 1992, p.18)

In a recent study of parental involvement in early intervention programs, White, Taylor, and Moss (1992) researched 172 studies, 80% of which had a prime focus on using parents as intervenors in their child's program. White et al. (1992) concluded "we found no evidence of larger effect sizes for intervention versus no-intervention studies which involved parents versus similar studies which did not involve parents" (p. 108). These researchers admitted "most of these studies focussed primarily on using parents as intervenors instead of involving them in other ways". The researchers also argued that "no evidence exists in this admittedly indirect type of evidence to argue that parent involvement in early intervention programs will lead to any of the benefits that are often claimed" (p. 109).

The researchers were quick to remind us that:

> if parents are being involved because program administrators and policymakers believe that parents have an obligation to be involved or because greater support and advocacy is desired, the data in their review is irrelevant and unimportant. If, however, parents are being involved because of expected benefits for the child or the parent(s) or because cost savings or better maintenance of benefits are expected, the results from these analyses are relevant and sobering. (p. 118)

White et al. (1992) saw four main reasons for this lack of substantial evidence to support parental involvement. First, the present studies focussed almost exclusively on the parent as an intervenor. Second, there was little research to verify that the intended parental involvement program was well implemented. Thirdly, researchers were only beginning to evaluate the effect of parental involvement activities on parents and family members. Finally, much of the perception that parental involvement was beneficial "has been based on anecdotal reports and poorly designed research" (p. 119).

Abramson, Willson, Yoshida, and Hagerty (1983) developed a questionnaire to assess how sixty parents of children with learning disabilities viewed: (a) their relationship with school personnel, (b) their child's academic and social progress, and (c) integrated programs involving handicapped and nonhandicapped students. Abramson et al. (1983) discovered that "even though parents felt they could provide useful information to educators, an unexpectedly large percentage of respondents (72 percent) felt they had little to contribute . . . and did not see themselves in a partnership role with the schools" (p. 185).

There was a significant correlation between the level of parent participation and the parents' views as to whether they had a partnership with the school. These researchers also found that parents who viewed the relationship with the school as a partnership, perceived teachers and principals as being more open to their suggestions. While this study sample may not have been representative, which tends to limit the generalizability of the findings, it did provide insight into parent perceptions, and it is "perceptions rather than reality (that) often impede the special education process" (p. 193). Abramson et al. concluded "that the role of parents as partners is important". The researchers advised that "a true partnership must be realized" (p. 194) and parents must be seen as active participants who are satisfied with their role in the educational process. Finally, Abramson et al. recommended that "school personnel must become more receptive to parental participation and more informed about the meaningful role parents can play in planning educational programs for their handicapped child" (p. 194).

Similarly, Rich (1988), based on a study of community involvement in education, advocated "the real, best and only way to improve education . . . is to combine the educational forces of home, school, and community" (p. 90). Given the fact that studies, over the past twenty years, have indicated that parents are significant educators of their children, "teachers are realising more than ever that they must work in partnership with parents and the community" (p. 92). Rich (1988) referred to a bill in the United States Senate called the Family-School Partnership Act which was intended to focus on the role of the family as educator and on teacher training to support the efforts of families.

In an earlier study, Epstein (1984) looked at the various ways in which parents could become involved in their child's learning and concluded that "there may be district-level policies that enable, encourage, and reward teachers who emphasize particular types of parent involvement" (p. 72).

Approaches for Involving Parents in Special Education Programs

Lewis, Marine, and Van Horn (1991) compiled a series of approaches which involve parents in special education programs in a number of different ways. This document arose from the Effectiveness Indicators for Special Education: A Reference Tool which was developed by Regional Resource Centre (RRC). Some of the indicators addressed in the document included:

- the establishment of effective two-way communication and collaboration with parents and school staff
- the encouragement of parents to actively support their children's learning through the building of partnerships between home and school
- the maintenance of on-going support for parents
- the involvement of parents in on-going program improvement efforts and the provision of on-going training programs for parents (p. 3)

The authors of the Effectiveness Indicators for Special Education supported the establishment of a Special Education Advisory Committee (SEAC). This first approach involved parents from all grade levels and representatives from the community whose responsibility was to advise the district on issues relating to special education. In addition, the SEAC and the Department of Education host an annual conference for parents which is completely funded by the district.

In order to accomplish this goal "school districts across the country are dedicating their efforts toward the goal of building and maintaining a relationship within their school communities that fosters openness, honesty, and cooperation between parents and school personnel" (p. 3). One of the most important goals was "that the participation of parents in the education of their children and cooperation among advocate groups were desirable outcomes for any educational program" (p. 4).

A second approach for parental involvement was initiated in the Massachusetts area entitled the Responsive Parent Program which consisted of a mixed group of parents of children with moderate special needs and of parents of normal children. The program sponsored an eight week course which involved half-hour teaching sessions on subjects such as positive discipline, self-esteem and sibling relationships. Each session was followed by a half hour discussion period. The primary purpose for the group was to provide parents with connections. Parents were also given information regarding PL 94-142 special education legislation. The group was a vehicle to facilitate parental involvement and to provide a means for establishing effective two-way communication. While working collaboratively with school personnel, parents were encouraged to assist in the identification and assessment of existing or potential learning problems of preschool children.

A third approach was developed in Nebraska where an Advisory Committee redirected the focus of a Parent Training Program to include training for both parents and educators. The Committee acknowledged that "the philosophy that emerged . . . embodied the idea that professionals were not always experts" (p.10). By utilizing a state-wide staff development conference, parents and teachers received information and training on topics of mutual interest to both educators and parents. As a result of working together, parents and teachers began to support each other in their attempts to solve problems. At the school level, there was a noticeable spirit of cooperation as both educators and parents worked as a team. In Nebraska, parental involvement was also fostered through a Parent-Professional training team which sponsored two presentations per year to their local communities. The training teams developed groups of parents and educators encouraging and supporting each other.

Nebraska also encouraged parental participation through its newsletter, Sharing Connection, which was based on the premise that parents are consumers of special education services; thus parents concerns are taken into serious consideration. The newsletter had a mailing list of 3000 homes and addressed issues of interest to both educators and parents alike.

A fourth approach was developed in Connecticut by the State Department of Education and the Bureau of Special Education and Pupil Personnel Services where parents were invited to become involved in the education of their special education children. The emphasis was on two-way communication. A comprehensive resource packet for parents of students in special education programs was included as well as copies of state legislation concerning children who require special education services. The information included definitions, explanations of various exceptionalities, time lines for providing various services, and descriptions of various programs as required by law. The packet also included information about parent/student rights and responsibilities, and explained due process procedures. The packet also included an 800 toll free number.

The Special Education Resource Centre (SERC) in Connecticut was another attempt to encourage parental involvement. SERC existed to provide materials and training to anyone who was interested in the education of exceptional children by providing support in five areas: library services; personnel development; supportive services; media services; and exhibits and expositions. SERC published a quarterly newsletter to over 11,000 homes with money provided by PL 94-142.

In 1990, Connecticut established a Parent/Educator Partnership Program with twenty-two school districts participating in an effort to increase communication between parents and educators. Each district sent parents and educators to training workshops with personnel who then acted as a liaison team to help other parents and educators bridge the communication gap. In 1991, a total of thirty-five districts participated in the same program.

The CASE Research Committee, 1991, highlighted a fifth approach called a Master Plan for Special Education in the San Diego School District which was designed "to serve parents of handicapped children from birth through age twenty-one" (p. 22). In this program parents of children with handicaps were employed by the program to provide support and information. The users of the program included other parents of children with similar handicaps, special education teachers, regular classroom teachers, administrators, and other interested community groups. In this program, parents were actively seeking ways to support their child's learning in partnership with the school staff. This program provided a cadre of parents who both understood the issues of parenting a handicapped child as well as the resources and constraints of a school system. Parents learned from other parents how to work with the school system to achieve a cooperative effort. As a result, the "requests for fair hearings dropped markedly since the program's inception in the San Diego schools" (p. 22).

The San Diego school district developed the Special Education Parent Facilitator Program (SEPF) where fifteen parents were hired to work as community aides in the school system. The coordinator's role included nine hours of inservice training per week for parents. The initial program included classroom observations, organizing and conducting informal parent meetings, and coordinating home and school efforts to achieve goals for each child's individual education program. The state funded the development of a curriculum entitled "Connections".

Today the parent facilitator, employed by the school district, provides a link between the home and the school. In addition, training on various aspects of school including school district organization, legislation, legislative procedure, the IEP process, communication skills, and normal child growth and development are among the topics discussed.

It was the facilitator's responsibility to develop training for school staff and community members. The facilitator also served on various community committees. The results of the SEPF evaluations showed that parents receiving individualized services tended to become more involved in their child's program.

A sixth approach known as the Parent Involvement Project in Coeur d'Alene, Idaho, focused on the parents of secondary school students who were classified from moderately to severely disabled. The program was in its fourth year and was designed to develop ways in which parents and school staffs can bridge the gap between the world of school and the world of work.

The program claimed 100% parent participation for a number of reasons: the majority of students have been involved in special education since elementary school; parents were the foremost advocates for their disabled child and every parent was encouraged and expected to participate; and teachers were considered to be ambassadors and became the first line of support for the parent.

The program for the student focussed on success. In the transition program students worked in a resource employability class and they received individual instruction based on a functionally-oriented curriculum. At the end of the first three year study, 81% of the students were still employed. The program was also supported by the mayor's committee for hiring handicapped persons as well as weekly articles in the Coeur d'Alene newspaper promoting the local school programs. The coordinator had also located mentors in the community to further the needs of disabled individuals as they moved from the classroom to the workplace. The focus for the entire program was on the development of relationships with parents based on a mutual respect for their roles in achieving benefits for their children.

The seventh approach was the PACER Centre, or the Parent Advocacy Coalition for Education Rights Centre which was located in Minneapolis, Minnesota. The centre was designed to help parents become better informed and more effective advocates for their children, so that the parents were better able to participate effectively in the decision-making process within the educational arena. The centre was staffed with personnel who were themselves disabled or were parents of disabled children.

The programs for parents included general information workshops explaining special education laws, the decision-making rights that parents had in the special education process, and basic school procedures so that when the school called, parents understood their roles. Parents were also taught communication skills so they were more comfortable when working with schools. Other workshops included special topics which would be conducted on an 'as needed" basis, advanced workshops which would focus on a specific area of interest so that parents were able to represent their children in educational settings. The centre also conducted disability awareness programs, and assisted parents and students with computers and adaptive devices. The PACER Centre could serve as a model for local school districts who provide special education services to special education children and who are also interested in further developing existing local resources.

Lastly, the eighth approach, the Parent Communication Network has been functioning in the South Bend, Indiana Community Schools since 1982. The initial purpose for the project included: 1) providing a means of genuine communication between the home and the school; 2) identifying the real needs and concerns of parents regarding any aspect of their child's education; 3) generating positive public relations and support for the South Bend schools; and 4) identifying community resources for both home and school.

The network has developed into an elaborate system of local school groups, a school district group, and a corporation level group.

In summary, these last eight projects listed the many and varied ways in which parents can become involved in their child's special education program.

Other types of parental involvement

Epstein (1984) developed a model of school and family connections that consisted of five types of involvement: (a) the basic obligations of parenting which includes responsibility for the child's health, safety and supervision, discipline, and learning at home; (b) the basic obligation of schools to communicate with the home; (c) the involvement of parents at school as volunteers, supporters, and spectators at student performances; (d) parental involvement in learning activities at home; and (e) parental involvement in school decision-making, governance, and advocacy.

Warner (1991) established a program entitled Parents in Touch because she believed it was necessary "to facilitate the kind of two-way communication that enables parents to stay in touch and to become partners with the schools in the education of their children" (p. 372). The issue of "parents as partners" must not be overlooked or forgotten when it comes to students with special needs.

Vandercook and York (1989) described in detail the MAPS process which was designed to:

> Provide a structure to assist teams of adults and children to creatively dream, scheme, plan, and produce results that will further the inclusion of individual children with labels into the activities, routines, and environments of their same-age peers in their school community. (p. 205)

The seven key questions in the MAPS process provided a structure for the team including parents, professionals, and peers to discuss the needs and services required by the individual. The seven key questions were:

1) what is the individual's history?
2) what is your dream for the individual?
3) what is your nightmare?
4) who is the individual?
5) what are the individual's strengths, gifts, and abilities?
6) what are the individual's needs?
7) what would the individual's ideal day at school look like and what must be done to make it happen?

Once the answers to these questions were clear, the team priorizes the actions to be initiated, identifies persons responsible, and establishes reasonable time lines for implementation.

As White et al. (1992) suggested, "no current discussion of parent involvement . . . would be complete without reference to the concept of empowerment" (p. 93). Cochran (1988), as cited by White et al. (1992), "suggested that empowerment occurs if there is a shift in the balance of power from being primarily in the hands of professionals to being substantially in the hands of the parents" (p. 93). These authors also reminded us that "empowerment is often discussed as if it was a new approach to parent involvement" (p. 93), but as several researchers including Mindick (1988), Rotter (1966), and Seligman (1975) "have long emphasized the importance of people's ability to feel like they are in control of the situation" (White et al., 1992, p. 93).

There have recently been a number of court rulings in the area of special education placement decisions. The Charter of rights and Freedoms, and the advent of self-help programs and advocacy groups have given rise to well-informed parents who are willing to challenge decisions made by professionals.

Increased Consumer Militancy

Peters and Waterman (1982) sparked the notion of consumerism within the public sector by examining private sector companies and discovering among other things that the most successful companies-- the "excellent companies"-- were those that were close to the customer. "The idea was picked up by the public sector, 'excellent companies' became 'excellent administrations', and the drive to remove the barriers between the administration and the consumer was on" (p. 10). When we talk of consumerism in the public sector, we are talking about ways "to increase efficiency, cut costs, improve image, enhance international economic competitiveness, motivate staff, . . . and more generally, improve the quality of public sector service" (p. 11).

Consumer complaints about service in the public sector include issues like: the lack of information about what services are available; the inaccessibility of public services; the apparent rigidity in public services; the little opportunity for consumers to obtain redress decisions in the public sector and the fact that there is little or no way of influencing the decision-making process. The problems facing the consumer in the public sector are analogous to the problems facing parents in the education arena. The Learning Disability Association of Canada (LDAC) and the Learning Disability Association of Alberta (LDAA) have been working with parents of learning disabled children for a number of years to encourage the parents to be "good consumers". The LDAA has recently published an Advocacy Manual which is "designed to provide basic information to help parents work more effectively with the school system in obtaining the best possible education for their children" (p. 1). The LDAA has also recently sponsored a number of workshops for parents on the Appeal Process. The purpose of the workshop was to assist parents of children with learning disabilities to become informed and involved parents in the education of their child.

An example of this fact was an article which appeared in the Edmonton Journal dated Tuesday, March 24, 1992, entitled "Parents fight for learning-disabled daughter", described Mr. and Mrs. Gajda's "fight to get their daughter the educational help she needs" (p. 1).

As noted earlier, in Alberta the Appeals and Student Attendance Secretariat revealed that Alberta Education is processing one case per week for the Minister because parents are appealing school board decisions regarding their child. To date, sixty-four reviews have been completed, with eleven still in process. Of these sixty-four, forty-one involved special education placement decisions. This information would indicate that to continue to ignore parents of children with special education needs, as consumers of special education services, is dangerous.

Advice for Parents

Whaite and Ellis (1987) in their book, From Me ... To You, provided some very strong advice for parents in their discussion of professionals:

> It may be hard to "hear" some of the things that are said and the presence of another person with whom you can discuss things afterwards may make this easier.
>
> You are entitled to information. Knowledge about your child's problem is your right, not a privilege.
>
> You, as parents, have a right to expect this from them (the professionals). If you feel you are not being given all the facts, ask for them.
>
> Ask questions.
>
> Don't take 'no" for an answer.
>
> Ask for explanations.
>
> You don't have to be 'eternally grateful' to professionals. They have chosen their career - they earn money and they have other options. You have a right to expect a quality service from them.
>
> Don't be in awe of professionals - they are people and must earn your respect.
>
> You CAN complain about an inadequate service but make sure that you complain to the right person, i.e., the person who can do something about it.
>
> Remember that professionals have a job to do and a responsibility to do it properly. (pp. 25-36)

Whaite and Ellis (1987) concluded by stressing the importance of teamwork and communication:

> Contact with professionals is an inevitable part of your life if you have a child with a disability. Both parents and professionals need to work to establish good communication with each other. Parents say that you may need to become more assertive in order to obtain the information and help that you need. (p. 35)

While this comment seemed negative, it was an indication of the framework from which parents have begun their involvement with professionals.

Parent Advocacy

Cutler (1981), in one of the first books devoted to parent advocacy, Unraveling the Special Education Maze, reminded parents that according to PL 94-142, that "your child (with special needs) is clearly entitled to a public education, and that both you and your child have rights recognized and protected by the law" (p.12). Cutler elaborated on the importance of knowing the educational system as well as both the effective and ineffective ways to deal with school personnel.

The author highlighted for parents the importance of collaboration, "in this process, the school people accept the parents as legitimate and equal partners in planning services, and respect and value the information and concerns that parents present" (Cutler, 1981, p. 74). Cutler cautioned parents to be aware of the difference between collaboration and co-optation when "you begin to sense that you are giving in or giving up more than you are getting" (p. 76).

Anderson, Chitwood and Hayden (1982) reminded parents that school systems and parents each have a planning cycle for children with special needs. The understanding of the two cycles and how they work is important for both parents and professionals as they work together in the best interests of the child. (See Figures 2.1 and 2.2.)

Now that we have looked at the issues parents have to address in the process of making decisions for their children with special needs, let us now discuss the strategies and issues for professionals.

Strategies for Professionals

There have been a number of books which have focussed on working with parents of children with special needs including Paul (1981) and Cunningham and Davis (1985). It would be impossible to begin to summarize the books in this brief discussion. However, there appeared to be some generally accepted principles which should be highlighted. Cunningham and Davis (1985) summarised one of the difficulties when they wrote:

> Professionals require a set of frameworks to help them make sense of parenting, families and reactions to handicap. They need some knowledge of the major characteristics of parenting and families in relation to well-being and development of the child. They need some conception of what parents' value in being parents and a framework to understand the likely reactions of parents having a child with special needs. They need a framework to determine how to help families to take action to prevent or reduce a problem. (p. 44)

Probably the single most important statement the authors made was, "there is little unequivocal knowledge in many of these areas, and so the frameworks discussed are necessarily general and cannot be imposed on individual parents or families" (p.44).

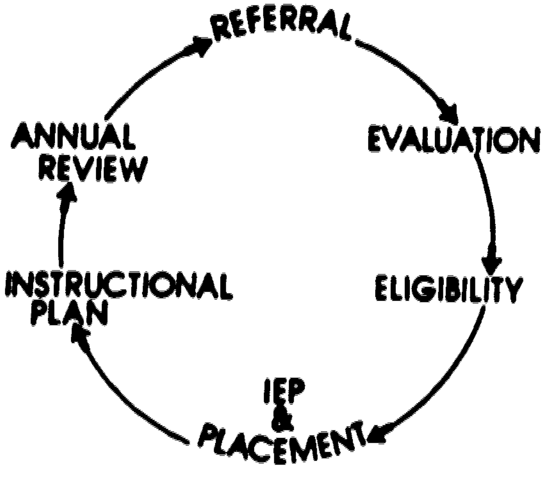

Figure 2.1 School System Planning Cycle

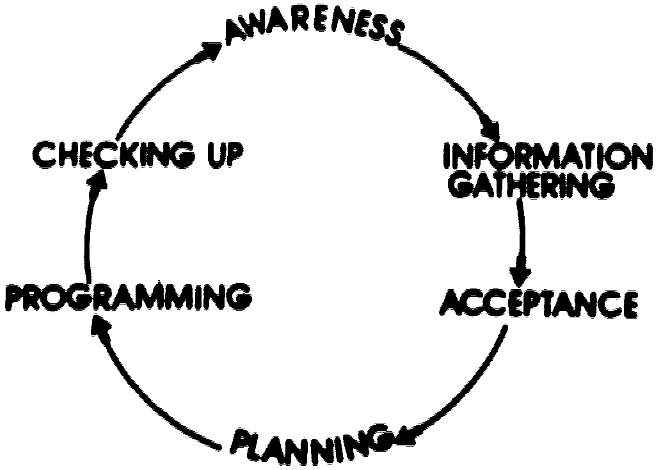

Figure 2.2 Parent's Planning Cycle

Note: From Anderson, W., Chitwood, S., & Hayden, D. (1982). Negotiating the Special Education Maze. Englewood Cliffs, NJ: Prentice-Hall, pp. 9-10.

Cunningham and Davis (1985) advocated that the Personal Construct Theory (CPC) as developed by McCoy (1977) be utilized by professionals to understand the emotional aspects of being a parent of a child with special needs:

> Concepts such as anxiety, threat and guilt are understood as the individual's awareness of change or imminent change in aspects of his/her construct system. They refer to the individuals' own constructions about the ways they are currently understanding events, and they are essentially related to the process of change in that understanding. They are not therefore seen as 'things' to be treated, stopped or prevented, but as functional in the process of reconstruction. (p. 46)

For professionals, the authors recommended that a process called the CPC cycle be utilized when working with parents. The CPC cycle, then, "refers to the stages of reconstruction in which alternative ways of viewing events are considered (Circumspection), particular ways of understanding are adopted and others rejected (Pre-emption), and events become sufficiently meaningful for a course of action to be plotted (Control). The CPC cycle can be used to explain the parent's feelings including anxiety, guilt, and threat, and attachment as it related to having a child with special needs.

At this point, the distinction between the terms "involvement" and "participation" became paramount as Cunningham and Davis (1985) reminded professionals that:

> In fostering active parental involvement with the child, the professional will need to delineate the current level of involvement and the 'natural' style of teaching used by parents. They should then try to build on this rather than impose a style that may be contrived. The style and the areas focussed on by the parent will depend upon how worthwhile they construe the knowledge or skill to be for the child and their constructions of the child's and their

> abilities. It is these aspects which are likely to be highly influenced by the recognition of the handicap in the child and, therefore require careful appraisal by the professional. (p. 53)

Paul (1981) reminded professionals that:

> Parents can participate in your program in many ways. First and foremost, parents should be involved in some of the basic program decision-making, perhaps as members of an advisory group. After all, the parent is one of the two main consumers of your services (the other, the child), and in one way or another is involved in financing the program. (p. 95)

Notwithstanding,

> This is not to say that parents should make program decisions unilaterally. You are the trained professional and should be able to provide alternatives for most aspects of your program. Parents will look to you for leadership in program decisions, and will expect it. In return, you should expect from them valuable assistance in program decision-making. (p. 95)

Probably the most significant factor in the entire section was stated by Paul (1981):

> Professionals should be reminded that handicapped children do not, in any sense, constitute a homogeneous group. They show considerable range in their abilities and feelings of ambivalence, as do their parents. The combination of the their unique attributes of all the family members, and the social circumstances under which they live suggest the need to individualize our approach to children. (p. 124)

Other professional issues

Unfortunately, as Gear and Gable (1979) discovered, most classroom teachers felt most confident in their ability to establish classroom climates conducive to accepting individual differences. Most teachers felt adequate in areas like classroom management, goal setting, and instructional strategies. However, most teachers in this study felt least confident in communicating with parents, students and colleagues regarding the goals of mainstreaming exceptional children. These teachers rated as inadequate their knowledge of special education and the use of resources for teaching children with special needs.

Sonntag (1982), in a study of special education preparation and administrative/supervisory roles of elementary school principals in Saskatchewan, concluded that "there was a significant relationship between principals' special education preparation and their perceptions of their activity level in administering and supervising special education services" (p. 110). Equally as important was the finding that "a similar significant relationship was found between the principals' special education preparation and their teachers' perceptions of the principals' activity level in the administration and supervision of special education services" (Sonntag, 1982, p. 110).

The lack of expertise from both the classroom teacher and the school administration has a serious and significant impact on the parent-professional partnership that must exist when we are talking about children with special needs.

Yoshida, Fenton, Kaufman, and Maxwell (1977), in a study of planning team members' attitudes about the kinds of activities in which parents should participate during the planning team meeting, concluded:

> Only two activities were selected by more than 50% of the members as being appropriate for parental participation: presenting information relevant to the case and gathering information relevant to the case. The remaining 22

> activities were said to be appropriate for parental participation by less than half of the planning team members. (p. 532)

Similarly, Gallagher, Beckman, and Cross (1983), in a study which identified a shortage of knowledge and understanding on the part of professionals about families of children with special needs, called for "research to focus on the family as the unit of study and for a 'families' focus in the training of teachers and other helping professionals" (p. 301).

In a more recent study, Ramey, Krauss, and Simeonsson (1989) commented on the increasing documentation of diversity in family adaptation for families with a child with atypical needs. The authors noted that family values, beliefs, social resources, and experiences significantly affect parenting stress and family adjustment and called for research in studying families that combined both qualitative and quantitative methods.

Summary Statement

Morgan (1986), in the introduction to his latest book Images of Organizations, argued that "our theories and explanations of organizational life are based on metaphors that lead us to see and understand organizations in distinctive ways" (p. 12). Morgan continued:

> We use metaphor whenever we attempt to understand one element of experience in terms of another. Thus metaphor proceeds through implicit or explicit assertions that A is (or is like)B. When we say 'the man is a lion', we use the image of a lion to draw attention to the lion-like aspects of the man. The metaphor frames our understanding of the man in a distinctive yet partial way. It is easy to see how this kind of thinking has relevance for understanding organization and management. For organizations are complex and paradoxical phenomena that can be understood in many

different ways. (p.13)

For the purposes of this study, the researcher viewed the parent-professional partnership as a shamrock. According to the *Gage Canadian Dictionary,* the shamrock is "any of various plants having leaves, composed of three leaflets" (p. 1030). For this researcher, the main or central leaflet would symbolize "the child with special needs". The supporting leaflet on one side symbolizes "the parent" while the leaflet on the other side would symbolize "the helping professions". The intent here is to help the reader keep in mind "the child with special needs", while focussing primarily on the parent-professional partnership as symbolized by the shamrock. Using this symbolism, let us investigate the nature of the parent-professional partnership.

The Nature of the Parent-Professional Partnership

The debate continues as to who is responsible for providing care to society's disabled children and adults, the parent or the professional. Schulz (1985) maintained that "as we grow in our understanding of the needs of the child, hopefully we will realize that the handicapped child is dependent on the cooperation of concerned parents and professionals" (p. 9).

Paul (1981), in an entire section dealing with parents and professionals, made several suggestions which must be highlighted:

> They (the parents) have already had an intense history with their child. They may be concerned with issues of placement and advocacy. They may have already built a number of defenses to protect themselves and their children against negative experiences with the outside world. (p.124)

The parent-professional relationship must deal with many issues. The availability and the quality of the services is only one issue. Parents must decide:

> How to use the services, how to relate to professionals, how to understand complex technical vocabularies, and in the midst of it all make peace with their own feelings of ambivalence about their child. In many instances, this involves feelings of guilt and failure.
> (Paul, 1981, p.124- 125)

Moroney (1981) argued that "any unnecessary intervention (by the State) in family life will harm both the family and the State (p. 184). This unneccessary intervention would not only undermine the fabric of the family but it could be interpreted by the family as an invasion of privacy. A good example is in the area of mental retardation.

Approximately seventy years ago, as Moroney (1981) chronicled, "parents of retarded children were viewed as deficient insofar as retardation was believed to be genetically transmitted" (p. 184). Children at that time were removed from the home and the community and placed in an institution.

> Twenty five years ago, certain aspects of this policy were modified but the outcome was essentially the same. While parents were not seen as defective in the sense that they were to blame, they were not accepted by professionals as capable care-givers. (Moroney, 1981, p. 184)

Turnbull and Turnbull (1986) believed that the eugenics movement "contributed greatly to the view that parents are the source of a child's disability" (p. 2). In fact, the authors devoted an entire chapter to the historical development and the current roles of parents. The researchers categorized parents as fulfilling roles in a number of groups including: parents as organization members; parents as service developers; parents as recipients of professionals' decisions; parents as learners and teachers; parents as political advocates; parents as family members; and parents as educational decision-makers.

Turnbull and Turnbull (1986) concluded that "given their children's right to an education and their rights as parents, parent-professional relationships have become more equal, and parents by and large are justified in believing that they can help shape their children's present and future capabilities" (p. 17). Turnbull and Turnbull (1986) summarized the current parent-professional partnership by stating "expectations and philosophies have drastically changed since the eugenics movement and the initial formation of parent organizations" (p. 22), but some professionals have continued to experience a "parent-role jet lag" in terms of their work with parents.

Stainback and Stainback (1990) supported the important role that parents play when it comes to children with special needs:

> Professionals will come and go in a student's life, but family members are a constant and have a long term investment in the quality of life the child is experiencing. Integral involvement of family members can assist in achieving continuity of programming over time. Educational priorities identified by family members, therefore, should receive primary consideration. (p. 99)

Schaffner and Buswell (1991), in discussing collaboration and collaborative teams, also supported the important role of parents:

> The inclusion of the student's parents on the team is important. Parents are the primary advocates for their children. Their commitment to the child's success extends

> beyond concern for current schooling to the big picture of the child's life and future. (p. 10)

Urbano (1992), delineated the roles of both parent and professional in dealing with preschool children with special health care needs:

> Family members have the ultimate responsibility for decisions that will affect the life of the child with special health care needs. It is the responsibility of all professionals to help the family by practicing family centred care. . . . To practice family centred care, professionals must first understand family responses to living with a child with special needs, factors that influence adaptation, common family concerns, and recommended professional strategies for helping to meet family concerns. (p. 59)

Thousand and Villa (1989) made a strong case for the role of the parent on the team when they cited a parent's view: "Parents should be thought of as scholars of experience. We are in it for the distance. . . . We have our doctorate in perseverance. We and the system must be in concert or the vision shrinks" (p. 4).

It appears obvious from the literature that both the parent and the professional must be working together as a team if the child is going to be encouraged to be the best that he/she can be.

Frameworks for the Parent-Professional Partnership

Various frameworks for viewing the parent-professional relationship are discussed by Cunningham and Davis (1985). The three frameworks included: the expert model; the transplant model; and the consumer model. For the expert model, the authors believed:

> Professionals use this model if they view themselves as having total expertise in relation to the parent. Here

> essentially professionals take control and make all the decisions. They select the information that they think is relevant to the parent and likewise elicit only that information that they feel is required. (p. 10)

Here the professionals see the parent's role as that of carrying out the instructions given by the professional. Ley (1982), as cited by Cunningham and Davis (1985), found in these situations that the parents were reluctant to question the professional, and that there were distortions of understanding with the resulting high level of dissatisfaction and noncompliance. The parent's feelings of dependency and helplessness increased the demand for professional services and decreased the parent's ability to help the child.

The second model was labelled the transplant model by Cunningham & Davis (1985) because "professionals are using this model when they view themselves as having expertise, but also recognize the advantage of the parent as a resource" (p. 12). For example, if a child is in need of physiotherapy, the professional would provide the exercises for parents to use with their child. Here the professional retains control of the decision-making as in the expert model, but views the parent as an extension of the services. As Cunningham and Davis (1985) noted, "this recognition of the relative competence of the parents is likely to reinforce their self confidence and adjustment, as is their active involvement in helping their child" (p. 12).

For the authors, the consumer model was in evidence when "professionals using this model view the parent as a consumer of their services" (p. 13). For the parents it means that they have the right to decide and select what they believe is appropriate for their child. In this type of relationship, the ultimate decision- making authority is in the parent's control. The professional is to provide a range of options and the necessary information. "The professional respects the parents and acknowledges their competence and expertise in knowing more about their total situation than anyone else" (p. 13). Here it is the professional's responsibility to listen and help the parents as a consultant and as an instructor would do. Since it is the parent's ultimate responsibility to make the decisions, the decision-making process must be founded on a basis of honest, mutual respect for each other.

Unfortunately, as Cunningham and Davis (1985) suggested, "in much current parental involvement, the flow of information is largely one-way from the professional to the parent, from the school to the home" (p. 13). In these situations, it is clearly the professional's responsibility to negotiate all avenues of the decision-making process.

Using the consumer approach, the professional is "less likely to treat parents as a homogeneous group or to impose one approach as a solution to family needs" (p. 14). It is apparent that this approach requires flexibility in terms of meeting individual student and family needs. The other advantage is that there is a built-in evaluation process because there is an emphasis on understanding and meeting the needs of the consumer.

In this sort of parent-professional relationship, the parent's rights and expertise are accorded equivalent status in the relationship with the professional. For the professional, the two keys to success in this relationship are the professional's ability: to establish a negotiating process, and to help to locate suitable solutions to issues. Much of this discussion has involved the professional's perspective on the parent-professional relationship, but what are some of the parents' views on the issue.

Parent Views of the Parent-Professional Partnership

According to Whaite and Ellis (1987), professionals are those:

> whose job it is to assist you (the parent) and your child in a number of different ways. Depending on their particular area of expertise, their aim is to assist as much as possible in the diagnosis, treatment, and well-being of your child and your family. (p. 25)

Several books have been written by parents of children with special needs (Anderson, 1989; Pivato, 1990; Seligman, 1979; Turnull & Turnbull, 1978, 1985). These books included chapters and even sections where parents have expressed their views of battles, struggles, and successes with professionals. Many of the books have been very prescriptive, almost to the point of being a cook-book approach to assisting parents to get the assistance their children need. Some of the issues addressed included: deciding which professionals you need; making the most of your appointments; seeking information/strategies; asking for help; child and parent rights, assertiveness training, etc. All these books used parents' personal stories and/or case studies about children with special needs to describe their child's situation, and their involvement with professionals including school personnel.

It was certainly noticeable that the more recent books devoted more attention to the legal rights of children and their parents. Lillie and Place (1982) devoted a section and step by step lessons on issues like "When Parents and School Disagree". The authors also discussed the due process hearing, their rights (as parents) to due process, and what to expect after the hearing. The format Lillie et al. followed was usually: a summary of the parent's right, one or two exercises on the concept being developed, as well as an evaluation format to ensure that the concept was understood.

Many of the latest court cases have been reviewed in considerable detail, including the implications for the Canadian *Charter of Rights and Freedoms* (1982).

In the introduction to *Changing Canadian Schools*, Fullan (1991) acknowledged:

> The book contains many ideas for strategies and practical suggestions for success. It combines advocacy with insight, and demonstrates that both will (persistence) and skill (good strategies) are needed for success. There is no other book of its kind in Canada that provides such a timely and comprehensive account of the state-of-the-art of special education reform. (p. i)

McCallum (1987), in her story describing the power of parents, forcefully concluded:

> The power of parents to act on behalf of their children is based on the child's constitutional and legal guarantees.

> Where the goal is inclusion, the power of the parents is inexhaustible. It will continue to whittle away at the barriers that persist in practice and in law. Those who resist the inevitable transition to integration should recognize that because the power of parents is exercised in the name of equality, it will prevail. (p. 71)

While the quotation specifically related to integration, the potential power of parents must not be overlooked in any situation involving special education decision-making.

Turnbull and Turnbull (1978) realized the power of parents and the importance of teamwork in discussing the parent-professional relationship:

> Articles, books, and lectures dealing with the education of handicapped children seem to agree wholeheartedly on one point: the team approach is indicated. While the composition of the team may vary with the disability, the discipline, or the situation, usually the classroom teacher and the parents are prominent members. This is certainly appropriate, for who spends more time and energy with the handicapped child than the teacher and the parents? Who is more involved, more concerned, more knowledgeable? (p. 29)

In their more recent book Parents Speak Out, Then and Now, Turnbull and Turnbull (1985) succinctly summarized the issues facing the parent-professional partnership: "There appear to be two factors crucial to any effective parent-professional interaction: communication and respect. While these elements are essential to any relationship, they seem to be missing in many of our parent-teacher confrontations" (p. 5).

The authors devoted considerable time to the importance of good communication in the partnership but they also reminded us as professionals that "Communication can be facilitated; respect has to grow. Parents of handicapped children are subjected to constant humiliation; it is incredible that much of it comes from persons engaged in the 'helping' professions" (Turnbull & Turnbull, p. 6).

These authors concluded that "part of the block to understanding and respecting parents may come from the age-old, hopefully changing idea that the professional knows everything. We have particularly elevated the physician and the college professor into positions of unerring wisdom" (p. 6). These statements were viewed as startling by the present researcher considering that the authors as professors were also parents of a handicapped child.

In an effort to further develop the parent-professional partnership, Turnbull and Turnbull (1985) offered these suggestions:

1) professional behavior must be tempered by humility,
2) most formal training programs are extremely limited in preparing professionals to interact meaningfully with parents of special needs children,
3) when professionals interact with parents, respect is a necessary ingredient,
4) a parent-professional partnership is essential if handicapped children are to be provided with opportunities to reach their full potential, and
5) too often the need for handicapped children to have personal relationships outside the family is overlooked (Turnbull & Turnbull, 1985, p. 131-134).

The parent-professional relationship is a complex set of interactions that can become confrontational and adversarial if both parties are not working as a team.

What happens when the partnership doesn't work?

So what happens when the parent and the professional disagree about what is best for the child? It may be at this point, as Cutler (1981) suggested, that:

> You (the parent) will shift to a process which involves not only information and assertiveness, but which requires the continued use of strategies and the frequent presence of someone who is willing to back you up at meetings, either as a witness to the proceedings and a silent supporter, or a contributor of suggestions. (p. 77)

Cutler (1981) reminded parents that in the process of negotiation, "the mark of a successful parent advocate in the process of negotiation is the skill to obtain more than you give away, through the judicious use of strategies and compromise" (p. 77).

Cutler referred to the notion of the 'squeaky' wheel when she encouraged parents to be persistent, "after enough parental squeaks and a growing awareness on the part of the system that the squeaking won't go away until something, services, like grease, are usually applied. Negotiation determines how much 'grease' is used" (p. 77).

It was hoped that the parent-professional partnership can resolve many of these difficulties for parents:

> Such as arranging a time to visit the classroom, setting an appointment to read the child's records, and finding a mutually convenient time to meet with the child's teacher, (but) the most intensive and challenging negotiation will usually happen in the meeting(s) when the IEP is developed. (p. 78)

Cutler had several suggestions for parents at this stage of negotiation: a willingness and determination to share the information they have; a readiness for honest disagreement, discussion and compromise; and "a strong belief in your ability to make a valuable contribution to your child's IEP" (Cutler, 1981, p. 78). She also suggested:

> You at least need to hear the ideas, suggestions, and criticisms of the school people before you can make a rational decision to accept or reject their recommendations. Therefore remain open to suggestion, and even disagreement, as long as the process is an honest one, meaning that everyone is at least trying to understand what the other person is proposing.

In order for the process of mediation to be successful, Gallant (1982) recommended that:

> One of the serious considerations that must be faced if mediation is to become part of special education due process regulation is the need to have senior administrators who are in favor of the process. (p. 21)

Lillie and Place (1982), in the first lesson with respect to the issue of when parents and school disagree, suggested that if the process of negotiation does not proceed as the parents expected and the parents continue to have major concerns with regard to identification, evaluation, or program placement for their child, then the parents should seek another meeting with those involved in the dispute. It would be appropriate before this meeting for parents to write down all their concerns.

If, at the conclusion of this meeting, the parents are still dissatisfied and an agreement cannot be reached, the most logical solution would be for the parents to request mediation with some impartial person who would conduct a session to discuss the dispute. Baine (1988), wrote an extensive article on the mediation process in which he described the various steps in the process of mediation. However, as Lillie and Place (1982), noted "this mediation . . . may not be used to deny or delay your right to a due process hearing" (p. 66).

Gallant (1982), in his book, Mediation in Special Education Disputes, has attempted to circumvent the more adversarial parent appeal hearings by suggesting:

> The adversarial nature of such hearings exacerbates the antagonism that so often exists between school personnel and parents. The destructive aspect of many special education hearings has led to the exploration of a more positive optimal form of dispute resolution - mediation, a process by which disputants, guided by a neutral third party, seek the common ground between them as a basis for the resolution of their disagreement. (p. 1)

Gallant (1982) recommended that parents at this stage of negotiation should commit their questions to writing and the questions may be any or all of the following:

1) Why is referral indicated for special education?
2) How is the problem described in specific terms?
3) What are the child's achievements?
4) What assessments or diagnostic tests have been utilized?
5) Is a date set for formulation of an individualized education program?
6) What are the short term objectives?
7) How will the long term objectives be established? When?
8) When will the final plan for the IEP be implemented?
9) How will the evaluation be determined?
10) Who will report on the program and evaluation results?

11) Who is the coordinator or contact person to report to the parents?

12) Have due process procedures been explained clearly step by step with time lines and written notices explained?

13) What is the student's level of instruction as determined by daily instruction or diagnostic evaluation?

14) Are yearly achievement levels comparisons available?

15) What are the norms being used and have they been compared carefully?

16) Why does the behavior or achievement necessitate special programming?

17) How is the least restrictive environment determined for this child?

18) What are the necessary components that involve the parents?

Are they spelled out? (Gallant, 1982, p. 10, 11)

With such an array of concerns, it is no wonder that parents come to such meetings with many questions.

Gallant (1982) concentrated his efforts on exploring and developing both the parents and the school personnel's point of view in the mediation process. The first section was advice for parents:

> The mediator needs to recognize the desire to win that some administrators and parents feel. (Gallant, p. 11)
>
> Many parents look to the law for a solution to all their problems. (p. 12)

> Parents must try to understand that handicapped children must receive an 'appropriate' special education program, not the best' program. (p. 12)
>
> Another major factor that must be confronted (by the parents) is the unfeeling or 'all business' manner of some school personnel. (p. 12)
>
> Mourning for a handicapped child is usually necessary if the parents are to develop a mature approach to the problem. However, if any part of the process of mourning has been skipped, the mechanisms of projection, rejection, manipulation, and especially of denial are often used to resolve the pain. (p.12)

Patterson (1978), as cited by Gallant (1982), reported on the role of denial in this context:

> Denial is a powerful force that allows people to collect themselves in the midst of a painful situation. In effect, it serves as a protective device that leads individuals to a gradual, constructive recognition of reality. In most cases, denial is a temporary defense that is soon replaced by partial acceptance. However, all parents have hopes and dreams for their offspring, and adjustment to more limited dreams is a difficult transition for all people. (p. 68)

Gallant (1982) then elaborated on some of the characteristics of some school personnel:

> School personnel with limited staffs and budgets recognize the impossibility of satisfying the spirit of the law.
>
> School personnel sometimes use techniques such as stalling, blocking, or resistive behavior. (p. 12)

Because parents of special needs children are so vulnerable, it is not uncommon for them to experience many other emotions including loneliness or even lack of patience when no one responds to their concerns. For as Paul (1981) remarked "parents who are hurt have the capacity for strong feelings: appreciation as much as anger, acceptance as much as resentment, and when there is healing and hope, joy as much as despair" (p. 125).

According to Paul (1981), parents have frequently reported:

> The most important aspect in their encounter with a professional is that person's sensitivity to them and the needs of their child. The personal and professional quality of the encounter may well be more important in the immediate situation than the technical services that are provided to the child. (p. 125)

The professional who sees the long-term benefit of a technical service being provided, such as physical therapy, for example, and considers the need to be sensitive to the feelings and perspective of the parents as unimportant, is indeed shortsighted. (p. 124)

In order for this parent-professional partnership to be beneficial for the child:

> The sensitivity of the professional brings dignity and integrity to the moment for the parent. It is a condition - a prerequisite - for professional treatment. Parents who remember their encounters with professionals remember first the quality of the relationship, the feeling of being respected, and of having input that was unique and useful. (Paul, 1981, p. 125)

Urbano (1992) in a chapter entitled 'Working Collaboratively with the Family' had several suggestions for professionals:

1) respect the family as a unique unit;
2) listen to families;
3) accept variability in family interest, coping styles, and degree of involvement;
4) include families as equal partners in all activities related to needs assessment, planning, and evaluation;
5) provide full and clear information to families;
6) assist the family to find support networks. (p. 71-74)

Settle (1992), in an article to professionals who are working with parents of handicapped children, gave four specific suggestions:

1) listen to parents;
2) treat each family differently, but all need support and information that must be given openly;
3) sensitise yourself to your own biases and beliefs;
4) enter into the family system.

For this researcher, according to Settle, there was additional advice, "These (children with special needs) are not 'yes' or 'no' children. When they (the parents) are asked a question, don't expect a yes or no answer. Be ready for explanations, stories and listen. The repercussions can be very big if a child gets another diagnosis or label assumed" (p. 12).

Urbano (1992) also quite clearly described for professionals, various family responses to learning when a child in their family has special health care needs. The author described the various responses in terms of stages. First, there was a state of shock as a family finds out that a member has an unexpected difficulty. Second, there is a stage of denial when a family does not want to admit or accept that their child will not have a normal life.

> The next stage is characterised by sadness, anger, guilt, and anxiety. During this stage, guilt and self accusation may be apparent. Parents generally anticipate nothing less than the perfect child. The process of grieving the 'loss of the perfect child' often results in guilt and related alterations in self-esteem. (Urbano, 1992, p. 61)

The fourth and final stage is adaptation when according to Gallo (1991), as cited by Urbano (1992), the family seeks to develop a new sense of balance in the family system.

(Urbano, 1992, p. 64) was quick to remind us as professionals:

> Although families agree that these stages are valid, they hasten to note that they are dynamic. Progression may not be made from one stage to another in sequence. Indeed, families frequently move back and forth between stages and may share elements of several stages simultaneously. Thus, it is critical to be sensitive to the needs of the family at the present and to accept frequent changes in family response.

Turnbull and Turnbull (1986) have conceptualised the complexity of working with families who have children with special needs. They have developed a model of family systems theory which has four key components: family resources, family interaction, family functions, and finally, family life style. Turnbull and Turnbull's (1986) model is diagrammed in Figure 2.3.

Turnbull and Turnbull (1986) concluded this informative discussion by suggesting:

> The same concept of individualization embraced by the field of special education as pertinent to children and youth also applies to parents and other family members. A family systems philosophy suggests that an understanding of family resources, interaction, functions, and life-cycle can serve as the basis of meaningfully individualising parent-professional relationships for the benefit of all concerned - the child, parents, other family members, and professionals. Furthermore, we can begin to consider family-professional relationships rather than merely parent-professional relationships. (p. 21)

Yoshida and Gottlieb (1977) developed an earlier model which identified the variables related to parental participation in the decision-making process. These three phases of parental participation included: the input phase, the process phase, and the product phase.

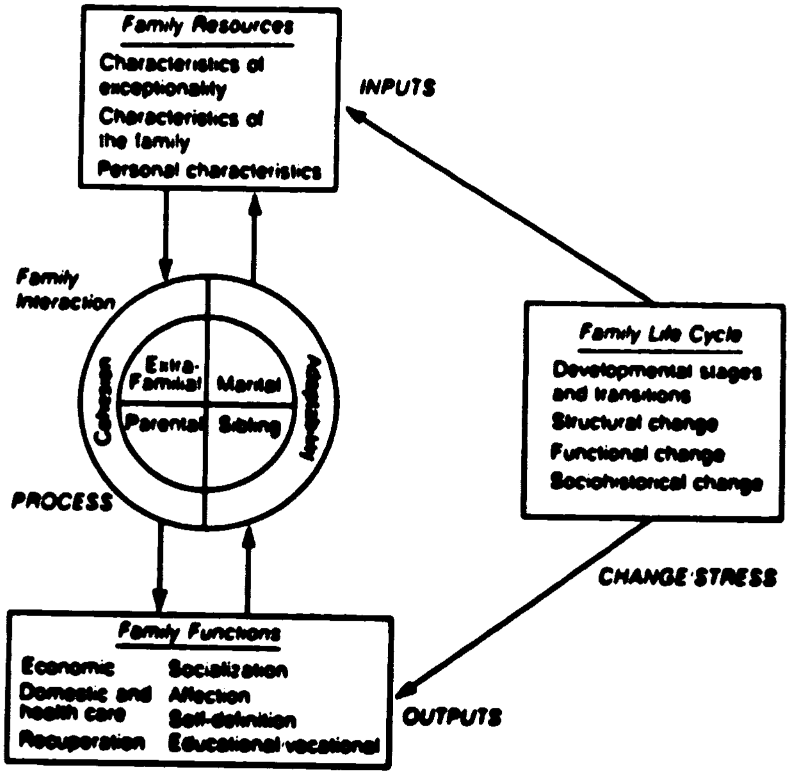

Figure 2.3 Family Systems Conceptual Model

Note: From Working with Families with Disabled Members: A Family Systems Approach (p. 60) by A.P. Turnbull, J. A. Summers, and M.J. Brotherson, 1984, Lawrence, KS, Kansas University Affiliated Faculty, University of Kansas.

Within each of the phases, the authors suggested various roles which the parents could assume. For the input phase, the parent role could be one of permission-giver, information-giver, or preference-giver. For the process phase of the model, the parent's role could be one of outsider, passive participant, or active participant. For the product phase, the single role for the parent would be that of legitimizer. The authors believed that if schools used this model to involve their parents in decision-making for their children with special needs, there would be less likelihood of the parents rejecting the school placement decisions as readily. They also believed that using this model would assist in helping parents become more receptive and less hostile to school demands. Finally parents may be taught ways to deal with the child at home. As Yoshida and Gottlieb (1977) concluded:

> These efforts to increase parental involvement in determining the educational placement and programming of theirchild focus on legal procedures which must necessarily be followed. However, fulfilling legal criteria should not beequated with remedying the fundamental problem which due process was intended to relieve. Do these procedures result in educationally sound practices which increase the student's achievement and adjustment? Until this question is answered postively professionals and laymen alike should be cognizant that improvement in due process procedures does not necessarily imply a concomitant improvement in educational performance among those the litigation and legislation was designed to help most - the child. (p. 20)

Gallagher (1981) as cited by Paul (1981), discussed eight future trends which will significantly impact on the interaction between parents of children with special needs and professionals: the family in flux; parental interaction with professionals;

the cultural influence; parents and the law; parent capabilities; social values and family policy; the fallible family; and models of the family. Gallagher admitted that while the model below seemed simplistic in form, the interacting forces that are brought to bear on the family with a child with special needs are very complex. (See Figure 2.4.)

> Within the helping professions there are the wide variety of disciplines that the family must deal with - pediatricians, educators, psychologists,, etc. - each with their own idiosyncracies to which the family must adapt. There are substantial interrelationships between all the dimensions of the model. The child impacts on the family and professionals; through legislation and guidelines the society can influence professionals, families, and children. (Gallagher, 1982, p. 266)

Gallagher concluded his remarks on the parent-professional relationship by suggesting:

> It has been traditional for the professional to operate under the self-illusion that they are motivated by doing what is best for the client at all times. (p. 270)
>
> The need for power and dominance, for example, to control other people is not an unknown force in the professional-parent relationship. The need for the professional to appear all-wise or all-powerful is one that does not stand up well under the close scrutiny that comes from more intimate parent/professional relationships. A healthier relationship will emerge, if the professionals understand their own, less than perfect needs and adjust to them just as they ask the parents to adjust to their needs. (p. 267)
>
> It is vital to be specific and to use language that parents understand. (This advice is in italics because of its importance).
>
> There is a feeling of resentment on the part of some school personnel that hinders their ability to listen to parents.
>
> Some of this is a refuge from parents' demands, which can be overwhelming.

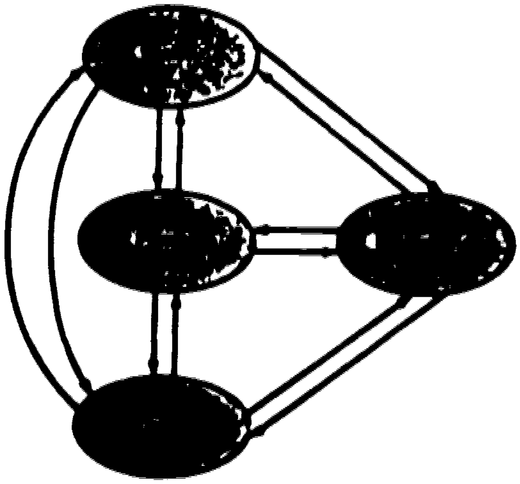

Figure 2.4 Interacting forces on Family of Handicapped Child

Note: From Gallagher, J. J. Future of Special Education. In Paul, J. L. (1981) *Understanding and working with parents of children with special needs*, p. 266.

> School personnel must have ongoing in-service training because new concepts and research emerge constantly.
>
> School personnel sometimes need help to resist powerful parents who want an inappropriate education for their child. (p. 269)

Key Issues for Parents of Children with Special Needs

Wilgosh (1990), in studying issues in education and daily living for families of children with disabilities, concluded "I strongly support . . . the value of both quantative and qualitative research in increasing our understanding of families with children who have special needs" (p. 300). This author identified six major themes common to families regarding their child's disability, "using typical parent quotations to demonstrate some of the richness and variety within the themes" (p. 300). The following is a major discussion on the Wilgosh study. Its relevance to this particular study is self-evident.

The first theme in the Wilgosh (1990) study was coping with knowledge of the child's disability. Wilgosh highlighted:

> The parents all reacted with strong feelings to being told that their children had disabilities. However, the parents' reactions were at least partly affected by the way they were given the news, by how long it took to confirm the disability, and by difficulties finding information about the disability and about how to cope with each child's special needs. (p. 303)

Wilgosh (1990) agreed with several other researchers including Blacher (1984), Allen and Affleck (1984), and Glendinning (1983) when she stated:

> We have found that parents seem to go through active adjustment to increasing life demands, rather than going through stages of grieving up to final acceptance. The idea of acceptance is too simple to explain how parents

> will adjust; they will have many feelings, affection as well as regret, making realistic plans once they are certain about the disability, while fantasizing about other possibilities. (p. 302)

In addressing the second theme, support services through a team approach, Wilgosh (1990) stated:

> The families may need direct support and assistance with caregiving. They may also need emotional support from professionals and parent support groups to help them deal with personal and family stresses. Parents want to have a parent-professional partnership of open discussion with knowledgeable and caring professionals who take the time to listen to them. (p. 304)

With respect to advocacy and parental initiative, the author summarized the parents' views:

> Many of the parents believe that their child's educational and other opportunities have been determined through the parents' initiative and have a sense of mission, direction, or purpose as a by-product of their efforts to raise their child (with special needs). (p. 304)

In fact, in the Wilgosh study, she included one of the most profound parent comments:

> I really didn't know, when I became a mother, that I was supposed to be a warrior. I thought, "nurture", not "battle." Yet as I am talking, I am aware that I need to fight if I want things to change. (Wilgosh, 1990, p. 304)

In discussing theme four which involved the parent's search for the best educational opportunities, Wilgosh found:

> Parents believe strongly that an excellent teacher leads to school success for children with special needs, and that both the personal and professional qualities of the individual teacher are important to success. (p. 304)

In addition, "parents appreciate honest and open feedback from teachers and want to be actively involved with the school" (p. 304).

Parents expected that:

> Children with disabilities have special needs which must be considered by the school. Foremost, they need sensitive and competent teachers who can respond to each child's needs, who don't reject the child because of the disability and can work in cooperation with the parents. Parents feel angry and frustrated because of difficulty finding good programs. Forsome children, attending special programs requires long hours of travel. In some cases, programs may not exist because of high costs, or because teachers have not been trained to teach children with special needs. (Wilgosh, 1990, p. 305)

Wilgosh also found that having a special needs child in the family has both positive and negative effects on the family. Featherstone (1980) wrote, as cited by Wilgosh,

> The child's disability amplifies problems in ordinary families and makes the parents more vulnerable to stress and conflict, particularly when they are feeling tired, afraid, or angry.
>
> Many parents feel guilty because this (search for services) may leave less time and energy for other family relationships.
>
> Parents may need to disentangle their feelings about the disability from their feelings about their marriage, and that, although some marriages will fail, most will survive. (p. 306)

In discussing the future of the child with special needs:

> Parents may feel optimistic about adult independence for children with mild disabilities. On the other hand, parents worry about the work training, community employment, and independent living opportunities for children who have moderate to severe disabilities, particularly when the parents are too old to be the primary guardians for their children. (Wilgosh, 1990, p. 307)

Wilgosh concluded this very significant study by highlighting the needs of families' with children with special needs:

> Training for medical and other helping professionals and teachers to avoid the lack of sensitivity and lack of knowledge experienced.

> It is important to recognise the ongoing nature of the stress and other feelings experienced by these families and the absence of stages of adjustment. Counseling them to go through stages of grieving to acceptance is too pat an answer to their needs.
>
> Parents want to be accepted as partners in the task of providing for the development of each child's full potential.
>
> Parents have described the qualities of good teachers. They value teachers who show respect for the child and focus on the child. They also value teachers' qualities of patience and sensitivity, dedication, knowledge, and understanding of the needs of the child and family
>
> We cannot ignore the need to provide all student teachers with special education training, particularly in assessment and development of individual program plans, in classroom management, and in parent-professional relationships. (p. 308)

Summary of Chapter 2

As discussed at the outset of the chapter, the researcher viewed the parent-professional relationship as a shamrock. As with the shamrock which requires sunlight and nourishment to sustain itself, the parent-professional partnership requires similar care and attention if it is to be productive. At this point, the literature review has attempted to highlight the complexity of the parent-professional partnership. It has also pointed out the need for further research into this phenomena.

It is with this background that we begin the study of parental involvement in the process of making educational decisions regarding their child with special needs.

Chapter 3

Research Design

The purpose of this chapter is two-fold. First, a brief description and validation of the rationale for qualitative research is outlined. Second, the application of that rationale to the method of data collection and analysis used in this research study is also discussed.

Orientation

This study can best be described as descriptive/exploratory research. Descriptive studies involve the description of "what is" (Borg & Gall, 1989) and the intrepretation of the meaning or significance of the phenomena (Verma & Beard, 1981). A descriptive study may take many forms including surveys, case studies, developmental studies, or comparative studies. This study was designed to survey the situation regarding parent participation in educational decision-making in Alberta as it relates to the child with special needs.

Bogdan and Biklen (1982) described qualitative research as "an umbrella term to refer to several research strategies that share certain characteristics" (p. 2). According to these researchers,

> The data collected has been termed soft, that is, rich in description of people, places, conversations, and not easily handled by statistical procedures. Research questions are not framed by operationalizing variables; rather, they are formulated to investigate in all their complexity, in context. While people conducting qualitative research may develop a focus as they collect data, they do not approach the research with specific questions to answer or hypotheses to test. They are concerned as well with understanding behavior from the subject's own frame of reference.

> External causes are of secondary importance. They tend to collect their data through sustained contact with people in settings where subjects normally spend their time. (p. 2)

Husserl, a German philosopher, is credited with this research method, which is an approach designed to understand and interpret human behavior. One of the most common methods used to capture the experience of a particular phenomenon is to engage in a dialogical interview with the individual or, in this case, the parent, who described the phenomenon as experienced. These tape-recorded, real-life experiences of the parents became the raw data for analysis. Bogdan and Biklen (1982) would define these interviewees, the parents, as key informants because "they are more willing to talk, have a greater experience in the setting, or are especially insightful about what goes on" (p. 63). In order for the researcher to ascribe meaning to the raw data, he/she must put aside all presuppositions or prejudgements about the topic. The researcher strives to achieve a state of being presuppositionless (Polkinghorne, 1981), which is accomplished by a process of bracketing. The researcher searches for his/her personal assumptions about the data, lays out the assumptions, and then attempts to look at the data with a fresh approach. This form of content analysis requires the researcher to continually bracket and rebracket his/her personal bias in an effort to extract the true meaning from the data as intended by the interviewee.

In summary, qualitative researchers have attempted to explore a particular question in its entirety by going to the source of the data, which in this case was the parents themselves. After a careful and systematic analysis of the descriptive data contained in the interviews, conclusions about the phenomena studied were extracted from the descriptions of the parents' experiences.

The purpose of the study

The purpose of this study, then, was to investigate the experiences of two groups of parents in their efforts to become involved in decisions that related to their child's special education program. As a result of a lack of research information in this area, many professionals are either overlooking or ignoring the parent's right to be involved in making decisions which have a direct impact on their child or their family.

Type of study

The multi-case study scheme was utilized for this research since more than two subjects will be studied (Bogdan & Biklen, 1982:65). This strategy was used primarily because the study involved the aggregation of a number of individual case studies. Lincoln and Guba (1985), as cited by Bottas (1988), suggested, there are many advantages to a case study approach:

> 1) The case study is the primary vehicle for emic inquiry. The naturalistic inquirer tends toward a reconstruction of the respondents' constructions.
>
> 2) The case study approach builds on the readers' tacit knowledge of the world rather than being mere abstractions of the same.
>
> 3) The case study is an effective way to demonstrate the interplay between the researcher and his respondents.

4) The case study provides the reader with an opportunity to probe for internal consistency.

5) The case study provides a "thick description" of the event so necessary for judgments of transferability. (p. 359-360)

This technique was also recognised by Miles and Huberman (1985) when they acknowledged that:

> Multi-site studies are especially appealing because they can purposively sample, and thereby make claims about, a larger universe of people, settings, events, or processes than can single-site studies. (p. 37)

In this study, the multi-case study provided an opportunity for 14 parents, 10 families, to express their views on the process of education decision-making for their children.

Participants in the study

The two groups of parents involved in the study were the Gateway Association for Community Living and the Learning Disabilities Association of Alberta.

The former association is composed of parents whose children had severe to profound special needs. It was incorporated in 1975 as the Gateway Association for Community Living. Its members had at one time belonged to the Edmonton Association for the Retarded. However, they broke away and established their own organization because they had a different philosophy regarding education. The Gateway members oppose the segregated classroom environment and believe that total inclusion is best for their children.

The latter association, the Learning Disabilities Association of Alberta, is composed of parents whose children did not suffer from physical or mental disabilities but were children who learned differently. In other words, these students have at least average to above average intelligence as measured by a standardized intelligence instrument but who continue to have difficulty learning in school.

The Alberta Association for Children with Learning Disabilities was formed in Edmonton by a group of parents in 1968. At that time, the group received a charter and was registered under the Societies Act. However this group never functioned as a provincial organization. In January 1974, representatives from seven local branches met to discuss reactivating the Alberta ACLD. In 1981 a national association was formed and adopted the name Canadian Association for Children and Adults with Learning Disabilities. The Alberta Association followed suit during the same year. In 1985, the national association changed its name to Learning Disabilities Association of Canada (LDAC) and a year later the provincial association became the Learning Disabilities Association of Alberta. The basic aim of the association is to provide support and counsel for learning disabled persons and their families and to secure provision of services required to enable these persons to realize their potential. In Alberta at present there are 20 chapters with a total membership of approximately 5000 individuals and families.

The context chart (see Figure 3.1), describes the relationship between Alberta Education, the school systems, and

Alberta Education

Alberta Federation of Home and Schools (AFHSA)

Alberta Association for Community Living (AACL)

Learning Disabilities Association of Alberta (LDAA)

School Systems

Parent Advisory

Local agencies (Gateway Association)

Local chapters

Individual families of regular children

Individual families of children with severe to profound needs

Individual families of children with learning disabilities

Figure 3.1 Context for the Study

how the various parent associations influence the education system.

Research procedures

The semi-structured interview was the major source of data for this study. Bodgan and Biklen (1982) described the interview as "a purposeful conversation, usually between two people (but sometimes involving more) that is directed by one in order to get information" (p. 135).

Spradley (1979) described the interview as a "particular kind of speech event" (p. 55), similar to a conversation except that this particular conversation is "supposed to go somewhere" (p. 59). It is the researcher's responsibility to make the purpose clear and to direct the interview so that the information is made relevant to that purpose.

Bogdan and Biklen (1982) reminded the researcher that:

> In keeping with the qualitative tradition of attempting to capture the subject's own words, and letting the analysis emerge, interview schedules and observation guides generally allow for open-ended responses and are flexible enough for the observer to note and collect data on unexpected dimensions of the topic. (p. 71)

This particular approach was used by the researcher during the open-ended interview process which will be described in Chapter 4.

Bogdan and Biklen (1982) also advocated that:

> The qualitative research approach demands that the world be approached with the assumption that nothing is trivial, but everything has the potential of being a clue which might unlock a more comprehensive understanding of what is being studied. (p. 2)

2

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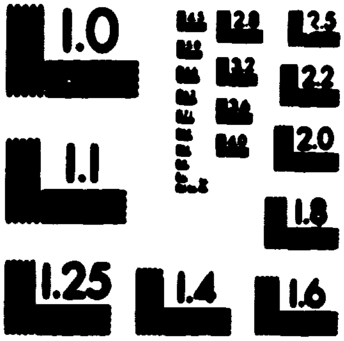

PRECISION℠ RESOLUTION TARGETS

It would appear that the emphasis during the interview should focus more on understanding the data rather than following a particular interview format.

Instrumentation

The sampling method used to select the parents or key informants of this study was a purposeful sampling approach. According to Bogdan and Biklen (1982), you "choose particular subjects to include because they are believed to facilitate expansion of the developing theory" (p. 67).

The "snowball sampling technique", (Bogdan & Biklen, 1982, pp. 66), was used to select the Gateway Association participants for this study. As one member, a program facilitator of the Gateway Association was interviewed with regard to her involvement in education decision-making, she was asked if she knew of other parents in the association who would be interested in participating in the study. As a result, a total of five families from the Gateway Association became involved in the study.

The parents from the Learning Disabilities Association were invited to participate in the study via their association's newsletter entitled Agenda (See Appendix B). Interested parents were asked to contact the provincial office and their name and phone number were forwarded to the researcher. Consequently a total of five families from the Learning Disabilities Association of Alberta became involved in the study.

It should be noted that the researcher talked individually on the telephone with each of the key informants prior to establishing a suitable time to interview. The purpose of the initial contact was to develop a relationship with each parent. This opportunity was also used to communicate the purpose for the study, the ethical issues, and the method for data collection. As a result, almost all of the parents came to discuss their involvement prepared with written notes, copies of briefs, and a zeal to "tell their story". As all respondents had volunteered to be interviewed, it was presumed that they were willing participants, and that they had considerable experience in making decisions regarding their childrens' special needs from their various perspectives.

The pilot study

The two open-ended question interview guide, developed to interview the parents, was developed in consultation with the researcher's supervisor. Chomicki (1992), in a similar study, utilized a two open-ended question format. The pilot study in the researcher's school district provided insight into the amount and nature of the data that would be collected during the interview process. The pilot study also helped the researcher become comfortable with the interview process and to determine the approximate length of each interview. The pilot study provided the researcher with an opportunity to develop a degree of confidence with the interview process and an assurance that the study was meaningful and purposeful. Two members of the Learning Disability Association and one parent with a child with severe handicaps participated in the pilot study but their data was not included in the data bank for the major study. Based on the information derived from these pilot activities changes were made to the interview guides.

Interview procedures

All 10 families were contacted and appointments made during the period January to November 1992. There was always an emphasis on selecting a date that was suitable for the parent. Because these parents were so involved with their children, dates had to be altered to avoid particularly stressful times for the family. The parents were informed that the interview would explore their involvement in decision-making in depth and there were no time limits on the interview. They were also assured of anonymity and of their freedom to withdraw from the project at any time. Each tape-recorded interview lasted from two to three hours and the interview was conducted in their home, at the kitchen table or in the living room. The researcher was completely flexible and because of the nature of the study, the parents' "home turf" seemed most appropriate.

Researcher Bias

Throughout the interview process, the researcher kept a journal to record personal reflections as well as positive and negative responses to the interviews that alerted the researcher as to his personal biases. Being an educator and an administrator as well, the researcher had to continually be aware that now he was a researcher to ensure that the parents were able to fully disclose their story. These personal reflections were shared with the thesis supervisor and colleagues at several points during the interview and content analysis process.

Data analysis in qualitative research

Berg (1989) used the term "content analysis" to describe the process whereby descriptive data are categorized. According to Berg, the descriptive data can be coded into two levels: manifest content or surface structure of the data; and the latent content or deep structure; or a combination of the two levels. Berg defined the manifest content as what is said by the interviewee while the latent content is deemed to be the symbolic meaning of what is said.

The analysis of the data, then, involved extracting the meaning units or themes from the forty to fifty pages of tape-recorded text per interview, which are then clustered into groups of themes or thematic clusters. The process is reductionist in nature, reducing the interview data to the highest level of abstraction possible in order to capture the decision-making experiences of the parents involved in the study.

Chomicki (1992), in a qualitative study involving mothers obtaining health care for their children with special needs, developed a model for content analysing qualitative data. Her analysis involved extracting meaning units or themes from the interview protocools and reducing the data to the highest level of abstraction possible in order to capture the essence of the data.

This researcher used similar strategies to analyze the parents' experiences in decision-making. (See Figure 3.2.)

Each interview protocol was read and all essential elements or meaning units were highlighted and labelled according to the decision-making themes that were stated by parents (manifest content) or implied (latent content) in the text. Once each protocol had been analysed, it was presented in tabular form on two levels that served to demonstrate the manifest or latent content of the protocol. The first level of abstraction involved a paraphrase of what had been said by the parent. This exercise was used to focus the researcher on the precise nature of each parent's intent, and to, as accurately as possible, express the intent. The next phase involved the abstraction of the data to a higher level of meaning, the latent content, that was embedded in the meaning unit. (See Appendix C.)

The themes were then grouped into clusters to form a common, global theme which portrayed one aspect of the parent's involvement in decision-making. The thematic units for each group of parents were then presented in a format which facilitated further analysis. It was at this time that a between-persons or within group analysis was conducted in which the protocols from each of the five parents in each of the groups was analysed for common themes.

Osborne (1989) described a comparison of the thematic clusters arising from interviews from several parents a between-person or within group analysis. Specific subthemes emerged

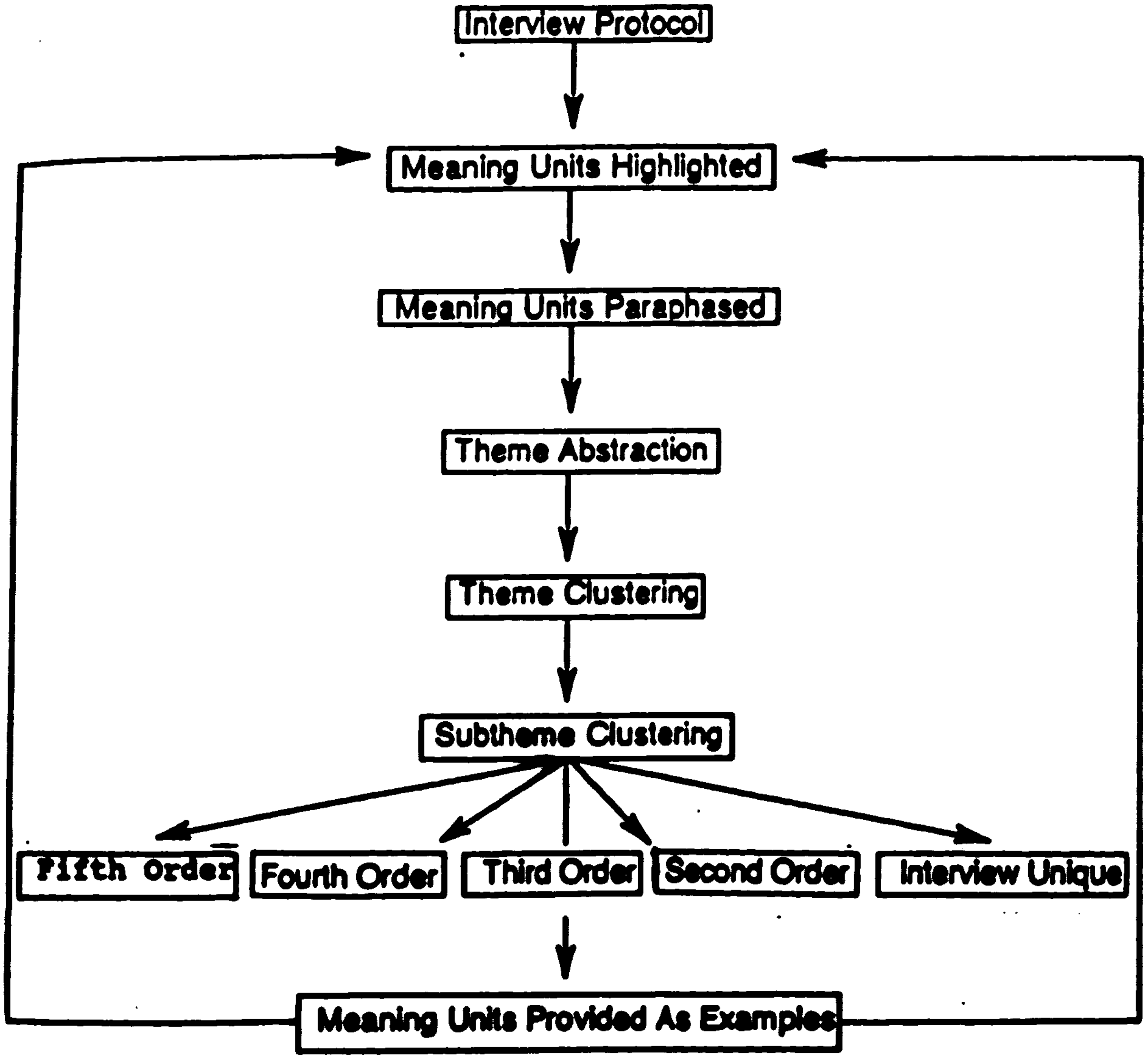

Figure 3.2 Flow chart of the content analysis process

within the thematic clusters which were then [illegible]ed according to the number of times they were repeated [illegible] example if all five parents mentioned a theme, it was labelled a fifth-order subtheme. A theme mentioned by four parents was labelled a fourth-order subtheme. Once the within-group analysis was completed, the between-group analysis was conducted in a similar fashion in order to compare the responses of the parents who had children with severe to profound needs in comparison to the those parents with children with learning disabilities.

Using Berg's strategies (1989), the researcher engaged in negative case testing throughout the analysis in order to locate instances where the theme was not demonstrated by a parent in that group. The theme or subtheme was then adjusted so that all cases could be incorporated or the theme was rejected altogether. The establishment of a hierarchy of subthemes enabled the researcher to incorporate all relevant interview data with integrity.

In the next two chapters, the thematic clusters which emerged from the interviews with each of the parents from both advocacy groups are discussed. Following this discussion, the results of the between group analysis are discussed. Examples were extracted from the protocols to illustrate each thematic cluster as per Berg's (1989) suggestion for verification.

The research data came from two sources. Members of two advocacy groups in the Province of Alberta agreed to take part in the study. The Learning Disabilities Association of Alberta and the Gateway Association for Community Living were most interested in this research project. A select number of parents from both organizations were interviewed to allow them to "share" their story with respect to the process of being involved in making educational decisions for their children.

The techniques used to obtain data included unstructured interviews, relevant document analysis, and personal observation of the activities of the parents.

The data analysis portion of the study involved a combination of steps. The interview data from the parents as they shared their stories was content analyzed.

Documentation

While the use of documents was a limited data source, these documents became part of the data collection process when the parents discussed their involvement in the decision making process. The documents included copies of letters sent to various individuals in the school systems involved. In some cases, where parents had appealed a decision to a school board, copies of the brief were made available to the researcher. In two cases the parents had obtained a legal interpretation of their situation and these interpretations were also made available.

Quality controls

The open-ended interview guide was developed after a series of interview guides and surveys failed to capture the "richness" of the data that was expected. The concept of trustworthiness was addressed and care was taken to ensure that ethical standards were met.

Trustiworthiness

In a qualitative study, it seemed more appropriate to address the issue of trustworthiness rather than reliability and validity. Major proponents of this approach including Iles (1984), Guba (1981), and Lincoln and Guba (1985) clarified this matter:

> The basic issue in relation to trustworthiness is simple: How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of? (p. 290)

In fact, it was Guba (1981) who previously identified four aspects of trustworthiness: credibility; transferability; dependability; and conformability, all of which will be described next.

It should .e noted that at least three of the parents from the Gateway Association met the researcher during the 1992 Colloquim on Special Education sponsored by the University of Alberta and the University of Calgary. The researcher has concluded that this continued relationship which was developed with the parents from the Gateway Association lends to the trustworthiness of the data.

Credibility

Credibility is synonymous with internal validity in a quantitative study and is concerned with the degree of confidence that can be placed in the findings of a given study. Since social realities are based on the perceptions of the informants, care needed to be taken to promote and ensure credibility. Every effort was made to ensure credibility for the study.

The researcher has been engaged in the world of working with children with special needs and their parents for the past eighteen years in a number of capacities. During the collection of the data, the researcher devoted considerable time with the parents discussing: the importance of the study for all parents of children with special needs; his own personal philosophy and the nature of his work in the area. The researcher believed the credibility of the data was ensured by the rapport which was developed with each and every parent. Raw data in the form of cassette tapes and verbatim transcripts of the interviews were maintained for frequent review. The researcher attempted to become familiar with the professional literature as it related to expanding his interpretative background.

Transferability

Transferability is the counterpart of external validity in a quantitative study. The quality of the data gathered is instrumental in determining the applicability of the findings. As Bogdan and Biklen (1982) recommended, the researcher endeavoured to provide thick or rich descriptions of the lives of the parents of children with special needs. It is the thick description provided that ultimately enabled the researcher to make judgements with respect to transferability.

Dependability

Dependability in qualitative research is the counterpart to reliability in quantitative research. The two concepts of consistency and stability are of utmost concern relative to dependability. Allport (1955) concluded that perceptions, which were the main source of data in this study, "remain relatively constant over time" (p. 598). A journal system was maintained so that the data collection, analysis, and interpretation could be explained. Journal entries, tape-recorded versions of the interviews, and the hard copies of the interviews were retained.

Confirmability

The operational term in qualitative research is confirmability rather than objectivity as in a quantitative study. The paper audit was used to establish the relationship between the researcher's interpretations and the actual raw data.

Furthermore, the researcher was aware that his values and personal views were a potentially biasing factor in the study. To avoid potential researcher bias, the coding categories and processes were checked by the thesis supervisor and another colleague, and the direct responses of the parents were used to substantiate the conclusions.

Ethical considerations

The Department of Educational Administration Research Ethics Review Committee approved this research on June 26, 1992. Therefore this study has conformed to the ethical guidelines of the University of Alberta General Faculties Council and the Department of Educational Administration.

As noted previously, the researcher talked individually to each of the parents on the telephone for an extended period of time prior to establishing a suitable time to interview. The purpose of the initial contact was to develop a relationship with each of the parents as well as to communicate the purpose of the study, and the ethical issues. Also the method for data collection including the use of the tape-recorder was outlined. The parents in this study verbally consented again to take part at the beginning of the interview, indicating that they understood the purpose of the study, as they voluntarily consented to participate. They had also been assured of their anonymity and their right to withdraw without reprisal at any time. They also agreed to the use of the tape-recorder to record the interviews. Careful and deliberate attention was taken not to mislead the parents in any way.

The children from the Gateway Association for Community Living, whose parents took part in the study, ranged in age from six to fourteen years of age. Two children were of preschool age, one was of upper elementary school age, while the other two were teenagers. All five children were boys and there were siblings in all the families. With one exception, all parents in this group were birth mothers.

The children from the Learning Disabilities Association, whose parents took part in the study, ranged in age from eight to fifteen years of age. Two children were of school age, one was in junior high school, and two students were in high school. Of the five students involved, two were girls and there were siblings in all the families. With one exception, all parents in this group were birth mothers.

Interview procedures

All ten interviewees were contacted and appointments made between January and November 1992. Emphasis was placed on choosing a date which was convenient to the parent and when the family was not undergoing undue stress which might have affected the parents' recall of their experiences. Of the ten interviews with parents, eight were conducted in the family home either at the kitchen table or in the living room. All the interviews were tape-recorded. Participants were advised that their experiences would be explored in depth and no effort was made to rush the interview. All parents were reassured of anonymity and of their right to withdraw from the study at any time.

The data collection interview was largely semistructured as only two specific questions were asked of the parents, thus permitting the interview to develop freely. The parents were asked to "Describe for me (the researcher) your experiences with respect to education decision-making regarding ________,(the name of the child who has special needs)". The term "education decision- making" was defined as those life experiences when the parent's attention was focussed on times in the child's life when interactions with professionals revolved around deciding on placement, programming, or personnel issues. In addition, the parents were also asked the following question: "What impact has the process had on you and your family?"

With this as background information, let us begin our study of parents' views of decision-making for their children with severe to profound needs.

Summary

The research design for this study was described as a descriptive and explorative multi-site case study. The study was designed to examine how parents of children with special needs viewed the process of decision-making. Relevant data were collected from 10 families, 14 parents, through the use of semi-structured interview format. The two advocacy organizations which took part in the study were the Learning Disabilities Association of Alberta, and the Gateway Association for Community Living.

Analyses of the data were carried out using content analysis. The themes and subthemes which emerged from the rich descriptions of the parents' experiences were only highlighted and discussed if the theme was mentioned by all members of the study group. The following chapter discusses the views of parents of children with severe to profound needs.

Chapter 4

A STRUGGLE FOR POWER: PARENTS' VIEWS OF DECISION MAKING FOR CHILDREN WITH SEVERE TO PROFOUND NEEDS

This chapter will discuss the "life experiences" of several parents who are members of the Gateway Association for Community Living. Their children have special needs that would be described as severe to profound. Table 4.1 below summarises the childrens' ages and their disability:

Table 4.1 Children's Ages and their Disability

Child	Age	Disability
A	13	Down's syndrome
B	6	Brain injury
C	6	Severe developmental delay
D	14	Profoundly hearing impaired
E	15	Multi-handicapped

The chart reveals that the children being discussed in this part of the study, covering a broad range of ages, are faced with significant challenges to their learning.

Three general themes emerged as these parents discussed their involvement in the educational program decision-making process: (1) the major actions taken by the parents as they began to understand their child's difficulty; (2) the common characteristics of this group of parents; and (3) the parents' views on the decision-making process.

Fourteen common subthemes emerged from the parents interviewed when they discussed their child's various developmental stages:

> Parents began to 'take control' early in the child's life.
>
> Parents had to deal with labels others place on their child, and on themselves as parents of that child, even though they realized that the label ensured access to services.
>
> Parents began to realize that they were becoming an expert in knowing their child.
>
> Parents experienced a wide range of emotions as they began to work with their child.
>
> Parents seemed to be in a constant battle to have their opinions heard and respected.
>
> Parents wanted to have input into decisions related to their infant's situation.
>
> Parents searched for opportunities for social integration.
>
> Parents developed strategies to help them deal with professionals.
>
> Parents recognised the stressors on other family members when they have a child with special needs in the home.
>
> Parents developed a series of community networks to support them as adults.
>
> Parents wanted to participate as a "team" member.
>
> Parents stressed the need for open communication between home and school.
>
> Parents struggled for power over decisions.
>
> Parents described the attributes of a good partnership with professionals.
>
> Parents indicated that they sought legal advice regarding their particular situation.

It should be noted that these subthemes emerged from the data and are not limited to any particular developmental stage.

Only the fifth order subthemes, those identified by all five parents, will be analyzed.

Major Theme: Common types of actions taken by parents of children with severe to profound needs

When describing their experiences with decision-making for their children, these parents discussed six major subthemes.

Subtheme 1: Parents begin to "take control" very early in the child's life.

This parent's first encounter with medical professionals was not very positive and has influenced the family's way of life since the child arrived home from the hospital. Comments like these, made by this mother, were common:

> And then he (the doctor) said as boldly as this, 'She has profound nervous system damage, she is blind and I wouldn't be surprised if she is deaf too. We can give her therapy for a while, but it's really not worth doing. If kids come along that can benefit more, we'll have to bump her. I recommend you put her in an institution'.

To further illustrate:

> When we brought our son home we were told that he probably wouldn't have much of a life and that he should have been institutionalized, so we felt very strongly that that was not an option for us, so I suppose our entire focus has been very strongly in the other direction.

Another mother explained one of the family's first decisions:

> Certain choices in our family were made six years ago when our son had his accident that he became brain-injured, and we decided to take him home. That was a decision that we made with hope and with some kind of vision and with some kind of support that there was out there in society, that there was help available for us. Not all parents make that decision; not all parents make the decision to keep a severely handicapped child at home.

One parent alluded to Mitchell's (1982) comments in her book

Taking on the World when she discussed her experiences at the hospital:

> And you learn to start fighting and saying what you want to happen from day one when he's in the hospital, and, actually, the hospital staff in the first hospital encouraged you to do that and to make decisions about when he should have his medicine and when he shouldn't. So you start taking control at that point . . . .

Another parent noted:

> I went home and that was at nine months and in two days she was enrolled in the (name of institution) early education program, because I had connections before. I hate to think what it would have been like not to know anything about the system, but I did.

In summary, these parents of children with severe to profound needs began taking charge very early in the child's life which included making significant, life-long decisions from the very beginning.

Subtheme 2: Parents have become "expert" in knowing their child because they have had to implement many of the professional's recommendations.

As a result of these early experiences, parents quickly learned that because they knew their child best, the child's future was primarily their responsibility:

> You become an expert about your own child. I wouldn't like to tell anybody else what another handicapped child needs, because I don't know them. But I know him (my son), very well. In the hospital I was told that he wasn't in pain, and I knew he was, and I'd fight for the medicine. He'd get the medicine. He'd be fine.

> And I guess for me it was difficult because I felt like I had a lot of knowledge that I could share, but the situation had been made difficult for me because of that reputation that they said I had, being unreasonable and so on.

There was little doubt about how parents became experts when they discussed the role of consultants as a support mechanism for themselves. This parent noted:

> The consultants that come out to tell the parents what to do with the child only come out once every three weeks for two hours, and basically the responsibility of educating the child or stimulating the child is still left up to the parent, who is often just terribly fatigued already by the work involved, especially if the child has high needs.

Another three parental comments:

> With a child with special needs you often have a lot of experts telling you, 'Well, this is what you do here, and this is what you do there.'

> They (the consultants) would give step-by-step things, plus you have your DS (developmental specialist) coming into the home for six-and-a-half hours a day. And that feels mighty good to have that kind of control, because I went from having a child that could speak for himself, tell you when he was hurting or hungry or thirsty, or whatever it was that he needed, he could tell you, to having a child who, basically the only people that understood what he was telling you were the people that were very, very close to him, and people that just came in to look after him had to learn how to read those signs and figure out what he wanted.

> The lady walked up beside her with a rattle and said 'Look' (name of child) and (name of child) turned her head in the other direction. (Name of child) avoided her up to seven times in a row until finally she didn't have the muscle strength to do anything and she just buried her head in the mat and cried. The lady wrote down on her form, fail, fail, fail. I said, 'What do you mean fail?' 'She didn't respond.' she said. I said, 'She did so respond.' So we went on like this with these arbitrary little programs. The trained seal approach I call it. Meanwhile, I was doing my own thing with (name of child), I was toilet training.

It was not surprising to hear the parents proclaim that they knew their child best.

Subtheme 3: Parents expected to have input into decisions related to placement, programming and even who worked with their child.

As a result of being so involved with their child since the onset of their child's disabling condition, parents have become accustomed to having input into any decisions regarding their child:

> So all along we as parents have been very much involved in hiring, in having a say as to what we want emphasized in terms of his program planning. The way GRIT is set up is several times a year there are meetings held with parents about your child's progress, about how he met his or her goals, and if not, how can we modify them so that those goals can be met.
>
> It's ridiculous for me to sit down and say, 'The goal I want for him is, by the end of this month I want him to walk'. That's a stupid thing, so you sit down and you go over with all the consultants where he's at right now.

And as one parent decided:

> What is a reasonable expectation and what things you see for your child, and if they think that that is reasonable, which it usually is, then you set those goals out, and they figure out how it is you're going to accomplish them.

When discussing the importance of teamwork, one parent commented:

> In September he got on the GRIT program, and again, we were very much involved in the planning and programming, and we were the ones that made the final decision about what goals we wanted to achieve and accomplish.

One parent actually resorted to moving her entire family as a solution to her child's placement problems:

> So we took a look at, we could either move into the city or further away, and we took a look at the programs, and at that time we were feeling very defeated in that, although we wanted our son to continue in an inclusive environment, we were beaten down and we really needed some time to recuperate. So we chose to move to where we are now.

By the time these children with severe to profound needs reach a structured school setting, their parents know their children best and to deny them an opportunity for input into any major decisions seems hazardous at best.

Subtheme 4: Parents seemed to be in a "constant battle" to have their opinions heard and respected.

Certainly as children moved from the safe environment of their home into the community, there were new challenges to be faced. As one mother noted:

> I couldn't care for anybody else but him, not even myself, so we made a plan to call the social worker and say, 'Look, this child is needing a lot of care. These parents are having trouble; let's get help in the home.' So I phoned the social worker back and had another meeting. I gave him the names of other families that had a system like this, so he looked it up in the files and said okay.

Another parent remarked:

> When (name of student) was old enough to attend playschool, we actually had, not so much in the fight to have him included in the playschool, because they were very accepting, but the issue revolved around the playschool, and as a family we felt (name of student) needed an aide.

On discussing early entry into a kindergarten program, one parent remarked:

> They (the school system) weren't going to take him to begin with, but eventually we persuaded them that this was going to be okay. So he stayed on the GRIT program; the GRIT worker went into the kindergarten with him, which the school board was not thrilled with, but I was not willing to trade in six-and-a-half hours a day of a DS coming in and all the consulting staff for two-and-one-quarter hours a day in a kindergarten program. Anyway, we finally persuaded them that this would work, having the GRIT people involved in their school system.

Subtheme 5: Parents have developed a network of community contacts to support them as adults.

When working with a child with severe to profound needs, there was a tremendous number of complex issues for parents to deal with. These three parents looked to others to support them in their daily lives:

> So by chance a friend of mine happened to know about Gateway Association, so she said, 'You should go and see them, because they're advocates for people with disabilities. Maybe they know of a way to help you.

> So it was a mom who came to my home and she kind of helped me go through my day and what my child's needs were and kind of set up a structure of how much time (name of child) took of the whole day in terms of his care and his stimulation, his feedings and his suctionings and his chest physio, all that stuff, and it was unreal.
>
> Four times a year we would go to Calgary for a kind of set-up of his program, and then we got volunteers from our church. We had about thirty-five volunteers, and we'd have two people coming in the morning from ten till twelve, and then two people in the afternoon from two till four coming into our home following this whole program, and with a lot of hope, of course, that things were going to improve, and we carried that on for two years.
>
> From the beginning I had a lot of support from both sides of the family and from our church, and then there were some other people that kind of just arrived from nowhere.

Certainly as a result of the series of networks established, the parents of children with severe to profound needs acquired some new skills.

Subtheme 6: Parents have developed strategies to help them deal with professionals.

All parents indicated that they had developed a number of strategies to help them work with professionals. Some parents indicated that they realized that one strategy they could pursue to achieve their goals for their child was through the principal of the school:

> We attempted to have (name of student) included at kindergarten and tried a couple of strategies and were not successful. We approached the principal. He said 'Yes'; then we started looking for dollars, of course.

Another parent noted the importance of the principal:

> And those were his (the principal's) ideas. I think together we talked about how can we make this transition easy. But in a sense he had to work hard at that; he had to give her (the teacher) the morning off to come and visit and so on, so it does take insight on the part of a principal.

> So then our next strategy was to try to go in through the back door, so to speak, and when September came around the year that (name of student) was five, we just went to the kindergarten and enrolled him and showed up at the door, and that wasn't received very well.

In order for one parent to feel somewhat at ease with her child attending school, she confided:

> I needed to feel that I could trust the school as much as they needed to trust me.
>
> It's very scary because now you're trusting these people with your child, and they don't know him. I don't have huge confidence in the school system for my regular child, let alone my child who can't communicate very well, and so it is very scary.

This parent then went on to share some other strategies:

> One of the things that we did every year when (name of student) was in elementary is that we would meet with the principal about this time of year, in March, April, sometimes May, and started talking about, I guess, almost like a report card, some of the things that we felt that had happened that were really positive, and some of the things that we needed to work on, and in looking at that, what would (be) some of the skills he needed for the following year.

The follow-up on decisions was vitally important:

> I would stop by the principal's office every now and then and talk, and let him know how good I thought things were going. I needed to make myself comfortable, and I needed to feel that I could trust the school as much as they needed to trust me.

The importance of early planning was evident in the next strategy when the parent noted:

> Each year where I would notice that the teachers in the next grade level would all of a sudden, when they'd see me in the school, start to talk to me about things they'd noticed, and, you know, I guess checking us out and trying to find out what we thought was important and how we were feeling about the situation.

The importance of the teacher being willing to accept and learn to work with the student cannot be overemphasized:

> We were the only ones that had looked at having a child included on a full-time basis, and it really has been a success story; but also sensitive to the teacher's needs, so we asked them whether they would be interested in having (name of child) in their class in the following year.
>
> So I had to walk with tender shoes, give them (the teachers) a little bit of information, let them know about workshops, give them handouts from workshops when I thought it was appropriate, be very supportive and very encouraging, let them know about all the changes that we saw as a family, because we felt that it was because of the environment that he was in.

The importance of the grade four year was noted by the parent when she remarked:

> We had these ideas in our mind. They needed to be fine tuned, and we needed to find ways to have them incorporated, but before we could do that we also had to build a relationship with the teachers and the school.

For the children to be included in the school, the parents realized the importance of the "circle of friends" concept:

> They had a really strong peer support group within the classroom that had been working with (name of student) on peer support, and some of the kids had been coming over on their own, but nothing was formalized.

Some parents began to realize the importance of inclusion as it related to academic gains for the student:

> In special education we were told (name of student) would never learn lower-case letters. He was in our neighborhood school for approximately three months, and he was bringing home sheets where he was matching up on lower-case letters; it was wonderful.

Grade Five was an excellent year for (name of student) because:

> We realized that that wasn't enough, so grade five we started meeting on a monthly basis, and things really seemed to go well in grade five.

In terms of classroom support for (name of student), the parents realised the importance of their child not being singled out:

> Actually, the aide who was working with (name of student) was also a teacher, so the teacher and the aide switched places doing things, and that was really positive, because (name of student) wasn't always seen as being the one receiving all the one-to-one attention.

These parents were particularly concerned about the stigma or label attached to anyone in the classroom:

> We didn't want the aide there specifically assigned to (name of student) although he/she was there because of funds, because of (name of student), and to be supportive to him. What happens sometimes when you have that aide assigned to the child, depending on the personality, is, they are stuck to the child, and we didn't want that.

The importance of the classroom teacher being willing to get involved and work with the student cannot be overlooked:

> The teacher that I had hoped that was going to work with (name of student) had decided to change schools, and I had heard that this teacher was coming and that he was very sensitive, but I also knew that he had worked at (name of school) . . . and I was very apprehensive about that, so I went and I spoke to the principal about it.

Out of sheer desperation, two parents have resorted to seeking legal advice regarding their situation:

> Her(person in charge of special education) philosophy does not agree with what we're asking her to do, and yes, every time we talk to her she eventually comes around and says, 'Yes, you're right', and that would be the best place for (name of student), in a regular grade one. Then the next time you walk into her office to discuss it, you're right back to square one and back to (the special education school). This last time I was just so angry with it that I felt like saying 'Well, fine, I'll see you in court!'
>
> It could go to court, so then we look at, where are we going to get the money? We don't have the money, so we look at other advocacy organisations to see if they would agree that this is discriminatory. He's made a legal opinion that's what we would do it under, under the Charter.

> We have a ten page legal opinion from a lawyer, and he says that that's how we will proceed.

As the literature search revealed, families with children who have special needs have many challenges to face. While this list of strategies was not exhaustive, there was certainly enough evidence to suggest that many strategies were needed in order to effect a change in attitudes. Table 4.2 describes the attitudes and actions taken by the parents of children with severe to profound needs.

Most parents acknowledged that without the support of others, the task of raising a child with severe to profound needs would be impossible. Certainly the transition from the home environment to another unfamiliar environment was stressful and troublesome for all the parents. This discussion concludes the six major actions the parents described when it came to their involvement in decision-making.

Major Theme: Common characteristics of this group of parents.

Four subthemes emerged which will be used to describe the characteristics of this group of parents.

Subtheme 7: Parents demonstrated a whole range of emotions related to their child's challenges.

The parents of children with severe to profound challenges experienced and expressed many different emotions on the continuum as they began to deal with their child's difficulties: hope and despair; contentment and anger:

> Initially when our child came home from the hospital, I hadn't even registered him under Handicapped Children Services because I thought he was going to get better. A lot of parents go through that where you think, 'Well, my

Table 4.2 Parent Attitudes & Behaviors

Parent	Feelings/ Concerns	Decisive/ Indecisive	What doing	Coping/ Not Coping
101	Angry, parents told they were 'bad'	Moved. Pulled out of spec.ed. preschool	Demanded an aide for playschool	Trying several strategies
102	What about my two other regular kids?	Making decisions on programming	Child enrolled in preschool & home program with DS	Trying to balance child's needs with family needs plus "educate" others
103	Taking control Wants child to be accepted	Organized home program with church volunteers	Involved in community programs - swimming Expected regular ECS program with an aide Difficulty with transporting	Always breaking new ground Had to set priorities
104	Foster care information for child with profound hearing loss still not available			
105	Angry, resentful	Developing own 'home' program	Experimenting with integration	Trying trying trying

> going to be the one child who's going to get better'.
>
> Because I knew him before the accident as being a whole person, that whole person is still inside there somewhere; it's just sometimes difficult for him to communicate what he's feeling. And I don't know how much the disability camoflages the person, somewhere inside, that person is still there.
>
> They (the teachers) told us we were bad parents, we were incompetent, that we didn't know what was right for our child and that we weren't educators, and the list goes on and on.
>
> Its so easy to lose your confidence as a parent, and it takes a while to build that up again. Once you've built that up again, you become a really strong advocate for your child because you've been way down there and now you've built yourself up again and you think, 'Now I can start to make some decisions, and I'm going to choose rather than everybody telling me what my child needs'. That's all part of becoming very much involved with your child's life.

This parent's comments summarized the issue of emotions:

> We all seek a state of equilibrium in our lives and obviously, having this kind of situation thrown at you, creates chaos and it is human nature, I believe, to struggle to re-establish order but how that order should be re-established when, in fact, often it means shattering a paradigm, a paradigm of what was your dream of the normal Canadian family. It's a rupturing, a fracturing of your life to bring together the pieces and re-create your life, taking into account this massive change in your expectations and in the limitations operating on you in all sorts of ways that weren't there before. It's a very demanding exercise in abstract thinking which I think is frankly beyond the ability of some people, and certainly beyond the interest of many.

Subtheme 8: When social integration was an issue, parents have attempted to integrate the child into the local community wherever possible.

The parents of children who are severely disabled realised the importance of integrating their children into the fabric of the local community very early in the child's life:

> At a very early age we became involved in having (name of child) included in our community recreationally as often

> as we could. When he was three, we demanded he be able to take dancing lessons with his sister. We also had him involved in Boys' and Girls' Club, at churches and the community, and Cubs.
>
> The first year he was at home all the time and we just took him to small afternoon programs just to get him with other children and just to be part of the community. He went swimming; we took him to a regular swim class. The other children were by themselves with the teacher, and we just went in with him, but it worked out very nicely. He went to a craft program and he went to a library program.

The importance of being able to ride on the school bus should never underestimated:

> He could have ridden the Handibus. I could drive him as well as he could go on the Handibus, but the whole point was the social aspect of going on the bus.

Another parent emphasised the importance of the bus ride:

> It was amazing, actually, the difference in how the children treated him once he started to ride the bus with them.

This parent recounted her story about her child which emphasized the importance of peers:

> (Name of child) was on his bike and they (two boys) put this rope around (name of child)'s neck, and they were going to get on their bikes and go in the opposite direction as he started and put him off his bike. By the time I saw this and I got my shoes on and got out the door, there were six or seven kids from the neighborhood who knew (name of child) at school who had surrounded him and the other children and told them to leave him alone, that they were his friends, and from that day on we haven't had difficulty with those boys.

For parents of children with profound to severe needs, their views on integration are best summarized by these two parents' comments:

> I sometimes share with people if they ask me, 'What does inclusion mean to you?' and because it is an emotional feeling, the best way for me to share that is to say that inclusion isn't a philosophy, it's a way of life. But it's something that I feel every part of the day, and it's

> something that's inside each of us if we'd let ourselves experience it. I feel it in my head, I feel it in my heart, I feel it in my gut, and it's like a warm fuzzy that's inside of you, and it radiates and it envelops you, and it's a passion.

> But what I can't do is give him friends. I can't show him what's acceptable from a peer point of view. One of the things he learned in kindergarten this last year was that it's not okay for a six year old to have his mom kiss him, but I never would have taught him that! . . . What *we* think is acceptable for children of any age is completely different than what *they* think is acceptable.

Parental involvement with their child was the cornerstone to their child's continued development. Now that they were involved, it would be counterproductive for the child if the parent was anything less than totally committed.

Subtheme 9: There were additional stressors on other family members when living with a child with special needs.

It was certainly evident from these five parent comments that having a child with special needs in a home creates stressors for other family members:

> I had forgotten it was the night my daughter was supposed to pick up her Rutherford Scholarship and so I was just trying to figure out how I could make the excuse about this the next day. I heard (name of child) on the phone . . . and I'm planning to tell a lie, which I don't do very often, but I think this is dreadful that parents can't be present when she gets her scholarship and it doesn't look very good for her quite apart from having possible ramifications for (name of child with special needs).

> I like to say, that before this happened we just kind of had a normal family life. Now it's kind of a planned normalcy in the sense that I should do something with the other kids, and (name of husband) and I should go out. You have to plan all these things, and if you go on a holiday it has to be an accessible one. Unfortunately for the other kids, we're going to have to go to (name of handicapped camp) for the next ten to fifteen years.

> They called my daughter at the high school to come down one day when they couldn't reach me. She (the teacher) felt that I needed to be accessible twenty-four hours a day to the school, and, yes, I want to be supportive to the school and I want to be available if I can help in any way, but I should not be receiving five, six phone calls a day asking how to deal with behavior. If you want to put a phone in my car so you can reach me all the time, well, put a phone in my car if you really think that that's critical. But also you have to recognize the stress that that places upon a family.
>
> I found out that there was a group in Calgary that would come from the States. It was a breakoff from the other approach and much more family oriented because the other approach involved almost fourteen to fifteen hours of patterning and all kinds of intensive exercises, all kinds of people coming into our home. This approach was modified in the sense that perhaps five hours a day would be all right. So we decided we wanted to meet with these people to see if they could set up a plan for our child, so we went to Calgary. These were all costs we had to pay for ourselves because this was so-called unconventional medicine and therapy.
>
> I was almost in tears. I don't usually do that, but it was at the end of the three years, and we would get fifty-page submissions from the (name of school board) to the committee to respond to from their lawyers in Vancouver. I would sit up till two, three in the morning going through each page of the submission, coming up with a counter response. So I also said there's another issue here. The (name of school board) uses taxpayers' money; unequal access to lawyers, to everybody.

The stress factor on the family with a child with special needs involved a number of issues including emotional stress, time, energy and money.

Subtheme 10: Parents had to overcome labels placed on them by others, including professionals, as they tried to take part as full partners on the 'team'.

Parents admitted having difficulty dealing with labels that others had placed on them as a result of their involvement with their child:

> I guess one of the hurts that I still have about the whole experience is, I've always felt that I'm not an irrational person, and I've always felt that I try to be very supportive.

Another two parents commented:

> After spending almost a year being very supportive in that classroom, the teacher turned to me one day and said, 'You know', she said, 'I don't understand. You're the most supportive parent I've ever come across, and yet we were warned that you as a family were irresponsible, irrational, that we couldn't deal with you.
>
> They were still very cautious about how they proceeded with us and were confused because as parents we seemed very supportive, very involved, wanted them to take ownership for (name of student)'s program. As I've become friends with them (the teachers) they have told me years later down the road, 'We were told when we were hired that we were being hired because of our social skills in dealing with difficult people, and you're not a difficult person.'

While the parents realised that they had to begin to deal with labels for their child in order for the child to have access to services, they were deeply troubled that they as parents were also labelled as they tried to advocate on behalf of their child.

This discussion of the parents' emotions, the labelling issue, acknowledgement of the stress on all members of the family, and the key issue of the parents' philosophy on integration conclude this section on the major characteristics of this group of parents.

Major Theme: Parents' views of the decision-making process

Three subthemes will highlight the parents' views on the decision making process for their children with severe to profound needs. In addition, one subtheme will focus on the most significant roadblock to developing a sound parent-professional partnership.

Subtheme 11: Parents stressed the need for open communication between home and school.

Parents of children with special needs wanted and expected to know what was happening with their children:

> In hindsight I think some of the things I tell families now if they're in that kind of situation, is that everybody needs to come to the meeting prepared to discuss, first and foremost, something positive that's happened, and then a challenge and do brainstorming. And in recognizing that we all have strengths and talents and things that we can share as a group, that helps to begin to bond that process.

This same parent also noted:

> We were committed in that we met every month as well as in between times with the teacher or the aide, and it's very delicate for us to make sure we continued to educate ourselves but somehow have that education passed off to the school, but without having them feel that we were being intimidating or the experts, even though in many ways, as parents, we *were* the experts and are the experts of not only our son, but our other children as well. So we really worked hard at developing a relationship and a team approach, which is crucial at any stage of the game.

Another parent with a child with profound needs entering the grade four program in the neighborhood school noted:

> We keep a communication book. Every morning when (name of child) leaves he has a book in his backpack that I have written in that morning about anything that's happening, any show and tell that he might want to share, and I will write it so that the aide can talk with (name of child) about it in front of the class or whatever.

The communication issue was the key to building a trusting relationship between home and school.

Subtheme 12: Parents wanted to participate as a 'team' member in the process of making decisions.

As evidenced by the media today, the emphasis is on teams, partnerships, and working together. These parents, as good consumers and advocates for their children, expected to be treated as members of the team, doing what's best for the child. As one parent aptly described it:

> I really wish that I could have been involved all along, but you can only get so much, and you have to be careful! But now that I've gotten so far that I'm being involved, there's no way that they're going to get rid of me.

In discussing the importance of teamwork, one parent noted:

> The school really needed support, and the most obvious thing would be professional support because, although as a parent I feel I have a lot to offer, I don't have all the answers, and I think that it's much better to bring a group of people together and have four or five different strategies that you can find. I mean, we're going to make mistakes.

After struggling to be involved in decision-making for a number of years, this parent remarked:

> This principal didn't want (name of student). He didn't go out of his way to make things work. For example, (name of student) was always in school and wasn't even asked if she wanted to go to camp and I found out and I said she can go to camp. The school didn't ask me. I could hire assistants to go with her. We could help out. We could take her and bring her back. Finally they got the message I would like at least to be asked.

This same parent commented on the "new reality" regarding the principalship and the present thinking regarding integration:

> So every year we went through the same process at the end of the school year. 'Would (name of student) be allowed to stay in school next year?' We would pull out all the stops, threatened to go to court, got in contact with all the agencies, lined up legal support if I needed it and financial support, etc. and so we got (name of student) into high school.
>
> So this year we got a new principal and we had this wonderful, fateful meeting and so I thought that, this time. this time, I'm not going to be caught short. So I brought the President of the Gateway Association and the President of Integration Alberta to help decide what was going to happen to (name of student). I said I'm tired of going through these meetings every year. I have to start

> thinking about what's going to happen to (name of student) when she's an adult. I can't put my efforts into debating the merits of integration versus segregation every year. I said I would like a commitment that she can stay in her home school as long as she is in school. And the principal said, 'I have no problem with that'. Everything was said. There was nothing else to say.

And this parent continued:

> I should have been happy, grateful. I wasn't grateful, I was just angry. I knew the world had changed. No more struggling, scrambling, begging, wasting mammoth amounts of time and energy. This was the 'new reality'. You want your child integrated. Well, of course. All the parents that come after me won't have to go through all this.

Subtheme 13: The parent-professional partnership must be built on trust and respect for each other.

Turnbull and Turnbull (1985), in their book Parents Speak Out, noted that communication and respect were the essential ingredients for a positive working relationship involving both parents and professionals. These authors noted that "Respect for the child is, of course, the essential bond between the parent and the professional" (p. 7).

In discussing the hiring of an aide for her child, this parent remarked:

> We wanted to be involved in the interview process for his aide. We were quite used to it, and actually we found it very important because (name of student) has a lot of physical needs, and just for us to imagine someone working with him on a real direct physical basis and not knowing who that person is, is just insane, really, because you have to trust a person a lot, so it's very imperative that parents are involved in the hiring process, just to develop that trust.

One parent tried to get a public school board to hire support staff for her child with severe disabilities, whom she placed in a private school setting. The decision went to a

Ministerial Review:

> The Minister didn't want to take it to court, so it was hung. We kept pushing. kept pushing our MLA. We kept pushing and saying, 'You said under this act you would hear appeals. You've got to go through with it'. It took us a total of, from the day we started, May 1989, we went first to the (Name of Position), that process was done by September first. September first we went to ministerial appeal. Three years later we got a decision.

Needless to say, the parent has very little respect for, nor does she trust that particular school system.

Subtheme 14: Parents struggled for power over decision-making which directly affected their child or their family.

It would appear that the issue was not so much the placement or programming for the child that's at stake so much as it is a struggle for power. As one parent so appropriately articulated the issue:

> One of the issues I see happening, over and over again, is that people who have power take their power for granted and don't even see it as power. So it's not so much that they are not willing to share as they basically don't grasp the issue. They don't recognize how disempowered and how intimidated some parents feel. So this is a very important point, it is not just a question of meanness or some conflict of interests or some attempt to keep power, it is recognising what is power, that's the first question.

In discussing the issue of preparing for an appeal hearing before their local school board, three parents commented:

> We went through the same process, letter after letter, hand delivered, xerox, special meetings, take time off work. Get together evidence, document, get different people involved to advocate. So this year we got a new principal and last spring we had this wonderful, fateful meeting and so I thought that, this time, this time, I'm not going to be caught short. This time, by gum, they're not going to screw me around. So I brought the President of the Gateway Association and the President of Integration Action to help decide what was going to happen to (name of child) this year.

We didn't realize the seriousness of all this, the way they had it all, it made it look like they were real intimidating, the whole packet and everything, and then with all this official policy they had, and I thought, those buggers! But, anyway, it was too late for any of that. Monday night we go trouping up to this appeal. And there's my husband, myself, our son, the principal (of the private school) and the teacher, so there were five at the most. Them, there was probably thirty. . . . I was just horrified.

And this parent continued:

When it was all over they said they would render a decision the following night, okay, and 'thank you very much' and stuff. I did have one employee come up to me and say they had never in their history seen a presentation of the kind of calibre that we had done. I said we could have had a lawyer. Yes, I don't even think we realized that we could have had a lawyer. Mind you, we really didn't have money for a lawyer, but maybe we could have found somebody who was willing to come. We have a few friends.

A second parent remarked:

When we were arranging our meeting with the board of trustees, I phoned the secretary treasurer and I told him that we were going to be coming with my husband and I, but also about five or six other people just as supporters, and he said, 'Well, that never happens!' and I said, 'How many of you are going to be there?' and the answer 'Oh, there'll be about twenty-two.' And then the whole sense that they can almost scare parents by their very presence and by their very number.

The whole sense that you need to prepare in a strong way and that you have every right, if they're going to be there with a bunch, that you may be there with some people to speak on your behalf.

A third parent commented on the process:

And I think that as a parent you can get very discouraged, because the school board has lawyers and people that are paid for by them, whereas a parent in a sense is pretty much alone. They have people behind them, but for us, too, where are we going to get the thousands of dollars from? In a sense you also have to advocate for the money if you want to fight a legal battle. Hopefully, it won't come to that, but in a sense we are preparing for it.

It could go to court, so then we look at, where are we going to get the money? We don't have the money, so we look at

> other advocacy organisations to see if they would agree that this is discriminatory. A lawyer has made a legal opinion that's what we would do it under, under the Charter.

The issue of power had to be one of the single most important findings for the study. As one can see from these parents' points of view, they were hesitant but willing to go the distance, if necessary, in order to re-establish the balance of power.

Summary statement

It can be argued that despite the fact that these children have significantly different needs, their parents were all struggling with basically the same issues. The children's needs were paramount to the point where they required much intervention. In each case there were other family members who also required attention. The parents were continually searching for ways to better meet their child's needs while at the same time they were 'educating others' who didn't share their views of the child. They were aware of their rights as a parent through their various networks and they were prepared to exert pressure, even through the courts if necessary, in order to ensure their involvement in decisions affecting their child with severe to profound special needs.

Chapter 5

A STRUGGLE TO BE HEARD: PARENTS' VIEWS OF DECISION-MAKING FOR CHILDREN WITH LEARNING DISABILITIES

This chapter discusses the "life experiences" of parents who have beeen involved in making decisions regarding their learning disabled child's education. These parents are members of the Learning Disabilities Association of Alberta. Their children have special needs in that they are at least of average intelligence or better as determined by an individual assessment measure but the children have experienced minor to significant difficulty when it comes to learning.

For the parents involved in this particular part of the study, Table 5.1 summarizes their children's ages and their specific learning disabilities:

Table 5.1 Children's Ages and their Specific Learning Disabilities

Child	Age	Disability
A	11	Attention span; Speech Problems; Possible FAS
B	15	Mathematics; Behavior problem
C	16	Social skills; Self-esteem Two years behind in all academic areas
D	10	Language delay Attention span
E	17	Social problems Difficult to motivate Behavior problems

The chart reveals that the children included in the study covered a broad range of ages and had difficulties in a number of areas.

In order to better understand the learning disabilities of the children in this part of the study, the following, Table 5.2, describes the school history of one child with an undiagnosed learning disability. While the words speak for themselves, the symbols on the chart depicted a positive experience (++) or a negative experience (--) for the parent.

Table 5.2 Profile of a Child with an Undiagnosed Learning Disability

Grade	Consultation w/teacher	Problem Identified	Process	Result	Behavior @ home
1	++	--	Swim & gym	No change	
2	--	Difficult to get along with	Unable to cope in class	No change	
3	++	Hyperactive?	Unable to work with	Above average reader	Difficult to deal with
4	--	--	Child picked on	Child wanted to quit school	
5	++	--	Child had some friends	Some caring & respect	
6	++	-- Obnoxious		High marks in math/ reading	

(Table 5.2 continued)

7-9 (In private school)	++	--	High academic standards	Behavior starts to affect learning	Lack of social skills persist
10 (Return to public school)	--	--	School rules not enforced	Still strong in academics	Child almost died due to illness
11	++	--	School was boring/ 1st boyfriend	Several suspensions Young offender	Still hard to deal with
12	++	++ A.D.D. label from a psychiatrist	Suspended in Oct. 90	Six suspensions Child in counselling	Abusive @ home Moved out Parents pay rent

The history of this learning disabled student, with an undiagnosed learning disability until grade twelve, pointed to the importance of an early assessment.

The following three general themes emerged as these parents discussed their involvement in decision-making:
(1) the common characteristics of this particular group of parents; (2) the specific actions of parents; and (3) those comments referring to parents as partners on a team. The following sub-themes emerged throughout the interviews:

> Parents had to deal with others placing labels on their child, and on themselves as parents of that child, even though they realized that the label ensured access to services.

Parents believed they were becoming an "expert" in knowing their child.

Parents experienced a wide range of emotions as they begin to work with their child.

Parents recognised that there were stressors on other family members when there is a child with special needs in the home.

Parents recognised the child's strengths and weaknesses and adjusted their expectations accordingly.

As a result of the child's situation, a relationship developed between the child and his/her parent.

Parents seemed to be in a constant battle to have their opinions heard and respected.

Parents searched for educational opportunities which were alternatives to the regular classroom delivery system.

Parents have developed strategies to help them deal with professionals.

Parents have developed a series of community networks to support them as adults.

Parents indicated that one of their strategies was to consult a lawyer regarding their situation.

Parents wanted to participate as a "team" member.

Parents stressed the need for open communication between home and school.

Parents stressed the need for early identification.

Parents struggled for power over decision-making.

Parents indicated that there was a "lack of trust" from time to time between parent and the school.

Parents wanted to have input into decisions affecting their children's education.

Parents indicated an awareness of the dilemma for the teacher when there is a child with a special need in the classroom.

Parents indicated that their case had been appealed to a local school authority and/or the Minister of Education for a review.

Unlike the parents of children with severe to profound needs, the issues for these parents did not surface until the child entered school. The reason for this occurrence, of course, was that for learning disabled children, most of their difficulties arose upon entering school when they began to read, write, do mathematics, and interact with others for long periods of time. As a result, there was no discussion of the learning disabled child's infancy/toddler and preschool years. Only those subthemes which became fifth order themes will be discussed under the three general themes.

Major Theme: Common characteristics of parents as their learning disabled child entered school.

The interview protocols revealed that there were a number of common qualities that characterised these parents as their children left home and entered the school system. In comparison to the children with severe to profound needs, the five children included in this part of the study, diagnosed as learning disabled,never really began to experience difficulty until they entered grade one. Five fifth-order subthemes emerged from the data. Clearly, one of the most difficult issues that parent co-researchers of both organisations had to deal with was the issue of labelling.

Subtheme 1: Parents had the greatest fear of their children being labelled even though they admitted that the label ensured access to services.

The literature review discussed the issue of labelling.

Wilgosh (1990) highlighted the strong feelings associated with a parent discovering his/her child's disability. In discussing the issue of labelling, one parent was exasperated because the assessment was so delayed and yet she was relieved to know:

> It was with some difficulty we got (name of student) to agree (to testing), and we did have her go see a psychiatrist. He doesn't know whether or not she's hyperactive, but that she has an extreme attention deficit disorder. He said, 'I can't believe she wasn't diagnosed as a preschooler!' Here she is, seventeen years old, and we're finally getting it. I know people say, 'Don't label,' but you don't know what a relief it was, because then you can start understanding, and all these years, we have a kid that you're embarrassed to take into other people's houses because you can sense other people don't like your kid, and it really comes across quickly. . . it was just wonderful for us to hear what the problem was.

Another parent also discussed labelling:

> We're all afraid of labels, and we don't want to label our kids, but I found that once my kid was labelled, LD, things started improving for him. He wasn't a brat; he wasn't slow. That teacher looked at him a little bit differently and kept mentioning over and over again how bright this child was, and he has this problem.

When discussing the child's first year at school, this parent commented:

> By the end of the first year the teacher just said, 'I think I made a mistake about (name of student),' but not enough was said, and it was too bad. And I guess, too, we weren't informed because we thought our daughter was bright, and I guess we needed to be told more about what 'learning disabled' meant, rather than just the term. And I guess we needed to ask more, we needed to read more: we didn't do those things. I guess we needed to be taken by the hand, sort of thing.

For the learning disabled child, the assessment was often more difficult to access and longer in coming. Not only were the children labelled, but as the literature suggested, often the parents were also labelled in a similar way which resulted in consistent views, (i.e. a second fifth-order subtheme).

Subtheme 2: Parents had to overcome labels placed on them by others, including professionals, as they struggled to become a full member of the 'team'.

It has often been said that children are cruel to each other, but as this parent implied, adults may not treat each other with much respect either:

> All these years we had a kid that you're embarrassed to take into other people's houses because you can sense other people don't like your kid, and it really comes across quickly. You watch your kid in a play group, and you can see that your child doesn't fit in well. She might have one or two friends. She has a good ability to make friends, but she can't keep them long.

The parent in this interview was struggling with many issues including not only her child's difficulty but also her own feelings of self-worth as well as her perceived inability to help her child:

> I guess I should have beem more aggressive than I was, but I reached out to every avenue I was aware of, and I was patted on the head. One of (name of student)'s teachers from this year was doing some research, and she found that the person who is least likely to be listened to is the mom, and yet they always say, 'You know your child better than anyone else does', and yet when a mother goes to bat for her child, she's the least likely to be listened to because it's regarded as emotionalism, time and time again.

Especially for the parents of hyperactive children, the idea of respite care or a break from the child was critical. However, as this parent found out, the labelling confused the issue:

> We don't have much in the way of an extended family, so there were no avenues or too many other resources. There's no way you could ask a friend to take her in the house. Like, you could say to friends, Oh, I wish we could find somewhere for her to live outside the home. If only we had a big family or something. If only we had somebody we could ask to do it. And nobody ever said, 'I'll do it.'

While the diagnosis was difficult to accept, this parent was relieved to know, "because then you can start understanding" (Parent, 205). Understanding the child with a learning disability is crucial to his/her positive development of self-esteem. Another fifth-order subtheme emerged:

> Subtheme 3: Parents became 'expert' in knowing their child because they have lived with the child for five or six years before the child entered school.

For the learning disabled child, the diagnosis was often proclaimed later in the child's life, and as a result, the parents had to be more aware of the child's strengths and weaknesses:

> They tested (name of child) the same as everybody else, and she did really, really well on it. The teacher phoned me to tell me she was so flabbergasted at how well (name of child did; she couldn't believe it. And I said to her, 'That's why you can't give up on her. I _know_ she's smart, but I realise she's difficult because she's impossible at home, too.' So it was a two-way thing.

And as this parent later noted:

> You couldn't discipline her; she was a law unto herself. If you tried a reward system, reward was important enough to her to follow through to earn the reward. No punishment was bad enough to deter her, so either way we couldn't do anything. It seemed the easiest way was if we had no expectations and then no disappointments. It was hard. She did not make friends easily yet she's really a gentle-hearted person, a real gentle heart, but she just has this way of being quite difficult to get along with, and this is for everybody, everywhere she goes, and it's been like that since she started talking.

Another parent obviously knew her child very well:

> There was quite a concern about him being a behavioural problem, and I didn't think so, but I tried to talk to the teacher and told her what I do at home. I'm really positive and if I want some kind of chore done I might set a time limit and say, 'Let's get this done' and break things down into small steps for him to reinforce him for accomplishing

> things. I told her that the worst thing you can do with my son is to be negative. The minute you start punishing him and say that he's going to miss recess or going to have to stay in after school, he gets his back right up against the wall, and you're really going to have trouble.

While a learning disability is not as visible as other handicapping conditions, the assessment and the labelling were critical to understanding the child with a learning disabled.

Another fifth-order theme emerged as the parents described beginning to grapple with their children and their schooling.

Subtheme 4: Parents experienced a range of emotions as they began to deal with the child and his/her challenges.

Parents of children with learning disabilities experienced both extremes of the continuum of emotions, from sheer delight at their children's successes to sheer exasperation when significant others in their childrens' lives did not understand them. One parent remarked on her frustration with the school:

> When (name of student) did not get a report card, we went to the school to see what was going on. After the interview, we left the school feeling irritated, talked down to and not treated as partners in our son's education. What really got us mad was we have been involved with the school with their bingos, their hot dog sales, etc., and to have them treat us like this was wrong.

With copies of the previous report cards in hand, another parent expressed frustration with the school, as she noted:

> This child has attended (name of school) for the past five years in a number of different programs. As you can see from the report cards, he has made very little academic progress during that time. It was obvious to me that he had not received the degree of assistance that he needed, and his reading level had not improved in five years. We had very little time left as he will be sixteen years old in four years and if his reading has not improved, he will quit school and be lost forever. We had to do something.

One parent commented on the success for her child:

> This teacher caught on to this skill that my son has, this gift as he calls it. He calls me, and by this time he and I were meeting once a week and talking about (name of student). And one day I went in there, this teacher comes out of the office, and he's practically white. He said, 'Come in here. I want to show you something.' So there were the teacher and me and the guidance counsellor and my son in this small office, and he shows me the gift, the skill that my son has and how he can look at a word and close his eyes and he can see the word.

After sending her learning disabled teenager to a private school, one parent remarked on the positive changes:

> She started off in September, and it was quite a year. And of course she was going to quit umpteen times. They finally told her, 'We will not be kicking you out of this school, no matter what you do. If you leave this school, it will because you chose to leave. We know you can do well; we want you to stay and succeed. . . .' Well, it took a long time, but she eventually bought into it, and I guess by about February I don't think we were having any more quitting. She finished her year, she was valedictorian, she received the Governor-General's award, she wrote three diploma exams and got first-class honors in all of them. So there you go.

One more success story:

> (Name of student) summed it up best herself when she spontaneously said a few words as she accepted her grade nine graduation certificate last year, 'I know I have some problems that are not going to go away. I want to thank the teachers at (name of private school) for teaching me how to cope with those problems. I'm really excited about going back into the public system and I think I'll do just fine there.'

The learning disabled children's apparent lack of success at school and the perceived unwillingness of the school to respond to their needs, gave rise to another fifth-order subtheme.

Subtheme 5: There were additional stressors on all family members when a child with a learning disability lived in the home.

This theme was emphasized in many of the studies cited in the literature review. In describing her daughter's difficulty with social skills, this parent commented:

> She's begging to come home. She was living in pretty tough circumstances. She got involved with some really bad people; she got involved with some gang guys. Just before she was actually moved out of her apartment they came with baseball bats, hoping to kill, supposedly her and her roommate, when the police came, offered the girls protection from these guys if the girls would testify against the guys. Well, then, we had the police in our life, too!

And to further complicate matters:

> So it wasn't really wonderful, and I still just couldn't have her home. I really wanted to get our younger daughter through at least her school year before this upsetting force came home.

Another parent sought outside help to resolve her difficulties:

> I went in and I talked to this guidance counsellor, I told him the problems that I'm having with my son. There was also kind of an emotional problem. (Name of student)'s father moved out the year before, in grade seven. But I made all the decisions anyway with not a lot of backing from my spouse, because he never did accept that (name of student) had this problem, and a lot of our marital problems stem from this. So this guidance counsellor started working with my son, and he was really interested in (name of student) and spent a lot of time with him.

One additional comment on stress in the family as this parent attempted to balance the needs of other family members:

> There's only so far I can go, and sometimes that puts a lot of stress on me because so much of my time and so much of my energy is devoted to my son in this program with him, that sometimes I just look at my girls and I think, 'They're doing fine and they're passing and they're average students and they're fine', that sometimes I let that slip. That has been stressful on me because sometimes the guilt sort of gets to me.

It was obvious that having a child with exceptional needs in the family can cause additional pressure on the family unit.

Major Theme: Common types of actions taken by parents of children with learning disabilities

The interview protocols indicated that there were a number of actions and strategies that each parent pursued while trying to get assistance for his/her child with a learning disability. The result was four fifth-order subthemes:

Subtheme 6: Parents seemed to be in a "constant battle" to have their opinions heard and respected.

One parent expressed her frustration when she tried to have her child assessed:

> We went to the (name of testing centre), and they asked me some questions. They spent very little time with us unfortunately, and the question that always, always, arose wherever we went trying to access help, that finished us, they would say, 'Does your child watch TV?' We'd say, 'Not very much, because we're not a TV-watching family.' 'Does she read?' I'd say, 'She's an avid reader.' 'Well, then, she can't possibly be hyperactive if she's an avid reader.' So there was no point in testing her, because she was an avid reader. So the problem continued.

In an effort to get her child assessed and subsequently better understood, this parent also encountered resistance:

> (Name of student)'s report card indicated that she was easily distracted, had poor work habits, was not keeping up with the rest of the class and took considerable time to learn new concepts. It was at this time that I requested testing which was not completed for approximately 4 months. We requested a move to the English program but we were told by the teacher and the principal that she would lose her year anyway so she should remain in Immersion. Despite her problems, there was no offer or suggestion for extra help.

This same parent commented on her reaction after receiving the results of the assessment:

> When we received the test results, including IQ and aptitude, one of the resource specialists advised us that she would likely never progress beyond grade 5. (Name of student) was about eight at the time. We were livid and requested another opinion which was much more optimistic. I wonder what would have happened if we had accepted that diagnosis?

The child's transition from elementary to junior high school posed some challenges for these parents:

> (Name of student) comes home really ticked off. He's saying, 'There is no resource.' Then he hands me this paper saying that there's been a change in the procedure this year, or the planning for resource, and what's going to happen is that the kids are going to be in the regular classroom, and the resource room teacher is going to go from class to class with these kids. . . So I thought, 'Oh, good God!' (Name of student) was having a fit over this. He was embarrassed in the language arts program. All of a sudden he's expected to read in front of the kids, produce all this written stuff.

And she continued,

> The kid was threatening that he didn't want to go to school; there was a fight in the morning to get him to go to school. This went on for two days, and I contacted the school. I wanted to find out how many minutes a week is (name of student) given of this resource?
> So I waited a few days and thought about it, and finally I phoned up the head of the new . . . I think it's a new position that last year. She understood where I was coming from, she listened, she suggested that I get on the horn to the guidance counsellor immediately.
> So I took it from him, the guidance counsellor, and I wrote a letter to the superintendent and told the superintendent that, 'Listen the school program is not meeting my son's needs, and I want to get together. Let's talk about this. We have finally come to realise that there are some ways that my son's going to achieve, and we've got to get cracking and we've got to catch up, because this kid's got a lot of catching up to do.' So we get the superintendent in and had our meeting and everything, so the superintendent turned around and gave my son a one-to-one special ed. teacher for a 'point six'.

As a result of a perceived lack of support for their concerns, many parents took the next step which emerged as another fifth-order theme.

Subtheme 7: Parents began to "take control" once they realised their children were not progressing.

This parent's comments reflected her concerns for her daughter since the beginning of school:

> She's had troubles in school right from the beginning. Her grade one teacher knew something was different, but couldn't pinpoint it, had us going to a program on Saturday mornings, a recreational swim-and-gym program for LD kids. She didn't come out and say that she thought (name of student) was LD, but she just felt this program would be good for her self-confidence; she felt it was really, really lacking. We did the program and we really couldn't see any change in it, but I guess, you know, you expect to see change quickly, too, and we didn't see anything.

The importance of early identification for children in the foster care system was highlighted by this parent:

> When we took (name of student) into foster care, we knew he had several problems including possible symptoms of FAS, problems with his attention and speech. (Name of student) has a good sense of humor and lots of friends in the neighborhood, but the situation at school became so bad that at one point he climbed into a burning barrel. . . Now that he's at (name of private school), he's receiving speech therapy, he was named Student of the Month, and the school uses a communication book to keep us informed about his program and his progress.

Some parents began to take control out of sheer frustration:

> I requested an interview with the principal in October. (Name of student) had not made any gains in the past three years and was in need of intensive remediation. She was in a class with five very disruptive boys and because of her distractibility and inattentiveness the situation was getting worse. (Name of student) was left to work on her own a lot of the time with no where to go for help. As a result, she spent a great deal of time daydreaming, and she was frustrated because she couldn't get the help she needed. I even volunteered to assist in the classroom on a weekly basis to assist with the reading program thereby giving the teacher more time to work with others. By December the situation had not improved so I requested a meeting with the program specialist who agreed that the placement was not appropriate and agreed to move her to another L.D. class. After extensive investigation and much consultation we decided to pull her from school and place in the (name of private school).

In an effort to buttress themselves against the difficulties their children were experiencing, the parents in the study looked to other adults to provide a balance in their lives. Another fifth-order theme emerged:

> **Subtheme 8: Parents have developed a series of networks to support them as adults in the community.**

These parents initially looked to the family doctor for support:

> At the end of grade three I felt that maybe she was hyperactive after something I had read, some stuff I'd heard. I went to my family doctor; I'd gone to him a couple of times to discuss (name of child), and I would get a one-word comment from him, and then that was the end of it. He was not willing to discuss it.

Another parent also sought the support of her family doctor:

> And in between there I made decisions myself to go and have him tested outside the school board. My pediatrician was involved; he knew what was going on. He was a good link, my pediatrician, because they wouldn't come across with any of the psychological testing. But I knew that if I got him in on it, he would just photocopy the results and hand them to me.

To some extent, this strategy was similar to the strategy adopted by the parents of children with more severe disabilities, who often looked for support beyond their regular family doctor. Because their children were already in the school system, these parents also looked to the children's teacher and principal for support. This parent described her experience with her child's teacher:

> Sometimes we look to the teachers to have all the answers and they don't, but they certainly got some of the expertise we don't. We've got other practical kinds of things. So then he went back to grade three and he had a really good teacher, just a regular teacher, who looked at (name of student) as a special needs person and tried a lot of different things. I give her a lot of credit. She had thirty other kids in her class, but she did try.

In order to provide a balanced point of view, these parents also looked to other personnel outside the school for advice:

> So I got on the phone and I phoned up the reading specialist. This is something that really was a surprise to me, too, she said, 'I haven't heard about (name of student) all year. I assumed that things are going just fine.' And I said, 'NO, things aren't going just fine, and he's lagging behind.'
> So she said, 'Okay, there's this other program. It's at (name of school) and it's a centre of a grade four, five and six year for kids.'

For one parent of an older student with a learning disability, the support of other agencies in the community was essential but disappointing:

> There's a Jimmy Program for juveniles which will finance them while they're going to school. But I didn't want her home. I wanted her to receive some kind of treatment. There's no treatment for them; there's nothing mandatory unless they are a physical danger to themselves or others. So there we are, so you have to put up with a lot.

One parent enrolled her child in a private school as a result of her first impressions:

> The best thing that I accessed, I guess, was the (name of private school). I went over there, looked around, had a talk with them, and I liked it. I just got a wonderful feeling.

One parent negotiated the terms of her teenage daughter's return to the home, which included involvement with an outside agency:

> She could come home at the end of June under three conditions: One was that she have a job; that she agreed to go to counseling with the psychiatrist who diagnosed her . . and so the third thing (name of student) had to go look into the school.

In summary, when the situation was desperate, the parents became very resourceful in terms of seeking outside support.

At some point during each of the interviews regarding their children with learning disabilities in the study, their parent(s) indicated that they began to work "outside" the system.

Subtheme 9: Parents have attempted to correct the perceived imbalance of power by seeking to redress their grievances through a local special education appeal committee, a Ministerial Review, or even the courts.

When the relationship between the parent and the school had deteriorated to the point where there was a confrontation, the parents in the study mentioned that they looked for an appeal mechanism to reestablish that balance of power. The venue for such an appeal is dependent upon the school system as some school systems have a special education appeal committee; others do not. If the appeal is not successful at the local level, the parents may request that the Minister of Education review any decision regarding their child that a school board or any of its employees has made. The present School Act 1990, Sections 103 and 104, provide for the establishment of both a local appeal committee at the school system level as well as an appeal to the Minister of Education in an effort to resolve some of these disputes. One parent (Parent 202) realised that "at the age of 10, (her daughter) was two years behind in her academic progress" when they enrolled her in (name of private school). The parents appealed to the local school board for funding to enable their child to continue in the private school until she finished grade nine.

In some instances the parent has approached the issue of redress of a decision through litigation:

> So I'm sort of thinking like this is a big decision. I have to make this decision, and I have to be confident and I have

> to be aggressive to do this. I think that that's a hard thing to do for some people. It's hard for me, but not that hard. I'm still going to do it. I don't feel like I'm alone, because I know other people have had to do it, and I'm not afraid to go and look for support. And through the Alberta Association, I've contacted them and I've told them that I'm going to be doing this, and they've referred me over to this lawyer woman. So I'm going to get some connections with her and get some support from her, because I probably will have to appeal all this.

The parents of the children with learning disabilities included in this study were certainly aware of the avenues to appeal such decisions.

Major Theme: The concept of parents as partners in the decision-making process

In order for the learning disabled child to be successful, there must be a close, collaborative working relationship between the child's classroom teacher and the parent. The parents in this study elaborated on four fifth-order themes which formed the basis for this relationship.

Subtheme 10: Parents wanted to participate equally as a "team" member in making any decisions involving their child.

All parents stressed the need for this relationship between the teacher and the parent to develop over time:

> I'm quite enjoying spilling my guts about this. It feels good to tell somebody who actually is listening. So then grade four, five, and six he had an excellent teacher. She was really good. She tried a lot of different strategies. I was involved with the IPP. We looked at it, we planned it, we talked about it, and we set goals, we talked about it, we talked about what her responsibilities were, what my responsibilities were, and what (name of student)'s were. I found this was a really good working relationship.

This next parent was particularly upset because she had not been involved in a special education placement decision:

> The school knew before (name of student) entered grade one that he was an 'at risk' student, particularly because of his speech problems. But they placed him in a split 1/2 classroom and he had no special education. Finally in grade two he began getting extra help which lasted for two years. He was finally starting to make gains. In grade four, the school decided to integrate all their kids with special needs into the regular classroom. For (name of student), they decided he still needed more help so they placed him in an EMH class without consulting with us. Now he was in a small class with two other deaf students who communicated using sign language. In order to improve his speech, he didn't need sign language, he needed to talk and practice his speech. That really irritated me. Were we treated as partners in this decision? No, definitely not.

The concept of treating "parents as partners" with open communication and respect cannot be over emphasized.

SubTheme 11: Parents stressed the need for open communication between home and school.

The parents of children with learning disabilities in this study indicated their need to be involved in decisions regarding their child's education:

> At (name of private school), (name of student) was starting to see that school could be fun again. They kept me well informed using a communication book. I had some say in the development of the IPP. At that school, I felt that I did count and that many people there were interested in involving me and helping my son.

In another case, the mother of another child with a learning disability was actively involved in decision-making:

> So then after Grade Two, I knew my son wasn't ready to go into Grade Three, and I worked quite a bit. The resource room teacher was very good, and once we got in for the assessment, then we had the psychologist, and I had the reading specialist. Then they told me about this Learning Centre, and I was sort of for it. My son certainly wasn't; he was very upset having to be moved and everything. My husband was very upset about it. It was a very hard decision to make. I was on my own. They were suggesting that this was a really good placement. I got to go over. I got to visit.

Unfortunately, when this parent tried to return her child to the public system after being in a private school for three years, she did not get the information she needed to make a good decision:

> So we got down to this school, she was registered in mainstream, and her classes were set up for her. This school is the area high school which has the LD program, and we weren't told about it. My husband goes in and says, 'My daughter has an attention deficit disorder.' But nothing was mentioned. Not one word was said to him. 'We've got a program. Let's try it.' Nothing.

Subtheme 12: Parents expected to have input into decisions related to their children's placement, programming, and even who works with their children.

The importance of being involved in the decision-making process was stressed by every parent:

> Yes, it was segregated, and there was no integration. There might have been maybe the phys. ed. -- I don't remember back then--but recess and that kind of thing. But I certainly was involved in that decision, and it was a hard decision to make, but I did choose that decision, and he went away to another school. So he went over there, and he did succeed, but not to the degree that it was hoped he would. It was sort of my hope that this would be a catch-up period. I've had a lot of hopes sort of put down the tubes, and a lot of good things have come of it, too; it's not all negative. But then he went over there, and at the end of the year we just didn't know what we were going to do with him. So I listened to what the reading specialist and the psychologist had to say and the teachers, because I didn't know, but they felt that because (name of student)'s self-esteem was so low, that maybe he felt so much of a failure that maybe if he did go back to his own school that things would be better. So *we* decided to do that, and it wasn't because I didn't have the choice to make that decision; I just wasn't sure. And I think sometimes, too, as, parents, we don't know the answers.

Subtheme 13: Parents developed a series of other strategies to help them work with professionals.

Parents placed a great deal of trust in their children's teachers. They expect that their children will be treated fairly and with respect and they will be educated so that they can become self sufficient, responsible adults. As Turnbull and Turnbull (1985) suggested, the key to a successful partnership is communication and respect. It appeared from the study that once the trust aspect of the partnership between parent and teacher was violated, parents wasted very little time before: writing letters to the local school superintendent and trustees; locating other education delivery systems; getting support from provincial advocacy groups; and even pursuing a Ministerial Review regarding an administrative decision which they felt was not in the best interests of their child.

According to one parent, she recognised very early in the child's school career that the child functioned much better in a small group setting where he could be better served with one-on-one instruction. The child needed to have vocabulary words repeated for him and he could manage quite well when assignments and stories were read to him. As this parent remarked:

> Once I started looking around and located the (name of private school), I found that there were many staff members who placed value on (name of child's) education and where my views as a parent really counted.

In discussing her child's entry back into the public school system after six years in a private school, this parent elaborated on the search for alternatives:

> We did a thorough search for an appropriate high school for (name of student) to attend. The staff at (name of private school) was most supportive in this area. The first choice as parents was to have her attend a private school in (name of city). However, after sitting in on classes for a

> half day with a good friend who was already there, (name of student) decided she did not want to go there. Of the three public schools we "interviewed", we decided on (name of school) for several reasons: they were the most optimistic about her possibility for success and were willing to offer a few special considerations; they had a strong choral and drama program which is of high interest to (name of student); and they had a few LD courses which (name of student) did not need to attend, but they offered her the support normally only offered to students in the LD classes.

The parents of children with learning disabilities have quickly learned how to deal with professionals. They were aware of the hierarchial nature of schools and school systems and they knew that if they were dissatisfied with a decision or an action of one person they could take the issue to the next level in the hierarchy. This parent became a strong advocate for her son who was experiencing difficulty with mathematics:

> So it was just about November, I requested that she (the teacher) get some testing done for him. Apparently she did look it and arrange it, but it was quite a holdup, and then these behavioral problems; my son started running away from school. I contacted the principal and I said, 'Listen, we need some testing done with him right now.'

And she continued:

> So she (the therapist) came in and tested (name of student), and I figured well okay, she didn't really seem to think that there were any kind of behavioral problems. She suggested that it probably was a clash of personalities. So that was sort of a turning point for me. The behavioral therapist said to me, 'You've got a right to make decisions, and if you find there's a personality conflict, you have the right to pull your kid.' That was my first child and I didn't know what my rights were, and that really meant something when she told me that, that I have a right to make these decisions. Well, as things went on he did go ahead and he was tested and everything, and it did show that he was certainly behind and that his intelligence level was very high.

The School Act for the province of Alberta, Section 103, made provisions for board and administrative decisions to be appealed to the Minister of Education. The process is called a Ministerial Review. This process only recently became apparent to this parent:

> The school, (name of private school), was wonderful to us. In the fall they suggested we appeal our kid's placement, and I didn't have a clue how to do that. I joined the Learning Disabilities Association here and got all the mailouts, and there was something that came out, a seminar they were conducting in the new year.

And the parent described her understanding of the appeal process:

> They tell you not to appeal for money; you appeal for placement. I've got a daughter in grade twelve; what can I possibly get? But I thought, I'm still going to do it because I want the story to be heard, the fact that there was a chronic problem that nobody did anything about, because the bottom line was 'Is she passing?' And that is not always the most important thing. My daughter was passing. She was miserable. She was a social misfit. So passing wasn't important.

So the parent prepared the appeal based on two issues:

> My appeal was on the basis that she (her daughter) was never tested in depth, and she should have been and was not. Then we went to (name of school) with an LD program, and they don't even tell you that they've got it when you have told them that your child has A.D.D.

And she continued:

> In preparing the appeal I went back to (name of student)'s school records that they have on file. Interestingly enough, her kindergarten, grade one, and grade two files were missing. It was her grade one teacher who suspected she could be LD. I sure wish those files were there! But I got some files and I photocopied them. I decided that when teachers do the files in June, and there's all this paperwork, that they file it and shove it away and don't ever look at the files again. I think if maybe at the beginning of November when they've got a face and a personality for every kid in the class, they should be looking through those files. If a person who just took three consecutive years of (name of student)'s file, there's a pattern there. One of the final comments when she was kicked out of grade twelve was '*Refuses* to pay attention!' She wasn't refusing to pay attention; she *couldn't* pay attention! is what it was. So I think it would

> be really important for teachers to sit down and maybe spend some time looking at these files and familiarizing themselves, especially in the case of any student that is causing them some concern. I think they should really do that.

In this particular case, the appeal was upheld and the school system was found negligent in that they had not tested her daughter and had withheld services.

The resolution of the case was worked out between the parent and the principal of the school:

> What I really would like to do, I don't want any other kid to go through all that our daughter's gone through. It's really a shame; it's really sad. It's no big deal having ADD, but they're misunderstood. It's not really a big deal. It was really too bad that all those teachers had to teach somebody who was so difficult. It was too bad that all those kids in all of her classes had that disruptive person in there making it a less pleasant experience for them. So it was bad for three different groups. So my request was that the school hold a professional development day during the next school year on attention deficit disorder. If teachers were aware of it, it would make a world of difference for a lot of people.

Summary of Chapter 5

In conclusion, this chapter has highlighted the issues that some parents of children with learning disabilities have encountered. The themes and subthemes which emerged from the data have been supported by interview data from the parents interviewed. After reading this chapter, the reader should have a betterunderstanding of: the common characteristics of parents of children with learning disabilities; some of the strategies that parents have used to achieve school success for their children; and the essential components of a relationship between parent and the school that the parents believed to be in the best interests of their children.

Some key concepts emerged from the discussion with the parents of children with learning disabilities. These parents viewed the early identification of children with learning disabilities as critical to not only understanding the child but also as a means to accessing services. The issue of 'parents as partners' cannot be overlooked. These parents expected to be involved as a team member in the process of educating their child. The key ingredients to a productive partnership were identified by the parents as trust and mutual respect for each other. In this relationship, the parents expected to be treated as equals. The issue of power in the parent-professional relationship must be balanced and maintained throughout the child's days in school.

Parents today are being strongly encouraged to get involved in educating their child. The parents of children with learning disabilities have high expectations for their children as well as for the staff who work with their children. As the literature demonstrated, parents are continually being forced to be good consumers of the services they receive. The field of education is now included in these discussions. The parents of children with learning disabilities are no longer willing to sit back and accept the school's decision. They must be meaningfully involved in the decision-making process from the beginning. Parents of children with learning disabilities today are generally very knowledgeable and the networks they have established, have provided them with support and advice on difficult issues. If these parents perceive that their views and opinions are being ignored, they will use whatever strategy necessary including the courts or a Ministerial Review, to ensure that their story is heard.

Chapter 6

CONSOLIDATION OF FINDINGS

This chapter was written in an effort to begin to consolidate the findings of the research into decision-making for parents of children with special needs. After reading the last two chapters, it was very apparent that there were distinct similarities and differences between and among the two groups of parents. This chapter will explore these similarities and differences, but the differences will be discussed first.

Each group of parents has children with different levels of need

With regard to differences, both groups of parents were presented with children who had challenges to face that most children do not. The parents of children with severe to profound needs have been dealing with issues since the child was brought home from the hospital. For these parents, the task was akin to that of caring for a new born baby. For these children, the disability was more obvious. To date, these parents continued to work with their children at a very intensive level because of the nature of their childrens' disabilities.

For the child with learning disabilities, the child's difficulties in learning, whether that be in the area of reading, mathematics, speech and language development or developing appropriate social skills, only became apparent when the child entered the school system. For these parents, the challenge was equally rigorous in that while these children did not have the physical characteristics of their peers in the other group, their needs were just as great. For these children, the disability was more subtle and therefore more difficult to understand. These parents only began to ask questions about their child's development after the child entered school.

As a result of the different needs of the children, the parents' reaction to issues like integration or segregation were totally dissimilar. The parents of the children with profound needs wanted and expected their children to be treated as much as possible like other normal children. In other words, they were strong advocates for the process of integration or total inclusion. These parents strongly supported the notion of the community school concept so that the children could develop appropriate social relationships within the local environment.

The parents of the children who were learning disabled had a viewpoint that was entirely opposite. They felt their children had special needs which could be best met in a small, segregated group setting where their individual learning needs might be remediated by learning specific coping strategies. Integration was not an issue for them as they often searched for private schools at some considerable cost and distance from home so long as the program was able to meet the children's needs.

Regardless of the level of disability, both groups of parents were highly involved with their children, and had high expectations for their children and for those who worked on behalf of their children. Both groups of parents were prepared to devote endless time and energy to ensure that the child's needs were met. The extent to which the child's needs were met outside the home was determined to a large degree by the parent's involvement in the home.

> I know that right now a lot of the integration is not by choice, but it becomes a more known thing. As with all special needs kids, there's more integration now. And I think from the LD Association's view, integration for some of those kids isn't the answer, despite the Minister's vision that all kids would be integrated. (Parent 205).

Recruitment of parents for the study

The parents themselves were recruited to take part in the study in a much different manner. For the parents of the children with profound needs, the "snowball" effect was utilised. Once two members of the Gateway Association were recruited to the study, the usual ice-breaker introductions were facilitated through these two key informants.

For the parents of children with learning disabilities, the President of the Alberta Association facilitated the process by allowing the researcher to advertise the study in the Learning Disabilities newsletter, called the Agenda. Any questions, comments, or concerns regarding the study were initially fielded through the provincial office. The fact that the researcher won the Association's scholarship during the year of research was an added bonus in terms of introductions and credibility for the study.

Despite some of their differences, the parents from both groups, in the final analysis, discussed many common issues and concerns. Both groups of parents were unanimous on three important issues: the focus has to be what was in the child's best interest; the importance of the classroom teacher in relation to their children's needs; and partnerships. It is these themes which will now be discussed.

Issue 1: Parents focussed on what was in the children's best interest.

It was quite apparent that despite the differences in the child's needs, both groups of parents were strong advocates for what they deemed to be the best interests of the child. In that both groups of parents were representative of members of their respective provincial associations, the researcher had to conclude that the experience and knowledge demonstrated by these parents must be attributed in part to the role of the two associations as advocacy groups.

Issue 2: Parents stressed the importance of the classroom teacher.

It was recognised that this theme could in fact be a thesis unto itself. The common bond that binds the two groups of parents is that they both have children with atypical learning needs. So what did parents of these atypical learners emphasize when it came to working with and teaching both groups of learners?

> If you're going to teach any kid with a learning disability you have to put in more time. These teachers at (name of private school) have small classes, and they have this six-to-one ratio which the regular classroom teacher doesn't but these teachers work so hard, and they do things for these kids that are not done by high school teachers. These teachers work harder, and they're so lucky because of what they see.

One parental comment from the theme regarding input into decisions was worth repeating:

> So then, grade four, five and six, he had an excellent teacher. She was really good. She tried a lot of different strategies. There weren't many decisions. I was involved with the IPP. We looked at it, we planned it, we talked about it, and we set goals, we talked about it, we talked about what her responsibilities were, what my responsibilities were, and what (name of student)'s were. I found this to be a good working relationship.

The two most important words in the quotation were "We talked". When discussing the possibility of using medication for one child, the parent was never alone in the decision:

> The physician spent a couple of afternoons with (Name of Student), or a couple of hours anyway, but it was suggested by him that (name of student) had an attention deficit disorder. Now, that had never come up before, and I didn't really think so, and I had to really think about this because this was my specific decision whether or not we put this kid on medication. This was totally up to me. The teacher was really supportive, and we thought, okay what are the side effects? What is this ritalin? We did a bit of research, and neither of us was sure. I talked to his pediatrician and we decided, okay, let's give it a try. It doesn't have to be forever; we'll try it. No harm in trying it. So we did, and it made no difference. So, of course, we just pulled him off the medication, and we both kept records. That teacher was excellent. She kept all the records. She kept daily logs of symptoms and side effects and all that.

Another decision the parent and the special education teacher made together was with respect to the IOP program:

> And the special education teacher was saying, 'No, (name of student) is too bright; he can do better than that.' So we finally made the decision that he would go into the regular grade seven and get pulled out. That was okay.

It was interesting to note the change in the tenor of this particular interview as the child progressed to grade eight. There was a change of teacher and the work was becoming more difficult. The parent started using more "I" statements instead of "We" statements as the situation became more confrontational. The parent eventually took the case to an appeal hearing.

Both groups of parents stated that they knew and understood the predicament the classroom teacher was in:

> I've also learned that you have to realize that the teacher is under stress, too. These teachers are under stress. The amount of work that they're expected to do, and the lack of support, and especially the regular teachers that are supposed to be having all these integrated kids into their program, and they're not given any extra time to do prep work or anything. And it's not that they don't want to integrate these kids; the majority of them want to. (Parent 204).

A parent with a child with more profound needs elaborated on the expectations she had of her son's teachers:

> I think that it's important that the person who is going to work with my son has to be *flexible*. There's a lot of demands put upon that person. They have to be a *key communicator* as far as sharing what's happening at the home and at school. That person has to be a strong advocate for the child. But that person also has to work; the teachers have to *be prepared*, and this is difficult because I don't want it to sound like I'm saying that the teachers have to put all their focus on educating my son, because that isn't what I want. I want (name of student) to have an *equal* amount of their time in their planning for what is suitable for his education for any other student. Whether they have a label or an unknown label, each student, whether it's thirty-two students in that class, needs an equal amount of time of that teacher's preparation. (Parent 101)

Certainly for this parent and her son, the process of making decisions has had a number of benefits:

> It's given me some self-esteem, and I feel like I have a bit more power to make decisions, that I *have* to have this power to make these decisions. But what I wanted to mention, too, is I think the communication between my son and me has been improved, because we've had to communicate a lot more than maybe some other kids and their parents have had to. Sometimes I haven't been able to do everything that (name of student) has wanted me to or I've done too much or I haven't

> done what are his ambitions or his hopes or whatever. I think that's been a plus for us, just making us a little bit closer, and that I listened to him and respected his opinion. (Parent 203).

Issue 3: The Importance of the Parent-Professional Partnership is crucial to any Decision-Making Process.

The parent-professional partnership in decision-making, as symbolized by the shamrock, is based on two key components: trust and respect for each other. The partnership must be cultivated and nurtured over time so that the focus will always be "in the best interest of the child". If the trust or respect issue or if the balance of power is compromised in any way, the parents involved in the study were prepared to seek redress through whatever means to reestablish that balance of power. The redress is either achieved through an appeal to the local school board, a request for a Ministerial Review, or even to the courts.

The issue of partnerships involved not only the teacher and the parent but also the principal and the parent:

> Not only on my part but on the principal's part in that I know that to date he's trusted me and we've worked well together, and I've been able to sort of guide as far as suggesting that the consultants have worked in the past and that's important, but in him not knowing enough about the whole area, put it back on me, and then I ultimately had to carry the responsibility for that. I don't mind doing that because that's, I guess, in my mind part of being supportive to the school, that's how I can help. (Parent 101).

This parent (101) also had some advice for other parents:

> You want to be supportive to the school, you want to share some of your expertise, you want to share your vision, you want to be a team member, but you also have to know when to pull back and say, 'Okay, I might not agree,' and I really think this would be important, but these guys are professionals', and I have to say, 'but you have to develop sort of an intuitive sense as to how far you can push when

> things are dicey. Between that rock and the hard place isn't a nice place to be, and I guess it all comes back to trust'.

When discussing inclusion as a philosophy, this parent expounded on it best:

> The best way for me to share that is to say that inclusion isn't a philosophy; it's a way of life. But it's something that I feel every part of the day, and it's something that's inside each of us if we'd let ourselves experience it. I feel it in my head, I feel it in my heart, I feel it in my gut, and it's like a warm fuzzy that's inside you, and it radiates and it envelops you, and it's a passion. I think that it's important for some people to realize that that's how strongly we feel about it. (Parent 101)

In summary, the issue of power or empowerment is one of the central themes in the study. Parents wanted and expected to be treated as 'equal' partners on the team. The path towards meeting the needs of both the children with severe disabilities as well as those children who are learning disabled, is a personal and a collective journey for all members of the partnership, the parents and the professionals who have to be working together for these children.

CHAPTER 7

SUMMARY, CONCLUSIONS and RECOMMENDATIONS FOR EDUCATIONAL PRACTICE

This chapter contains an overview of the study. It begins with a summary of how the study was conceived and how the problem was structured for investigation. The findings are stated as observations. Conclusions are then formulated on the basis of those tentative observations. The chapter concludes with recommendations for policy and practice as well as for further research.

Summary

The study is described in terms of its rationale, purpose, research design, interpretive framework, data collection, and data analysis. The major findings are then conceptualized in the form of tentative observations.

During the last five years, there has been a growing awareness of the need to involve parents as partners in the process of making decisions on behalf of children with special needs. As the literature review demonstrated, the research on parental involvement in special education decision-making, aside from possibly their involvement in the IEP process, is virtually nonexistent.

In Alberta, the rewriting of the School Act 1988 made provisions for parents to become more involved in the education of their children with special needs. In January 1992, a survey of parents seeking a Ministerial Review of a school board decision which affected their children, indicated that there were 75 appeals to that point.

This study is justified, therefore, on both practical and theoretical grounds. Practically it should provide educators and administrators with a parental perspective regarding their involvement in decision-making as it related to children with special needs. Theoretically, it should add to the present body of knowledge relative to decision-making which is grounded in the interview data obtained from parents as they describe their experiences in educational decision-making. The tentative conclusions developed around the necessity to involve parents, and ways of working with parents could also be tested empirically which could lead to the development of further theory.

Purpose of the Study

This study attempted to examine how parents viewed their involvement in the process of making decisions about their children with special needs and to offer some guidance as to how this can be achieved. Its specific purpose was to determine from parents how they could participate as equal partners in the decision-making process. In conducting the research for this study, parent perceptions relative to the following questions were sought:

1) What processes do school boards in Alberta use to involve parents in educational decision-making for their children with special needs?
2) What are the parents' views of the processes?

3) Do parents desire more input into decision-making?
4) What is the process of dispute resolution when the board and the parent disagree over placement and/or programming issues?
5) How is the disagreement resolved?
6) How are the children's rights to "due process" protected in school board policy?
7) Where and how do parents obtain advice, assistance and/or support with regard to decisions related to school programs relative to school programs for children with special needs?

Linking the Data

A descriptive/exploratory approach was utilised for this multi-site case study. This approach allowed for a broad exploration of the perceptions of parents of children with special needs relative to decision-making for their children. The two groups of parents involved in the research project were the Learning Disabilities Association of Alberta and the Gateway Association for Community Living.

Both associations have had long standing histories as organizations which supported and prepared parents to become advocates for their children with special needs. It was recognized from the outset that the parents involved in this study would be predisposed to a similar point of view. The researcher believed that this particular bias would not detract from the findings of this study. However, the researcher had to continually be aware of this bias. The issue of transferability and applicability of the findings had to be recognized. Using Bogdan and Biklen's (1982) advice, the researcher provided thick or rich descriptions of the parents' views of decision-making in order to make judgements respecting the transferability of the findings.

As an educator and administrator, the researcher had to be aware of his own bias relative to the issues and concerns the parents discussed. Throughout the collection, analysis, and interpretation of the data, the researcher reflected upon and utilized Pocklinghorne's (1981) advice regarding "bracketing" in an effort to maintain his objectivity. The use of a personal journal and continuous feedback and discussions with the thesis advisor permitted the researcher to maintain a focus.

Findings

Both groups of parents agreed that if the parent-professional partnership was working effectively and keeping the needs of the child foremost in their discussions, the child was progressing and the relationship was productive. One key ingredient for the partnership was mutual respect for each other and frequent contact and communication. A second key ingredient in the partnership was the role of the principal of the school and more importantly, the role of the teacher. If the school personnel were open, flexible and willing to be supportive of the parent's view for the child, the partnership was indeed a partnership. Finally, the parents believed there had to be a balance of power relative to decision-making between the parent and the professionals with whom they are working. With these sets of conditions, the parents viewed the process of making decisions regarding their children as positive. However; if any of these conditions did not exist, and there was a lack of trust or respect for each other, the process of making decisions became adversarial and confrontational.

According to the parents, there did not appear to be a uniform approach to decision-making for children with special needs in the province. Each of the ten school systems where the parents' children were resident students did not approach decision-making from a similar perspective. Some school boards have developed fairly elaborate systems for dealing with decisions and disputes. Several parents commented on the task of having to prepare presentations to the local school board to appeal a particular decision only to find that the board had asked its administration to prepare similar, elaborate information packages. The situation became extremely frustrating at the time of the appeal hearing when the parent and possibly a spouse or an advocate were met by several school administration personnel. In order to assist them in the preparation of their presentations, these parents mentioned the two advocacy groups involved in the study as well as other professionals including doctors and lawyers.

There was no debate with regard to whether or not parents desired more opportunity for input into decisions. They felt that they knew their child best and they were prepared to ensure that the child's needs were met.

According to the parents, a dispute usually arose as a result of an imbalance of power. If the parent believed they could retain their membership on the parent-professional team, and if their views would be considered when making future decisions about their child with special needs, the balance of power was re-established and the dispute was resolved.

The findings of this study were linked and consolidated in the form of 21 observations:

1) The parent-professional partnership in education decision-making is not well researched.

2) When dealing with children with special needs, there should be a focus on "family" and efforts should be made to individualize support for them.

3) Parents of children with profound needs see total inclusion as the only alternative.

4) Parents of children with learning disabilities see individualized instruction possibly even in a private school as the best way to help their child.

5) Both groups of parents were aware of their rights under the law and were prepared to "push" to ensure that their child had every opportunity to succeed.

6) Despite what others may believe, both groups of parents knew their child best.

7) Both groups of parents used many different strategies to bring about the changes they wanted.

8) Both groups of parents realized that teaching their child was going to be challenging.

9) Both groups of parents were prepared to support the classroom teacher in whatever way they could.

10) Parents of the children with severe handicaps quickly took control of situations.

11) Both groups of parents experienced the full range of emotions.

12) Despite the research findings on the stages of loss and grieving, these parents would refute that they went through all the stages in the process of adapting to their new situation.

13) Both groups of parents struggled to have their views heard and respected in the process of making decisions about their child.

14) Parents demanded and expected to have input into decisions related to their child's individual circumstance.

15) These parents had to deal with labelling by professionals not only of their child but of themselves as well.

16) Having a child with special needs in the home added stress to all family situations.

17) Both groups of parents have established an extensive network of support in the community through the two advocacy groups involved in the study.

18) The court system is not a viable means to resolve a dispute between a parent and the school system because the courts are reluctant to tell schools how to do their business.

19) In the process of making decisions, school personnel must be aware of the necessity to maintain a balance in the power struggle between the parent and the professional.

20) Parents wanted to be treated with respect and expected to become involved with their child's education as a "full" member on the team.

21) All professionals who work with families should develop a continuing professional development program to discuss issues related to children with special needs.

Recommendations for further research

In addition to the findings of this study, there needs to be further research into the impact of involving parents in the decision-making process from the prospective of superintendents and principals who would be working directly with parents of children with special needs, particularly in a time of fiscal restraint.

A further study into the impact of the cases involving children with special needs which have gone through the court system would be informative for school-system personnel.

Conclusions and Recommendations

The study findings served as the basis for developing conclusions relative to parental involvement in decision-making for their children with special needs. The conclusions and recommendations are supported by the perceptions derived from the interviews of parents of children with severe to profound needs as well as those children with learning disabilities. The conclusions and recommendations are also supported by the related literature.

The conclusions are related to the research questions and emerging themes and are presented in two categories. These are: the present state of the parent-professional partnership in decision making; and what changes are required to strengthen the relationship.

The present state of the parent-professional partnership

The strength of the parent-professional partnership in Alberta is being challenged by the fact that there are many children in Alberta's classrooms with differing needs. More parents are becoming "consumers" of the educational "product" and they are demanding input into decisions which affect their child.

Further, they are prepared to challenge decisions made without their input in an effort to restore that balance of power discussed in the research. These findings constitute the basis for the first conclusion of this study:

1. The present legislation on special education and parental involvement in decision-making needs to be revisited.

As the literature review demonstrated, the legislation in Alberta on this topic is inadequate if the government wants to truly empower parents to be involved in the process of making decisions for their children. Probably the most progressive legislation exists in the province of Quebec. Such a change would recognise that parents probably do know their child best and that as professionals we should be there to support them in their efforts to do what is best for their child. These findings lead to the second conclusion:

2. School boards in the province of Alberta need to re-examine their policies, guidelines and procedures related to parental involvement in decision-making for their population of children with special needs.

There are school board policies and procedures in place which recognise the parents' responsibility to ensure that their children receive an appropriate education. These policies also outline very clearly the parents' right to be involved in the decision-making process as well as their right to appeal any decision with which they are not satisfied. Accordingly, it is concluded that:

3. There should be at least one person on staff of each school board that has at least some formal training in dispute resolution. The Alberta Arbitration and

Mediation Society offers such courses.

With an increasingly diverse population of students to be served, and with parents insisting that schools be accountable for the education of their children, one of the results will be increased confrontation between parents and schools. The human and financial costs related to a Ministerial Review are significant and distasteful and the courts are reluctant to become involved. A mediator to resolve these disputes would strengthen the parent-professional partnership by empowering the members of the team to solve their own problems. These findings led to a fourth conclusion:

4. That at least one course in special education be a requirement in all programs at the graduate level that prepare future principals and administrators for school systems.

The literature review highlighted the importance of having personnel in schools with course work and experience in special education. The parents found that the key to a successful special education program in the school was the principal. Yet they often mentioned that they were "educating" the principal with respect to special education. Similarly,

5. That the Teaching Profession Act be amended to ensure that all teachers be required to begin a program of continuous professional development to enable them to appropriately provide for the increasing diversity of students whom they serve.

While it is recognised that there are a great many teachers who continue to pursue professional activities which will help them meet the challenges of the classroom today, the changes are coming too quickly and some teachers have not advanced their knowledge, skills and attitudes to keep up with the changes. This led to a sixth conclusion:

6. All professionals working with parents of children with special needs must maintain a "family" focus.

Because of the demands and stressors involved when there is a child with special needs in the home, it is important for everyone working with the family to remember that there are other members of the family. Every family is a unique system of relationships and to maximize the strength of the family unit, each family must be understood and treated as individually as the child with special needs who is in their care. Finally, a recommendation for the parent.

7. The basis of the parent-professional partnership begins with the classroom teacher. Every parent of a child with special needs is encouraged to begin to develop the partnership and to be supportive of their child's teacher in any way possible.

The parent-professional partnership begins by focussing on the needs of the child. If the partnership is treated as a learning experience for both teachers and parents, and if there is mutual respect and support for all members, the child will have the benefit of a strong team working together on their behalf.

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APPENDIX A

School Act Legislation

(11) If there is a dispute as to the number of resident students of a board, the Minister may determine the number or the method to be used to calculate the number.

(12) If there is a dispute as to the residency of a student, the Minister may determine that the student is a resident student of a particular board.

1988 cS-3.1 s27;1990 c36 s12

Responsibility to resident students

28(1) A board shall provide to each of its resident students an education program consistent with the requirements of this Act and the regulations and, for the purposes of providing the education program to the student, the board shall

(a) enroll the student in a school operated by the board, or

(b) direct the student to attend

(i) a school operated by another board or the Government,

(ii) a school operated by a school board in or a government of another jurisdiction,

(iii) a private school accredited under section 22, or

(iv) a school or institution approved by the Minister

and pay the fees of and costs consequent to the student's attending that school or institution.

(2) Where

(a) a board is willing to provide an education program to a resident student as required under subsection (1), and

(b) the parent of that student wishes to send the student to a school other than a school

(i) operated by the board, or

(ii) that the board directed the student to attend under subsection (1)(b),

the board may, subject to subsection (7), provide all, part or none of the funds necessary for placing the student in a school chosen by the parent.

(3) Where a board directs a student under subsection (1)(b)(i) or (ii) to attend a school that is not operated by the board, the board shall ensure that the board or the school board in another jurisdiction that operates the school that the student is directed to attend is able to accept the student.

(4) Where

(a) a board directs a student under subsection (1)(b)(i) to attend a school, and

(b) the board that operates the school that the student is directed to attend has sufficient facilities and resources to accept that student,

the board that operates the school that the student is directed to attend shall accept that student in its school.

(5) If a student is a resident student of the Government, the Minister must make arrangements for that student to receive an educa[illegible] program.

(6) The Minister may enter into an agreement with a board or any other person operating a school to provide education programs or services to resident students of the Government.

(7) Repealed 1990 c36 s13.

1988 cS-3.1 s28;1990 c36 s13

Special education program

29(1) A board may determine that a student is, by virtue of the student's behavioral, communicational, intellectual, learning or physical characteristics, or a combination of those characteristics, a student in need of a special education program.

(2) A student who is determined by a board to be in need of a special education program is entitled to have access to a special education program provided in accordance with section 28.

(3) Before a board places a student in a special education program it shall

(a) consult with the parent of that student, and

(b) where appropriate, consult with the student.

Special Needs Tribunal

30(1) A board may determine that a student has special needs that cannot be met in an education program that can be provided by the board under section 28.

(2) If a board makes a determination under subsection (1) in respect of a student, the board shall refer the matter to a Special Needs Tribunal, which shall confirm the board's determination or determine that the board is able to provide the student with an education program that is appropriate to the needs of the student.

(3) If a Special Needs Tribunal confirms the determination of a board under subsection (1), it shall develop or approve a special needs plan that is consistent with the needs of the student and, in accordance with that plan, shall

(a) determine the relationship between the student, the board and any other person or government that may provide the services required under the special needs plan, and

(b) apportion the cost of providing the services required under the special needs plan between the board and the Government.

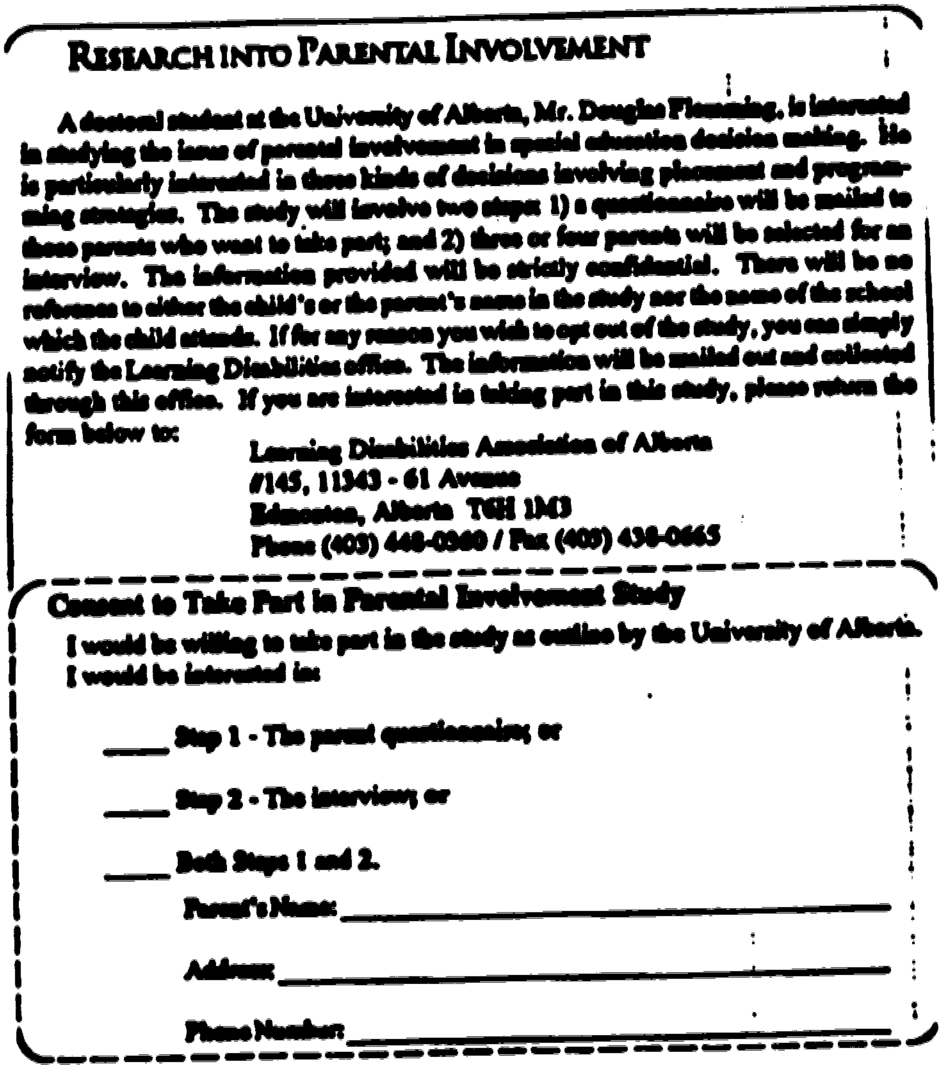
(4) If a Special Needs Tribunal determines that a board is able to provide the student with an education program that is appropriate to the needs of the student, the board shall provide the student with that education program.

(5) A board and the parent of a student in respect of whom a determination has been made under subsection (1) shall comply with decisions and determinations made by a Special Needs Tribunal under this section.

(6) A decision made by a Special Needs Tribunal under subsection (3) or this subsection shall be reviewed by the same or any other Special Needs Tribunal at least every 3 years after the decision is made until the student is no longer entitled to have access to an education program under this Act.

APPENDIX B

AGENDA Advertisement



RESEARCH INTO PARENTAL INVOLVEMENT

A doctoral student at the University of Alberta, Mr. Douglas Flemming, is interested in studying the issue of parental involvement in special education decision making. He is particularly interested in those kinds of decisions involving placement and programming strategies. The study will involve two steps: 1) a questionnaire will be mailed to those parents who want to take part; and 2) three or four parents will be selected for an interview. The information provided will be strictly confidential. There will be no reference to either the child's or the parent's name in the study nor the name of the school which the child attends. If for any reason you wish to opt out of the study, you can simply notify the Learning Disabilities office. The information will be mailed out and collected through this office. If you are interested in taking part in this study, please return the form below to:

Learning Disabilities Association of Alberta
#145, 11343 - 61 Avenue
Edmonton, Alberta T6H 1M3
Phone (403) 448-0360 / Fax (403) 438-0665

Consent to Take Part in Parental Involvement Study

I would be willing to take part in the study as outline by the University of Alberta.
I would be interested in:

_____ Step 1 - The parent questionnaire; or

_____ Step 2 - The interview; or

_____ Both Steps 1 and 2.

Parent's Name: ____________________

Address: ____________________

Phone Number: ____________________

APPENDIX C

Sample of Data Analysis Strategies

Parent A

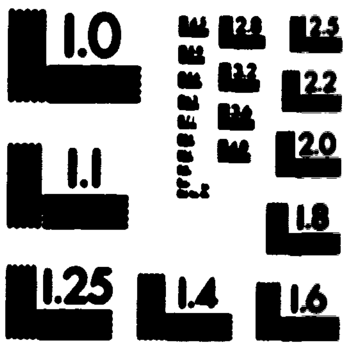
Excerpts	Paraphrase	Theme
He was in Grade two when the problem really began- I guess it was Grade one. We knew there were problems but we were sort of under the impression that maybe it was a maturity thing	Parent sensed some difficulties in grade one but was unsure	Both parent and teacher unable to identify the reason for the child's problem
There was quite a concern about him being a behavior problem, and I didn't think so, but I tried to talk to the teacher and say what I do at home is	Parent and teacher were disagreeing on the best way to manage him.	Parent's expertise of her son was not accepted by teacher
The behavioral therapist said to me, You've got a right to make decisions, and if you find a personality conflict, you have a right to pull your kid.	Parent obtained another opinion from some one else	Parent found a network of others to help make decisions
I don't know if this has anything to do with your study, but I wanted to mention this too. We're all afraid of labels, and we don't want to label our kids. But I found that once my kid was labelled LD things started improving for him. He wasn't a brat; he wasn't slow.	Parent was hesitant to label a child but found the label helped to understand him.	Parents have the greatest fear of their child being labelled even though they realize that the label ensures access to services.
I certainly was involved in that decision, and it was a hard one to make, but I did choose that program and he went to another school.	Parent was aware that her son was not successful in the regular school program, and looked for options.	Parents wanted to have input into decisions related to their child's schooling.

It's like May and I'm wondering, my God! This kid has improved but not very darned much when I look at the work that a child has to do in grade four, and I thought to myself "No way". So I talked to the teacher. She did try all these things but she suggested to me that maybe I should be looking at an IOP program for (name of student).	The parent realized the student continued to struggle and she looked for alternates that would address the child's needs.	Parents looked for segregated programs where the child's specific needs could be addressed in a small group setting.
She said, "We've got our kids picked and there's a chance that somebody's not going to show". So it was just a fluke that I got in. I sort of learned that I've got to be more on top of things, and I have to be monitoring and evaluating all through the year.	Mother realized that she had to be checking at school frequently to determine the progress.	Open communication with the school was critical and the parent needed to be constantly monitoring and evaluating.
I was involved with the IPP. We looked at it, we planned it we talked about it, and we set goals, we talked about what her responsibilities were, what my responsibilities were, and what (name of student)'s were. I found that this was a really good relationship.	Parent felt a need to be a part of the planning process.	Parent wanted to participate as a "team" member.
I started collecting. I've got a thick file. So I started collecting all this stuff, and I also wanted (name of student)'s doctor	There was a need for information and it was collected in many different ways.	As a strategy, parents devote considerable time collecting and dating

collecting it so that he knew what was going on.		information.
I just didn't know what to do. The kid was threatening that he didn't want to go to school; there was a fight in the morning to get him to go to school. This went on for about two days. I contacted his teacher and I asked him, "how many blocks are there?" I went in and I decided to find out exactly what's going on here, exactly. How many minutes a week is this kid given of this resource?	The child is experiencing difficulty to the extent that he won't go to school yet the parent is unsure how much extra help he is receiving.	Parents begin to "take control" in the child's life.
I went in and I talked to this guidance counselor, I told him the problems that I'm having with my son. There was kind of an emotional problem. (Name of student)'s father moved out the year before. But I made all the decisions anyway because he never did accept that his son had a problem, and a lot of our marital problems stem from this.	A lot of relationships in the family are affected by having a child with special needs in the family.	There are stressors on other family members with a child with special needs in the home.
So now we've come to a point where next year the superintendent has said that this teacher is cut off at the end of June. So I have gone over and looked at the private school, and when I first even mentioned this to the guidance counselor he hadn't even heard	The school had hired an extra teacher to help her son improve in a number of areas but it would not exist next year.	Parents struggle for power over decisions that affect their child.

3 of/de 3

PM-1 3½"x4" PHOTOGRAPHIC MICROCOPY TARGET
NBS 1010a ANSI/ISO #2 EQUIVALENT



PRECISION℠ RESOLUTION TARGETS

of it. I was very surprised he hadn't even heard of that school.		
I don't feel like I'm alone, because I know other people have had to do it, and I'm not afraid to go and look for support. And through the Alberta Association, I've contacted them and I've told them that I'm going to be doing this, and they've referred me over to this lawyer woman.	There was a need to seek additional support.	Parents have developed strategies to help them deal with professionals.
I have to be on top of things and keep contact with the school so that you do make informed decisions and you know what's going on to monitor and to review.	Close contact with the school is vital.	Another strategy for parents.
The minute you get on the phone or write a letter - - especially write a letter, good grief!	The power and the value of writing and documenting.	This parent has learned the importance of good communication skills.
I just look at some of the parents that I know that just don't have the confidence to do that, and there's so many of them.	This parent lists some of the parent attitudes needed to be a strong advocate.	Parents know among themselves who will probably succeed.
I just don't read everything that I get from that school board and believe it as gospel truth any more. I sort of read between the lines and I think, OK, that's what you'd like things to be like, but it isn't always so.	There is an element of skepticism for this parent.	Parents do not believe everything they hear from the school.

I've also realized that the teacher is under stress, too. These teachers are under stress. The amount of work that they're expected to do, and the lack of support, and especially the regular teachers that are supposed to have all these integrated kids into their programs, and they're not given any extra time to do prep work or anything.	There is a realization that integration has put teachers under added stress.	Despite the child's own learning difficulties, the parent is aware of other demands on teacher time and energy.
Sometimes I found that the teachers avoid making the decisions, that maybe there is a conflict of interest of what they should be doing and what they really feel, and I feel that has sort of been an issue.	This parent has a fairly good grasp of issues facing teachers today.	This parent is realistic in terms of her expectations of the teacher.
That maybe those systems or those programs or supports aren't in place and yet the teacher feels that they need to be and yet they're not, and there isn't the money and there isn't this, and they're kind of a little bit afraid to say, Your child needs such and such, and there's no damned way you're going to get it.	There is a feeling by the parent that the teacher agrees with the parent but they know that the child will not be served.	The teacher is caught in a double bind, because they know what is best for the child but they know the child is not likely to be served.
It's given me some self-esteem, and I feel like I have a little bit more power to make decisions, that I have to have this power to make decisions.	This parent feels strong enough to make decisions on behalf of her son.	Parents continue to struggle for control over decisions which affect their child.
I think the communication	The parent and the	The parent-

between my son and I has improved, because we've had to talk a lot more than maybe some other kids and their parents have had to, so I think that has been a plus. He and I sit there and we have to talk about things and that I have to involve him in some of the decision making, too and I have to respect his feelings, his opinions, and his rights.	child have had to discuss many of the issues facing the child in his schooling.	child relationship has developed as a result of having to make these decisions together.
I think that it's getting more so that the child is involved, that I think they should be more involved in this decision-making with their goal setting and objectives.	The parent realizes the importance of involving their child in the decision making process.	The parent realizes that for the process to be effective, both the parent and the child must be involved.
I say to all teachers and parents, that we aren't going to be here forever for these kids, so we have to basically empower them with these strategies that they can be successful and some skills that they can say, Look I can do it this way. I know what I've got to do, and I think that makes them better citizens as well.	The parent believes that the child has to be given strategies to enable them to become better citizens.	Parents want to empower their kids in the same way that they want to be empowered to make decisions for their kids.
Another thing how this process has affected me as a parent--well obviously my husband and I	Being so involved with the child has affected the marital relationship.	Having a child with special needs in the home adds extra

have split.		stress to the family.
A good portion of it is besides that that has affected my parenting because of this process of making decisions is because I have been the one that's had to make these decisions that he hasn't agreed upon a lot of the time that I do not regret making because I've had to. And this process indirectly affects my parenting of my other kids.	The parent recognizes how the process of decision making has impacted on her parenting skills.	There are additional stress factors in the family trying to parent a child with special needs.
It makes me get in there and take a look at what's going on in their programs, but you know there's only so much jam I've got in me and sometimes that puts a lot of stress on me because so much time and energy is devoted to my son in his program with him, that I sometimes just look at my girls and I think, They're doing just fine and they're passing and they're average students that sometimes I let that slip. That has been a real stress on me because sometimes the guilt sort of gets to me.	The parent feels guilt because she has spent so much time with her son that she maybe has neglected her other children.	As a single parent she has had to juggle many family issues which has added stress to her life.

END

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