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Parents' Perceptions of Communication Practices with School Professionals  
during Initial Years of Special Education Placement

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A dissertation  
presented to  
the faculty of the Department of Educational Leadership and Policy Analysis  
East Tennessee State University

In partial fulfillment  
of the requirements for the degree  
Doctor of Education in Educational Leadership

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by  
Susan Ladd Latham  
May 2002

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Keywords: Special Education, Communication, Parents, IDEA, Initial Placement

## ABSTRACT

### Parents' Perceptions of Communication Practices with School Professionals during Initial Years of Special Education Placement

by

Susan Ladd Latham

Special education has evolved into a dominant area of education since first brought to the forefront. The reauthorization of the Education for All Handicapped Children Act to the Individuals with Disabilities Education Act updated and addressed many issues, including parental issues. Initially parents had to fight to be heard when addressing the needs and concerns of their child. Now parents are considered a crucial part of the special education process.

The purpose of this qualitative study was to explore the thoughts and experiences of parents of children with disabilities related to the initial special education placement and the ongoing communication between parents and school professionals. Data were collected through interviews with 20 parents of children with disabilities in their initial years of service from a rural county in East Tennessee. Interviews were conducted mainly in parents' homes. Data were identified using interpretative analysis. Descriptive information about participants and their initial reactions were recorded in a journal

From the findings the researcher concluded parents whose children were identified from birth to school age knew much information about their child's disabilities; however, parents with children identified with disabilities after entering school needed a great deal more information than was provided, such as specifics on the child's disability and the process of special education implementation of the IEP. Most parents who addressed concerns to school professionals had positive outcomes, although there were communication breakdowns and conflicts before resolutions were reached. The majority of parents stated they were as actively involved in their child's school experience as they were initially; however, a few parents stated they were more involved because of conflict situations. Parents agreed that communication had increased with school professionals but more frequent and clearer communication was needed.

## DEDICATION

This study is dedicated to the memory of my father, William Thomas Ladd, the greatest man I have ever known.

To my mother, Dorothy Butler Ladd. Her unconditional love and diligent prayers are steadfast. She is my inspiration.

To my wonderful husband, Mark Alan Latham. He is always by my side. He is my strength, my rock. His humor has helped me remember not to take life so seriously. You are my world. I will love you forever and a day.

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## CHAPTER 1

### INTRODUCTION

Special education has evolved into a dominant realm of education since it was brought to the forefront in the early to mid 1970s. Public Law 94-142, better known as the Education for All Handicapped Children Act of 1975, began the addition of information and understanding of children with disabilities in school.

The reauthorization of Public Law 94-142 in 1997, now called Individuals with Disabilities Education Act (IDEA), updated and addressed many issues. One issue focused on parents as dominant members involved in the education of their disabled child. Previously, parents had to fight to be heard when addressing special needs and concerns for their child. Parents are now considered equal members of the Individualized Education Program (IEP) team and are a crucial part of the special education process (Federal Regulations for Implementation of Individuals with Disabilities Education Act, 1997).

#### Statement of the Problem

The researcher conducted a focus group with parents in a rural county in east Tennessee who were experiencing their initial years of having a child in special education services (see Appendix A). The parents discussed concerns from their initial encounter into the special education arena.

Findings from the focus group meeting indicated that a problem stems from the lack of knowledge most parents have about appropriate avenues to obtain information to make educated decisions for their child with disabilities and ways to provide suitable input. Because of this lack of knowledge, communication often breaks down between the school and the home during the initial three years of a child's placement in special education. The parent's attitude often shifts from positive and trusting to negative and distrusting.

The main concerns from this focus group of parents related to obtaining the best education possible for their children. Although most parents were pleased with the education their child was receiving, they had concerns about the lack of information given by the school professionals. Although school professionals were open to answering questions from the parents, the fact that the parents did not know what to ask led to frustration. The parents in the focus group indicated they had difficulty obtaining information about their child's disability and what they could do to help. Most parents stated they relied on information from outside sources, such as physicians, the Internet, and other parents.

The problem, as indicated by the focus group, was that parents are not given needed information from school professionals about their child's disability and that this lack of adequate communication about their child leads to frustration. This ultimately affects the child.

The focus group of parents experiencing the initial years of their children's placement in special education described their experiences relating to communication practices with school professionals. The purpose of this study was to explore the thoughts and experiences of parents of children with disabilities as they related to the initial special education placement of their child and ongoing communication between parents and the school.

The study addressed the following research questions:

1. What was the parent's initial understanding of his or her child's disabilities as related by the school professionals?
2. What were the parent's experiences when he or she had questions and concerns that required a school professional to answer?
3. What were the parent's involvement practices with the school and school professionals since the initial placement of his or her child into special education services?

4. What was the communication practice between parents and school professionals and did it change during the initial years the child has been provided special education services?

Parents of children with disabilities are the principal source of data to answer these questions.

#### Significance of the Study

This study is significant in that it has the potential to help school professionals develop a clearer understanding of parental concerns, fears, and knowledge levels on special education issues. In addition, it helped determine which methods and frequencies of communication from schools to parents of children with disabilities are effective in terms of improving parental knowledge of what the child is accomplishing and providing new information to better understand the disability and services available. Finally, information obtained during the interviews may assist in making adjustments to policies and practices used during initial placement IEP team meetings.

#### Limitations and Delimitations

The results of this study represent only the individuals who participated in the interviews. Although the results might be used by school personnel to reflect on the experiences of the participating parents and to consider their policies and practices in light of the experiences expressed, the results are not intended to be generalizable to any population or group as a whole.

#### Background

In 1975 a federal law was passed, Public Law 94-142. It mandates that all children receive a free, appropriate public education regardless of the disability (Office of Special Education and Rehabilitative Services, 2000). The Support and Training for Exceptional Parents, Incorporated (STEP) explains the main areas covered in IDEA. One of the main areas

covered in this law is identification of children with disabilities, which states that the state and local education agencies must actively seek and identify children who have special education needs. Evaluation of a child prior to placement in special education services is another area covered in IDEA. An IEP must be developed for each child receiving special education services. This program must be individualized and based on the child's needs. Related services may be individually provided to assist the child. Each child receiving special education services is to be educated in the Least Restrictive Environment (LRE) for that child. A child with disabilities may be educated in the same setting as other children; however, more restrictive settings are available when appropriate. The rights of parents and children are guaranteed through due process. A final area covered by STEP on IDEA is that parents have rights to access their child's records (Office of Special Education and Rehabilitative Services).

The law explains the role of the parent in developing the IEP. It states that parents are to be equal partners in the IEP process. It further explains that parents should prepare for the meetings by reviewing records of the child and have in mind goals and objectives for their child (Turnbull, Turnbull, Shank, & Leal, 1999).

Much information is available to parents in the amended Individuals with Disabilities Education Act, Public Law 105-17, § 682 Parent Training and Information Centers. It states that "The Secretary may make grants to, and enter into contracts and cooperative agreements with, parent organizations to support parent training and information centers to carry out activities under this section" (Individuals with Disabilities Education Act Amendments, 1997, p.133).

Since Congress enacted Public Law 94-142, there has been a continual push for equal educational opportunities for all children with disabilities. The Office of Special Education and Rehabilitative Services (OSERS) is a federal agency that oversees the special education process from the training of special education teachers to ensuring that the rights of all disabled children are met.

The process of referring a child to possible placement into a special education program has many steps. Each state follows guidelines based on federal regulations. The steps include gaining permission from the parent or guardian for assessment of the child, explaining the rights of parents of children with disabilities, the assessment, and the writing of the IEP by the IEP team (Office of Special Education and Rehabilitative Services, 2000).

The entire process of developing the IEP has its own standards that must be met. An important aspect of the plan includes input from the parent. If a parent does not agree with the plan or with any part of the services for the child, he or she may request a due process hearing (Office of Special Education and Rehabilitative Services, 2000).

Parental emotions are a major consideration when dealing with children with disabilities. Many school professionals do not realize that parents have feelings of vulnerability, guilt, and isolation in the overall picture of dealing with their child's special situation (Leff & Walizer, 1992).

Another aspect of concern from many parents is the issue of labeling. Labels provide a justification for differences in appearance or behavior where children may be blamed or stigmatized for their disability (Hallahan & Kauffman, 1997).

Negative thoughts toward schools are an issue of concern for both the parent and the school professional. Many schools see active parents in the parent advocate role as a negative one because of past experiences (Hornby, 1995).

Parents' attitudes toward the school are mixed. Following, or as a result of the special education process, many parents are more willing to take an active role in school than they were before they encountered the process. Parents bring a different perspective of the child than school personnel, and both should be taken into consideration during the decision-making process (Green & Shinn, 1995).

Communication between parents and the school should be based on mutual trust. Parent involvement throughout the process is crucial to the relationship. Parents serving as volunteers

and working with parent organizations are two areas through which developing parent involvement has been successful. With parental knowledge and involvement in the decision-making process for their child, a more positive relationship between school professionals and parents can develop over time (Henry, 1996).

### Overview

In Chapter 1, an introduction to this study has been presented along with a statement of the problem and significance of the study. Chapter 1 also provides a set of limitations and delimitations of the study. Background information covering the topics of special education law, steps of the referral process, and parental information dealing with the legalities of special education are included. Chapter 2 contains a review of literature with emphasis on six main areas: (a) the federal laws pertaining to special education, (b) parents and IDEA, (c) parent's role in special education, (d) parental emotions, (e) parents and labeling, (f) parent involvement in schools, and (f) parent/school communication. Chapter 3 provides the methodology and procedures used in this study including information about the sample and data gathering techniques. Chapter 4 identifies the participants in the study and provides an analysis of the data as it addresses the research questions. Chapter 5 includes a summary of the study, conclusions, and recommendations for practice and for further study.

## CHAPTER 2

### REVIEW OF RELATED LITERATURE

The review of literature includes a wide range of information in order to provide a true perspective of the details and nuances in the relationship between parents and school professionals. The review of literature covers many of the legal issues addressed with parents of children with disabilities, some statistical information used in related studies, and many social phenomena covering interaction between parents and school professionals.

The literature review covers federal laws pertaining to special education, then moves to specific areas where IDEA mandates parental involvement. Parental perceptions of special education and the emotions of parents of children with disabilities are included. Improving parent involvement in schools is addressed, along with parent and school communication.

#### Federal Laws Pertaining to Special Education

Special education has advanced during the past two decades concerning the rights of individuals with disabilities. The IDEA is a federal law passed in 1997 that is based on the law formerly known as P. L. 94-142 that passed in 1975. IDEA ensures that every school in the nation must provide a free, appropriate public education for all children between the ages of 3 and 21 regardless of the severity of their disability (Hallahan & Kauffman, 1997).

IDEA does not simply identify children with disabilities and the services they are entitled to, it also specifies the benefits. There are six principles to IDEA. The first one is the zero reject principle. This principle ensures that each child receives the appropriate education needed, no matter the severity of disability. The second principle of IDEA is the right to a nondiscriminatory evaluation. This is an unbiased evaluation identifying strengths and weaknesses. Another principle is ensuring an appropriate education. This is to be accomplished by developing a specific instructional plan that may be administered in regular or special classes

or programs. A fourth principle of IDEA is to ensure student placement in the Least Restrictive Environment. This means that each student with a disability must not only be provided with an IEP but also that the IEP be carried out in the least restrictive environment including mainstreaming, integration, and inclusion (Turnbull et al., 1999). Least Restrictive Environment requires the government to achieve purposes through the least oppressive and restrictive means (Thomas & Rapport, 1998). The fifth principle is the right to procedural due process. Due process is followed if the education agency does not carry out the first four principles of IDEA. If parents and state or local education agencies disagree and mediation is not successful, due process will be invoked. A final principle of IDEA is parent and student participation. Parents have shared decision-making rights. They must be able to participate in all aspect of the child's education (Turnbull et al.).

The Rehabilitation Act of 1973 is another federal law pertaining to civil rights that is designed to protect the rights of individuals with disabilities. This act ensures nondiscrimination to individuals with disabilities and promotes affirmative action of employment to persons with disabilities (Office of Special Education and Rehabilitative Services, 2000). The Rehabilitation Act has been amended several times, and is usually referred to by specific sections. Section 504, added in 1998, established that any federally funded program, such as public schools, is not allowed to discriminate on the basis of disabling conditions (Office of Special Education and Rehabilitative Services).

Public Law 101-336, known as the Americans with Disabilities Act (ADA), became law in 1990 (Office of Special Education and Rehabilitative Services, 2000). ADA is a federal law that has dramatically affected the lives of children and adults with disabilities. ADA ensures that there is no discrimination to individuals with disabilities in any area of their lives. This includes protecting their civil rights in the areas of employment, transportation, public accommodations, state and local government, and telecommunications (Hallahan & Kauffman, 1997; Office of Special Education and Rehabilitative Services; Turnbull et al., 1999).

## Parents and IDEA

In the reauthorization of P. L. 94-142, now known as IDEA, an emphasis was placed on the inclusion of parents in all areas of the special education process for their child. The term parent, as written in IDEA § 300.20, is a natural or adoptive parent, a guardian but not of the state, a person acting in the place of a parent (such as a grandparent or stepparent), a surrogate parent, or a foster parent in certain circumstances (Federal Regulations for Implementation of Individuals with Disabilities Education Act, 1997).

Another addition to IDEA for parents was that children in public charter schools receive the same rights as children in other state schools, § 300.312. A clarification in § 300.345 stated that the notice to parents about an IEP meeting must inform them of their right to bring someone with knowledge or expertise to the meeting. The guidelines for parents placing their child with a disability in a private school were outlined. The due process amendments were added in § 300.500. Guidelines for the discipline of a child with disabilities were entailed. IDEA also changed the evaluation procedures in identifying disabilities to add parental input.

A major change in IDEA was the addition of parent counseling and training through the section on related services. This section was added to help parents acquire the skills needed in the development and support of the IEP for their child, § 300.24 (b) (7). This is in line with § 682 parent training and information centers. It states that the Secretary may give grants to parent organizations to support parent training and information centers. A parent training and information center that receives funding must provide training and information to meet the needs of parents in the area. It must also educate parents on procedural safeguards and dispute resolution, such as the mediation process. It must serve all parents with children with all forms of disabilities. The centers must assist parents in understanding their child's disability, in communicating with various personnel, in participating in decision making for their child, in obtaining information about programs and services available, in understanding IDEA and all its

provisions, and in participating in school reform activities (Federal Regulations for Implementation of Individuals with Disabilities Education Act, 1997).

There are additional activities that the parent training centers can provide such as giving information to teachers and other professionals who provide services to children with disabilities. They can also assist children in understanding their rights when they reach appropriate age (Federal Regulations for Implementation of Individuals with Disabilities Education Act, 1997).

### Parents and Their Role in Special Education

Parents are meant to play a crucial role as advocates for children receiving special education services (Green & Shinn, 1995). They are to help ensure that the appropriate education is being provided for their child. Parents are to be recognized as a child's first and most important teacher. Teachers are to be viewed as sensitive and caring partners (Rockwell, Andre, & Hawley, 1996).

The role of parent as advocate is important in the special education process of the child; however, most parents admit that they do not play an active role in this process. In a 1982 interview study by Lynch and Stein (as cited in Green & Shinn, 1995), parents were asked if they were actively involved in the development of their child's IEP. In the study, 71% said "yes," they were involved. When asked how they were involved, only 47% reported having made any suggestions during the meeting. In comparison, Leyser (as cited in Green & Shinn) reported that 33% of parents attended few or no school conferences. These findings suggest that parent satisfaction may not be based on thorough knowledge of the content and procedures of special education.

Reisner and Simpson (1995) developed a guide for parents of children with disabilities on how to be their child's advocate. Parents are urged to believe in their child and in their own intuition and to educate themselves. Parents are encouraged to document events and encounters, document and negotiate telephone calls, support telephone calls with effective letters, attend and

advocate for their child in meetings, utilize legal representation when necessary, and use anecdotes to illustrate points.

The parental role is crucial in addressing perceptions of various programs introduced and the impact they may have on the child and family. The consideration of placing a child in an inclusive setting or institution is one example. Parents may hold strong beliefs about a program and how it may impact their child (Palmer, Borthwick-Duffy, & Widaman, 1998). The Parent Attitudes Toward Inclusion (PATI) Scale is one example of an instrument that can be used to measure parent perceptions. The scale was designed as a subset of a larger instrument to identify factors that impact parental perceptions of inclusive programs for children with significant disabilities. The scale, or others like it, could be used to identify apprehension on the part of a parent about a program and consequently enable school professionals to collaborate with the parent to identify ways to address their concerns (Palmer et al.).

Parents and professionals' roles are unique in that they represent different points of view. Seligman and Darling (1997) stated that even with the differences in points of view, parents still search for advice from varied professionals. Parents who share stories and information with other parents develop a bond and sense of understanding (Seligman & Darling). The quality of partnership between parents and school professionals is based on the competent educator who is sensitive to the diverse needs of a child receiving special education services and his or her parent (Sileo & Prater, 1998). Barriers in keeping parents from participating in the education of their child are based on how comfortable a school feels with parent involvement. Other barriers include parents who are not proficient in English, parents who have minimal experience working with the schools, and parents with diverse cultural or racial backgrounds who may have already experienced negative situations (Sileo & Prater).

Smith (2001) stated that barriers to parental participation in the IEP process are communication problems, lack of understanding of the school system, lack of knowledge of their

child's disability, and feelings of inferiority. In order for parents to have a more productive meeting, a suggestion is to find out their preferences and needs prior to scheduling the meeting.

A shift is being made to consider parents and professionals as partners (Selgiman & Darling, 1997). Partnerships will foster equality and mutual respect between parents and professionals. Selgiman and Darling concluded by stating that parents and professionals can work together to eliminate barriers that prevent them from attaining the best possible life for the child.

### Parent Satisfaction

Ideally, parent satisfaction should be tied to a child's improved outcomes over those previously achieved without special education services (Green & Shinn, 1995). Even with the problems of labeling children and the concerns of the culturally diverse families, parents of children with disabilities who received services stated that the program was helping their child. Those parents agreed that if their child was having difficulties, they were willing to accept appropriate help in the form of special education services (Harry, 1992a).

Throughout the 1970s and into the 1980s, parents voiced concerns of not being heard by professionals in regard to their questions, concerns, and input about their children's disabilities. The Bridging the Family-Professional Gap Family Member Survey was created by a graduate student at Western Carolina University to provide information about parent concerns and questions (Ogletree, Fischer, & Schulz, 1999). The demographics in this survey did not represent an average group of parents. They were primarily Caucasian females from two-parent homes who had high level occupations. Although it was not representative of an average group of parents with a disabled child, it was representative of parents who are advocates for family members. The issues that came out in the survey were asking professionals to listen to family members, asking for strategies and suggestions, and asking for patience with the parent and

child. The parents were also asking professionals to give honest information, and stressing the need for support groups (Ogletree et al.).

Parents are acknowledged more since the reauthorization of IDEA. Studies are being conducted to look at identifying issues concerning parents who have children with disabilities. Studies concerning reintegrating a child back into the regular education program have been conducted. Parents typically are supportive in the reintegration of children with disabilities into the regular program; however, they are not as supportive when asked to reintegrate their own child (Green & Shinn, 1995). Only 14% of parents indicated that they believed their own child's academic performance would improve upon reentering the regular program.

In 1987 McDonnell (as cited in Hornby, Atkinson, & Howard, 1997) conducted a survey of 253 parents of children with severe disabilities regarding their satisfaction with their child's placement. The results showed no differences in levels of satisfaction from being integrated and being separated in a special school. In another study conducted in 1989, Simpson and Myles (as cited in Hornby et al.) surveyed parents of children with learning disabilities and behavioral problems concerning mainstreaming. They noted that 76% supported mainstreaming if certain resources were provided, whereas only 25% supported this without the guarantee of these resources (Hornby et al.).

There have been increased efforts of reintegration resulting from the IDEA policy of educating children with disabilities in the least restrictive environment. Parents are still reluctant to change their child's program when they are satisfied with the current program (Green & Shinn, 1995). In a study by Green and Shinn, parents were asked for their opinions of reintegration. One-third gave positive responses to the concept of reintegration, but they were still reluctant to have their children lose special education services.

Parental satisfaction in the area of pupil/teacher ratios indicates that parents consider the ratio too high in the regular education classes where children with disabilities are reintegrated.

Parents recommended the ratio be lowered significantly. Parents suggested that more research in this area is needed and that funding should be provided (Steinberg, 1983).

### Parent Expectations

Parental expectations play a major role in the life of a child with disabilities. In the National Education Longitudinal Study of 1988, parental expectations were shown to influence the lives of their children in respect to life-long expectations (Masino & Hodapp, 1996). The study indicated that children, disabled and nondisabled, whose parents had high educational expectations, pursued higher aspirations educationally. The study also indicated that children whose parents had low expectations were less likely to pursue further education. The children with disabilities in the 1988 study were identified as visually impaired, hearing impaired, deaf, and orthopedically impaired (Masino & Hodapp).

Professionals who work with families should be aware of preconceived expectations from parents. Parents' expectations have been shaped by their view of society, the subculture in which they live, and by the experiences they have had in the past. Awareness of these preconceived expectations and perceptions can help the professional improve the services he or she provides (Seligman & Darling, 1997).

Masino and Hodapp (1996) suggested that parents and school professionals begin eliminating some of the barriers to pursuing further education by placing high school children with special needs in more college bound courses and by improving transition service programs. Early parental involvement is considered the key element in ensuring the further success of these children.

### Emotions from Parents of Children with Disabilities

Many parents of children with disabilities stated that when they were informed their child had a disability, they went through many of the same feelings as a person who had experienced

the death of a loved one (Hornby, 1995; Simpson, 1990). Hornby identified these stages as shock, denial, anger, sadness, detachment, reorganization, and acceptance.

Cantor and Cantor (1995) established five main ways to deal with the emotions parents might be feeling. One is to identify and establish a support network. Parents need to know that they are not alone. Developing or locating a support group of parents with disabled children is often the beginning. Also, parents need to learn all they can about their child's specific condition. Gaining knowledge about the condition will help in dealing with the unknown. Next, parents need to express their ideas and opinions about their child's needs medically and educationally. A fourth strategy for parents in dealing with their child's disability is to find ways to communicate their feelings to their family and friends. The final and most important strategy developed by Cantor and Cantor is for parents to learn to take care of themselves.

Re-experiencing the grief of finding out their child has a disability can be triggered in parents during a time of transition in the child's life or if they are told of additional problems (Hornby, 1995). Parents can work through many of these feelings through programs and services such as information exchange, partnership and advocacy training, counseling and consultation, and parent/family coordinated programs (Simpson, 1990).

Hornby (1995) and Simpson (1990) both stressed to school professionals to be mindful of parents' feelings when disseminating diagnostic and classification information. It may be appropriate to assist the parents in dealing with the emotional issues upon learning of their child's disability and postpone the development of the IEP until a later date in order to facilitate more clear thinking and full participation on the part of the parents. Development of an IEP is one example of an occasion that may cause tension and anxiety for parents. Parental concerns seem to have "common threads: vulnerability, guilt, and isolation" (Leff & Walizer, 1992, p. 136). Parents are vulnerable because they consider that their pain will only worsen and that their ability to cope will be inadequate. Continuous feelings of guilt burden the parents of children with disabilities. The feelings of conflicting responsibilities rule the guilt of these parents,

including scheduling of appointments for the child, work roles, other family obligations, and the desires for a normal life (Leff & Walizer). Parents ask themselves such questions as:

Are we doing enough for our child? What will happen if he or she misses a therapy session? When will we ever have enough time (or money) to do all that we must do for our child with special needs, our other children who need us, our aging parents, ourselves as a couple? (Leff & Walizer, p. 137)

School professionals should consider the gravity of the guilt feelings of parents and should work to prioritize and set manageable short-term and long-term goals.

### Parents and Labeling

With the range of emotions parents go through during the initial identification of their child's disability, coming to terms with the stigma of a label generates another range of thoughts. "Parents have been shown to be more accepting of terms such as brain injured, learning disabled, and slow learner than of retardation-related labels" (Barsch, as cited in Harry, 1992a, p. 28). Harry noted that "Pollack pointed to negative effects if parents cling to other terms, such as physical disorders and attention span, to escape facing their child's real needs" (p. 28).

If a parent disagrees, Harry (1992a) stated that it would be more appropriate to assume the parents are disagreeing with the label rather than not accepting the problem. She further explained that parental rejection of labels does not mean that a parent does not realize that the child has problems. Harry continued to say that the literature shows parents mainly disagree with the professionals naming the problem, but not with describing the child's behaviors or performance levels.

Another view of labeling by Greenspan and Wieder (1998) is that the label often does not let parents and professionals know where a child's ability level is according to his or her age group. According to Greenspan and Wieder, current categories of labeling summarize a child's symptoms but do not tell the way a child processes, takes in, or responds to information. The authors further stated that children with similar labels may be more different than alike and children with differing labels may actually be very similar. A child's developmental capacity

can be instrumental in tapping into where a child's ability level is in relating, preverbal communication, and creative reasoning (Greenspan & Wieder).

Greenspan and Wieder (1998) initiated a different approach for assessment and intervention. Instead of labeling, they suggested focusing on each child's unique profile of biological challenges, family patterns, and developmental levels. After this assessment is finalized, the information should be used to design an intervention plan, involving the parents and professionals.

Greenspan and Wieder (1998) further stated that moving away from labels might bring new opportunities to children. Labeling makes it too easy to make predictions and assumptions about what a child can or cannot accomplish. Only when parents and professionals look at the child's developmental abilities will the focus turn to the child's true potential (Greenspan & Wieder).

A third view comes from Harry (1997), who revealed that there are different parameters of normalcy depending on which cultural backgrounds are being presented. She stated that the goal for the professionals is identifying what is normal and separating it from what is not normal, and trying to fix the problem.

In many cultures, labels such as "retarded" mean different things. There is a differential use of language that may make the translation of American terms different, such as retarded being interpreted to mean "crazy." Also, there may be a disagreement as to whether the child's differences are severe enough to be termed as disabled (Harry, 1997).

An additional problem some parents may associate with labeling their child is that the characteristics ascribed to one family member may reflect the character and health of the whole family (Harry, 1992b). Although professional confidentiality is always of importance, it takes on additional importance when understanding the effects it may have on the family unit.

Hallahan and Kauffman (1997) stated that labeling a child could carry negative connotations as well as make the child feel different. Parent advocates have suggested using no

labels at all. The use of labels many times takes precedence over recognizing individuals, themselves.

In contrast, Hallahan and Kauffman (1997) stated that labels might also make nondisabled people more tolerant of those with disabilities. Labels may provide a justification for differences in appearance or behavior. Hallahan and Kauffman (1981) also stated that labeling violates the ethical and moral point of individuals with disabilities rights.

If the labels were no longer used, within time another set of words to identify the different disabilities would be developed (Hallahan & Kauffman, 1997). In the special education field, the use of labels helps in identifying the population of those receiving services. Individuals who receive labels are assumed, often incorrectly, to have generic difficulties. One should question how children are labeled as disabled and what consequences the label may have to their education and with self-esteem (Hallahan & Kauffman, 1981).

### Parent Involvement in Schools

Parent involvement is a substantial factor in the education of all school-aged children (Leler, 1983). Schools have not adequately involved parents in the special education process, resulting in a lack of parent interest that can further be perceived as contributing to problems of the child (Paul et al., 1997). Special education must undergo a restructuring to enhance what is working and to develop new systems to fill in the gaps. Parents and school professionals agree that parent involvement is necessary. Researchers also agree that the fastest way to improve student academic performance is through parent involvement (Fuller & Olsen, 1998). Parents' involvement is also needed in order to gain insight about children, to make better decisions, to enhance learning opportunities, and to build support for schools (Henry, 1996). Parents note they often feel awkward or excluded when dealing with school professionals. Parents respect the school professionals and want to become more actively involved, but inevitably consider they must rely on the expertise of the school (Cullingford, 1996). Parents ultimately can educate

teachers regarding their own child's strengths and weaknesses, as well as family interests and concerns (Rockwell et al., 1996).

Reasons given for variations of participation by the parent are child-related, parental attitudes, school characteristics, and family resources. Obtaining school-related information was a major reason for parents to get involved (Coots, 1998). Coots elaborated by saying families with fewer resources typically accepted the general information and services. The way a school welcomes and initiates parent participation and the availability of family resources are of great importance. A final note from this study is that the more the school professional shows the parent how to help his or her child, the more involved the parent becomes.

A study on parent and school involvement for children in special education programs showed that families wanted their children to be treated like all other children in school. It also stated that parents wanted an increase in communication with the school and an increase in access to services and resources (Cortez-Torrado, 2000). Structural and comprehensive changes in special education are needed to enhance this involvement on a daily basis.

Another study addressing parental involvement in schools examined parents' attitudes (Suver, 2000). The results of this qualitative study demonstrated that what school professionals think about parent involvement is not always what parents think about it. Parents want to communicate to help their child succeed, they want homework, and they are willing to volunteer. Suver continued by stating that school professionals who are aware of and address parent perceptions and attitudes may promote valuable connections throughout the community.

The common goal for both parents and school professionals is to work together for the benefit of the child. Many attempts to bridge the gap have been implemented. Parents and school professionals have long worked together, but have not necessarily worked well together or equally as partners (Henry, 1996). Parents indicate that they are not informed about what is going on in their children's school (Hughes, Wikeley, & Nash, 1994). Nevertheless, parents need school professionals and their support services. As noted by Fuller and Olsen (1998),

“Schools also need parents as co-educators and political allies” ( p.144). Without the dedication and perseverance of professionals, educators, and parents, there would be a loss of one of the most valuable factors in programming--parent involvement (Rockwell et al., 1996).

### Methods for Parent Involvement

The ultimate reason for fostering parent involvement models is that children do better in school when their parents are involved (Fuller & Olsen, 1998). School systems cannot just start improvement programs to get parents more involved. School professionals must assess themselves and the improvement programs to determine what the needs are for the school, the students, and the parents (Dietz, 1997). Understanding the reasons why a program does or does not work is the first step to improving it. This is necessary to increase parent involvement and the success of the program (Dietz).

The traditional ways for parents to be involved in their children’s education have been through school-based activities such as parent-teacher organizations, parent teacher conferences, open house, newsletters, school volunteering, homework, and school board meetings (Coots, 1998; Henry, 1996). Coots further stated ways for parents to get involved in schools is through home-based activities, which include reading to children, signing notes sent by the teacher, and discussing school activities with their children.

A model for parent involvement developed by Joyce Epstein, a researcher at Johns Hopkins University (as cited in Henry, 1996), is made up of five types of corresponding goals. The five aspects of Epstein’s model of parent involvement are (a) parenting, (b) communication, (c) volunteering, (d) learning at home, and (e) representing other parents. The parenting goal is to help families establish a home environment to support learning and positive partnering. The communication goal is to design effective forms of communication to reach parents. The volunteering goal is to recruit and organize parent help and support. The learning at home goal

is to provide ideas and materials to parents on how to help their child at home. The fifth goal, representing other parents, is to recruit and train parent leaders.

A new approach to getting parents actively involved in their children's lives, is through parent advisory councils (Henry, 1996). These councils have become established as part of the site-based management system.

Paul et al. (1997) stated that integrating community-based services for children with disabilities and their families is essential in getting parents involved. Three mechanisms for achieving the goal of an integrated system are leadership, collaboration, and financing. The integrating of services incorporates the education system, health, and social services. The services are delivered in a coordinated way to help improve the outcomes for families and individuals.

Cullingford (1996) cited specific parent involvement practices focused on reading. One program is called "Leading to Read." This program encourages parents to provide a variety of opportunities to allow their child to read. Home Learning Resource Project is another program to help get parents involved. This project encourages parents and teachers to develop and distribute reading materials for use in homes.

Fuller and Olsen (1998) stated that although there are examples of approaches in getting parents more actively involved, there are still areas that need review in order for genuine involvement to take place. One area is the need for adequate resources, or budget priorities, from the local to the state levels. Also, more information is needed about the effects of parent involvement on students. Teachers and administrators need more in-service training on communicating effectively with parents and actual parent involvement practices (Fuller & Olsen; Leler, 1983).

### Parent and School Communication

The breakdown of effective communication between parents and school professionals is a concern. Teachers have indicated that they find interacting with parents to be a major area of stress in their jobs (Turnbull & Turnbull, 1986). Some teachers may be hesitant in bringing up matters that could evoke emotional responses from parents. This is dependent upon the teacher's experience, education, and past communication encounters (Cantor & Cantor, 1995). Parents equally identify the stress of communicating with teachers (Hornby, 2000). Parents find it is hard to communicate with teachers because of the feeling of control the school professionals exhibit and the awareness of the parents lack of knowledge about the curriculum (Vincent, 1996). Karen Osterman (as cited in Hornby, 2000) noted that school leaders who concentrate on being right become isolated and ineffectual. Gemmet (as cited in Hornby) advised that the art of listening must first begin with developing the attitude of wanting to listen, followed by developing the skills to express that attitude.

A study by MacMillan (1995) dealt with parents of children with disabilities who have had communication breakdowns with the school professionals to the point of having to resort to mediation and litigation. The main areas of the study were school personnel behavior, methods of instruction, placement of the child, and related services. Communication problems seemed to exist in all areas of the study. MacMillan (1995) further stated that improving communication by using constructive communication may be the best step in preventing these conflicts.

Deitz (1997) stated that the key to quality communication is to vary the method of delivery. The goal is to convey information. One method of delivery that could be used by the school is a newsletter. This needs to be tailored to the audience. News releases are another means of communication. These releases should be used sparingly, in circumstances such as letting parents know how students will be dismissed during inclement weather. Individual telephone calls from the teacher to the parents letting them know of a problem or to share positive information are effective. Handbooks are effective forms of communication between

the school and parents. Assignments can be written in them, along with written notes to and from the teacher and parent (Dietz).

Dietz (1997) not only explained methods of communicating information, but also included ways to invite parental input. One method is to conduct open forums. This approach allows parents to voice concerns, and to ask about programs and other school issues. Another method is for school professionals to include, in the newsletter, an invitation for parents to visit personally, with specific questions or problems (Dietz).

Parents can be more effective in parent-teacher conferences by identifying what is being done to help a child overcome a problem, examining the teacher's expectations, creating a plan, and scheduling a follow-up conference (Clark, 1999). It is further suggested that parents ask questions such as "What does my child do that surprises you?" or "What can I do at home to support what is being done at school?"

Hornby (2000) identified five methods of developing and maintaining communication between parents and school professionals. They are (a) informal contacts, (b) telephone contacts, (c) various forms of written communication, (d) parent teacher meetings, and (e) home visits. These are all ways that teachers typically communicate with parents. Most of the time this is an opportunity for teachers to tell parents about their child or about an upcoming event, but not a two way communication opportunity (Fuller & Olsen, 1998).

Fuller and Olsen (1998) continued by stating that teachers have not been formally trained in having successful two-way conversations with parents. Teachers often take a communication class in college, but it is generally a public speaking class where the instruction is directed at how to speak to a group, not how to communicate with others.

Parents and school professionals must collaborate to begin to remedy this lack of communication. Collaboration is interacting with professionals, parents, and where appropriate, students, to share information, make collective decisions, and develop a common goal (Hornby,

2000). Working together to set flexible meeting times, develop early intervention programs, and integrate programs are some beginning strategies of collaboration (Steinberg, 1983).

Training for both parents and professionals would assist in the development of positive communication techniques. Special education professionals should include in this training an emphasis on the team concept, and discussions on the roles and responsibilities of each team member. Direct parental contact with a combination of practical experiences should also be included (Frith & Kelly, 1981).

The collaboration of school professionals through team meetings concerning the planning, assessing, and problem solving of the program for children in special education will benefit each child involved (Flach, 2000).

Professionals can help in the collaboration process by following some of the following strategies: (a) emphasizing the family system whenever possible, (b) treating families and their cultures with respect, (c) understanding that there are no quick fixes, (d) allowing other family members to assist in offering suggestions, and (e) providing families with resources (Rockwell et al., 1996).

Before the implementation of IDEA, parent involvement in educational decision making was minimal. Now school systems must inform parents not only of the purpose of the evaluations and of their rights, but also to have them involved in the process of developing the IEP (Mowder, Doberman, & Prasse, 1980).

A crucial point made about parents and professionals working together in the decision-making process in special education is that any of the discourse through the IEP meetings assumes the school professional has greater technical information than the parent. This gives parents the impression that the power of what and what not to discuss is given to the professionals (Harry, 1992a).

When trying to plan the most appropriate program for a child with disabilities, the teacher, school psychologist, school counselors, administrators, and parents must be involved

(Dow & Mehring, 2000). School professionals understand that parents play a pivotal role in the collaboration effort because they spend much more time with the child than professionals do. They become an extension of the professional team. Collaboration with parents increases the chances of supporting proposed interventions (Dow & Mehring).

### Overview

Special education has come a long way in the past two decades regarding the rights of children with disabilities. IDEA has been a steadfast law that governs the activities of schools. ADA ensures that the civil rights of all disabled persons are protected.

Parents of children with disabilities have been brought to the forefront in order of importance in their children's lives at school. School professionals are obligated to ensure parents are given equal partnership in the decision-making process.

The parental role in special education has become more prominent since the implementation of IDEA. Parents are a valued asset in the decision-making process of creating an IEP and in any other part of their child's education. Although many parents do not play as active of a role as they might wish, most seem satisfied with the education their child is receiving. Parents who do play a more active role and have high expectations will see more positive outcomes in their child.

The emotions parents indicate in discovering their child has a disability are very similar to those they feel when someone dies. School professionals need to be particularly sensitive in dealing with parents during all meetings, especial the initial meeting when disseminating data about their child. Setting up a meeting at a later date to develop the program is a good practice. This allows parents time to deal with the emotions and to gain knowledge about their child's disability.

Labeling is a controversial topic for parents of children with disabilities. Some parents would rather address their children's disability using a different term than the given one by the

school professionals. Culturally diverse meanings of labels are a problem for many in dealing with friends and family and in understanding the disability.

Labels are not necessarily negative. Perceptions of a disability make some persons more tolerant of behaviors and inconveniences. Also, many realize that if one has a labeled disability, there are real problems being experienced. Developmental assessments must also be considered instead of labeling alone.

The traditional means of involvement such as parent-teacher conferences, open house, and volunteering are valued. Newer approaches such as parent advisory councils and individual reading programs with parents are being explored. The benefits of parent involvement are positive. More resources are needed to gain knowledge and ideas and to study the effects of increased parental involvement.

Parent-school communication and collaboration are concurrent strategies. Stress is noted by both parents and school professionals in trying to communicate with one another. Listening is key for both. Phone calls, written communication, and possible home visits are good ways of beginning productive means of communication.

Collaboration is a difficult concept to develop. Parents and school professionals who act in partnership benefit children by working together to decide the best means of educating them and enabling them to be productive throughout their lives.

## CHAPTER 3

### METHODOLOGY

This chapter describes the methodology and procedures used in the study, including information about the sample and data gathering techniques. The purpose of this study was to explore the thoughts and experiences of parents related to the initial placement of their child into special education services and the ongoing communication with the school professionals. A letter was sent to the Director of Schools for approval of this study (see Appendix B).

Some of the questions explored were:

1. What was the parent's initial understanding of his or her child's disability as related by the school professionals?
2. What were the parent's experiences when he or she had questions and concerns that required the school professionals to answer?
3. What were the parent's involvement practices with the school and school professionals since the initial placement of his or her child into special education services?
4. What was the communication practice between parents and school professionals and did it change during the initial years the child has been provided special education services?

#### Research Design

This study was conducted using qualitative research methods. Qualitative research develops knowledge of a subject by collecting verbal data through studies of specific cases on a chosen topic and then analyzing the data into generalized deductions.

Lincoln and Guba (1985) called qualitative research the naturalistic approach. They explained the naturalist approach in five axioms. The first axiom of a naturalistic design is the

nature of reality. There are multiple realities constructed holistically. Each of the realities may be shown during the research that brings an uncontrolled outcome than that of a positivistic research design.

The second axiom is the relationship of knower to known (Lincoln & Guba, 1985). The researcher and the focus of the research interact to influence one another. This is evident through the rapport established with the researcher and the parent participants. As the interviews unfolded, each devoted his or her time and information to the subject addressed. Axiom number three is the possibility of generalization (Lincoln & Guba). The explanation of this is that the researcher is developing specific information that can generalize an individual case. In this study the researcher gathered the information from each interview and analyzed the intent of the parent participant.

The fourth axiom of a naturalistic research is the possibility of causal linkages. This is, simply stated, that all areas of the research are being shaped together. This makes it impossible to distinguish cause and effect until the study is completed. Although the researcher analyzed the intent of each interview as in axiom three, it was not until all interviews were completed that a true analysis of the data could be reflected.

The fifth and final axiom described by Lincoln and Guba (1985) is the role of values in inquiry. This encompasses the researcher's values that may influence the study. The final influence considers the results of the research; either the research is reinforced or conflicted (Lincoln & Guba). In order for the research to have meaningful results, all the inquiries must be congruent. Parents in the original focus group gave initial input that set the grounds for the study and the four research questions. The analysis of the interviews depicted both reinforcing and conflicting results.

### Selection of Participants

In qualitative research, sampling techniques tend to be more flexible in respect to the emergent design. An emergent design refers to the continual changing of the research as the researcher gains new insights into the context of the study (Gall, Borg, & Gall, 1996).

This study used the techniques of purposeful sampling through the strategy of typical case sampling. The goal in purposeful sampling is to select cases that are rich with information about the purpose of the study. The typical case sampling specifically involves selecting cases that are characteristic of the ones involved in the study (Gall et al., 1996). The researcher studied the concerns and experiences of parents of children with disabilities, with the exclusion of children identified as gifted. Typical case for this study was of a parent during the initial three years of their child's placement in a special education program.

The researcher, along with the department of special education for the county, identified parents with children served during their initial years. Parents were contacted by telephone to ask if they would participate in the interview. Each parent was given the choice of time, location, and if they preferred one or both parents to be interviewed. The majority of parents interviewed were female. This was the choice of the custodial parent. Of the parents interviewed, 80% were the birth mothers, 15% were the adoptive mothers, and 5% were the grandmothers of children. All of the children were in the custody of the person interviewed at the time of the interview. Fathers of four of the children were also present during the interviews.

The sample size of a qualitative research study is “entirely a matter of judgment, there are no set rules” (Gall et al., 1996, p. 236). There is a trade-off between breadth and depth. A researcher could include a larger number of people in the study, seeking breadth, or could use a smaller more open range to be studied, seeking depth. Initially, the exact number of parents to be interviewed was not known; however, redundancy was reached with 20 participants. The point of redundancy is when no more new information is presented (Lincoln & Guba, 1985). Therefore, the number of parents in the study was determined when there was a deficiency of

new information given by these parents. Seidman (1998) stated that the researcher must know when they have interviewed “enough” participants. There are two criteria for enough. The first is sufficiency. The number of participants interviewed in this study was sufficient. The participants, parents with a child receiving special education services during the initial years, reflected the range of the population so that others outside the sample could relate to the experiences of the parents interviewed. The second criterion for enough participants interviewed was a saturation of information. The interviews during this study reached saturation, or the point at which the researcher was hearing the same information repeated. Seidman stated that enough is a reflection of every step of the interview process and is different for each study and each researcher.

#### Interview Protocol

Interviews were used to collect data in this study. The interview process allows the researcher to obtain "greater depth of information and clarify statements" (Gall et al., 1996, p. 289). The participants signed a consent form prior to their interview (see Appendix C). The researcher used an interview guide to help in the sequence of questions to be asked (see Appendix D). Each interview spanned approximately an hour and a half and was audio taped throughout the entire process. The researcher transcribed the taped interviews and coded the data for the computer program QSR-NUDIST 4 (Qualitative Solutions and Research Pty Ltd, 1997) that was used to code and categorize the information obtained in the interviews.

The interview guide was developed using information gathered from the focus group of parents with children served in special education programs. Some of the parents in the focus group brought up questions and concerns they encountered when interacting with school professionals during the initial years of their child’s services. Their experiences, both positive and negative, triggered ideas for questions to be added to the interview guide. The interview guide was preset to allow the researcher to follow a set path of topics to be covered, but the

questions were open-ended to allow the participants to expand on questions or issues of significance to them (Gall et al., 1996; Siedman, 1998).

The purpose of the researcher's interviews was to obtain information from parents pertaining to individual events, feelings, concerns, and other capacities (Lincoln & Guba, 1985). Care was taken by the researcher to note in a journal details of the interview's circumstances and nonverbal reactions from the interviewee. This helped in presenting as accurate a picture as possible of each parent interviewed.

### Verification

Trustworthiness is a criterion in a qualitative study established in the qualitative or naturalistic research format. The criteria for trustworthiness are internal validity, external validity, reliability, and objectivity (Lincoln & Guba, 1985). Guba & Lincoln (1981) used different terms for the naturalistic research in identifying internal validity as credibility, external validity as transferability, reliability as dependability, and objectivity as confirmability.

To establish credibility in this research study, two techniques were used. They were member checking and peer debriefing. Creswell (1998) stated that credibility could also be established through an external audit. This study included an external audit to establish external validity as confirmability and dependability; however, it can also benefit the internal validity as an aspect of credibility.

The peer debriefer helped analyze the information obtained in the interviews and was impartial to the information obtained, and was not involved as a parent with a child served in a special education program. This person is in the special education field and has an education specialist degree. The peer debriefer and the researcher discussed the experiences captured through the interviews of parents, interpreted the findings captured in the interviews, and debated the decisions of the conclusions and recommendations (Lincoln & Guba, 1985).

Member checking was the second technique used to establish credibility. Member checking is the act of having the person interviewed judge the accuracy of what the researcher has recorded (Gall et al., 1996). Member checking was conducted by the researcher mailing interview transcripts to the parent participants followed by a phone call to each participant discussing the accuracy of the transcription. Information obtained during member checking was considered during the analysis and discussion of the results.

To establish transferability in this study, the method of thick description was applied. Thick description helps to recreate situations, such as the interview sessions, using as much context as possible. The thick description includes meanings and intentions apparent during the interview (Gall et al., 1996). The researcher used thick description from the interviews. A description of what was said by particular parents along with a statement of the intended meaning, provided from member checking, was developed.

Dependability and confirmability was established through the use of an audit. An auditor was employed to evaluate the transcriptions from the interviews to ensure accuracy (Lincoln & Guba, 1985). A memorandum was sent to the auditor stating the procedures that must be followed (see Appendix E). The auditor, a high school assistant principal and former special education teacher, helped ensure that the research report accurately reflected the data obtained during the interviews. The audit included identification of the source and method of raw data collected by listening to the audio tapes and the diagnosing of data reduction and reconstruction by analyzing the coding of transcripts. The audit continued with processing of notes from interviews by studying the researcher's notes and journal entries, and inspection of the material relating to the intentions by distinguishing the themes used through coding. The audit concluded by verifying the results in relation to the interview guide. The auditor sent a memorandum to the researcher reporting results of the audit (see Appendix F).

## Overview

Chapter 3 outlined the qualitative methods used in this study to determine the concerns and experiences of parents of children with disabilities as they related to the initial placement of their child into special education services, and ongoing communication with the school professionals. A qualitative study was conducted followed by a detailed account of the information obtained. In-depth interviews were conducted with parents to gain insight on their attitudes, communication practices, and knowledge of the special education procedures throughout their experiences with special education. A general interview guide approach guided the researcher through the interviewing process.

The parents were chosen using typical case sampling. Parents in the initial stages of dealing with the special education process were chosen to interview. Trustworthiness was established through the techniques of credibility, transferability, dependability, and confirmability.

Chapter 4 provides detailed descriptions of each parent interviewed, along with their statements on particular questions from the interview guide. Related themes that were presented through the study of the QSR-NUDIST 4 search are explained, along with an analysis of the data collected from the interviews.

Chapter 5 includes discussion, recommendations for practice and further research, and conclusions.

## CHAPTER 4

### FINDINGS

This chapter includes findings obtained during indepth interviews with 20 parents who have children with disabilities. The interviews focused upon their experiences with the initial placement of their children in special education programs and communication between the school and home since that placement. Following an introduction of the respondents are issues that were discussed during the interviews that are organized into categories and analyzed. The QSR-Nudist 4 (Qualitative Solutions and Research Pty Ltd., 1997) program was used to aid the researcher in coding and identifying the categories. Narratives of the interviews along with descriptions of the participants are presented to aid in understanding the context of their remarks. Precise dialogue is used throughout this chapter.

Of the 20 parents interviewed, 80% were the birth mothers, 15% were the adoptive mothers, and 5% were the grandmothers of children with special needs. All of the children were in the custody of the person being interviewed at the time of the interview. Fathers of four of the children were also present during the interviews.

#### Introduction of Participants

##### A.B.

The first interview was with a pleasant woman who seemed very willing to talk about her grandson. The directions to her house took me on a very narrow, winding road through the mountains. She gave excellent directions. I had no trouble finding her beautiful home on the side of a mountain. When I drove in the driveway, she told me it was the house with the iron gate at the entrance, next to the trailer. The house was a very large two-story home with rock on the bottom portion and a rosy colored brick on the upper portion. Two women greeted me at the door. I was unsure whom I was to interview. Immediately the elder woman asked me to come

in. A.B. was a thin woman in a denim, ankle-length dress. The other woman was wearing medical scrubs. I was told soon after we sat down in her very elegant and comfortable home that the other woman was A.B.'s daughter who lived in the trailer next door. A young girl about 10 years old came in and asked A.B. something. A.B. introduced her to me as her granddaughter who was staying with her for the summer. The young girl's mother was another daughter of A.B. and also the mother of the grandson she was rearing. She did not explain why she was raising him, and I did not ask.

Not long into the interview, I realized that A.B. was very opinionated. She expressed herself fluently. I could tell she had educated herself regarding special education and school policies. She was also an outspoken individual. It became apparent that when displeased with things in the past, she had let herself be heard by the school system and had proposed solutions to situations to make them better.

#### B.C. and B.C. 2

B.C. asked to be interviewed in the city park, not only because she lived so far away that it would be hard to get to her home, but she also had five children who would need to play while she was talking. B.C. was a woman in her mid to late 30s, fairly overweight, and with mismatched clothes and unkempt hair. Her appearance seemed a bit impoverished, as did her children's who were running to and from her side at the picnic table. She was a very pleasant woman with whom to speak and seemed to have a loving relationship with her children.

B.C.'s middle daughter sat in a wheel chair beside her at the picnic table during most of the interview. Half way through the interview, an old black truck with a camper covering the bed pulled in the parking space closest to the picnic table. The two older children got out with their father. To look at the father, one might assume he was the grandfather, because he appeared quite old. He explained later that he was, in fact, retired and that B.C. did not work.

### C.D.

Pulling into the driveway of C.D.'s house, I drove through deep ruts, hoping my tires would make it. Four small children were sitting on the long narrow porch with no steps leading up. It was assumed they were some of the neighborhood children all playing together, but they immediately told me that they were brothers and sisters.

C.D. came to the door. As I walked in it was noted that there was no flooring in the front room, just the subflooring. We sat on a couch in the front room. A large floor fan blew straight on us. C.D. had gray hair, cut in a chin-length style. Her hair fell in her eyes. She appeared much older, but looking at her closely she had soft looking skin with very few lines and wrinkles.

An older son came from another part of the house and sat on a couch beside us; minutes later one of the younger boys came in and sat with him. They listened quietly as their mother answered my questions. She answered all my questions with very short answers and without a lot of detail. C. D. was a very quiet, shy woman, but I wondered if she might have told me more if the boys had not been there. She did inform me that she does not have any transportation, that her husband has the only vehicle, and that he works every day.

### D.E.

While driving out to D.E.'s house, I was very unsure of where I was going. The general location was known, but she could not tell me exactly which road to turn on in order to get to her house. I ended up having to call her from the side of the road. From where I was, she could not tell me how to get to her house. Her daughter, who sounded very young, got on the phone and gave me directions. When I finally pulled up, I was a little apprehensive about getting out, wondering if this was really the right address. No one came out to greet me. I was parked at the edge of the road. There was no driveway. There were two trailers on the property, one in front of the other. The one I headed toward looked like a very old model that had not been cared for over the years. A large dog was chained to a tree, barking and looking very ferocious. Walking onto

the porch and standing at the front door, I knocked, but no one came to greet me. As I was peering in the screen door, someone yelled to come in--into a dark room with only the television light for illumination. A boy about 10 years old sat in a chair, a little girl about seven, sat on a couch, and D.E. sat in a chair behind a lamp. No one got up as I walked in. Everything from the children's clothes and hair to the furniture and carpet looked dirty. I sat on another couch at the side of the room where D.E. sat. She looked as if she had just woke up when I called. A little dog jumped at my legs.

D.E. and I just had begun our interview when we looked over and saw the little dog relieving himself on the carpet. No one did anything. We just kept on talking. Soon into the interview D.E. told me she had also been in special education classes during her schooling. She did have things to tell me about her children, and she told me that she worked with them on homework. D.E. did not say if she was employed, or if they had a vehicle; there was not one outside. She seemed to do the best she could under the circumstances.

#### E.F.

I met with E.F. at a school. She brought her three children who were all under the age of 10. They played in a room with toys while E.F. talked with me in the cafeteria. E.F. was a woman in her late 30s with short, dark wavy hair. She was dressed in an oversized shirt and long shorts. She told me that she was a teacher. E.F. seemed very confident in her knowledge of the disabilities of which she spoke. She described having many experiences with the special education process while working with her students but indicated that it was a much different experience with her own children. She told me her oldest son was in a program for gifted children. Her youngest son had speech problems with possible learning disabilities. E.F. was a woman who seemed to be on top of what her children were doing and who would ensure that they received all the help to which they were entitled.

## F.G.

F.G. and I met at another school. We had our interview in the office conference room. She was an attractive woman in her late 30s with dark brown hair and eyes. She was eight months pregnant at the time of the interview. F.G. told me this would be her fourth child, but that she also had two stepchildren. While she talked, she seemed very comfortable explaining the experiences her family had encountered. F.G. and her husband have only been married a few years. The son she spoke about as having a learning disability was her husband's child. F.G. was the one who initially thought the child might have a learning problem.

F.G. had some negative experiences during the initial years of being involved in special education, but she did not seem to be hostile or angry when she spoke of them. She did not mind telling me about any of her experiences, whether good or bad. F.G.'s willingness to tell of her family's experiences seemed to vent some of the frustrations she had with the school and to let someone be aware of the problems that can occur and how she overcame the obstacles.

## G.H.

When I drove to G.H.'s home, I got off the main road and drove approximately one mile on her driveway to get to the main house. On the way up the driveway, I passed a few nicely built barns and well-manicured stretches of grass. I saw cows, ducks, dogs, chickens, and peacocks on my way to the house. None of these animals seemed to be in any hurry to move out of my path. A beautiful pond with a fishing boat and paddleboat was neatly docked at the edge. To the other side of the pond on a hill was the main house, a very impressive, large, two-story country style farmhouse, with a wrap-around porch. The house was white with emerald green shutters and an emerald green roof. G.H. met me outside and I followed her to the guesthouse where we conducted the interview. Her children were at the barn at the guesthouse helping their father.

I followed her in my vehicle to the guesthouse. She drove a golf cart. The drive was approximately another mile. This house was a small one-story farmhouse. It was furnished with country accessories and antiques.

G.H. was a slender woman in her late 30s who wore no make-up; her blond hair was in one long braid reaching all the way to her waist. She wore a yellow tank top and jean shorts. She spoke with a bit of a northern accent. She told me she was from New York but had married a Southerner. G.H. was very direct in her answers; she was not one to give great detail, just straight-to-the-point answers. She seemed like a very devoted mother to her three sons, all between the ages of 8 and 11. She said she was very involved in her sons' schools.

#### H.I.

H.I. and I met at a school where she is the secretary. She was a former special education assistant. This is where she said she acquired some of her information to best address her son's needs. H.I. was a tall woman in her mid 30s. She had red hair that characteristically fit her fiery personality. Her knowledge and information of how a school operates made our conversation easy.

On the day of the interview, she happened to have her six-month-old nephew with her. We sat on the floor of the office in order for her to be able to keep her nephew occupied and quiet. H.I. spoke with knowledge and confidence about special education and her experiences. She said she had learned a lot more with her son being in special education than she had when she was a special education assistant.

H.I. was a very self-assured woman who did not have a problem voicing her opinions. She told me she searched out information on her child's disability and also on the legal process of developing and implementing an IEP.

### I.J.

I.J. and I had spoken on the phone only briefly when I recognized her voice as a woman I knew from years before. I had taught her oldest son during his middle school years when he needed homebound services. I.J. was a woman in her late 40s who had adopted a nine-year-old boy when his biological mother could no longer care for him.

Again, I had to drive quite a distance on narrow mountain roads. I knew I was almost there when I passed a junkyard of approximately five acres of old cars. I.J. greeted me at the door when I drove up the driveway. Her home is an old trailer that she told me was in need of remodeling. Although the trailer and the furnishings were old, the home was very neat and clean.

Soon after the interview began, the young boy she had adopted came in and sat with us. He tried to join in where he could, in talking about his teachers. He soon grew bored of our conversation and went outside.

### J.K.

J.K. and I met at a school so her two children could play outside. She was a single mother who had just moved from Florida at the end of the past school year. J.K. was a heavyset woman with very blond hair who wore quite a bit of make-up. Her children appeared to be slightly overweight as well. She had already had an IEP meeting at the school her son was attending. She had prior knowledge of special education law from working with group homes in Florida.

J.K. seemed confident in her knowledge of her son's disability but had a slightly insecure tone when speaking about the new school her son would be attending. She had some struggles in the past when dealing with the school and the special education process, but she hoped that they would not continue at the new school and in a new state.

### K.L.

K.L. was very anxious to speak with me about her concerns with the school system and hoped I would discuss my findings of the system. K.L. requested I meet her at the city hospital in the main waiting room. She told me she lived just across the street but that she preferred meeting at the hospital.

I was already there when she came in the front doors. K.L. was a big, strong-looking woman in her mid 30s who had long blonde hair that was still wet when she came in for the interview. She wore no make up and was dressed in a blue tee shirt, with a logo where a front pocket would be, and jean shorts.

K.L. spoke of many negative aspects of her son's schooling. She seemed to have negative feelings about school in general. She repeatedly brought up that she had graduated college and that she had a high IQ score, but that they had lived through tough times. The positive experiences she spoke of were during her son's primary years in school.

### L.M. and L.M. 2

As I approached their home, I noticed that the yard looked as if it had not been mowed in weeks. There were toys in the midst of the tall grass. L.M. and her husband welcomed me into their small home. The interior was vastly different from the exterior of the home. The house was small but very neat and clean and was decorated in modest furnishings. The couple looked to be in their late 20s. L.M. was pregnant. In addition to their child in school, they had a small baby approximately 6 months old.

My quick initial judgments of this young couple were very wrong. L.M. and her husband proved to be very knowledgeable and were involved in every aspect of their child's schooling. L.M.2, the husband, had received good information from his parents, who are teachers in another state, where his father is a special education teacher.

Initially, when their first child was born they began gathering as much information as they could from all available sources. Neither L.M. nor L.M.2 was shy or easily quieted when it pertained to the concerns of their child.

### M.N. and M.N.2

These participants, originally from Georgia, were rather frightening at first. When I spoke on the phone to set up the interview, the woman was very short in her responses to me. I almost decided not to add them to my list of parents. The man got on the phone to give me directions. He had a deep rough voice with a heavy Georgia accent.

They had a very small house, similar to the other four houses on this small isolated road across from a cow pasture. The houses were square and painted white with country blue shutters and a black roof. I saw only the kitchen and the small, dark living area. I sat at their only table, which was like a tall round bar-type table with two tall chairs. Three people lived in this house, but there was only room for two chairs. The wallpaper was peeling down all over the kitchen.

I called the woman M.N.2 because she did not talk as much as M.N. When I drove up, a large older man greeted me and told me in his deep, strong Georgia accent to come on in. M.N.2 did not say much, but seemed receptive to the fact that I was in her home. She was a woman with graying hair and older looking clothing. She seemed quite a bit younger than her husband. Before I left, they told me that he was 65 and she was 45. She had been his children's babysitter during his first marriage.

M.N. did most of the talking with a very direct approach in speaking of their experiences. He summed up the people he had been in contact with very quickly, and many times not in a very favorable manner. His choice of language left nothing to the imagination. He said he spoke the way he thought.

M.N.2 mainly just answered the questions about which M.N. was unsure. Both were very gracious in answering all questions. Their responses were direct and did not include much

extra information on the topic at hand. They did have a lot to say on varying subjects not directly related to the interview topic.

#### N.O. and N.O. 2

I met N.O. and her husband, N.O.2, at a school cafeteria. They were a couple in their early 40s. They were both neatly dressed in summer cotton clothes.

N.O. began describing her special education experiences and the frustration she and her child encountered. She and her husband had been very involved in their son's schooling and had educated themselves in the art of communicating in order to get the most appropriate education for their child.

N.O. and N.O.2 articulated how they felt in their struggles with the school and the differences in varying schools. Their son began his special education process in an elementary school, then moved to a middle school when he was of age. The differences in the schools and the way these parents and their son were treated illustrates how communication can be key in a successful program.

#### O.P.

O.P. and I also met in a school. O.P. told me she was in her mid 40s and had already raised two other children with severe disabilities before her youngest, who is five, was born. One of her older children died a few years ago and she home schooled the other one.

She seemed more of a grandmotherly figure than a mother one because she had already gone through so much with her other two children. She was in a calmer but more protective mode with this child. O.P. spoke of dropping her daughter off at school for the few hours she attended and then going to the gym to exercise and going out to eat lunch with friends. The school seemed more like a daycare environment in O.P.'s eyes than a learning environment.

P.Q.

P.Q. lived in the city's low-income housing development. It looked as expected with rows of apartments, most looking unkempt. One of P.Q.s two daughters came to the door to greet me. She was a child about nine years old, with strawberry blonde hair. The other daughter, a four-year old, had darker red hair. P.Q. was a woman who was probably in her mid 30s, but who looked about 10 years older. She wore no make-up and had black graying hair that looked uncombed.

Because her apartment was very small and sparsely furnished, we all sat in the same room. The daughters and a friend watched television. P.Q. was very shy and possibly intimidated by my presence in her home and by my questions. She told me that her children were taken from her custody for 18 months soon after her youngest daughter was born. P.Q. told me her father got temporary custody until she eventually got them back. I did not pursue the reasons for the custody changes.

P.Q. could not answer many of my questions. She did not talk much at all. I rephrased the questions in a number of ways, but with little success. P.Q. told me her father attended the IEP meetings with her. She said that he was the one who got her daughter involved in special education. She also told me that she has no means of transportation, so she did not get involved with school activities.

Q.R.

There seemed to be many people at Q.R.'s home because of the four vehicles in the driveway and in the grass. I saw a man leaving as I walked up. Q.R. soon told me that she teaches piano lessons and runs a day care. The children were napping during our interview. Q.R. seemed frazzled from all she had going on in her life. She also told me that she had six children.

The house was a modestly sized home. But with six children, an in-home day care, and a husband sleeping in the next room who works at night, it was crowded. Q.R. was a woman in her mid 40s with blonde hair and a motherly appearance. She indicated that she was a religious person and often spoke of including God in her plans for her children and their rearing.

Q.R. home schooled her children for years until her divorce from her first husband. Upon discovering her middle son's disability, she was in denial. She expressed that she had difficulty facing his disability as a reality.

### R.S.

R.S. was a very vibrant woman. She had many things going on in her life, from dealing with her own children to being a foster parent for the past seven years. When I entered her modestly sized home, I noticed pieces of the flooring were coming up and the wallpaper was torn. She immediately told me she was remodeling and she was finished with her two girls' room. She took me back and showed me the small room with bunk beds decorated with an ocean theme.

R.S. told me she and her husband had adopted their youngest child, a boy, after he had been in their home as a foster placement. He came to them when he was only 10 weeks old. She told me he was a shaken baby, from his biological father's abuse when he was only six weeks old. R.S. proudly told me that he was doing things now that the doctors assured them he would never be able to do.

### S.T.

When I was given directions to S.T.'s home, I knew approximately of the place she was speaking about, because it was near the lake's main marina. I did not realize that her home was the only trailer actually at the marina. S.T.'s home not only had a great view of the lake, but also

the marina and all the traffic it encountered. She told me her husband was the boat mechanic at the marina.

S.T. looked to be in her mid 40s. She had graying black hair, wore a black tee shirt and black cotton shorts. I entered the trailer from the back by walking across pieces of cardboard covering the mud and entered by steps made of stacked cement blocks. I expected to see four children, two of them teenagers. She has three children, but she was keeping a relative's teenaged daughter while they were vacationing. No one was there but her. She was relaxing. The relatives had been there to get their daughter, and took hers with them to their house; the two boys were at friends' houses. S.T. told me she was ready for a nap.

S.T. did not seem to know exactly what kind of services her daughter was getting. She had attended the IEP meetings and she was very satisfied with the way things were going. She did not need or want too much information. S.T. seemed to love her children, was protective of them, and expected them to behave.

#### T.U.

T.U. also lived near a lake in a small house with her husband and three children, and was pregnant with a fourth. T.U. looked to be in her late 20s. She had brown hair and eyes and small tattoos on her hand and arms. She told me that she does not drive, so she has to wait for her husband or her mother to provide transportation. Her children were all under the age of five and were running around us the whole time that we talked. She had two dogs that jumped on me when I entered the house. T.U. let the biggest dog out, and it continued to scratch on the door the rest of the time I was there. The smaller dog was put in one of the two bedrooms. She did not seem to be distracted by the chaos of the children pushing each other and crying and yelling, or of the dogs--but I definitely was.

T.U. was another person who spoke in a direct manner, answering the questions with short answers without providing many examples. She did not have much experience with the school system but indicated that she would stand her ground when necessary.

Now that the participants have been introduced, the categories into which their responses were placed will be introduced. Direct quotes will be included to provide the context as well as the contents of their remarks. The categories of topics were provided to help identify the themes that developed during the interviews with parent participants.

### Types of Disabilities

There was a wide range of types and severity of disabilities identified during the interviews of parents. According to the data gathered from parents, only 25% of the children's disabilities were identified at birth and 45% were identified during the first five years of their children's lives. The remaining 30% were identified after the children started school, in grades ranging from first to fourth.

### Disabilities Identified at Birth

The parents, whose children's disabilities were identified at birth, were very open to discussing the situation. Although the initial impact of learning that their child had a disability was difficult, most of the parents had become very active in making sure their child had the best and most appropriate education possible.

A.B. explained that her grandson was diagnosed with cerebral palsy. She said,

He was early and he had been in [an] intensive care infant nursery for weeks. He has many health problems. He should be actually much worse than he is. We've gotten pretty lucky because we were told he wouldn't speak at all. It was never a question--we knew.

B.C. said her daughter suffered two strokes at birth. Now she has "brain damage and seizure disorder." T.U.'s daughter also suffered a stroke. She said, "The stroke is what left her

with brain damage, partial paralysis on the left side.” She continued to say that the doctors thought her daughter would have Spina Bifida or Down’s syndrome.

L.M. and her husband knew that something was not right; but it was not confirmed until their son was four months old, during a routine doctor’s exam. Their son had not reached any of the goals for a normal four-month-old. She said, “We had pretty much noticed that he had stopped developing.” L.M. added that the doctor suggested her son had Cerebral Palsy. Later they discovered that their son had a rare disorder called “Cerebral Disgenesis.” L.M. continued to explain that “the technical term is cepto-displasia, which is even more rare.” “Cerebral Disgenesis,” as explained by L.M., “means that a portion of the brain did not develop.”

P.Q.’s youngest daughter was born with Hydrocephalus, explained by P.Q. as “water on the brain.” P.Q. was aware of this condition when she was just three months pregnant. She was further told that her daughter has “epilepsy.”

#### Disabilities Identified during the First Five Years

Four of the six children identified with a disability before the age of five had disabilities related to, and with, speech and language problems. The remaining two had other disabilities. E.F., the school teacher, explained that her youngest son was served by the Tennessee Early Intervention System (TEIS) “before he was in the school system . . . because the school system has to serve you at three, but the state has to serve you before that if you have needs.”

G.H. explained that her three boys had speech problems, but that her doctor told her they would “grow out of it.” During kindergarten screenings, her youngest son was checked by the speech therapist, who informed her that the child had a problem. G.H. told her, “I know, I mean ‘cause he. . . they made up their own language.”

O.P. said she took her youngest daughter to the neurologist because “she wouldn’t talk.” The neurologist conducted a Magnetic Resonance Imaging (MRI). O.P. further explained,

The neurologist said there was nothing in the world wrong with her; he said everything was normal. There was no reason for her not to be talking, but he said if you want to speed it up, put her in the school system.

At the time, O.P.'s daughter was two years old, but when she turned three she enrolled her in the school system's preschool program to receive speech therapy.

Q.R.'s son was two and had not begun to talk. She said she was in denial and did not talk to the doctor but worked with her son on speech. Q.R. said she understood him, but "I was his mother, and I was with him all the time." She indicated that she took him to a therapist twice, but "I didn't like what the therapist said because I was in denial." Later when Q.R. stopped home schooling, the school system explained his learning disability to her.

K.L. was attending a community college when she took her four and a half-year-old son for testing at the college. She explained,

When I went to school at Walters State they had a special learning thing where students of developmental kids stuff would help the children who needed help. So he was in a special class with five kids and one teacher.

K.L. later told me that her son's I.Q. score is 79 ½. She said, "It's got to be between 80 and 100 to be normal."

Doctors told R.S. that her adopted son who had been abused, suffered such a "severe blood clot on the left side of his brain that it completely killed it. They told us he would be blind and paralyzed from the neck down." She continued to say, "The boy can spot chocolate from a 100 yards and can outrun me." The doctors did not identify a specific disability. R.S. said, "They knew that he was brain damaged, that he would be retarded, and they knew that he had Cerebral Palsy because he quit breathing when he was beaten. Other than that, they had no clue."

### Disabilities Identified in School

Three of the nine children whose disabilities were identified in school had speech and language difficulties. One of the three parents, C.D., explained that when her daughter first

started talking, no one could understand her, “Me and her dad could, but if anyone else came in there, they couldn’t understand the words she used.” When C.D. took her daughter to kindergarten screening, she explained,

She knew when they asked you the colors and your right arm and left arm. She knew it, because me and her dad knew that she knew it. But they didn’t understand her, so she missed all of that. So when she went to school they started her in prekindergarten.

D.E. said that both of her children received special education services. Her son no longer receives services, but her daughter receives speech and language therapy. D.E. stated, “She’s straightened up a lot because they got her in it.” D.E. did not know a lot about the special education process or the qualifications to receive services. She was just glad she was getting help in school. S.T.’s understanding was similar to D.E.’s knowledge of special education. Her daughter was also receiving speech and language therapy. As we spoke, she asked me questions such as, “Is resource the same as speech?” and “What is resource?” D.E. did know one reason that her daughter was receiving services in the area of speech and language because “she was having a hard time pronouncing the ‘r’ sound.”

Four of the nine children identified while in school as having a disability were learning disabled. H.I. said she was told officially that her son had a learning disability in fourth grade, but that she had suspected something since first grade. Her reasoning was “because his reading was very slow and there would be days where he would know words and then the next day he wouldn’t know them.”

F.G. explained that when she and her husband married, she did not think of her stepson’s problems as being serious. She just thought it was because of the change in their family and his moving to a new school. She continued,

So it was a big change and we were, okay, that was the problem. So, my thought was, we have one semester left of school and then the summer. So, what I did was, I pulled him out and home schooled him to get him caught up. He was good in math and all that; so we didn’t work on that much, we really focused on the spelling and reading. That’s when I noticed, when it was one on one. This was your own cousin or niece or nephew. You won’t really notice until you sit down and pay attention to their reading, that they had a reading problem. I didn’t notice it, and he has an excellent memory. When we first met,

I was so impressed that he knows every book of the Bible in order and that was at seven or eight years old; and I was like, wow. I would not have thought there was a reading problem, and then when I'd listen to him read and he was skipping words, adding and things.

M.N. and M.N. 2 also found their son had a learning disability after he was in school.

This couple blamed much of their son's difficulties on the teacher. M.N. said, "They didn't give him a chance. The teacher he had in second grade or third. That old bat." M.N.2 stated their son was in third grade. M.N. continued by saying, "She wouldn't even let the child read. She let everybody else read but him. Now he didn't tell us that; some of the other students told us that."

Initially, M.N. and M.N.2 had problems similar to F.G.'s. Both sets of parents had obstacles with the school. F.G. solved her problems by hiring an outside source to test her child. M.N. and M.N.2 solved their problem when they moved to another state and got better results there.

The fourth child discussed with a learning disability also was identified as having Attention Deficit with Hyperactivity Disorder (ADHD). To listen to the parents, N.O. and N.O.2, talk, one may have perceived the child to have emotional problems. Initially, the parents only discussed their son's behaviors and outbursts. They explained that their child had shown behavioral problems since the age of two but no signs of problems at school until fourth grade. N.O. continued her explanation by saying,

He was able to go to regular classes and all that and he went through the fourth grade. They had talked about pulling him out for some classes and they decided because he's so structured that that would disrupt him more than help him so they left him. Then in the fifth grade he threatened a girl, and then that's when he got put in the class.

The other two of the nine children identified in school as having a disability were a boy who is mentally retarded and another boy who has Attention Deficit with Hyperactivity Disorder (ADHD) along with emotional problems. I.J. explained that her son, who had recently been adopted by her and her husband, was identified as mildly retarded. I.J. noted that she thought her son was receiving special education help when he initially came to live with her and her husband two years prior because "of his past life with his grandmother and stuff. I thought that they

didn't work with him and that he was behind." I.J. continued to say that she thought he was "just behind the other kids and he'll catch up." After her son's testing was complete, and the school professionals explained that her son was mildly retarded, I.J. said, "I sort of suspected it because of day to day living; but when they finally told me, it just hit me like a brick."

J.K. has a son who has been identified as having ADHD and with emotional problems. J.K. is a single mother who has two children. She did not show a lot of emotion when explaining about her son's disabilities. She seems to have educated herself about what she needs to help her son. She explained very matter of factly, "He has ADHD, and is emotionally handicapped, and has some type of growth problem, too." She further explained that she became aware of all these conditions at the same time. J.K. says he is taking medication and has been doing fairly well. Up until this point, it had been a battle with the school professionals to get him assessed. Because J.K. has recently moved, she states she does not know much about the school her son is in; but, she remains optimistic.

### Emotions of Having a Child with Disabilities

Only a small number of parents, when asked how they felt when they first learned that their child had a disability, verbalized it with terms of emotions. Most of the parents simply described the situation in which they were told about their child's disability.

The parents interviewed who had children identified at birth with a disability mentioned some of the emotions identified by Hornby (1995) and Simpson (1990) as experiencing the death of a loved one. These were the emotions identified in stages of shock, denial, anger, sadness, detachment, reorganization, and acceptance. Most of the parents were believed to be in the acceptance stage. The parents who had children identified with a disability can remember the experiences of the moment of being told about their child's disability, but the focus, during the interview, was on school experiences.

When L.M. and her husband learned that their son had a rare disorder, they went through a period of guilt. L.M. explained, "I think it would have been easier if someone had told us, 'okay, this is what happened.'" L.M.2, the father, further admitted that it was a scary thing to go through by saying, "We didn't know anything; which was worse sometimes, not knowing one way or the other, you know if you have a child that's going to be terminal, wheelchair bound, paralyzed, something like that." L.M. added, "They couldn't tell us anything."

B.C. explained that her daughter had two strokes at birth, causing her to have brain damage and a seizure disorder. She just agreed that it was a lot to deal with initially. B.C. did not expand further on her emotions or experiences at birth. She added, "She's done well. You can tell. She seems like a real happy child." B.C. said that it was a scary experience putting her daughter in school initially, because "she's defenseless. She can't take care of herself."

A.B. is the grandmother who is caring for her grandson. A.B. did not explain why she raises her grandson and not her granddaughter. The researcher was lead to believe, by observing some of her mannerisms, that the daughter was not able to take care of her son's special needs. A.B. did not use emotional words to describe the initial impact of hearing that her grandson had Cerebral Palsy. She explained,

He was early and had been in intensive care infant nursery for weeks. He has many health problems. He should be actually much worse than he is. We've gotten pretty lucky because we were told he wouldn't speak at all. It was never a question; we knew.

P.Q. is another parent whose child was identified with a disability at birth. She gave short direct answers and had ability to speak about her daughter's condition with both her children and a friend present. This woman was difficult to interview because she was a woman of few words. She lived in the local housing authority apartments and had previously had her two daughters taken away from her by the Department of Children's Services. To the researcher, P.Q. seemed to have some mental deficiencies herself. P.Q. explained that her daughter's "got hydrocephalus--that's water on the brain." P.Q. continued her explanation stating she was three months pregnant when she learned her daughter would have a disability. She said, "It was like

that, just as big as it is.” P.Q. showed the size of her daughter’s head with her hands. Continuing she said, “Her head ain’t grewed none since she was born; it’s been that big.” With further questioning, it was noted that P.Q.’s daughter takes medication to control any problems.

T.U. had three small children under the age of five and was pregnant with a fourth. She was also an example of a parent who seemed to be in the acceptance stage of dealing with her child’s disability. When we talked, all the children were around, which may be a reason T.U. was straight to the point and did not speak in emotional terms about her daughter’s birth. She stated her daughter had a “stroke and then had a tumor. The stroke is what left her with brain damage, partial paralysis on the left side.” T.U. stated doctors wanted to do tests on her when she was pregnant, once they found problems, and she said "no." The one emotional word that T.U. did use was “uncomfortable,” when explaining how she felt when meeting initially with the school professionals about her daughter.

Parents who learned through the school professionals that their children had a disability had a different approach from parents who became aware at birth. The parents who learned about a disability at birth did seem to go through stages of emotions because the disabilities explained were profound and had to be dealt with on an immediate basis. Parents who learned through the school systems, many times, already sensed there might have been a problem, either through speech difficulties, not getting along with others, or learning delays.

When it was explained by the school system that D.E.’s daughter had a speech impairment she said, “Actually it felt pretty good, because at home I could tell she struggled and it helped putting her in there,” [special education services].

E.F. watched as her youngest son went through the battery of tests at a learning center checking for areas of weakness. She explained, “He was pitiful. He was hiding over in the corner. He needed a safe, closed in place to be. It worried me.”

G.H. realized her youngest child not only had a speech impairment like her other two sons, but that he further had a learning disability. She said,

I felt better because I thought it was my fault. I thought it was something that I didn't work with him as much, because maybe I had more time with 'the oldest son' and 'the middle son,' and that I worked with them at school, and I didn't have time with him. So I felt like I screwed up somewhere. I should have worked more with the ABCs with him.

Q.R. went through a long period of denial that her son had a learning disability. She agreed that it was a scary thing to hear. Q.R. said, "I was just like, you know, what did I do wrong with this child? The rest of them were fine. What did I do wrong with this one? And nobody knows."

Many parents expressed emotions when discussing the initial IEP meeting. Many of the comments included that the parents felt uncomfortable. T.U. said, "The first time, I remember I was really uncomfortable. Really uncomfortable, 'cause I didn't know anybody and I felt awkward." She said that having a person with her from Tennessee Early Intervention System (TEIS) helped. D.E. and G.H. both used the word "uncomfortable" in describing their first IEP meetings. G.H. explained, "Well, you know, you feel, you're uncomfortable for one thing, because they use all these words that no one understands no more than I do. It's like listening to Charlie Brown's teacher."

Other words used to describe parents' feelings during the first IEP meeting were "bad," "nervous," and "concerned." I.J. said that she felt she had pushed her son too hard. K.L. said she felt that her son "was not normal like every one else." E.F. said she wanted to make sure her son got the services to help him.

### Descriptions of Initial IEP Meeting

Parent participants were asked to describe their first IEP meeting experience and to tell, in retrospect, what kind of information they might have needed either before or after that first meeting. Knowing that each parent had different experiences made this an interesting question. There were many interpretations on how to answer the question. Although it was found that many parents noted they felt uncomfortable and intimidated with the setting, most had a positive

experience in getting the services needed for their child. However, some parents implied they had to continually stress their point to be heard.

Positive comments made by parents included the comments by C.D. who said, “They made me feel like I belonged. They included me in stuff. They’ve always been real nice. They explained stuff to me.”

E.F. stated that her experiences were positive by saying,

The table was full. I could not believe that so many people had been called together and were giving up, what, an hour and a half of their time for this one little bitty two-year-old. The table was full and I felt like they were very concerned that they would devote that much time to a meeting about this child. I was very impressed and felt like they were very concerned about him.

H.I. had a similar positive experience during the initial meeting. H.I. explained, “It was very comfortable.” H.I. stated that the school psychologist was the one who explained the scores. She continued,

He explained everything very well I thought, and talked in positive terms about what [son] could do and talked about how much older that he seemed and in his language, and then we got down to the other part. So it was good to hear something good first and then hear what I already knew, and that’s when we made plans for what would happen.

S.T. did not have a lot of knowledge about her child’s disability when she entered the IEP meeting, but her experience seemed to be a positive one. She said, “Well they just talked about what they was going to, how they were going to work with her. The sounds and all, and comprehending words and putting the word in sentences.” When asked if she understood what the school professionals were telling her they would be doing for her child, she replied, “If I didn’t understand what they were saying I’d ask them what they were talking about. I’m just not going to say, ‘yeah I agree.’ You need to tell me what you are going to be doing and all.”

Seligman and Darling (1997) stated that parents who view professionals with respect and who believe that they know “what is best” will agree to their recommendations without question.

The researcher noticed as each parent spoke of his or her initial IEP meeting, that most did have the nervous feeling of unknowing, in having someone of whom they were unfamiliar

dealing with their child. The parents with children who had been identified at birth or before school age seemed to have more knowledge of their child and what they wanted for their child. Many of these parents had already dealt with doctors and outside agencies. They received a lot of information about their child's disability from the experiences.

T.U. said that she had brought a woman with her to the meeting who worked with TEIS. She said, "That helped. She would put out the points of what was going on to the teacher and the principal. It helped me, 'cause then I was more comfortable." When I asked T.U. if there was anything that would have made her feel more comfortable besides having the woman from TEIS, she said, "probably not, 'cause I'd never been in that school before." She further mentioned, "It takes me a while to ease up in a different environment with other people."

L.M. and L.M.2 had a very positive initial experience during their first IEP meeting because they came really prepared by having someone from each of their son's early intervention support programs. L.M. stated, "If there were any questions, these three women were in our household, had seen [son] for the first three years of his life, and were there to back us up and show reasons why we were asking for this."

A.B., a grandmother who knew of her grandson's disability from birth, initially followed what the school professionals decided to do with her grandson. However, when she moved to a new state and school system, she learned that every state and school system did not know her child the way she did, or know what his needs were. During her initial IEP meeting in her grandson's present school she described,

I didn't have a clue. The ones in Louisiana were so different because we were dealing with one early intervention program into the school. They just took it and ran with it. We really didn't have to do a lot. They knew exactly how to write it up to get him transferred over. I really learned about m-teams, the legalities, what you can and can't do, after I got here. We've had some good ones. I don't think parents are taken as serious always as they need to be. It took me two or three years to make them really believe and understand that [grandson] was doing things at home that he wasn't doing at school.

Parents who are truly learning about their child's disability for the first time from the school professionals, as well as those meeting the school professionals initially, have a sense of being overwhelmed and uncomfortable. D.E. stated that she felt uncomfortable, "cause you don't know what they are going to say to you. You don't know if it's bad or good or what she's actually having the problems in when you go in to the meeting." D.E. further stated that there was "too much information" at one time.

K.L.'s experience with her initial IEP meeting was unnerving for her. She explained, "Makes you nervous because your child isn't normal like everyone else; plus, I had a normal child and then one with disabilities. I always try to suggest to them what I think is best. It seems like they have a plan on their minds what they are going to do. They want you there, and they don't want you there. It's unnerving to me to be in a situation like that. You've got the principal, the assistant principal, the teacher, special ed. teacher, and then you have a psychiatrist, somebody you've never met before, somebody your child has only been with 15 minutes of his life--telling you about your child and I just don't know about that. I think they should have more contact with the child."

B.C. said of her initial meeting,

"When I first went in there it was like alienation with all these teachers and specialists, sitting at this table. They ask you "What do you think your child needs?" and you're like, "I don't know." They ask, "Well what do you do at home? Well what needs to be done?" Then you have to go through the process, like I said, she's 24-hour care. They're like, "okay."

Before the initial meeting, a few of the parents had already experienced some negative tones with the school professionals. These parents came into the initial IEP knowing that they had already battled to get their child some help and were on the defensive. J.K. explained that she had asked for her son to be tested when they were at their previous school in another state. She said,

"Basically it was supposed to take two or three months to get everything from square 'A' to square 'B.' It took almost a year. It wasn't a good experience, but because I knew more than a regular parent, and told them I knew the law, then the ball got rolling and within two months they had everything done and the IEP."

F.G. had problems before the initial IEP meeting in order for her child to be tested, even after she had requested it. She explained,

Before we started school here, I came in and had a conference with the principal concerning that I had him personally tested because I'd seen that there was a problem. I guess because there are so many children now that have problems, I was initially kind of shooed. And was told, "Well, let's just see how he does." Basically the responsibility was not the school's responsibility. That I had to personally get him tested somewhere else. Well financially we weren't in a position to do that.

Each parent has his or her own unique experience in the initial IEP meeting. The following chapter will address recommendations to try to make this experience less stressful.

### Needed Information for Parents

Of the parents interviewed, 35% reported needing additional information following the initial meeting. However, most who did need the information did not actually realize what they needed until some time later, after their child had received services for a period of time. Only 20% of the parents interviewed indicated they felt they had received all the information that was needed.

Where, or from whom parents received additional information ranged from school professionals, to doctors, to support personnel with whom the parents had contact. However, most parents did turn to someone with whom they felt more comfortable.

A.B. stated,

I didn't know what to ask. Didn't have a clue. Thought that they knew everything. And didn't know enough to help him. We were so new at it. Didn't know what the education system was. Didn't know what was available. What the limits were. It's an education process for parents.

A.B. continued to explain that anyone living or moving into an area who has a child with a disability needs to know where to turn for information. She stated that all agencies, schools, doctors, and vocational cooperatives need to work together to get the information in a directory or pamphlet.

F.G. echoed the feelings of A.B. about not knowing what to ask. F.G. said, "Maybe sometimes parents want too much. They want to know now. They want answers and sometimes, you know, time will answer, but I wanted to know a little more specifically what his

problem was and how to fix it.” She continued to say she wanted “more information on how to deal with it.” F.G. stated that she did not get progress reports from the special education teacher as expected. Her son’s regular education teacher communicated regularly with her, which helped. G. H. agreed with F.G. and A.B. in their desire to know what to do to help. G.H. spoke directly about what she preferred the school professionals to say. She said,

Okay, if he has a speech problem, where do we go? Here’s the worst-case scenario--that he may be in speech for six years, but we can handle that. We can pull him out of class, but we’ll work with that. Basically what you need to know. But you get all that paperwork. I have papers like this. I can’t tell you what any of it says. Because I didn’t listen, or didn’t hear, or it wasn’t even worth knowing.

J.K. and K.L. said they both needed more information about ADHD. J.K. said, “I knew a little bit, but there’s a whole slew of things to find out.” K.L. further stated,

I wish I knew the process more. You know those big packets of papers they give you. Like I say, say you just don’t even have your high school education, like you could understand that paper. I had to read across those papers two or three times when I was bored and stuff, to understand that I could appeal and all that. It looked so difficult.

Just as in K.L.’s experience, where she did not understand a lot of the information given to her during the initial IEP meeting, other parents admitted the same, such as N.O. and N.O.2, whose child has some behavior issues. N.O.2 explained, “I guess the biggest thing that we needed to understand was what we could do and what our options were. We didn’t realize we had options; just what they told us was the way it had to be.” N.O. further explained,

We’ve been into m-teams and had somebody say, and they say, what do you want us to do? And most parents, I don’t know. . . what options? I don’t know what you can do. You’ve been to a lot of them where they say, what do you want us to do, we’ve tried this and this. I hate to have this attitude but its like, he’s not doing this at home, I can’t help as much as I want to. I can’t do it, I don’t know what you need from me, when I’m not here I don’t know the situation exactly.

H.I. went a little further with her frustration on information seeking. She stated,

I guess my biggest misconception, and if I had known, if I had information I would have known. I thought that once "son" was tested and we knew that he had a reading disability, that it was smooth sailing from there. That was really just when the battle began. To get his classroom teacher to realize that, and to basically believe it, because I think, that particular teacher, even though she saw it on paper, she didn’t believe it.

Because to look at him you wouldn't say, "There's a kid with a learning disability."  
Because he doesn't appear to have one.

Some of the parents who did seek out additional information were like O.P., who spoke with her doctor about her daughter's speech problems. She said, "He was the one who said, you know, if you will go ahead and put her in the system, she'll start talking faster by being around other kids than being at home."

R.S. got additional information from her TEIS worker. She said she became a good friend with her TEIS worker and relayed, "If I had a question, or I needed help, or I needed a direction, she's the one I called."

Some parents received the additional information they needed after the initial IEP meeting from school professionals in a more personal, private meeting. H.I., who at one time was a special education assistant and now is a school secretary, said when she needed information she would speak with the assistant principal at her school and "other special ed. people." She also mentioned that she had done some reading on her own and looked on the Internet. G.H. said she went directly to the speech and language therapist in the school that her son was attending. She stated the therapist gave her direct answers to her questions. I.J. also received answers to questions, and received information from teachers she felt comfortable with. I.J. had already been through the special education process with her oldest child, but when she adopted her youngest son she had questions about things such as why he was making "As and Bs" and she knew after the IEP meeting that he was not on that level.

The researcher noted that a few parents did not have any questions after the initial IEP meeting. Most of these parents seemed to be less educated or did not want to be bothered with the details as long as his or her child was being provided for. C.D. stated, "Well, I really didn't need any, because I knew they needed it; and as it went on, I could tell they was improving some." P.Q. said she asked her doctor, but from the statements received in the interview, it did not seem that she received any additional information after the initial IEP, only before her daughter was born. P.Q. said, "He gave me a lot of information saying that she could be retarded

or different things that could be wrong with her.” S.T. did not have much comment on needing additional information,

Really none. 'Cause they really explained what they were going to do. Plus you know what they were doing, the paper that I would have to sign at the meeting. It was written right up there too, how they were working with her. Evidently she's done fairly well.

Q.R. seemed pleased with the information received from the initial IEP meeting. She stated, “They were very informative with what they gave me. I can remember they laid out exactly what our objectives were and our goals.”

E.F. is a teacher and an exception to the above four parents. She knew the procedures of developing and implementing an IEP. She conveyed she did not need additional information following the initial IEP meeting by saying,

Golly, they met at the time that I needed. I needed before school, and that's the time they all gathered. I was made very comfortable. I was introduced to everyone immediately. I couldn't think of a way to actually improve the m-team. I truly, and I guess it's not their fault, I guess it's funding, but I would like to see kids receive the level that they receive from the private [school].

### Parent Concerns with School Professionals

Each parent interviewed was asked how he or she was responded to when expressing concerns, offering ideas, or sharing new information with the school system. Most parents could remember an experience of having to express a concern about the care and services offered to their child. None of the parents interviewed stated that he or she had offered any ideas to the school or shared any new information.

Only two parents, C.D. and S.T., said that they had not expressed any concerns or suggestions for the school professionals. C.D. is the parent who told me she had also received special education services when she attended school. She was very complimentary of the school professionals in her experiences. S.T. said she had no reason to have a concern or share information, “cause what they would suggest was what I was thinking of, and they was all at each meeting. They would tell me [daughter] was just making remarkable progress.”

Expressing concerns to school professionals can be both difficult and uncomfortable for parents. Many parents reported, however, that when they did express their concerns, the situation most often changed in a positive way. Unfortunately, parents who did express concern had to become angry with the school professionals before anything was done to correct the situation. Communication between parents and school professionals is crucial in an area that can become volatile.

N.O. and her husband expressed a concern about the progress their son would make academically when he was placed in a behavioral class. N.O.2, the father, stated,

Well for the most part, they acted like our concerns were their concerns. His grades come to mind. Say the grade level. Now we told them whatever we did we wanted to make sure he stayed at grade level. We felt like he was smart enough to do that. They all agreed with us. That's a great thing. That's what we want to do. But in reality, they didn't even try.

N.O. and N.O.2 continued to have conflicts with the school because their son was not keeping up with other students academically. They further explained that once the teacher in their son's behavioral class changed, there were immediate and positive changes. . N. O. said,

Since we've had [teacher], very receptive. We know exactly where he's at and he would bring home homework. He brought home papers. She got all the teachers to let us know if he was lagging behind. At one point he wasn't reading the book that was sent home, and his teacher sent home a note about it. That was corrected. Everybody was real good. I would go and say, "Hey, I know this isn't your problem but can I have a week longer on this because we didn't know about it." They've helped us out that way, so that's been real nice.

P.Q. told the school her daughter was attending about a change in her medicine. She explained, "It makes her more hyper and mean. They told me they put her in time-out. I told them they could not do that 'cause it's the medicine." She continued by saying, "I told them, I didn't mind disciplining her, because I do." She ended by answering that they stopped putting her in time-out as much.

R.S. said that she's had to "go in toe to toe and fight for what I think he should have." She explained one incident when her son's ears were draining caused by a continual problem that the doctor was well aware of. She said,

One of the substitutes there who was in his class was talking about what a bad parent I was in allowing my child to come to school, and not taking care of his ears . . . in the lunchroom in front of other teachers, parents, and children.

R.S. had a conference with the special education director to express her displeasure. R.S. stated she was pleased with the outcome and of the quick response by the director to correct the situation.

A.B. stated that initially she had no need for concern or to offer suggestions, but that she began to feel like the special education teacher was competing with her to see who knew her grandson the best. A.B. explained that her grandson was not progressing because the teacher was not teaching to his ability. A.B. transferred her grandson to another school. Through working with the special education supervisor and the teacher, A.B. agreed to put her grandson back in his home school.

Another situation when communication from the school professional was either perceived wrongly or could have been handled differently, was with the son of E.F. E.F., who is a teacher, expressed concern when her son was dismissed from speech therapy. She stated that the therapist said, "Well, you may think he's not up to par, but we think he is, and so I let him go." E.F. said she felt as if she were being "brushed over." Being a teacher, she stated that she understood her son had to meet the criteria to receive services but she was still concerned about his "baby talk" getting worse. Fortunately for E.F., at the beginning of the next school year a new speech therapist observed her son and said that, "Yes, he did qualify for services, and they would begin immediately."

A similar situation occurred over miscommunication for O.P. and her daughter's services. If the school professional had taken the time to explain it further, O.P.'s frustration of what to do may have been eliminated.

H.I.'s concerns were largely because of communication problems between parent and school professional. H.I. stated,

It definitely depended on the year. In fourth grade when he was actually tested, it was not received well at all. She basically didn't want to hear how I felt, his teacher. We

struggled the whole year long, and it was bad. His fifth grade year he had a wonderful teacher, and she worked with him and did everything she possibly could.

An additional situation where better communication or a compromise could have saved undue stress and problems, is with parents L.M. and L.M.2. These parents are young, and have a three-year-old son who just started the preschool program provided through special education. Their problem stemmed over the use of a communication device that the parents had been taught to use, through an early intervention program with their son. The school's speech therapist refused to use the device because she was not as familiar with it. L.M. explained,

Well, don't just send the Alpha Talker home not used and give me no explanation for it, because at home that's what we were doing; because that's what we had been using in speech therapy where we started. I'm not a speech therapist, so I don't know what she's doing. I thought the results of what she was doing was working well and saying words I'd never heard before. But you know, it was one of those things where she'd say this is what I'm doing; and even though the Alpha Talker was what we knew and thought was going to work, we were not against what she had in mind. So, it had been a little of. . . okay, I'll give a little bit, if you'll give a little bit.

There were many parents who expressed a concern or need, and had very positive results. They considered everything to be going very well with their children receiving special education services. B.C. commented, "We pretty much at [the school] work together. If I have a question or concern, they answer it or address it." I.J. stated,

Like when things cropped up with behavioral problems, I would go in and suggest, let's do this; and they'd say, "hey that's a good idea." They always work with me because he knows I send him to school to learn--not to play and goof off.

M.N. and M.N.2 stated that when they had a concern with their son or a situation at school, they would address it to a school professional and it had always been handled immediately. T.U. was an additional parent who stated that when she expressed a concern or situation with the school professionals, it was handled appropriately. T.U. stated "They seemed to care what I was talking about and what my concerns were."

Only one negative experience was mentioned that did not improve after the parent expressed a concern. The situation was with F.G. and her son's classroom teacher. She explained,

When I noticed initially that she just didn't seem to care. She didn't know initially that [name] was special ed. And so when I came to the first parent teacher conference, there wasn't any advice or anything at all, because I asked her what he got on reading. He had an 'A' and it had a reading level, it matched up on where he should have been at. So my question to her was, well, how do you get this grading, I don't understand. Well, she said, well that's not based on [name] as an individual, it's based on the class as a whole. And I said, but I don't care about the class as a whole, this is his report card, this is his grade. How am I supposed to know how he's doing in reading if you are saying he's got an A and he was reading at the beginning of fifth grade? He was reading second grade.

F.G. and the teacher never did reach agreement during the school year. She is looking forward to the upcoming year with hope.

### Positive Aspects of Special Education

Each parent was asked to tell what he or she thought was the most positive aspect of having his or her child receive special education services. Every parent was able to give a positive element, even if all areas reported did not seem positive at first. Parents expressed extremely varied ideas of what they considered to be positive, from getting additional help, to knowing the law was behind them, and to concentrated time with their child.

### Interaction with Other Children

There was, however, one common theme throughout the parent responses. The parents who had their children in the preschool program reported that the most positive aspect was the interaction with the other children. They reported that the interaction had a huge impact on their children.

L.M. explained about her son, "Whenever he's there during the day, he's got the other kids there with him. Yeah, I think that's the most positive. I think it has shown him a lot of independence, too."

O.P. echoed the same remark as L.M. She said about her daughter, "Being around the other kids I think has helped a lot. I think it's helping her a lot being around other kids cause she talks about them all the time."

R.S. expressed a similar idea by stating,

He's making friends. One of the boys who's in his class, he started out in therapy with as babies, so they've known each other for 6 years now. They're buddies. It's hard to describe; he's becoming more outgoing in the last year and a half.

T.U. also stated her daughter is talking much more than before the services began. She continues,

She interacts so much better. When she first came in there, they said she couldn't sit still. She had a problem with getting up and moving in the middle of lunch. That she has, like a five second attention span. Now it seems like she can focus more on what she wants to focus on.

B.C.'s daughter has multiple handicaps but is not in the preschool program. She is in the elementary school setting in a special education class and is mainstreamed into the regular education setting. B.C. stated,

She gets to be around her own, not her own disability, because she is one of the worst there. But the other kids, they just love her. She's just got so many friends. Everyone knows who she is. They play with her as she goes down the halls. They are real good with her in the gym. They are real careful. They know her limits.

A.B.'s grandson is in the same situation as B.C.'s daughter. A.B. said that there were a lot of positive aspects. She said,

The biggest thing is that the kids that I don't think could have done anything are doing amazing things. I can see far enough down the road that [name] can hold down a job. Fifteen to 20 years ago, he would not have. The fact that they are keeping up on the computer end of it has changed a lot of kids' lives in special ed. I think it's just the fact that they are teaching them to be independent and earn a living.

### Increased Learning Skills

C.D., D.E., and S.T. all have elementary aged children in speech and language therapy. They stated that a positive aspect of having their children in special education programs is that they have learned to increase their skills where they had weaknesses. C.D. explained, "Well, they used to get mad because no one could understand them. But now they seem like they speak a little better. They don't get mad as easy." S.T. simply stated, "Well, it has helped their speech and their language and the way they talk. It really has."

J.K. duplicated C.D. and D.E.'s response regarding a positive aspect of having her child's skills increase. J.K. stated,

Basically, he's finally getting help to get control his emotions, so he knows it is not something he can help, that he can learn to get the positive side of himself. Okay, I didn't do this right today, but I can try it now.

P.Q. also commented on how much her daughter has learned since being provided services. She stated, "She's learned a lot. I've notice a big change in her." She continued, "She could not walk, none of that, and now she is."

### Concentrated Time with Each Child

E.F. stated that the positive aspect that she saw was "definitely more concentrated, professional time with my child. The groups are smaller. The improvement, too. Both of my kids, the problems that they've had are improving."

H.I. had a different view than those previously described. She said,

I think it's that the law is behind me. That he has rights, and whether they want to follow them or not, they have to; and whether they like me or they like him really isn't an issue. Even if they don't think he needs them, if the testing says he needs them, then he needs them, and he needs to get them.

### Legal Rights of Parents and Children

H.I. further explained that she had to force the issue of the special education law when a teacher refused to modify her son's materials even though the IEP stated that this must be done.

Along the same lines of H.I.'s comments on modifications, F.G. stated,

Well I know that having the work modified takes pressure and stress off of the child[ren], and it allows them to be able to take what they have and work with it. I was glad to see that. He was coming home initially spending three hours a night in homework, because he would come home with everything.

## Student Progress

N.O. and N.O.2 stated in their own way they also were pleased with their son's progress because of the modifications and also increased support from the special education teacher. N.O. explained,

Well, the thing I think about is when he was in regular classes, we kept hearing, "We can't cater to your child," and although I didn't want him catered to, I kind of felt like he needed a little, maybe five minutes a day, somebody. . . to say "Have you got your homework?" While he's been in special ed. we've had that. "Do you have your math book? Take this paper with you so you can fill it out." He's got somebody like [name] who [takes] just a few minutes a day [to say], "You've got to take your math home. You've got to do it or you get an 'F'; take it."

I.J. pointed to another positive aspect of having her child receive special education services. She stated that the assistants in many of the special education classrooms were positive. She said, "It is that basically they have the helpers; I feel like each child probably has more right there most of the time."

M.N. and his wife are so pleased with their son's teacher that he said she was actually the most positive aspect. Q.R. touched on a point not mentioned as a positive aspect. Q.R. stated, "I think it's built his self-esteem, 'cause I think he realizes he's not the only child with a disability. That there's just a wide range of disabilities."

## Negative Aspects of Special Education

Three areas were identified by the parents interviewed as negative aspects of having their child in special education. They were the stigma of being in special education, leaving the regular classroom, and the lack of communication from school professionals.

### Stigma

More than 50% of the parents said that the stigma of being in the special education program, at all, was negative; that the perception of just being different indicated that something was wrong with them. Of the parents who did indicate that the stigma of being labeled as being

in a special education program, there was not a distinction between disabilities and the age group. Hallahan and Kauffman (1997) stated that labeling a child could carry negative connotations as well as make the child feel different. Parent advocates have suggested using no labels at all. The use of labels many times takes precedence over recognizing individuals themselves.

B.C. was one who said her negative aspect was “the stigma” and provided an example:

Our oldest daughter gets really mad if we are out somewhere and people stare at [name]. She’ll say, ‘What are you staring at?’ So they say she’s retarded. And she says, “No, she’s not. She’s no more retarded than you are. She knows what’s going on around her. She just can’t tell you.” It’s just the stigma.

E.F. said at the moment she could not identify a negative aspect on which to report; but if her son stayed in special education classes, she knows a “stigma” will be there for him. She continued to say, “Not only being in a small school where everyone knows who’s in resource, but having a brother in CSA.” Children with Special Abilities (CSA) is the program for gifted students in the county.

F.G. said that her son is worried the other children in school will find out he goes to a special education class. She continued by adding,

That’s an issue. I remember back when I was in school about the classroom ‘special education.’ You knew the kids that went in there, and they were the dumb ones, and they got made fun of. They are more discreet now. He’s still very worried that other kids are going to find out.

H.I.’s son is in a similar situation as F.G.’s son. H. I. reported,

I think basically that he thinks he’s dumb or stupid or he can’t read like everyone else can, and that bothers him. And that’s why I think he decided not to go out to classes in sixth grade. Even though the bell rings and they’re all in the hallway, and I don’t know if anybody really knows which door you go into, but he didn’t want to go into that door. He wanted to go into the regular room and go where his friends were.

Fortunately things have worked well for H.I.’s son this past school year. H.I reported that the majority of her son’s teachers were willing to modify the program enough for him to succeed.

J.K. continued the examples of stigma being the negative aspect of being in special education. She said, “You get labeled. And children shouldn’t be labeled because they’re not jars of jelly. And people see the label, and a lot of people freak out. That is the worst negative.”

Q.R. explained her thoughts of the negative stigma of special education. “The stigma,” she says, “of being in special ed. and being taken out of the classroom cause the other kids to think, ‘Ha-ha you’re not smart enough to be in here with the rest of us. You’ve got to go to the dumb class.’”

K.L. was the parent who had many issues of her own about being accepted. She rambled about many things not related when asked to express her thoughts of the negative aspects of having her child in the special education program. Finally, when the researcher analyzed what K.L. had said, it looked to be more about the stigma of having her child in special education classes. She said,

That they’re separated from the other kids. That they’re picked on. I know all the special ed kids are picked on, because I know who some of his friends are, and they tell me that they’re picked on. Maybe they don’t tell their parents that, but they do tell me that. They hate it. [Name] begs to be out of resource every year. He’d rather just fail.

### Leaving the Regular Classroom Setting

One of the parents expressed displeasure by stating that her child had to leave the regular classroom in order to receive special education services. C.D. mentioned, “Well the only thing I felt negative about was taking them out of the classroom, from their regular class, like for math and stuff.” C.D. noted that her child was being taught the subjects in the special education class that were being missed in the regular education class.

### Paperwork Issues

Another parent did not like all the paper work that went with having a child in special education. G.H. said simply, “The paperwork. Just that you can never understand it.” Still another parent who volunteers regularly in her children’s schools mentioned that there was not as

much parent participation in special education classes as there were in the regular education classes. R.S. explained,

Because there are so many assistants and stuff in the special ed. rooms, they don't encourage parent participation in the class; and parents probably disrupt them because they don't have the attention span. I know that would be hard, but I'm chomping at the bit to be in my kid's room.

### Lack of Communication

One parent mentioned that she would like to have more direct communication with the special education teacher. D.E. explained that she would like more parent-teacher conferences with the special education teacher instead of the one meeting at the end of the school year.

When the researcher asked if she had tried to contact the teacher for a meeting, she replied that she had not. D.E. continued to express,

I think if they would communicate with the parents and the students together, we probably wouldn't have as much trouble in schools as we are having. If they would keep us informed better than what they have been doing.

D.E. further stated that a good solution would be for the teachers to communicate with the parent before grade cards come out instead of after.

### Educating the School on Communicating with Parents

Parents were asked to elaborate on what they would suggest to the school professionals in order to enable them to communicate more effectively with parents. Most parents reported wanting more consistent communication and more clearly stated communication from the school professionals.

### Precise Communication

G.H. and many other parents just wanted to be spoken to directly about their child and to receive thorough information. D.E. stated that if the school professionals would communicate

with the parents and their children together, it would remedy much of the trouble in schools.

G.H. said directly, "Talk to them, [parents] just tell them." She continued,

Don't give them the papers. I mean I know the papers have to be signed, but there's no reason for all of that. Just tell them bottom line, that these are your rights. This is what we can do for you.

I.J. wanted much the same as G.H., direct communication. She said,

When they have the m-team meetings, tell them everything. I mean if the child is retarded, say your child is retarded. I didn't know that was exactly what was wrong with [name] until February of this year, when we had that m-team meeting.

N.O.2 requested that they would like to know everything up front. He said,

My first suggestion would be to sit down and explain what you are getting into and explain it with as much detail as possible. All the options, everything that could happen to your kid. Just communicating is the biggest thing.

E.F. and G.H. both said the paperwork is very important to the process of having their child in the special education program. However, E.F. states,

The old 'Keep It Simple Stupid' (KISS) method. You need documentation. If it's something that's prepared and it's a standard form, you've got to read forever to get to the meat of it. You find yourself skipping to the bottom of it and signing it and going, whatever. The bare minimum. It turns into people like me, not reading it, just signing it, so we know less than we would have known if we kept it simple. I understand that we can't change it because some fool would find a loophole and sue them for a bazillion dollars.

L.M. stated that she has felt isolated, that she was the only parent who was calling the school requesting communication on how her child was performing. She said,

We felt that way at times. Mostly because of the input we get back from our requests and things. But communicate with us period. You know, keep us updated, I mean if they don't think we're interested, then that's not true. We love the notes home.

F.G. had a comment that may help in the initial communication between parents and school professionals. She proposed that at the beginning of the school year, the school should send out a survey to parents and students to get information and gain suggestions about the school and improvements needed.

R.S. stated she needed further information about the papers that are sent home at the end of the week. R.S. explained, "A progress report at the end of every week to say he did *this* this

week. This is what we pushed on this week. He really excelled here. He didn't do so good here." She continued, "You check all these papers that come home that they've colored and this and that; like, okay, when he colored this, did he know this was *red* when he used it?"

H.I. had a suggestion that may help R.S. and F.G. in their situations. She suggested daily e-mail for the parents who have access to it. K.L. also had comments about needing somewhere for parents to communicate openly and anonymously; this may help in this area as well.

### Treat Special Education Class Same as Regular Class

A couple of parents requested that school professionals treat the special education class just as they would a regular class, especially with parent participation. A.B. explained that her perception of the first thing that happens when a parent enters a regular classroom during the open house at the beginning of the school year is that the teacher wants the parents to know other parents so they can continue to help through out the school year. A.B. explained that the opposite is true in the special education class. She said, "Instead of isolating special ed. parents, we're the ones that need to get together. I think that there is this huge fear that we may figure something out. If there's nothing wrong, then what does it matter?"

### Educating Parents on Communicating with the School

Parents were also asked how they would educate parents regarding communicating with school personnel. All the parents united with the response of keeping in contact with the school through phone calls, notes, and visits. Each response differed slightly as to why and how parents should maintain contact. Another response mentioned by two of the parents was to educate yourself regarding your child's disability and the special education process. Parents admitted their support and involvement is important. Parents also mentioned lack of transportation kept them from being more involved, and suggested that other parents may have the same problem.

F.G. seemed to have had negative experiences communicating with the school. Her comments on how to educate parents were more on the same negative tone. She stated,

It seems to be that most of the parents that will actually stand up and come in and have a concern; you see, it depends on the initial feedback you get, and sometimes it 's unfortunate and it doesn't work, and you immediately shut down. So I don't know.

B.C. was one of the parents who suggested that to communicate in some way with the school was essential. She said, "Be more active, understand what your child's needs are and communicate them to the school, because if the school is doing something to teach your child and you don't follow up at home, that child's not going to learn." B.C. noted the school was doing a good job of communicating, but parents needed to get more involved in their child's education.

C.D. agreed that schools communicated well and tried to get parents involved, but too many parents were not active in their children's education. She stated that some parents, like her, had a problem with transportation. Her family has only one vehicle and her husband drives it to work daily. T.U., P.Q., and I.J. are other parents who do not have the transportation to go to the school as they would like. I.J. explains that a phone call can make a difference, too. She said, "Call and say, 'Hey. I'm not liking this,' or 'but can we get together a certain time and talk about this?' or whatever." She continued by saying, "I feel that a parent who is more involved in the education of their children--it's better on the parent and the teacher."

A.B. also worried about parents not taking an active role in their child's education. She said,

The problem you are going to hear, that they believe with all their heart, is that once they get their children to school, the school is taking care of everything. It's like pulling teeth to get parents to realize that if you don't come to the m-teams, you don't write the IEP, you don't participate, your kid's got a babysitter for the day. That's what they get. They don't know what you need to be working on. They don't know what this child is or is not doing at home.

A.B. suggested,

Maybe tap it into certain services somewhere that say unless you come review this, we can't continue. I think that if three homework papers go home and don't come back, then

parents ought to be called. Because you are not going to get a third grader to sit down and just love to do homework. Parents need to realize that they need to live up to their responsibilities and they will learn so much more.

L.M. and her husband both stated that parents must communicate with the school. They said,

Just communicate with them. Find out as much as you can and ask as many questions as you can. Don't let it slide if it bothers you. When you ask why and they give you an answer, challenge it. What are you basing this on? What do you have to support that?

M.N. and his wife made a similar comment. They said, "Go to them, and talk to them, and lay it all out on the line, and get the answer you want. Don't hold back. Don't be scared to talk to them, 'cause they don't bite."

T.U. agreed with L.M.'s and M.N.'s comments. She said,

To call and keep up with them. To keep up with the school. Ask the teacher how your child is doing, Ask the therapist what's going on in speech and in physical and occupational therapy. How long are they doing it for, and how long is the child actually doing it themselves?

H.I. commented on being knowledgeable about a child's disability and being prepared. She stated, "Be prepared, do some reading, or even ask them to give you something on the specific disability your child has." She continued to explain that at her initial IEP meeting, a school professional suggested she watch a specific video. She also mentioned she had gone to a support and training workshop for parents who had children with disabilities. She noted it was a beneficial workshop.

J.K. agreed that knowledge of a child's disability was important. She said, "Learn everything you can. If you find out your child has a disability, get any information, go to the library, ask people--basically so you'll know what they're talking about."

J.K., D.E., and K.L. were three parents who pointed out that parents needed to communicate with one another in something similar to a parent support group. J.K. suggested to parents,

Basically they need to learn everything they can. Try to get a support group going in each school. Find out what the weaknesses are and have a meeting like a PTA meeting, but with the special ed. aspect of it.

E.F. commented on parent support groups as a positive aspect but had concerns. She said that the meetings many times are during parents' work hours, and that the parents who need to attend the support group meetings are the ones who never will come, because they are not involved parents and never will be.

G.H.'s simple comment was "just get involved." She further stated that she did not know how to get parents to do it. One suggestion G.H. did have to get parents involved was to have events that their children would be involved in, such as a play, or musical, or athletic events.

R.S. had an idea to help get parents together and gain new information. She suggested the special education department put together a handbook for parents of children with disabilities who are in the initial phase of involvement with special education and for those parents moving into the county with children with disabilities. R.S. said,

Parents who have not been involved don't know what questions to ask. So get a group of parents together and do the "what ifs" and "why fors" and you know, "We do this because... it's done this way because... this is why. . ." A layman's term book.

She continued to suggest,

If you have a question, take your handbook; you think of a question that's not in there, write it down. At the end of the year, hand it to the teacher and say, "I've come up with some more." Make a copy of it and put it in the back of the book.

Q.R. stated that when she finally stopped being in denial of her child's disability, she came to a realization for herself and for other parents. She said,

There were a lot of caring people out there and the availability of the education is there, but God placed the life of that child in whatever state it is, in our hands as parents. It's up to us to seek out the help that that child needs in order to excel and be a productive adult.

### Overview

This chapter included the findings of the interviews with 20 parents who had children with disabilities. Although each parent gave different responses, there were many

commonalities. Although each parent considered himself or herself to be involved in the child's education, the degree of involvement was different for each as well. The degree of knowledge that each parent had on the process of special education and knowledge on his or her child's individual disability was varied.

Chapter 5 will include an analysis of the data, a summary of the study, conclusions, and recommendations for practice and for additional research.

## CHAPTER 5

### SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

#### Summary

The subject of parental involvement is a concern to both general and special educators. Recent changes in IDEA have brought this concern to the forefront for those involved in special education. Parents have shared decision-making rights and responsibilities and must be able to participate in all aspects of the child's education (Turnbull & Turnbull, 1997). In order to facilitate effective participation, parents must be provided with information and assistance, and must become members of the multidisciplinary team in the truest sense.

The purpose of this study was to explore the thoughts and experiences of parents of children with disabilities regarding the initial special education placement of their children and the ongoing communication between parents and the school. A focus group of representative parents was convened in order to determine the most critical areas of concern for parents of students receiving special education services. As a result, this study was guided by four research questions. The first sought to determine the parents' understanding of his or her child's disabilities. The second explored the parents' experiences when he or she had questions and concerns that required a school professional to answer. The third attempted to determine if the parents' involvement practices with the school and school professionals since the initial placement of his or her child with special education services had changed. The final area of inquiry was to determine if communication between the parent and school professionals had changed during these initial years. Answers to the research questions were sought by interviewing parents who were in the initial years of having their children receive special education services.

This study was completed with the intent of providing a clearer understanding of parent concern, knowledge levels on special education issues, changes in the involvement of parents with school professionals, and to begin to assess whether communication between these parents and school professionals had been effective in helping parents understand their children's disabilities and the services available. The information obtained has the potential to assist school personnel in making adjustments to policies and practices used during initial placement IEP meetings in order to increase the effectiveness of the process.

Key informants, parents of 20 students in a rural county in east Tennessee, ranging from preschool to sixth grade were interviewed. A general interview guide approach assisted the researcher through the interviewing process. The parents were selected by the technique of purposeful sampling using the strategy of typical case sampling.

## Conclusions

### Degree of Understanding Child's Disability

In assessing the degree of understanding of their children's disabilities, it was found that the majority of parents had developed an understanding dependant on the information obtained through the school professionals and by their own means. Although each parent could explain what his or her child's disability was, there was a wide range among the participants in the extent of knowledge about the disability and in terms of services that were available. The five parents whose children were diagnosed at birth expressed a much more thorough understanding and often a higher level of initial acceptance of the disability through the use of information, resources, and supports that were provided as soon as the disability was recognized. A.B. explained that her grandson had Cerebral Palsy. She was able to tell of his abilities and limitations. T.U. told of finding out her daughter would have disabilities while she was still pregnant. B.C., who already knew a great deal of information on her daughter's disability, had to

explain to the school professionals when she moved to a new state what her daughter needed, such as feedings, changing, and care from a nurse.

The six parents who were informed of their children's disability before the age of five could also tell a good amount of information on their abilities. The 11 parents whose children were identified before school age expected more from the school professionals when they came to the first IEP meeting. Early intervention programs had already been working with these children; therefore, the parents expected the same care and treatment from the school. One example is from parents L.M. and L.M.2, who found that the same care is not always continued even when they asked for more hours of therapy. These parents had been used to one-on-one therapy with their child and particular devices being used. In schools with so many children, most did not get one-on-one therapy or the use of particular devices.

The nine parents with children for whom their disability was identified in school expressed much more initial frustration. These parents had a different view of the services to be provided. All of these parents could provide information about what their child's disability was and the services they were receiving. Four of the nine parents were only able to provide basic information, and it was clear to the researcher that they did not have a thorough understanding of what the disability meant or what could be done to help. The nine parents of children identified at school age did not know until later what information they needed during the initial IEP meeting. It is interesting to note that for some parents, the diagnosis and beginning of special education services brought about a sense of relief for both the parent and the child. G.H. stated that she was relieved to find out it was not something she had done, like spending more time with her older sons. H.I. said that she and her husband were glad they were going to get assistance for her son.

### Parents' Experiences When They had Questions

After the initial IEP meeting, 80% stated they still needed more information. The information needed was on their child's individual disability and how to help at home. Information on the process of identification and implementation of the IEP was another common need. Four parents stated they did not need additional information and these parents were not highly involved in their child's education. Of the parents who needed additional information about their child's disability or special education procedures, 35% addressed their questions and concerns to others outside the school such as physicians or support personnel. Parents who had received support from others in the form of encouragement or advice reported being very grateful for that support, and the information and support enabled them to be more specific in their questioning of the school personnel.

Regarding their experiences as they had questions and concerns that required information from a school professional, parents reported that many went directly to a teacher or administrator of the school. Eighty-five percent of the parents reported that they were pleased with the results of the inquiry, whereas only one parent reported that his or her attempts to seek information resulted in a negative outcome. Two parents stated that they never expressed a concern or suggestion to the school professionals. C.D., one of the two, had been a student who received special education services when she was in school. The other, S.T., said, "What they would suggest--that was what I was thinking of and they was all at each meeting." Of the 85% who did express concern, 25% were not resolved until personnel changes took place, whether this was at the end of a school year or the change of schools. The underlying factor for concern from parents with the school professionals is the desire to have the best education and educational experiences for their child.

### Parent Involvement since Initial Placement in Special Education

The next area of inquiry attempted to determine if the parents' involvement in the educational process with school and school professionals since the initial placement of their child in special education services had changed. The parents who had children identified at birth as having a disability and those children who were identified before the age of five reported being actively involved in their children's programs from the beginning. Several of those parents reported being disappointed with the programs offered by the school and the information provided by school personnel as they differed so greatly from services and information they had received prior to school enrollment.

Six of the 20 parents reported that the peer group interaction provided for their children was a very positive factor in their special education experiences. One fourth of the parents stated that the most positive factor was seeing their child increase the skills where there were weaknesses. However, the stigma of being in special education was frequently mentioned when participants were asked about the negative aspects of special education. It was mentioned more frequently than communication problems, paperwork issues, and involvement issues. Most parents were mainly concerned with how their children felt about themselves and how the other children in school perceived their child. One of the parent participants in this study, Q.R., stated that as part of the curriculum it needed to be incorporated to teach children how to treat people.

Parents who have children with disabilities that were identified after entering the school system described a more mixed view of their thoughts toward school professionals and their involvement in school. One third of the parents stated that they had no problems with the school personnel, and that they were involved as much as they could be. One fifth of the parents indicated that transportation was a problem that kept them from being more actively involved in their child's school experience. Others reported that they have had some conflict with various school professionals concerning the appropriate educational programs for their children. Conflict ranged from the initial certification stage and the actual identification of the specific

disability to the degree of service that was proposed. Of the parents who reported conflict, all indicated that their involvement in the process had increased in order to ensure their child was being treated appropriately. As stated previously, in most cases the conflict was resolved in a satisfactory manner.

#### Communication Changes Between Parent and School Professionals during Initial Years

With regard to the final research question, to determine if the communication practices between the parent and school personnel had changed during the period of time the child had been provided special education services, there was general agreement that communication had, in fact, increased. A primary reason was that all of the parents indicated that they had become strong advocates of communication between parents and school personnel, whether through notes, telephone calls, or personal contact. Parents agreed that both parents and school professionals must communicate in order to benefit the child. Even though there was agreement that communication between parents and school personnel had increased since the initial placement of their children in special education programs, parents asked for more communication, clearer communication, and communication on a regular basis. Specifically, three parents recommended that support groups for parents with children receiving special education services would facilitate more effective communication through the sharing of needs, successes, and ideas. One parent reported the need for a parent handbook for those whose children are initially placed in special education programs. No other specific suggestions were made from parents on how to improve communication and involvement other than the most common practices of field trips, school plays, and parent-teacher conferences.

Parent participants in this study reported being pleased with the services their children were receiving, as well as with the progress their children were making. However, issues of communication seem to be the primary area of need requiring improvement. Giving parents the needed information about their child's disability and the process of special education will help in

strengthening the education of the child. Knowledge is essential in helping the parent to feel secure in addressing the needs of the child. Many parents will listen to the school professional and not question his or her knowledge and wisdom, but if they work as team for the benefit of the child, the possibilities are unlimited.

Parent involvement is crucial in keeping the educational program functioning in a way that provides maximum benefits to students and their families. Parents who are involved help propel the school professionals to greater heights by gathering new information or techniques to help teach the child who has a disability. Knowing that the success of a child's education is dependent on the involvement of the parent and the school professional working together should keep them striving for the ultimate level of success.

#### Recommendations for Practice

The recommendations for professionals and parents are the result of an analysis of the insights of parents who participated in this study, and the researcher's thoughts in synthesizing those data.

#### Recommendation #1

The researcher's original considerations before the interviews were that a parent support group would be the answer for parents to express their thoughts and concerns. Henry (1996) stated that one approach to getting parents actively involved in their children's lives is through parent advisory councils. He said these councils have become established as a result of the site-based management or decision-making movement. Parent advisory councils or parent support groups could be a productive tool in helping parents of children with disabilities have a more effective voice. One parent stated that such a support group may be more productive during the initial years of special education services, helping parents learn the about system, their rights, and procedures. The parent indicated that parents who had been dealing with special education

issues for a number of years had learned how to work within the system. A.B. agreed that a parent support group was needed. She said that it should be used as a tool for gaining information and a communication tool for the parents, not a “gripe session.” She noted, “We can muddle through what are legitimate complaints and what are not.” A parent support group can be a good starting place for parents just introduced into the special education program to gain knowledge and insight. A parent support group could also serve as an effective forum during which concerns and needed improvements might be discussed and possible solutions proposed.

A parent support group could possibly be most effective through each individual school. The support group would need to be conducted by a parent with prior knowledge of the special education process and one who could communicate with the school professionals and parents on issues presented. The support group would need to initially educate parents on parent rights and the IEP. From the initial knowledge of the process, each parent would need to gather and share information obtained about specific disabilities. These suggestions have been provided through the comments made from parents interviewed.

### Recommendation #2

One parent made a second recommendation. R.S. suggested the preparation of a handbook for parents whose children are in the initial years of special education services or parents of children with disabilities whose families have just moved into the area. She explained,

Get the parents together, write out a handbook on most asked questions, when you’re a new parent coming in and you’ve got a three year old, you don’t know what to ask. You’ve got this book with all these formal words and questions. So get a group of parents together and do the "what ifs" and "why fors" and you know, "We do this because... it's done this way because... this is why." A layman’s term book.

The special education department should develop this, R.S. explained, like each school develops its own school handbook. Deitz (1997) stated that handbooks are one of the most effective forms of communication between parent and school. This is an excellent idea because

the handbook is something that can be given to parents during the first IEP meeting for them to read over and get immediate answers to questions they may not have had time to ask. The handbook may also help them understand the parent rights booklet and copy of the IEP that they received at the meeting.

### Recommendation #3

A third recommendation to the school professional would be to give parents access to area services available, such as parent counseling and training centers. It was obvious when speaking with many parents that they were truly unaware of much of what their child's disability involves. They also did not realize what they could ask for or what services were available. Recent reauthorization of IDEA added § 300.24 (b) (7) that is the addition of parent counseling and training through "related services" as written in each IEP. This section is to help parents acquire the skills to help in the development and support of the IEP for their child. The centers must also assist parents in understanding and how to use the availability of procedural safeguards and dispute resolution, such as the mediation process.

Of the parents interviewed, none had come to the point in any disagreement with school personnel that required mediation. However, one parent, H.I., mentioned that she had attended a meeting of a parent counseling and training center workshop and that school professionals had not provided information about mediation or workshops. A.B. asked that if everything was going the way it should be going, then why not provide the information needed to the parents?

### Recommendation #4

The fourth recommendation is to keep parents informed of how their child is doing. In most cases reported, the minimum required reporting was being fulfilled. However, of the parents interviewed who discussed the progress reports, few could understand the wording or the markings. G.H. expressed this when she said, "The paperwork blows people away. The

paperwork is worthless. It's worthless because no one reads it, you don't understand it." As indicated in Chapter 4, parents requested more communication, more clear communication, and more frequent communication. They want to be told what is going on regarding their child's progress, what did he or she learn for the week, and how can the parent help. The minimum required reporting does not provide sufficient information.

Deitz (1997) stated that the key to quality communication is to vary the method of delivery. The goal is to convey information. She continued by saying that individual phone calls from the teacher to the parents letting them know of a problem or to share positive information was also effective. Henry (1996) provided five methods of developing and maintaining communication between parents and school professionals. They are informal contacts, telephone contacts, various forms of written communication, parent-teacher meetings, and home visits. Participants in this study and the literature agree that communication needs to be systematic, frequent, and varied.

#### Recommendation #5

Related to the previous recommendation, the fifth recommendation is to train school professionals in the proper techniques of positive communication. Fuller and Olsen (1998) stated that teachers have not been formally trained in ways to have two-way conversations with parents. Many of the reported aggravations of parents in dealing with the school are the perceived attitudes of the school professionals that they have all the answers and they know best. N.O. explained that by the time she realized what behaviors her son was exhibiting, it had been approximately six weeks into the school year during the middle of an IEP meeting. She said,

We were hearing things for the first time. It was like, we haven't moved. He's been here everyday; why haven't you sent a note saying call me, or jotted me a note? And their thing was, we don't cater to your child.

She continued by saying, "That's fine I'm not asking you to cater to him, but then you need to be telling me about it." Helping teachers, teacher assistants, principals, and other school personnel

to be more effective in communication skills would benefit all parents and students, not only parents of students in special education.

#### Recommendation #6

The sixth recommendation is that school personnel join with parents, their children, and the community in removing the stigma that often accompanies being in special education.

Labels that are necessary to the process are often misinterpreted and have a negative effect on children and families. The labels help in identifying disabilities and classifying conditions, but labels do not mean that the condition or disability is the child. Being sensitive in the description of individuals with disabilities can make a great difference here. Even small things matter.

Parents initially are dealing with their own emotions, as indicated in several interviews, of denial, confusion, sadness, and fear. Even though many parents in this study did not describe an emotional response when they first were told of their child's disability, it was apparent as interviews continued, that many experienced heightened emotions. Hornby (1995) and Simpson (1990) reported that parents who learn that their children have a disability often experience the same stages of emotion as parents who experience the death of a loved one; shock, denial, anger, sadness, detachment, reorganization, and finally, acceptance.

The addition of having to deal with the stigma of the label that their child receives from being provided special education services is often difficult. Greenspan and Wieder (1998) suggested a different approach to assessment and intervention. Instead of labeling, they suggest focusing on each child's unique profile of biological challenges, family patterns, and developmental levels. They further stated that labeling makes it too easy to make predictions and assumptions about what a child can or cannot accomplish.

### Recommendation #7

The seventh and final recommendation is to keep parents involved in all aspects of the school program. Parents will go to the schools for anything that their child is involved with, such as a performance, art exhibit, or sporting event, according to parents G.H. and E.F. Schools have not adequately involved parents in the special education process, resulting in a lack of parent interest that can further be perceived as contributing to problems of the child (Paul et al., 1997). Many times parents note they feel awkward or excluded when dealing with school professionals (Cullingford, 1996).

Many parents interviewed did state that they felt awkward going into the school and that they felt they were intruding. In spite of those awkward feelings, most parents indicated that they perceived themselves to be involved in their child's education. R.S., who regularly volunteers in her children's schools, stated that parents are not asked to participate in their child's special education class, possibly because of the additional help of teacher assistants.

### Recommendations for Further Research

Green and Shinn (1995) reported that most studies showed parents were satisfied with their child's special education program, but many of the reasons for this satisfaction had not been researched. Based on the results of this study, the field would benefit from additional research in several areas. This study could be modified and used to plan additional effective research, looking more closely at the specific needs of the groups of parents and students used in this study. Those who have recently had their first experience as parents of students with special needs, and whose children have been receiving special education service for many years may have very different sets of needs. The population of this study was too limited to be able to explore those differences. Parents whose children were diagnosed with a disability at birth may also have significantly different needs than parents whose children's disabilities were identified early in their school careers, and different still are those whose disabilities were identified later in

their school careers. Again, the scope of this study was too small to be able to explore those differences. Parents whose children experience different kinds of disabilities may also have different needs. Parents of children with multiple physical disabilities, for example, may have very different needs and expectations than those of children with learning disabilities or processing disorders. Research to determine those needs and the most effective means of supporting those children and parents is recommended.

Communication was a consistent theme expressed throughout the interviews. Research to determine the most effective means of communication between parents and school personnel is recommended. Research to determine the effectiveness or levels of understanding of written documents currently in use could also be initiated. Instruments are available to assess basic things such as the reading levels of documents. They could be used to examine materials currently in use, to ensure that the majority of parents could read and understand them.

Another frequently mentioned concept is that of support groups for parents of children with special needs. Diverse formats and materials could be investigated in order to determine their various levels of effectiveness.

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## APPENDICES

### APPENDIX A

#### Parent Letter

Dear Parents,

I am the assistant principal at Seymour Intermediate School. I am also a student at East Tennessee State University working on my doctorate in education. My background of teaching experiences has all been in special education. This led me to the subject of my dissertation that is about parents of children with disabilities and their concerns and attitudes.

I need your participation to assist me in focusing the direction of my research. I am inviting you to be a part of a focus group that will consist of a small group of parents who have children with disabilities. I will be asking you questions about your thoughts, experiences, and issues involved in special education. The information I get from you will be only for my use in helping to pinpoint areas of concentration for my dissertation.

The group will meet May 10 at 4:30 p.m. at the Special Learning Center. It will take approximately an hour and a half. I hope that you will be able to attend. Your thoughts and ideas will make a great impact in the direction of my dissertation.

Thank you,

Susan Latham

## APPENDIX B

### School System Permission Form

Director of Schools  
County School System

Dear Director of Schools:

I am a doctoral student at East Tennessee State University. My dissertation deals with the relationship between parents of children with disabilities and school professionals. The purpose of the study is to explore the concerns and experiences of parents of children with disabilities related to the initial special education placement of a child and the ongoing communication between parents and the school.

Parents will be interviewed to gain better insight of parental understandings of their child's disability, the experiences parents have with school professionals, attitudes parents have concerning special education in the beginning years of service, and communications of parents and school professionals during these years. These interviews will take place mainly in the parents' homes or in an agreed location.

I am seeking your approval to randomly select these parents to interview. These parents selected will be in the initial stages of their child's services in special education.

Please contact my doctoral advisor, Dr. Russell Mays, or me with any questions or added information. Dr. Russell Mays's telephone number is XXXXXXXXX and my telephone number is XXXXXXXXX.

Sincerely,

Susan Latham  
Doctoral Student

## APPENDIX C

### Informed Consent Form

East Tennessee State University

#### INFORMED CONSENT

Principal Investigator: Susan L. Latham  
Title of Project: Parents' Perceptions of Communication Practices With School Professionals During Initial Years of Special Education Placement

This Informed Consent will explain about a research project in which I would appreciate your participation. Please read this material carefully and then decide if you wish to be a volunteer. There is no pressure in any way for you to participate in this research project.

PURPOSE: The purpose of this study is to uncover the feelings and reactions of parents of children with disabilities to their communications with the school system. Each parent will be interviewed in depth regarding their personal experiences with the school system pertaining to their child's educational needs.

DURATION: The interview will only take approximately one to one and a half-hour of your time. This will allow you to carefully answer each question and to share any additional information you wish.

PROCEDURES: The instrument in this study is the interview guide. This instrument will be used by the Principal Investigator to lead the interview process from one question to the next. The interview will be audio-taped with the permission of each participant. Notes will also be taken. Fictitious initials will be used in place of each participant's name when reporting the information given during the interviews.

POSSIBLE RISKS / DISCOMFORTS: Feelings of discomfort or unease may only be experienced when speaking or thinking of unpleasant or difficult events. Any potential benefit to the participant would arise from that individual's reflections upon the questions answered. The benefit of the research project will possibly be to assist school systems in making adjustments to policies and practices during the initial period of placement of a child in the special education program. You may refuse to answer any question that makes you feel uncomfortable. No answer in the interview will be manipulated in any way. Participating in this study is strictly voluntary, and you may quit at any time. All information attained during this interview is strictly confidential.

Subject's Initials \_\_\_\_\_

Principal Investigator: Susan L. Latham  
Title of Project: The Relationship Between Parents of Disabled Children and School Professionals – A Qualitative Study

CONTACT FOR QUESTIONS: If you have any questions or problems, you may call Susan Latham at XXXXXXXX or Dr. Russell Mays at XXXXXXXX. You may also call the Chairman of the Institutional Review Board at XXXXXXXX for any questions you may have about your rights as a research participant.

CONFIDENTIALITY: Every attempt will be made to see that my study results are kept confidential. A copy of the records from this study will be stored in the Educational Leadership and Policy Analysis Department for at least 10 years. The results of this study may be published and/or presented at meetings without naming you as a participant. Although your rights and privacy will be maintained, East Tennessee State University Department of Educational Leadership and Policy Analysis have access to the study records. My records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above.

VOLUNTARY PARTICIPATION: The purpose of the project, the demands, risks, and benefits of the project have been explained to me as well as are known and available. I understand what my participation involves. Furthermore I understand that I am free to ask questions and may withdraw from the project at any time. I have read, or have had read to me, and fully understand the consent form. I sign it freely and voluntarily. A signed copy has been given to me. Your record of participation in this study will be maintained in strictest confidence according to current legal requirements and will not be revealed unless required by law or as stated above

\_\_\_\_\_/\_\_\_\_\_  
SIGNATURE OF VOLUNTEER/DATE

\_\_\_\_\_/\_\_\_\_\_  
SIGNATURE OF PARENTS OR GUARDIAN/DATE

\_\_\_\_\_/\_\_\_\_\_  
SIGNATURE OF INVESTIGATOR/DATE

## APPENDIX D

### Interview Guide

1. When did you first learn of your child's disabilities?
2. Describe your initial contacts with those working in special education.
3. Tell me about your first M-Team meeting (now called IEP team meeting).
4. How did you feel during this initial meeting? Why did you feel this way?
5. What kind of information did you need, either before or after, that initial M-Team?
6. Where did you get the information needed to best address the needs of your child, from school professional, physicians, self-study, other parents, etc.?
7. When you expressed concerns about your child's progress, offered ideas, or shared new information, what was the response of those from the school system?
8. What do you think about the special education services provided for your child?
9. What do you see as being the major positive consequences of being in special education?
10. What do you see as being the major negative consequences of being in special education?
11. If you could educate the school on how to better communicate with parents, what would you suggest?
12. If you could educate parents on how to better communicate with the school, what would you suggest?

## APPENDIX E

### Audit Agreement

#### MEMORANDUM

TO: Jennifer Laster  
FROM: Susan Latham  
SUBJECT: Auditing Procedures for Research Project  
DATE: November 6, 2000

I appreciate you agreeing on November 1 to proceed with the auditing of the research I am conducting for my dissertation. I appreciate your commitment to this project.

As written in Lincoln and Guba (1985), Naturalistic Inquiry, trustworthiness must be found in the findings of a qualitative study. In this study credibility must be identified through three techniques of prolonged engagement, triangulation, and member checking. Triangulation will be established through interviews, peer debriefing, and maintenance of a journal of observations and reactions.

Transferability will be identified in this study through the use of thick description from the interviews.

Finally, dependability and confirmability will be identified through the use of an audit. This is where you will identify the source and method of raw data, diagnose the data reduction and reconstruction, process the notes, inspect the material relating to the intentions, and verify original sources.

The audit trail components that I will be giving you include: audio cassettes of the interviews, computer disks of the transcripts, hard copies of the transcripts, my journal (containing field notes, permission forms, and scripted throughout the interviews, and personal notes). Also, included will be Chapter 4 of the dissertation.

Please call me with any questions or concerns as you are conducting the auditing process. Thank you again for your undertaking of this project.

## APPENDIX F

### Audit Findings

TO: Susan Latham  
FROM: Jennifer Laster  
SUBJECT: Audit Report  
DATE: February 20, 2002

I have completed the audit on your dissertation. I found that trustworthiness was established in your qualitative study.

Credibility was established through member checking analysis and your journal notes. Also, the peer debriefing was successful through your accurate account of the experiences during the interviews and through your decisions of the conclusions and recommendations.

Transferability was established through the thick description of parents interviewed and their quotes attained during the interviews. The changes you made to the descriptions of the parents helped to avoid researcher bias.

Dependability and confirmability was established through the audit I conducted. The results of the study were verified in relation to the interview guide. I listened to the audiotapes of the interviews and verified your deductions and analysis of the coding of transcripts.

Through the auditing process, I verify that all accounts of your reporting in the study are accurate.

