

PARENT NEEDS ASSESSMENT:  
A TOOL TO SUPPORT THE TRANSITION INTO SPECIAL EDUCATION FOR  
CHILDREN WITH AUTISM AND THEIR FAMILIES

By

Korin J. Matter

A Project

Presented to  
The Faculty of Humboldt State University

In Partial Fulfillment  
of the Requirement for the Degree

Master of Arts

In Education

May, 2006

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Approved by the Master's Project Committee:

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David Ellerd, Committee Chair Date

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Cathleen Rafferty, Committee Member Date

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Eric Van Duzer, Graduate Coordinator Date

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Donna Schafer, Dean for Research and Graduate Studies Date

## ABSTRACT

### PARENT NEEDS ASSESSMENT: A TOOL TO SUPPORT THE TRANSITION INTO SPECIAL EDUCATION FOR CHILDREN WITH AUTISM AND THEIR FAMILIES

KORIN MATTER

The purpose of this project was to develop a tool that would lead to a more positive transition experience into special education for students with autism and their families. After interviewing parents of students with autism and researching the literature, a Parent Needs Assessment was developed, which includes a checklist of parents' needs and priorities for their child. The Assessment provides a means for special education staff to understand the needs of the family during the transition period, and ultimately leads to a more effective education for the student with autism.

## DEDICATION

To all the amazing families who are touched by autism.

## ACKNOWLEDGEMENTS

I would like to thank the Humboldt State University Graduate Education faculty for helping me discover, explore and experience research. The women of the Education Department motivated me to find the researcher in myself. Cathleen Rafferty's ideas and diligent assistance in editing is deeply appreciated. I, especially, would like to thank David Ellerd for his support, encouragement and patience. If it were not for him, I would not have followed this path.

My appreciation and love goes to my incredible husband, Daniel, whose belief in me never falters.

To all the parents of students with autism, thank you. You are my inspiration.

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## CHAPTER ONE

### INTRODUCTION

The number of reported cases of autism is increasing dramatically (Center for Disease Control [CDC], 2004; Croen, Grether, Hoogstrate, and Selvin, 2002; Hewetson, 2002; Seligman, 2005) and with this comes the need for answers to the myriad of questions that surface around the diagnosis of autism. Parents of students with autism have expressed many concerns with the education system, and researchers have found that the transition years into special education are especially difficult for families (Kohler, 1999; Stoner, 2003). The purpose of this project was to develop a tool that would lead to a more positive transition experience into special education for students with autism and their families. After interviewing parents of students with autism and researching the literature, a Parent Needs Assessment was developed which includes a checklist of parents' needs and priorities for their child. This instrument provides a way for special education staff to understand the needs of the family during the transition period, and ultimately leads to a more effective education for the student with autism.

Chapter Two offers a synopsis of relevant literature as it relates to autism and the transition of children with autism into the special education system. This chapter includes an overview of autism, describing the history, definitions, prevalence, causes, and treatment of autism. The chapter also explains early education for students with autism as well as the different types of programs available. Additionally, Chapter Two



includes information regarding the parents' role in early education, their perceptions of their child's education program, and what influences these perceptions.

Chapter Three describes the process of creating the Parent Needs Assessment using Borg and Gall's Research and Development Cycle (1989). The Parent Needs Assessment, a type of checklist intended to indicate and prioritize needs of families during the transition into special education, is then presented in Chapter Four. The project concludes with Chapter Five which describes the intentions of use of the Parent Needs Assessment, limitations of this research project, and future implications for expansion of this project and the corresponding research.

## CHAPTER TWO

### LITERATURE REVIEW

#### *Introduction*

More children are being diagnosed with autism today than in the past (CDC, 2004; Croen, et al., 2002; Hewetson, 2002; Seligman, 2005). This increase in diagnosis of autism is creating many questions in the realm of education. There is growing body of research on the subject of autism, although, there is still no known cure (CDC, 2004). Nevertheless, researchers agree that early intervention for students with autism is advantageous (Wing, 2001). Researchers also agree that parental involvement is key in building an effective education for children with autism; however, these first few years of education can be confusing for parents of students with autism (Stoner, 2003). Yet, there is limited research on what parents' perceptions are of the early education programs that are available for their students with autism, and what their priorities and needs are as it relates to these educational programs. Investigating parental priorities and needs during the transition into special education would give professionals a better understanding and assist in building a more positive working relationship with the parents. In turn, this information would help to make the early education years most beneficial for the student with autism.

In this literature review, the reader will be provided with an overview of autism including a history of autism, autism definitions, characteristics of autism, prevalence, causes of autism, and treatment for autism. The review ends with a description of early

education for students with autism followed by a discussion of parental issues as they relate to the education for their children with disabilities.

### *History of Autism*

Leo Kanner was the first to describe the disorder that we now know of as autism. Kanner examined 11 cases of what he called early infantile autism (Kanner, 1943). He determined this was an inborn disorder that was related to schizophrenia; however, he later reconsidered the link to schizophrenia. The characteristics he found to be common in the 11 children that he studied included lack of ability to relate to others, extreme aloneness, strong rote memory, profound communication difficulties, desire for sameness, and limits in spontaneity. Many of his findings from this study in 1943 still hold true today (Hewetson, 2002; Volkmar, Klin, and Cohen, 1997).

### *Autism Defined*

Today, autism is defined under the umbrella of Pervasive Developmental Disorder (PDD) (Croen et al., 2002; Volkmar et al., 1997). The term PDD refers to impairment in development, manifested in various areas of functioning (Volkmar et al., 1997), and includes Asperger's Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified, as well as Autism (Powers, 2000). The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders' (DSM-IV) (2000) definition of autism is used in diagnosis and is one of the most current and extensively evaluated diagnostic approaches. This definition is internationally recognized and permits unambiguous communication among professionals (Volkmar et al., 1997). The DSM-IV specifies certain criteria that

the children must exhibit to be diagnosed with autism. A child must show impairment in social interaction and communication along with restrictive repetitive and stereotypic patterns of behavior, interests, and activities. Also, delays or abnormal functioning must be evident in social interaction, language, or play with onset prior to three years of age.

The U.S. Department of Education also defines autism. Under the Individuals with Disabilities Education Act, they describe autism as, “A developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance (1997).” The language used in these definitions of autism can be difficult to interpret. Therefore, these terms will be explored further.

#### *Characteristics.*

What do these criteria mean? How are these characteristics manifested in the child with autism?

The impairment in social interaction refers to the difficulty of developing normal social skills (Powers, 2000). A child with autism might find it difficult to talk, play, and relate to people and may not even be interested in people at all (CDC, 2004). Often, the child will have minimal or atypical signs of attachment and bonding to others (Powers, 2000). They may use people as a tool in achieving a means to an end. For example, the extent of contact with adults may be to lead a caregiver to the kitchen to get a snack from an out of reach shelf. One parent described her daughter:

She showed no eye contact. You could get right in her face and she'd turn her head either right or left. She made no attempt to interact. Having four siblings

one would have thought that she'd have no choice but to communicate in some sort of way, but she did not (Powers, 2000, pp. 42-43).

Abnormal patterns of behavior are also evident in the child with autism. The children typically have a need for routine and have difficulty when the routine changes (CDC, 2004). Furthermore, there is also a need for sameness and predictability in their daily lives (Powers, 2000). For instance, if there is an unexpected visitor or activity that is not part of their routine, the child may become agitated. Play activities may be out of the ordinary (Powers, 2000; Koegel and Lazebnik, 2004). Toys may be used in unusual ways; for example, children may spend time simply arranging blocks in perfectly even rows rather than building with them or they may turn a bike over to watch the wheels spin rather than riding it. The children may also have minimal pretend play (Powers, 2000), limited imagination, and an inability to engage in typical role-playing (Koegel and Lazebnik, 2004). Therefore, activities such as playing house or dress-up may not be a part of the child's repertoire. The rate of development may be uneven in different areas (i.e., motor, language, or cognitive skills) and within these areas (CDC, 2004; Powers, 2000). For instance, a child may learn difficult tasks before easy tasks, such as learning to read before learning to identify sounds.

Communication is an especially difficult area for children with autism. Typically, the children have difficulty maintaining a back and forth conversation. For example, the children might just repeat back what other people have said (CDC, 2004), or repeat what they have heard in cartoons. A child might be asked, "Do you want juice?" and the child might respond, "Do you want juice?" Pronoun use, such as referring to themselves as I

or me is difficult (CDC, 2004). A child might say, “Johnny wants cookie,” instead of “I want cookie.” In addition, children with autism often have poor pragmatics (Powers, 2000). This refers to adapting conversation to the situation and to those who are involved. Additionally, pragmatics refers to the ability to use verbal and nonverbal communication when interacting with others. This may be manifested by standing too close to another person, carrying on a conversation too long, or using inappropriate volume. Children with autism may have difficulty in understanding emotions, their own and others (CDC, 2004). They may not understand if an adult says that they are angry or they may not be able to recognize their own anger.

These similar characteristics of autism disorder are evident in a wide range of severities and symptoms (Powers, 2000). All children with autism have their own unique blend of characteristics and behaviors.

#### *Prevalence.*

Once thought to be a rare disorder, autism is now shown to be one of the most common developmental disorders (Hewetson, 2002). There are many studies citing data that the diagnosis of autism is increasing (Bryson, 1997; CDC, 2004; Croen et al., 2002; Seligman, 2005), however, the actual number of cases of autism is inconsistent across studies. We do know that more children are being identified with autism disorder than before. For example, in California in 1987, 5.8 children per 10,000 were identified as having autism disorder. Seven years later 14.9 children per 10,000 were identified (Croen et al., 2002). The number more than doubled. More recently in California, the number of people treated for autism has increased by 13% since 2003 (Seligman, 2005).

The Center for Disease Control summarized that between 1 in 500 (2/1,000) to 1 in 166 children (6/1,000) have an Autism Spectrum Disorder. It should be noted that the increase in prevalence could be due to changes in diagnostic criteria and an increasing awareness of autism (Bryson, 1997; CDC 2004). However, regardless of the reasons, the prevalence of diagnosis is higher than previously thought and indicates the need for more research in this area.

*Causes of autism.*

There is no consensus as to the cause of autism disorder. Brain research in autism has posed more questions than medical answers. However, evidence points to altered development of the brain from before birth and the National Research Council states, “it is clear that autism reflects the operation of factors in the developing brain” (2001, p.11). There is also evidence to show the influence of genetic factors. For example, the risk of having a child with autism increases significantly when a sibling has autism (Hewetson, 2002). It is also not uncommon to find autism in families that have preexisting social, linguistic, or cognitive problems (Volkmar et al., 1997), such as speech delays, social anxiety disorders, or mental retardation. Conversely, there is no evidence that shows connections between parental behavior and autism (CDC, 2004). There are many other hypotheses being investigated as to the cause of autism such as defective immune systems, effects of vaccinations, and complications at birth (Hewetson, 2002). The fact is that these children with autism are, “the victims of genetic and biological vulnerability that interferes with normal brain maturation” (Volkmar et al, 1997, p.12).

### *Treatment for autism.*

“There is no research base explaining how “recovery” might come about (National Research Council, 2001).” Currently there is no cure for autism disorder (CDC, 2004; Hewetson, 2002), and it is still thought to be a lifelong condition. Therefore, many treatments are being tried and tested. The goal in treatment is to assist the child with the complex symptoms of autism and to improve the skills needed to communicate, interact, play, learn, and care for themselves (CDC, 2004). Numerous treatments have been tried including vitamin-mineral intervention and specialized diets (Hewetson, 2002) but many of proposed treatments have little or no empirical evidence supporting them (Simpson, 2004). Some medicines have shown to be successful for some children in relieving symptoms (CDC, 2004). However, structured teaching, referred to as behavioral intervention, is currently the most effective way of treating autism (CDC, 2004). Furthermore, the earlier the intervention program begins for the child with autism, the better the outcome because pathways in the brain can be modified by the environment at a young age (Hewetson, 2002). Therefore, emphasis is placed on the education for young students with autism.

### *Early Education for Students with Autism*

Much evidence demonstrates the importance of early education and the impact it has on the eventual outcomes for individuals with autism. A highly effective program, which addresses the individual’s needs in early education, is vital for the development of the child’s full potential (Wing, 2001). The goal for this programming is to minimize the



effects of the disability that interferes with development in these young children (Egel, 2000).

Early education includes a wide range of comprehensive services that assist young children and their families (Egel, 2000). The type and level of services depend on the child's individual needs. Professionals provide services that focus on socialization, communication, and cognitive skills, depending on the child's developmental delays. The professionals help children improve these skill areas and also teach parents how to help their children with these skills.

Students with autism are served under special education. This is instruction designed to meet the unique needs of children with disabilities (Egel, 2000). At the age of three, students with a disability which includes autism are able to enter the special education system and have their services defined by their Individualized Education Program (IEP). An IEP is based on assessments of the child's abilities and is specifically designed to address developmental areas of concern (Wing, 2001). IEPs include an outline of the student's needs, goals for the student, and services that will be provided through the education system. Children receive additional related services that are necessary for them to benefit from an educational program. This may include occupational therapy, social services, psychiatric services, or transportation services (Egel, 2000).

Early education services may be delivered in a variety of ways. Services prior to special education, from birth to three years of age, are typically provided in the child's home (Egel, 2000). However in most cases, these home-based programs cannot meet the

need for socialization and communication training. Therefore, special education programs at schools are recommended as the child grows older to provide education that is more intensive and that provides services that are not available in the home-based programs. This would entail preschool programs which are available in various settings. Some preschool programs are segregated to include only special education students. Other programs are integrated or provide inclusion services where the special education students are educated with their general education peers for a specified amount of time. These preschool programs may look like traditional preschools, but they offer different instructional methods catering to the needs of the individuals and their disabilities.

The education program for students with autism typically includes methods to address cognitive, self-help, fine and gross motor, behavior, social interaction, and communication skills that are determined by the child's needs. Applied Behavior Analysis (ABA) is a common teaching technique in classrooms for autism (Egel, 2000). It is a scientific approach that focuses on teaching appropriate behavior in a systematic manner and is backed with evidence to be an effective treatment for students with autism (Professional Development in Autism Center, 2004).

Programs are generally implemented by special education staff. These professionals are trained in assisting children rise above learning problems that are inherent of their disability (Egel, 2000). For example, a psychologist may be involved to complete assessments or advise teachers on special education programs (Wing, 2001). Speech-language therapist would work with the children directly to help improve communication skills. The therapist may also work with parents and teachers to guide

ways of assisting the child. Teachers would be a central component to programming. They put recommendations from all other professionals into effect and have the responsibility to work collaboratively with parents.

### *Parents and early education*

Parents have been seen as a vital component in the education of students with autism (Stoner, 2003). They often contribute key information about the child's individual history, characteristics, and behaviors. The parents are particularly important in the education for children with autism because they play such an essential role in their child's life (Dunlap, 1999).

Parents are intended to be equal partners in the special education system, with legal rights to represent their children (Daniel, 2000). Parents are involved in the education of their child in many different ways including experiences in early childhood education, IEP meetings, involvement in related services, encounters with teachers, and encounters with administrators (Stoner, 2003). Additionally, parents are involved when professionals give them suggestions about activities to continue to try in the home (Egel, 2000; Stoner, 2003). Parents may be responsible for discussing problem behaviors with teachers to help enhance progression of the child's skills. Furthermore, families are involved with many different agencies and professionals. One researcher concluded that on average, families with autism are involved with 7.7 professionals at one time (Kohler, 1999).

*Parental perceptions.*

Because of the importance of parental involvement in the education of their child and also because of their role as primary care givers, parents' perceptions regarding their child's education are crucial. Parents' perceptions vary as they relate to the education of their child with autism. While some parents of children who have autism expressed satisfaction with certain aspects of the education of their child (Spann, Kohler, and Soenksen, 2003; Starr, Foy, and Cramer, 2001), other parents reported a range of concerns (Spann et al., 2003; Starr et al., 2001; Stoner, 2003). For instance, families with children with autism spectrum disorder are reporting difficulty in obtaining a diagnosis and services (Stoner, 2003). Parents also have reported mixed feelings in regard to the Individualized Education Program (IEP) meetings. Some families report high to moderate satisfaction of how IEPs are handled (Spann et al., 2003). Others report that the meetings were formal, not a team process and were limited by time constraints (Stoner, 2003). They also frequently refer to the lack of collaboration as a concern (Kohler, 1999). In addition, many parents revealed unease regarding frequency of IEP team meetings and the lack of expertise on the team (Starr et al., 2001). One parent noted, "The school needs to be better at giving parents information and support" (Spann et al., 2003, Figure 1). Yet, some families have expressed satisfaction with the communication with the schools (Spann et al., 2003).

In regard to the program planning of the child's education, parents reported several concerns (Spann et al., 2003; Starr et al., 2001). Parents of students with autism expressed that schools were doing little or nothing in addressing their child's needs

(Spann et al., 2003). They also did not believe that their children were progressing to their potential (Starr et al., 2001). Furthermore, parents felt that the teacher did not take on the primary responsibility for the student and needed more training in working with students with autism. One parent exemplified this by stating, “Why do I have to constantly hound my child’s teachers to get them to do their job well?” (Egel, 2000, p. 212). If these initial experiences with professionals are negative for parents, it could impair all future interactions.

*Influences on parental perceptions.*

Perceptions of parents are important in the team process of special education. However, the more crucial element might be what is influencing these opinions. There are innumerable factors that create the parents’ perceptions. The literature is limited in this area, but themes have been examined.

For instance, the fight for diagnosis and services has impacted parents’ perceptions. Parents find it difficult to obtain a diagnosis of autism (Kohler, 1999; Stoner, 2003). Parents have reported that professionals dismiss their concerns that eventually are found to be the symptoms of autism. Parents have also obtained different diagnoses by different psychiatrists (Kohler, 1999). There have been up to two year delays from the onset of symptoms for parents to receive an accurate diagnosis for their child. This difficulty in obtaining a diagnosis along with professionals dismissing problems reported leads parents to a lack of trust in educational professionals (Stoner, 2003).

Furthermore, these delays in diagnosis are compounded by delays and difficulties in obtaining related services, such as speech or occupational therapy. Parents have even reported having to fight for these services. The issue of having to fight or request services has left parents wondering if they are receiving all the services that their child needs. Parents report that the sense of having to fight has impacted their interactions with educational professionals (Stoner, 2003). In addition, when parents did receive services, they have reported that these services are inadequate (Kohler, 1999). Parents' expectations were disappointed when the professionals did not provide for the child's needs (Stoner, 2003). This difficulty in obtaining adequate related services, again, leads parents to feelings of distrust, confusion, and frustration in regard to working with education professionals.

The interactions between parents and educational professionals also affect parental perceptions. Trust is affected either negatively or positively, by the experiences with teachers (Stoner, 2003). The interactions do not always seem to support families. If there is not an effective, honest line of communication, trust can be reduced between the parents and professionals. For instance, parents reported during initial meeting with special education teachers that they were confused, and the meetings did not meet their needs. This confusion would not seem to be a product of open communication and would lead to a lack of trust. Furthermore, many families have reported concerns with existing services (Kohler, 1999; Stoner, 2003), and express that the teachers' interactions with children are inconsistent. They have reported concerns with communicating with the

different service providers. These concerns do not lead to trusting relationships between parents and professionals.

Besides the difficulty in obtaining services and the experience with education professionals, the transition between early intervention and special education can affect parental perceptions. When children with autism turn three years old, they transition from early intervention to special education services. This can be confusing or even frustrating for parents because they encounter different professionals, new terminology associated with special education, and a new agency with its own culture and assumptions (Kohler, 1999). This transition may entail discontinuing intensive services that were present in previous services. Special education also may not be as family centered as was the early intervention. Therefore, this transition can cause a feeling of conflict, confusion and frustration for parents (Stoner, 2003).

### *Conclusion*

The issues described above have illustrated a need for knowledge regarding parents' perceptions of education for their child with autism during the transitional years from early intervention to the special education system and steps to make this a more effective transition. There is a need to examine the perceptions of parents of children who have autism in particular because of the unique challenges that are associated with this disorder (Starr et al., 2001). The need for research also comes with the increased prevalence of autism and the legal requirements of parental involvement in education. There is little research on parent confusion resulting from entering special education and having difficulty obtaining related services as it related to autism (Stoner, 2003). The

distrust that has been reported also leads to a need for a better understanding between parents and educators. Therefore, the question “What are parents’ priorities and needs as it relates to the education of their child with autism during the transition years into special education?” needs to be examined. The education of students with autism will be greatly enhanced when parents and educational professionals understand each other’s perspectives (Stoner, 2003).



## CHAPTER THREE

### METHODOLOGY

#### *The Research and Development Cycle*

A Parent Needs Assessment was developed using a revised version of the Research and Development Cycle (Borg and Gall, 1989). The Research and Development Cycle generates an educational product by incorporating research knowledge. The process consists of a cycle where a product is created, field tested and revised based on the field data. The goal of the Research and Development process is to link educational research with educational practice. The steps are as follows:

1. Research and information collecting.
2. Planning.
3. Develop preliminary form of product.
4. Preliminary field testing.
5. Main product revision.
6. Main field testing.
7. Operational product revision
8. Operational field testing
9. Final product revision.
10. Dissemination and implementation

The present research was a smaller scale study than intended by Borg and Gall, and therefore, revisions were made to the cycle for the purpose of this study, including omitting Steps 7, 8, and 10. Figure 1 displays the process used to create the Parent Needs Assessment.

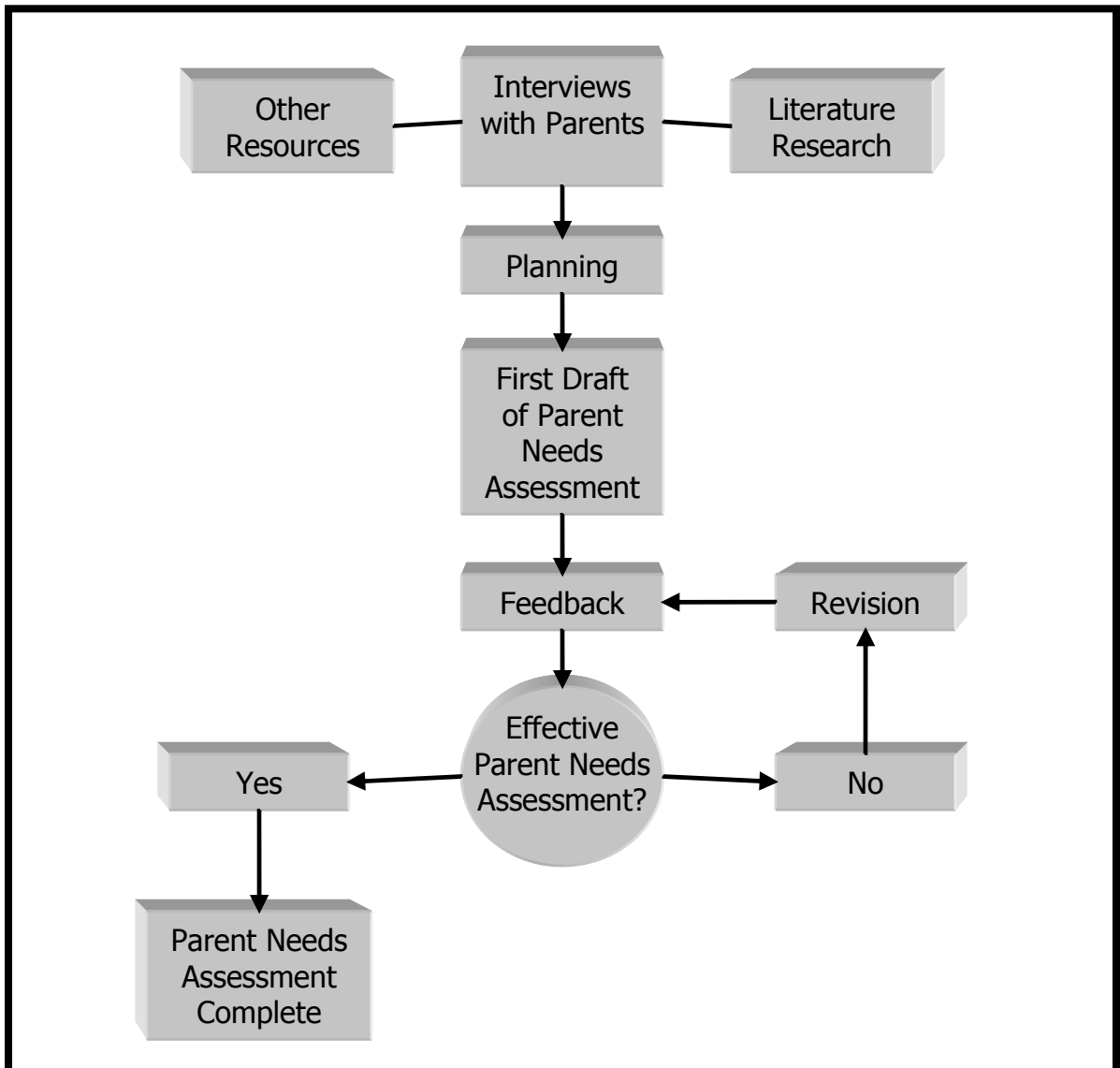


Figure 3.1 Creation of Parent Needs Assessment.

*Step 1: Research and information collecting*

The first step included researching and collecting information regarding parent needs. Literature was examined for themes of parental perceptions during the transition into special education. The recurring feelings reported by parents included distrust of professionals, lack of collaborative effort and confusion with the special education system. There was very little research on what the needs and priorities of parents are during this transitional period.

The next step in the research was to see what was being done in response to the negative feeling felt by parents during this transitional period. I searched for tools that may be used to investigate parents' wants and needs during this time. Many assessments existed that survey parents as to their child's needs, interests, and levels of performance. However, only one tool was found that discussed familial needs and it was brief and within a more extensive survey that was intended for different purposes ("Parent Inventory", 2002). Although, no tools were found that targeted familial needs which would help prevent these negative feeling for families, the parent surveys that were found led to the idea and assisted in creating a Parent Needs Assessment.

Three mothers of students with autism were then chosen from a convenience sample and interviewed on a voluntary basis. Each mother had a child enrolled in a particular Northern California preschool designed for autism spectrum disorders in a segregated facility. It should be noted that the principal investigator was involved in the education of the children of the interviewees, however, was not involved at the time of transition into special education. The interviewees all recently experienced the transition

into special education with their child but came with differing previous experience. One of the families had never been involved with other educational agencies previous to entering special education. Another family was receiving early childhood services including home-based speech therapy and an infant teacher prior to entering special education. The other family had been involved with local education agencies since birth because of the child's at-risk status; there was also an older sibling in the family involved with special education. At the time of the interview, all three mothers were actively involved with their child's education including attending parent groups, communicating with staff on daily basis, and reading autism research.

The parents were given an overview of the study and then asked if they were interested in participating. Each parent was interviewed initially for approximately one hour regarding experiences during the transition years into the special education system. The interviewer met with the parents individually at a setting and time of their choice. Two of the three interviews were conducted at the interviewee's home, while the third interview was conducted at the interviewer's office. The questions that were used as a basic guideline for interviews are included in Appendix A.

The interviews were tape recorded and transcribed. The goal of the interviews was to understand the diverse needs and priorities of these parents as their children transition into special education. The information retrieved from the interviews was used to generate a draft of the Parent Needs Assessment.

*Step 2: Planning*

After the interviews were transcribed, they were analyzed and coded as the sample exemplifies in Appendix B. Qualitative themes emerged from the transcripts that were consistent with the literature. For instance, all three mothers interviewed discussed the difficulty in having their child diagnosed. Each of the interviewees mentioned that many professionals they encountered were hesitant to mention the word “autism.” One mother even acknowledged how a worker told her that she was instructed by her employer not to use the term autism.

“They were instructed not to use the word autism: They were instructed not to say that they suspect autism.”

This seemed to create frustration with all the mothers, and in retrospect they wished that they would have been offered services earlier regardless of diagnosis. This is consistent with the professional literature and the frustration that ensues.

However, for the purpose of this study, the variety of the responses was essential in building the Parent Needs Assessment. The discrepancies in the needs and priorities described by these parents were expected and resulted in a well-rounded assessment tool that would be effective for all families with a student who had autism entering special education.

There were overarching categories that parents discussed which eventually lead to the sections of the Parent Assessment Tool. For example, the three interviewees discussed home programming but one mother described how vital home programming was initially and another mother described how it was overwhelming initially.

*Step 3: Develop Preliminary Form of Product*

An initial draft of the Parent Needs Assessment was created, using the information collected from the research and interviews. A variety of parent surveys was reviewed for formatting ideas. I wanted the assessment to be easy to complete for parents and easy to interpret by educational staff. I was aware of the language used because the parents completing this survey may be encountering some of the terms for the first time. I also wanted the assessment to be comprehensive of familial needs but also not so long that response accuracy would be compromised. I separated the assessment into sections using the categories that appeared during qualitative analysis. By separating the assessment into sections, educational professionals would be able to omit sections in the event that they do not apply to their program. The items for each section came directly from the parent interviews and what they described as their needs during this transition. The assessment was created using Microsoft Word.

*Step 4: Preliminary Field Testing*

The next step in the research and development cycle involved receiving feedback. The interviewees, along with educational staff, including a speech therapist, teacher, and psychologist, were given a copy of the Parent Needs Assessment and asked for general feedback related to effectiveness, clarity, social validity, face validity, etc. I sought comprehensive feedback as it applied to all areas of a child's education in order to ultimately create a well-rounded tool.

*Step 5: Main Product Revision*

The Parent Needs Assessment was then revised using the feedback collected. Suggestions for revision included formatting, terminology used, and clarity of assessment items. I changed the formatting to include a sufficient space for parent comments or questions. I received feedback from parents indicating that some of the wording assumed that parents had previous knowledge of different jargon. It was also pointed out that parents felt that if they checked certain items, they had to commit to certain services or responsibilities. Therefore, wording was revised.

*Step 6: Main Field Testing*

After the revising the Parent Needs Assessment, it was used with two families as their children initially entered special education into a program designed for students with autism. Up to this point, it was only conducted hypothetically with people who had previous knowledge of special education and autism. I wanted to observe how the product would perform in a natural setting to ensure practicality. Additionally, the revised copy was given back to the interviewees and educational staff for further feedback to follow-up on previous suggestions and revisions.

*Step 7: Final Product Revision*

With comments and experience of implementation, the Parent Needs Assessment was revised a final time. Items were added according to needs that developed during field testing, such as “assistive technology” due to parent inquiries. Sections were reorganized for a better flow during completion. For instance, I placed the “Transitional Period” section at the beginning because this would be the area of immediate importance.

For added clarity, headings were also repeated at the top of each page as demonstrated in Chapter Four.



CHAPTER FOUR  
PARENT NEEDS ASSESSMENT

The Parent Needs Assessment has been altered to meet the binding requirements including font size and table dimensions.

<b>Parent Needs Assessment</b>
--------------------------------

**Student:**

---

**Date of Birth:**

---

**Parents:**

---

**Persons involved in Assessment:**

---

**Date of Parent Needs Assessment**

---

**Educational Placement:**

---

This tool is designed to give parents an opportunity to describe their needs as a family with regard to their child and the educational placement of their child. This assessment is intended to be a collaborative effort between parents and staff.

**Directions:** Please put a check next to each item as appropriate. Please feel free to write any additional information in the comment boxes or attach additional pages.

**TRANSITIONAL PERIOD:** Please check the box according to the priority level during the initial transition into the new program and write comments as necessary.

	This is a priority.	I would like more information.	This is not a priority at this time, but may be in the future.	No, I do not need this.
I would like to discuss the philosophies used in the classroom.				
Comments:				
I would like to have time to get to know staff.				
Comments:				
During the first month, I would like additional communications with staff such as appointments or phone calls.				
Comments:				
I would like help creating a plan to make the transition easier for my child.				
Comments:				

## TRANSITIONAL PERIOD: Continued.

	This is a priority.	I would like more information.	This is not a priority at this time, but may be in the future.	No, I do not need this.
I would like to meet/talk with other parents currently involved with this program.				
Comments:				
I would like my child to visit the classroom before the start date.				
Comments:				

**COMMUNICATION:** Please check the boxes according to your communication preferences with your child's school and write comments as necessary.

	Daily	Weekly	Monthly	As Needed	I prefer not to use this mode of communication.
<b>Communication Notebook</b>					
Comments:					
<b>Email</b>					
Comments:					
<b>Phone Calls</b>					
Comments:					
<b>Regularly Scheduled Meetings with Teacher</b>					
Comments:					
<b>School Visits</b>					
Comments:					
<b>Team Meetings</b>					
Comments:					

**GENERAL INFORMATION:** Please check the yes or no box as whether you would like information on the following topics and write comments as necessary.

	YES, I would like more information on this topic.	NO, not at this time.
<b>Alternative Therapies</b>		
Comments:		
<b>Assistive Technology</b>		
Comments:		
<b>Autism Resources</b>		
Comments:		
<b>Community Resources</b>		
Comments:		
<b>Developmental Stages</b>		
Comments:		
<b>Inclusion</b>		
Comments:		
<b>Individualized Education Plan (IEP)</b>		
Comments:		
<b>Occupational Therapy</b>		
Comments:		

**GENERAL INFORMATION: Continued.**

	YES, I would like more information on this topic.	NO, not at this time.
<b>Parent Rights</b>		
Comments:		
<b>Regional Center Services</b>		
Comments:		
<b>Speech Therapy</b>		
Comments:		
<b>Transportation Services</b>		
Comments:		

**EDUCATIONAL INVOLVEMENT:** Please check the box according to priority level and write comments as necessary.

	This is a priority.	I would like more information.	This is not a priority at this time, but may be in the future.	No, I do not need this.
I would like more information on autism.				
Comments:				
I would like to network with other parents.				
Comments:				
I would like to have pre-IEP meetings to go over topics such as goals, assessments, etc.				
Comments:				
I would like to inquire about volunteering in the school.				
Comments:				
I would like to discuss opportunities to observe my child at school.				
Comments:				



**HOME PROGRAMMING:** Please check the box according to priority level and write comments as necessary.

	This is a priority.	I would like more information.	This is not a priority at this time, but may be in the future.	No, I do not need this.
I would like staff to make home visits.				
Comments:				
I would like support with implementing a visual schedule.				
Comments:				
I would like support implementing communication techniques such as Picture Exchange Communication.				
Comments:				
I have medical concerns about my child and would like support.				
Comments:				

**HOME PROGRAMMING: Continued.**

	<b>This is a priority.</b>	<b>I would like more information.</b>	<b>This is not a priority at this time, but may be in the future.</b>	<b>No, I do not need this.</b>
<b>I would like support implementing behavioral strategies.</b>				
Comments:				
<b>I would like support in teaching my child self-help skills such as toileting.</b>				
Comments:				
<b>I would like ideas for activities that would carry over what is being taught at school.</b>				
Comments:				



## CHAPTER FIVE

### CONCLUSIONS

The purpose of this project was to develop a tool that would lead to a more positive transition experience into special education for students with autism and their families. A Parent Needs Assessment was developed using qualitative research methods including interviewing parents who have a child with autism.

The Parent Needs Assessment is a tool that was designed to give parents an opportunity to describe their needs as a family with regard to their child and the educational placement of their child. The assessment was created with the intention of using during the transitional period into special education, where the special education teacher or other staff would sit together and collaborate with the parents in filling out this questionnaire. During this session, parents and staff would have time to discuss important issues concerning their child and family. The goal is that it would set a standard for future interactions between staff and families by opening the door for communication, trust, collaboration, and possibly eliminating frustration related to this transition.

This assessment could be adapted for other transitions in the special education years such as when transitioning from a preschool program to an elementary school program. Special Education Staff are able to eliminate sections as applicable. Parents may also want to use this tool to inform new staff of their family's needs. In the future, it is hoped that this tool could be expanded into an assessment for all disabilities and across

various transitions throughout the special education years. Another expansion of this project would be to create a webpage or CD-Rom with the same questionnaire but with hyperlinks to immediate information for the parents. If created as a webpage, it could be made accessible from County/Regional Offices of Education or other special education agencies. Furthermore, the effectiveness of this assessment needs to be determined and its affect on communication, trust, collaboration and frustration as it relates to parents during the transition into special education.

This leads to the limitations of this project. As stated, the effectiveness of the assessment was not studied. However, social validation data was collected from parents and professionals after implementation and all notations were positive. Another limitation was that this was created only with input from a small, similar population: families with a child who has autism. Issues and needs may be different for other populations such as families with students with mild disabilities or physical disabilities. For example, a family who has a child with a physical disability would not necessary desire information on autism. The researcher also had a previous relationship with interviewees which may have affected responses to interview questions. Finally, every program for students with autism has unique circumstances and characteristics, therefore, all items on the assessment may not be applicable.

By creating a parents' needs assessment, the goal was to add to the research in answering "What are parents' priorities and needs as it related to the education of their child with autism during the transition years into special education?" and to construct a tool that is practical and useful for special education staff and parents alike. The need for

this assessment comes from the increasing prevalence of autism, the unique challenges associated with autism, the legal requirements of parents' involvement in education, and the research reporting parents' feelings of confusion and distrust during the transition into special education. The Parent Needs Assessment is designed to create a more effective working relationship with parents and special education staff and ultimately lead to a more positive education experience for the child.

## REFERENCES

- American Psychiatric Association (2000). *(DSM-IV-TR) Diagnostic and statistical manual of mental disorders*, 4th edition, text revision. Washington, DC: American Psychiatric Press, Inc.
- Borg, W.R., and Gall, M.D. *Educational Research: An Introduction*. White Plains, NY: Longman, (1989).
- Bryson, S. (1997). Epidemiology of autism: Overview and issues outstanding. In D. Cohen and F. Volkmar (Eds.), *Handbook of autism and developmental disorders* (2<sup>nd</sup> ed., pp. 41-46). New York: John Wiley and Sons.
- Center for Disease Control. (2004, August). About autism, autism information center. Retrieved October 12, 2004, from <http://www.cdc.gov/ncbddd/dd/aic/about/default>.
- Croen, L., Grether, J.K., Hoogstrate, J., and Selvin, S. (2002). The Changing Prevalence of Autism in California. *Journal of Autism and Developmental Disorders*, 32, 207-215.
- Daniel, P.T.K. (2000). Education for students with special needs: the judicially defined role of parents in the process. *Journal of Law and Education*, 29, 1-30. Retrieved November 1, 2004, from <http://wilsonxt.hwwilson.com/pdfhtml/02292/POAQQ/ZS4.htm>

- Dunlap, G. (1999). Consensus, engagement, and family involvement for young children with autism. *The Journal of the Association for Persons with Severe Handicaps*, 24, 222-225.
- Egel, A. (2000). Finding the right early intervention and educational programs. In M.D. Powers (Ed.), *Children with autism* (pp. 181-212). Bethesda, MD: Woodbine House.
- Hewetson, A. (2002). *The Stolen Child*. Westport, CT: Bergin and Garvey.
- Individuals with Disabilities Education Act Amendments of 1997 (P.L. 105-17), 111 Stat. 37-157 (1997).
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*. 2, 217-250.
- Koegel, L. K. and Lazechnik, C. (2004). *Overcoming Autism*. New York, NY: Penguin Books.
- Kohler, F., (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities*, 14, 150-159.
- National Research Council. (2001). *Educating children with autism*. Washington, DC: National Academy Press.
- Parent Inventory. (2002). Retrieved November 29, 2005, from University of Kansas, Circle of Inclusion Project Web Site:  
<http://www.circleofinclusion.org/english/pim/eight/parent.html>.



- Professional Development in Autism Center, Personnel Development in Autism. (2004).  
Available at <http://depts.washington.edu/pdacent/sites/uw.html>.
- Powers, M. (2000). What is autism? In M.D. Powers (Ed.), *Children with autism* (pp. 1-44). Bethesda, MD: Woodbine House.
- Seligman, K. (2005, February 4). Scientists baffled as autism cases soar in state, with no relief in sight/Treatment centers, schools inundated by kids needing help  
[Electronic version]. *San Francisco Chronicle*.
- Spann, S., Kohler, F.W., and Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a support group. *Focus on Autism and Other Developmental Disabilities*, 18, 228-238.
- Starr, E.M., Foy, J.B., Cramer, K.M. (2001). Parental perceptions of the education of children with pervasive developmental disorders. *Education and Training in Mental Retardation and Developmental Disabilities*, 36, 55-68.
- Stoner, J.B. (2003). Parental perceptions of the interactions between parents of young children with autism spectrum disorders and educational professionals.  
Unpublished doctoral dissertation, Illinois State University, Normal.
- Volkmar, F.R., Klin, A., and Cohen, D.J. (1997). Diagnosis and Classification of Autism and Related Conditions: Consensus and Issues. In D.J. Cohen and F.R. Volkmar (Ed.), *Handbook of autism and pervasive developmental disorders* (pp.5-46).  
New York: John Wiley and Sons, Inc.
- Wing, L. (2001). *The Autistic Spectrum*. Berkeley, CA: Ulysses Press.

## APPENDIX A

### INTERVIEW QUESTIONS

1. Describe your experience with the education system.
2. Describe the process leading up to education, from the point of diagnosis, for your child. How was this process emotionally?
3. How do you view your role in the education of your child?
4. Describe initial experience with the education staff. How did you feel about the experience? What level of trust was there initially?
5. Describe your first IEP meeting. What were the interactions like between you and the educational staff?
6. How much did you understand what was happening during the initial meeting with educational staff?
7. How much did you feel an equal member on the IEP team? Did you feel like an equal member of the IEP team? Why or Why not? Did you feel your input was weighted equally to the other members?
8. What IEP processes/procedures did the staff explain to you clearly? What IEP processes/procedures do you wish you had more information or explanation of?
9. How comfortable were you asking questions during the IEP?
10. What was positive about the initial IEP meeting?
11. What were some of the most beneficial supports you had from the team during the first meetings?

12. What were some of the difficulties during the first meetings?
13. What could have made these initial meetings with educational staff easier or more comfortable?
14. How much control did you feel you had over the decision regarding the education of your child?
15. What choices were you given regarding the type of programming your child received?
16. What services were offered to you to make the transition into special education easier? What did you accept? What did you not accept? Why?
17. What were some of the beneficial supports you had from the team during the first year of school for your child?
18. What were some of the difficulties during your child's first year of school (i.e. academics, family life, school routine, etc)?
19. Who in your personal life played an important role during those first years at school? What did they do?
20. Who in the educational setting played an important role during those first years at school? What did they do?  
  
What services over the course of your child's' first year in school were the most helpful? Why?
21. What could have made this first year of school easier for your child?
22. What could have made this first year of school easier for you as the parent?

APPENDIX B

TRANSCRIPTS

Sample transcripts and qualitative analysis:

<b>Transcripts</b>	<b>My comments as it relates to project</b>	<b>Coding</b>
<p><b>Describe experience w/ ed. system.</b> Really good especially w/ [REDACTED]. It's been really positive. Hard transition to put him into [REDACTED]</p>		Feelings/transition
<p>I was a little concerned at beginning w/ restrictions put on him because he wasn't used to that. Made me uncomfortable, so in general good, in general good. There were times that I was uncomfortable but I didn't feel like it was because the system was lacking.</p>	Information regarding behavior procedures	Concerns/school
<p><b>Describe the experience leading up to education from diagnosis, how did that happen for you?</b> We got diagnosis from [REDACTED], then there was a point where I was having, I don't if it was before the diagnosis...I am trying to remember...there was just a whole series of, it was a little bit of a blur...while we were worried about his autism and then he was acting up a lot.</p>		Procedure behavior
<p>So I was going, you know, I was really concerned about him going into a preschool setting because I was really, I just didn't know how that would go. I didn't even know there were special ed. preschools. So I just thought the thought of putting in a preschool seemed so overwhelming.</p>		Decisions Concerns/school
<p>But then he was acting up so much and I think he was really bored. That I started getting short with him and I thought, you know what, this isn't working either so that's when I kinda turned to preschool</p>		behavior decisions

<p>And then when I got the diagnosis then they talked about [REDACTED]. At first I didn't want to because I didn't want him around other children w/ autism because I thought he'd pick things up. And I just wasn't ready to accept that. And then finally they said, [REDACTED] my special ed. teacher that was going to my house, she told us to go check it out and then finally we checked it out and thought it probably would be a good idea. And that's how we ended up there.</p>	<p>Observation time in class</p>	<p>procedure feelings/transition concerns/school decisions</p>
<p><b>How was that emotionally?</b> Going to [REDACTED] was really an emotional step than any of the others. Going to [REDACTED] or having a special ed. teacher coming to the house, which was no big deal.</p>		<p>Feeling/transition</p>
<p>But I really I remember the one time that he was crying a lot and [REDACTED] said that he was crying because he couldn't bring his bike inside and I was really worried it was the first day or two and she said he'd been crying for like fifteen minutes. And I thought my son has never cried for fifteen minutes straight, from the time he was a baby we attachment parented him we wore him we did all this stuff to minimize you know??? All the areas he was taken care and then all of the sudden we had this situation where he was being let cry.</p>	<p>Procedures</p>	<p>Feeling/transition</p>
<p>And that me kinda angry and [REDACTED] too and we said well we really don't want that so I think that just all of that was emotional and I think that would have been different with [REDACTED] than it was with [REDACTED]. I think [REDACTED] was a little more hard about??? things and I think that didn't work as well for us at the beginning. I think that made it harder than it needed to be.</p>		<p>Feelings/transition</p>

<p><b>What did you feel your role was in the education?</b> In the beginning I was just confused. I didn't know what was going on. I didn't know what autism was really. I didn't really; I was just confused, so I didn't know what my role was. I just wasn't sure you know. And I felt like, yeah I should have I have a role as a parent yet all these people are telling me what to do and I kinda feel like I don't know whether to trust my instinct as a parent or to listen to these people who are saying go against all your instincts as a parent. So my role was kinda confused. It wasn't really something that was set at that point for me.</p>		Feeling/transition
<p><b>How was your initial experience with the special education staff?</b> It was great she came to the house and then we had the speech therapist, ██████████, to the house. And I was really, I loved them. ██████ was great. I called ██████ and sometimes I would say, "██████ help"</p>		Feeling/staff
<p>And that was another very hard transition for me, losing ██████ and ██████, and this nice little system we had where they came over to the house and we talked about what was going on, to putting him into the school and losing them at the same time. So that was hard for me.</p>		Feeling/transition
<p>And again I think that would have been easier if, you know I really like ██████, but in the beginning it was a harder transition because she is very strict and comes off very strict in the beginning. And that's hard and I think that made the transition harder. Harder and I was scared.</p>		Feelings/transition Feelings/staff

<p><b>Were there specific actions [by the staff] that would have made that easier?</b> I think if they would have said something like is it possible or would you like to come to the classroom for the first two weeks. Would you like to, anything that would have made me feel more involved or more empowered would have been welcomed by me because</p>	<p>Observation for the first week</p>	<p>suggestions</p>
<p>I felt like I didn't know if I was doing the right thing or not. I didn't know about autism. ??? I just didn't know if I was doing the right thing or not. And it was very different from my parenting approach which had been up to that point very nurture, nurture, nurture. Right now they are telling me to be very strict..</p>	<p>Discussion on parenting matching w/ ed. philosophies</p>	<p>Feelings/transition Concerns/school</p>
<p>Anything that would have helped me to, I think, and even, you know, and during those early time more time to talk to the teacher. Maybe if it was like every week, we have a half hour meeting to talk to the teacher, or every time you pick them up do you want fifteen minutes at the end of the day if you are picking him up ??? that we could just talk.</p>	<p>Set aside time to meet w/ teacher at beginning</p>	<p>Suggestion</p>
<p><b>What was your level of trust w/ the special ed. system?</b> It started at my home so there was a high level of trust. I think if it would have started at school I would have been much more skeptical. But because people were coming into my home I still had control. It was my environment my children's environment and these people were just visiting. They'd bring toys, talk to me. But it was a much higher level of trust.</p>		<p>Trust</p>