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**Children with Autism Spectrum Disorder and the IEP Process: An Examination of
Parents' Perceptions**

by

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A Thesis

Submitted to the Graduate Faculty of

St. Cloud State University

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Abstract

Current research addresses the importance of information exchange and trust between medical professionals and parents of children with autism, but relationships between special educators and parents are often overlooked. Special educators, specifically case managers of children with autism, need to have an understanding of a parent's viewpoint regarding their child's autism. Unlike some other medical or cognitive disability categories, autism spectrum disorder is unique in its extreme variety of how mildly or severely impaired a child may be. Through interviews with four parents of children with autism, this thesis explored the experiences that parents had in the Individualized Education Plan (IEP) process and their perceptions of the extent to which case managers considered their needs and priorities. Findings indicated that initially parents had negative IEP experiences, specifically related to their feeling uninformed and overwhelmed by the content of IEP meetings. Positive parent experiences with case managers and IEP teams resulted from the team's willingness to develop personal relationships with them and their efforts to research options for their child with autism. Parents described two main situations that were central to their having positive experiences: (a) feeling included and supported in the IEP process, and (b) the IEP team having an accurate understanding of their child.

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Chapter 1: Introduction

Incidence rates for autism spectrum disorder (ASD) are increasing in the United States. For many decades, the rate of prevalence was considered to be 4 or 5 in 10,000 (Center for Disease Control, 2006). In 2004, the Center for Disease Control (CDC) stated that the prevalence was 1 in 166. A 2002 study conducted by the Autism and Developmental Disabilities Monitoring Network (ADDM) stated that estimates were as high as 1 in 150 (ADDM, 2007). The statistical data provided by the CDC supports the assumption that projections are expected to continue to rise.

Parents of children with autism face many questions. First, parents may ask what causes the disorder. Second, questions about improving outcomes arise. Whom the parent asks these questions may depend on who gave the child the diagnosis. The diagnosis may come from an early childhood referral service, a pediatrician, or both. Although early identification of autism is improving, many children do not receive the autism diagnosis until the elementary school years, possibly as late as 8 or 9 years of age (M. Powell, personal communication, May 2007). Because of this fact, it is important for special educators to approach each family in a unique manner, making no assumptions about their priorities or their understanding of the IEP process.

Only recently have researchers addressed the importance of understanding the parents' viewpoints in the concept of parent-teacher collaboration (Stoner & Angell, 2006). Under the mandate of the 1975 Education for All Handicapped Children Act (EHA), which preceded the 1990 Individuals with Disabilities Education Act (IDEA), the education of children with disabilities was teacher-driven, with little or no input from parents (Stoner et al., 2005). The

legislation of IDEA mandated that families be an integral part of the education process, having input into the goals, objectives, and implementation of services for their children with disabilities (U.S. Department of Education, 1990). Even more emphasis was placed on family involvement with the reauthorization of IDEA in 1997; Part C of IDEA mandates whole family and child services from birth until kindergarten age. It also mandates a seamless transition for the child into the next phase of schooling. It is here that the family-centered provision is mandated. When the child is eligible for Part B of IDEA, that is, ready to enter elementary school, there is no such mandate to include the family's needs when planning for the individual education of the child. There is a mandate that parents are a central part of the IEP planning process, but there are no requirements that the *family* (parent, child, sibling, extended family) needs to be taken into account when planning. This paper explored the perceptions that parents of children with autism had of the IEP process, particularly with regard to whether they felt their priorities and needs were taken into consideration.

Family-Centered Collaboration

Current research addresses the importance of information exchange and trust between medical professionals and parents of children with autism, but special educator-parent relationships are often overlooked (Harrington, Patrick, Edwards, & Brand, 2006). One approach to including participation by all members of the IEP team is the family-centered approach. The National Association for the Education of Young Children (NAEYC) describes the family-centered approach as consisting of multi-faceted components. There must be reciprocal relationships consisting of mutual respect, cooperation, shared responsibility, and negotiation of conflicts toward achievement of shared goals. These activities entail having the

family and school share their knowledge of the child through regular two-way communication. Parents must be welcome participants in decisions made about their children's care and education. This means that teachers must acknowledge parents' choices and goals for children, and respond with sensitivity and respect while involving them in assessment and planning decisions. A final important piece of collaboration is that of linking families with a range of services, based on identified resources, priorities, and concerns, (National Association for the Education of Young Children, 1997).

When educating young children with disabilities, success of a family-centered approach has been documented (Turnbull & Turnbull, 2001, 2006); however, there appears to be a deficit when working with elementary-aged children who are on the autism spectrum (Spann, Kohler & Soenksen, 2003). The reasons behind this gap may be that although the law is well-intentioned, the specifics of implementation are left to the individual state (U.S. Department of Education, 2006). Whether this variance is due to the lack of specifics regarding the family as a whole in IDEA Part C, insufficient funds for teacher training, misunderstanding the intent of the law, or for other reasons, is unknown.

The idea of family-centered services in relation to Part C of IDEA is captured in essence with the best practices suggested by Iowa's Early ACCESS Principles and Practices Synopsis (see Table 1).

Table 1

Key Points to Including Families in the IEP

<ul style="list-style-type: none"> ✓ Family empowerment which benefits the well-being and development of the child ✓ Mutual trust, respect, honesty and open communication ✓ Families are active participants in all aspects of services ✓ Families are the ultimate decision-makers in the amount, type of assistance and the support they seek to use ✓ Identify family concerns (priorities, hopes, needs, goals, or wishes) and the services and supports that will provide necessary resources ✓ Find family strengths and expand upon them ✓ Build upon and use families' informal community support systems before relying on professional, formal services ✓ Offer support and resources that are flexible, individualized and responsive to the changing needs of families

(Iowa SCRIPT, 2000)

Early childhood special educators may understand the importance of family-centered planning, but is this concept a fundamental piece of the elementary and secondary special education planning process? Do case managers include all stakeholders in the process of IEP planning? Does the extent of parent involvement depend on case managers?

Statement of Problem

Special educators, specifically case managers of children with autism, need to have an understanding of a parent's point of view regarding their child's autism. Unlike some other medical or cognitive disability categories, autism spectrum disorder is unique in its extreme variety of how mildly or severely impaired a child may be. The types of treatment or educational planning which may effectively help a student with ASD may also be vastly different. Autism spectrum disorder is a construct in which the exact origin of the disability is unknown, resulting in the need for an in-depth analysis of each student to determine the

appropriate educational plan. When planning for students with a physical disability such as low vision, there are commonly accepted interventions or adaptations to assist the students. The same may be said for students diagnosed with a condition such as sickle cell anemia, which would require standard medical interventions. The diagnosis of autism for a student, on the other hand, does not necessarily give the case manager a “rule” to go by when planning for the unique needs of that student with the exceptions of some general guidelines provided by the DSM-IV. Students with autism typically experience difficulties with social interaction, but that could mean that they do not verbalize or interact at all with other people, or it may mean that they have slight difficulty joining in activities with their peers. There may be allergy or immunity issues with some students with autism but certainly not all. Most students with autism become more successful if they are provided pictorial schedules or social stories but again, case managers cannot generalize that statement to all students with autism. Parents who are seeking additional help for their child with autism may subscribe to one or several schools of thought as to the most effective plan of action when managing the social, medical, and educational needs of their children. Each family with whom a case manager works may have differing opinions on what they believe to be effective interventions for their child.

Levine, Marder, and Wagner (2004) reported that of all of the disability categories, parents of students with autism found it most difficult to find and access services for their children. One-third of the parents in their study (n = 525) reported needing to spend “a lot of effort” on their children’s behalf to obtain services for them. In citing barriers to obtaining services, half of the parents stated that the needed services were unavailable, the student was ineligible for the services or the services provided were of poor quality. Parents of students

with autism tended to rely much more on other parents, parent groups, or family members to learn about services than other parents. They were also more likely to have a non-school professional as their child's case manager.

Having a child with special needs in the family impacts the family system, regardless of the child's disability. The family system refers to the social system within a family where each person's action and experiences affect the other members of that family unit (Friend & Cook, 2003). As pointed out by Friend and Cook (2003), it is important to understand that the challenges and strengths of a family impact the entire family, not just the child with a disability. This understanding may help build the level of trust needed to collaborate more fully as a team in planning for the child's educational needs. If a case manager understands the unique needs of a child with autism as well as the family's unique concerns or priorities, the parents may have an increased level of trust in that case manager. Increased trust may open the door to improved collaboration for the best interest of the child and family.

Current practices certainly focus on the best interests of the child, but it is unclear whether the family's needs are taken into consideration in the elementary school planning process. By 'family needs' I mean that the teachers are really listening to what the parent concerns and priorities are for their child and that the parents understand the IEP process and how to actively participate in that process. Most parents have a need for information, not only regarding the disability but also on the type of impact this disability may have on the family. A parent's concerns about their child may not align with what the school-based concerns are. For example, the parent may have concerns regarding their child's toilet training. They may have concerns about other self-care skills such as feeding, bathing, and dressing. They may

express concerns about their child's future, which in itself may catapult the parent into taking a more proactive role in the development process of the IEP. A parent's priorities may differ from the school's priorities for the child. If parents feel that teachers understand their needs, they are more likely to have confidence in a team-based planning approach.

It should not be assumed that parents are knowledgeable about their role on the IEP team and feel that they are empowered just because their child has entered elementary school. A large part of becoming empowered means that the professionals on the IEP team respect and understand the fact that the parent knows the child better than anyone else. Too often it seems that parents whose children are given the autism spectrum diagnosis are so informed without further explanation of what it means to have autism, what steps can be taken to help the child at home, and how to learn more about the disability (Autism Society of Minnesota, 2008).

In this paper, I explored the perceived relationships between parents of children with autism and special education case managers as well as the level of involvement parents feel they have in the IEP process. My goal is to provide case managers and parents of children with autism with insights that may be helpful in collaborating and planning with regard to parents' concerns for their child with autism spectrum disorder. For the case manager, ensuring that a family feels acknowledged and has a sense of control of the IEP process will be central to providing the best possible service.

Research Questions

The following four questions guided this paper:

1. What role do parents of children with autism play in their child's IEP process?

2. What are parents' experiences with their current and past IEP teams?
3. What suggestions do parents have for school personnel to improve the IEP process for children with autism?
4. What suggestions do parents have for other families of children with autism who participate in IEP meetings?

I selected my articles for the review of literature based on the extant research on parents' perceptions of special education and the IEP process as well as perceptions parents have regarding working with case managers. The focus of the literature review includes recent articles (1998-2006) that discuss parent perceptions about service delivery.

The search methods I used included the electronic databases ERIC, Cambridge Scientific Abstracts, and EBSCO; and websites from the National Institute of Health (NIH), the Center for Disease Control (CDC), Autism Speaks, the Autism Society of America, the Minnesota Autism Society, Cure Autism Now (CAN), Autism Watch and Defeat Autism Now (DAN). The key words used in my search of peer-reviewed journal articles included: *autism* in conjunction with *etiology*, *parents*, *parental attitudes*, *special education*, *treatment*, *perceptions*, *national guidance*, *collaboration* and *school*. I also reviewed several books published since the early nineties on the topic of collaboration.

Importance of Problem

The topic of collaboration between parents of children with ASD and the IEP team is very timely considering the exponential growth in cases of children identified as having autism (National Institute of Health, 2007). Collaboration is defined by Webster's dictionary as "to work jointly". This means that there is more to an IEP meeting than just telling the

parent what the results of testing are and what the prescribed course of action should be.

There is currently a movement within Minnesota to require schools to have special educators become licensed in the area of autism in order to best meet the educational programming requirements of these children (Autism Society of Minnesota, 2008). I believe that an integral part of meeting the needs of these children is to take into consideration the family's unique desires and reflect those desires when developing the student's IEP.

The information learned regarding families' perceptions may be helpful to parents of children who are newly diagnosed with autism spectrum disorder. Families go through a natural grieving process (Bowman, 1994, 2001). The hopes and plans created in their minds for their children's future must be changed. The family dynamics change as well. It is my hope that the findings of this research will help families who have children with autism understand what steps they can take to become empowered and collaborate fully with their child's case manager. Through reading this paper, parents may also become better informed on how to use their child's case manager as a resource and understand the importance of being assertive in bringing information to the IEP team. Just as importantly, the information gained from this research will be helpful to special education professionals who work with parents and help guide them through the realm of ASD. Although school personnel cannot recommend any particular programming to parents, they can help parents in their own search of what may help their child. Having an understanding of what the family's perceptions are is a fundamental part of family-centered planning. It is an indispensable part of the IEP planning and service delivery that is mandated by law.

Definition of Terms

Autism. A term for a developmental disorder characterized by marked difficulty in communication and social relations and by the presence of atypical behaviors such as unusual responses to sensation, repetitive movements, and insistence on routine or sameness (American Psychiatric Association, 2000).

Autism Spectrum Disorder. This term is used to refer to any disorder in the overarching array of pervasive developmental disorders (PDDs).

Case manager. An educational case manager is the special educator appointed to ensure that a student's educational program is cohesive, coordinated, responsive to the student's identified needs, and carried out in accordance with the laws and regulations that apply to the education of students with disabilities.

Collaboration. The term collaboration refers to a structured, recursive process where two or more people work together toward a common goal, typically an intellectual endeavor that is creative in nature, by sharing knowledge, learning and building consensus.

Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV). This manual is a publication of the American Psychiatric Association. It is used by clinicians and contains diagnostic criteria for all acknowledged mental disorders.

Family-centered planning. This term refers to the use of resources to support and preserve families through a respectful, strengths-based approach that views the family as central to the child's well-being.

Individual Education Plan (IEP). A written plan/program developed by the school's special education team with input from the parents that specifies the student's educational goals and the method to obtain these goals.

Individuals with Disabilities Education Act (IDEA). This Act is a United States law that governs how states and public agencies provide early intervention, special education and related services to children with disabilities. This law addresses the educational needs of children with disabilities from birth to the age of 21.

Pervasive Developmental Disorder (PDD). This term describes a neurological disorder that is usually evident by age 3 and is characterized by severe and pervasive impairment in several areas of development including social interaction skills, communication skills or the presence of stereotyped behavior, interests, and activities.

Chapter 2: Review of the Literature

There is very little research on the perspectives of parents who have a child with autism in regards to the special education IEP. The four peer-reviewed articles presented here were specifically chosen because they involved qualitative research with families who have children with autism and they addressed the areas of IEP meetings and relationships with the special education team.

Spann et al. (2003) conducted interviews with families of children with autism who participated in a parent support group. The goal of the study was to extend the existing research literature by addressing the following questions: (a) What is the amount and nature of special education services that children receive from their school?; (b) What is the frequency and quality of communication that parents have with teachers and other personnel at their child's school?; (c) What is the nature of parents' knowledge about and involvement in their child's IEP process?; and (d) What is the nature of parents' priorities, and how much are they satisfied overall with their child's special education services?

The participants were parents of children with autism (N = 45). The children ranged in age from 4 to 18 years. There were 11 children in the 4-5 year old range, 18 children in the 6-9 year old category, 10 children in the 10-14 year old group and 6 children in the 15-18 year old age range.

Data were collected via telephone interviews that lasted between 40 and 60 minutes. There were 15 questions developed to guide the interviews which were conducted with one parent, tape-recorded, and summarized at a later time.

Findings from the interviews were categorized under each research question. The researchers found that 73% of children spent some time in a general education classroom and only 27% were solely in a special education setting. Service from speech therapy constituted 66% of cases, paraprofessional services occurred in 55% of cases, followed by occupational therapy (40%) and physical therapy (7%). Due to service overlap the numbers were greater than 100%.

The teachers or paraprofessionals, rather than the principal or others such as the speech or physical therapist, were listed as the people with whom the parents communicated most often and who were central to their child's education. Fifty-one percent of parents said they communicated on a daily basis with either the teacher or a paraprofessional, followed by 31% who communicated between one and three times per week. Two percent said they communicated biweekly and 16% communicated fewer than two times per month. Families with children in the first three age brackets (4-14) had the highest frequency of communication, with most of them talking or sharing notes with educators at least weekly. Only half of the parents of children in the 15-18 year age group interacted with school personnel weekly; 17% of these parents stated that they interacted on a biweekly basis and 33% indicated that they shared information or talked to school personnel less than two times per month. Just over 90% of the parents said that they shared information related to their child's behavior or progress at school. Three-fourths of the parents said that they brainstormed about problems that occurred at school or at home. One-third of the parents said that the interaction focused on conflicts or disagreements. Interestingly, half of all parents of children in the 15-18 year old group noted that they had periodic conflicts with school

personnel. The researchers did not delineate what the specific conflicts may have been.

Parents of children in the youngest age group reported the highest satisfaction in communication with school personnel (90%), whereas no parents of the children in the oldest age group reported that they were highly satisfied. In fact, one third of these parents reported low satisfaction with communication.

In response to questions about the IEP, 36% of parents stated they were highly knowledgeable about the IEP document, 37% stated they felt moderately knowledgeable, and 27% felt they had low knowledge of the IEP document. Involvement in the IEP process was rated high, moderate, and low, the parental percentages being 28%, 59%, and 13%, respectively.

There was an inverse relationship in the perception of how extensively the school was working on the parents' most pressing priorities and the age of the child. "Considerable extent" was rated by 36% of parents of 4 and 5 year olds while none of the parents of 15-18 year olds rated the school's efforts considerable. "To little or no extent" was the response of 83% of parents of 15-18 year olds, and only 36% of parents of the 4 and 5 year olds.

The same held true for parent satisfaction in the school's ability to meet the needs of the child. Parents of young children were twice as likely to rate their satisfaction as high (36%) as those of older children (16%). Only 19% of parents with young children gave a low satisfaction rating while over half (67%) of parents of older students said they their level of satisfaction was low.

A similar study was conducted by Stoner et al. (2005), who examined perceptions of parents in a support group; the main difference between the two studies being the age of the children who had the diagnosis of ASD.

This study also focused on parents' perspectives of their interactions with education professionals. The research questions for this study were as follows: (a) How do parents of children with ASD describe the influences of their interactions with education professionals? (b) How do parents of children with ASD describe their experiences when interacting with education professionals?; and (c) How do parents of children with ASD describe their roles and relationships with education professionals?

Four married couples from a parent support group volunteered to be a part of this study. Data were collected through three interviews with each parent (24 semi-structured interviews over the duration of the study). The researchers conducted a cross-case analysis of the data, using line-by-line coding and categorization.

The findings were organized by research questions (a) and (b), with eight themes emerging. Theme 1 was that a struggle for a diagnosis initiated a pattern of persistent behavior by the parent and cultivated parents' sense of distrust with the medical professionals, which persisted in their interactions with education professionals. Theme 2 was that upon their child's receiving of the diagnosis, parents were propelled into a process of intense self-education. This initiated a two-step reactive pattern of behavior: self-education and external problem-focused behavior. Theme 3 was that early intervention services were perceived positively because they met the parental needs of self-education and external problem-focused behavior. Theme 4 was that parents felt that entering the special education system was

traumatic, initial IEP meetings were confusing, and obtaining services was complicated. These perceptions resulted in the parents' shifting their focus of distrust from the medical professionals and the struggle to obtain a diagnosis to education professionals and their perceived willingness or non-willingness to provide for all their child's educational needs. Theme 5 was that parents had an intense need for frequent open and honest communication from teachers for two reasons (a) because a lack of communication fostered distrust, and (b) due to their child's pervasive communication disorder. The sixth theme was that negative experiences reduced trust to such an extent that parents reported not trusting any education professionals or trusting them conditionally, even when their individual situations had improved. In theme seven, researchers identified parents' high value on positive teaching dispositions and spoke of a genuine appreciation for individual teachers who "had the heart to teach". The final theme related to parents' positive perceptions of administrators who were accessible, supportive, and addressed parental concerns.

One limitation to both of these studies was how the participants were recruited. Both studies found their parent volunteers from autism support groups. Choosing families from only support groups could affect the type of feedback received. Parents who choose to participate in a support group are likely to feel that they need an increased level support; either from other parents or from educators. It would be more encompassing to also recruit families who have not joined a support group.

While the study by Spann et al. (2003) contained extensive data broken down in various categories, it does not give any indication as to the types of teacher behaviors or situations that influenced parents' responses to items reflecting their satisfaction with the

school, for example. This type of information would have been very useful. The study by Stoner et al. (2005) provided an in-depth understanding of the things that were important to parents and the situations to which they responded negatively. With input from both parents, it would have been interesting to compare the perceptions of males versus females to identify any significant discrepancy in views. Authors of both articles stated that additional research needed to be conducted with regard to parent perceptions about special education and that this information would help provide the best possible service to children who are considered as having ASD.

A case study conducted by Fish (2006) discussed findings from research with a group of parents of children with autism. The focus was on parental perceptions toward the IEP meetings in the following areas: (a) The quality of services provided to the child as a result of the IEP meeting, (b) How parents felt they were treated and perceived by the IEP team members, (c) What changes the parent would like to see, (d) How districts can improve IEP meetings, and (e) How parents can improve IEP meetings.

Of the 10 families in the support group, seven participated in this study. Data were gathered through interviews which were audio recorded, transcribed, and analyzed. The findings were listed in the same order as the interview questions were asked.

In regard to the quality of service received, participants indicated that their initial IEP experiences were negative. Parents stated that they were “surprised to discover that the views of educators were often not consistent with the implementation of ideas that parents believed to be the best approach for serving their children.” The manner in which the district handled discipline and the quality of services for students with autism were noted as key factors in the

negative perception. Five of the seven participants disagreed with educators in regard to what services ought to be provided to their children. It is worth noting that although it was not explicitly stated, the students with autism in this study must have been in a non-inclusive setting as the parents believed that the students would be better served if they could have periodic contact with the general education student population.

When inquiring about the treatment and perception of the IEP team the researcher found that most of the participants had experienced negative treatment at one time or another during an IEP meeting. Three of the participants discussed how they had been blamed for their child's academic and behavioral deficiencies. It was noted that all the participants agreed that they seemed to be treated better if they had an advocate attend the IEP meeting with them. Several interviewees indicated that relationships improved over time and attributed that to the parent becoming better informed about the IEP process and to educators becoming more aware of students' disabilities.

When participants were asked what type of changes they would like to see in the IEP meeting they stated that they would like to see the IEP meeting become more of a "cooperative venture" and less of an "adversarial encounter". Parents felt that the IEP meeting was more of a formality than a means to meet students' educational needs. The parents also believed that some of the adversarial interactions were due to a lack of understanding about disabilities on the part of educators.

The participants suggested that school districts could improve IEP meetings by making the meetings more democratic and allowing parents equal input. They also felt that meetings could be improved if districts provided formal IEP training and workshops for

parents on special education law and the IEP process. At the same time, participants recommended that families take it upon themselves to actively seek information on special education law and the IEP process.

Limitations listed by the researcher were that the pool of parents came from one support group and that the parents were more likely to become a part of this support group after having had a negative IEP experience.

Although Stoner and Angell (2006) also used families from a parent support group, their research looked at the parent's involvement a bit differently from the studies previously described. They examined parent behaviors and categorized those behaviors into common roles that parents take on when working with special educators and members of the IEP team. The families were purposefully selected from a parent support group in a mid-western city. The primary form of data collection was semi-structured interviews using open-ended questions. All initial interviews were transcribed and analyzed, and based on the responses, second and third interviews were conducted.

After analyzing interview responses, the researchers identified "roles" that the parents filled when working with educators. The parents seemed to engage in these roles as an active part of the process of working with educators. There were four main roles that emerged as a result of the interviews with these families. The thematic roles and their significance were reported as follows:

1. *Negotiator*. Three critical findings concerning the role of negotiator were
 - (a) parents prepared for negotiation at the IEP meeting, (b) parents saw providing

rationales for their requests as an effective negotiation strategy, and (c) parents' use of outside mediators as negotiators achieved positive results.

2. *Monitor*. All of the interviewees participated in either formal or informal monitoring of the quality and content of their child's educational program. Attending the IEP itself was considered a type of formal monitoring of what was happening in their child's education. Informal monitoring included using communication notebooks, observing changes in the child's behavior, and parental assistance in the classrooms/schools. Also, more intense monitoring occurred when the parents believed there were problems; all the parents indicated that a change in behavior was a reliable indicator of problems at school. It was at that time that the parent would increase their monitoring.
3. *Supporter*. The role of supporter was defined as parents encouraging, assisting, or advocating for teachers. The critical findings of this type of role were: (a) parents engaged in the role of supporter by encouraging their children's teachers; and (b) parents provided direct assistance, such as producing classroom materials, purchasing items for the classroom, and reinforcing classroom intervention strategies in the home.
4. *Advocate*. The term advocate was used to describe parental participation in supplemental advocacy activities beyond those affecting their own children. The two critical findings for this role were that (a) all of the mothers in the study participated in some form of supplemental advocacy such as volunteering in the classrooms or other areas of the school or becoming members of autism groups in

their area, and (b) the fathers were not as active, but they supported their wives' efforts.

In addition to these roles played by parents, the researchers also identified several themes. Trust was a prevailing theme throughout this study. The authors stated that parents indicated "that education professionals, whom they considered experts, did not necessarily know as much about autism intervention as the parents" (Stoner & Angell, 2006, p. 184).

The authors made two recommendations based on the research they completed. The first recommendation was that educators "recognize the potential benefit of parents' assuming multiple roles within the education setting and encourage parents to be fully engaged in their children's education" (p. 186). The authors stated that educators should be cognizant of the fact that parents may want to be involved in a variety of ways and at differing levels of intensity. The second recommendation was to recognize the fact that "parents will vary in their levels of engagement in their children's education" (p. 187). While all parents have a right and responsibility to monitor the quality of their child's educational programming, some may do this on a regular, ongoing basis and others may monitor things less closely.

Summary

In the first article outlined, Spann et al. (2003) found that less than one-quarter of families interviewed felt that they had a high level of involvement in the IEP process. This is significant considering the fact that parents should be an equal member of the IEP team per IDEA. In addition, there was found to be an inverse relationship between the age of the child and the satisfaction of the family with the special education process. A similar trend was found with regards to the age of the student and how strongly the families felt that the school

was addressing the most pressing issues. Approximately one-third of the parents of the youngest children ranked the “working to meet the current priorities” as high while none of the families of the older students gave it the same rating. In fact, over three-fourths of the parents of older students rated the extensiveness of the schools efforts as “to little or no extent”.

Stoner et al. (2005) focused on the perceived relationships between parents and education professionals. Of the themes that emerged from this study, distrust and negative experiences were in the forefront. On the positive side, parents felt that their experiences with early intervention services were constructive because they met the underlying need of the parents.

The case study by Fish (2006) specifically addressed the parents’ perceptions about the IEP meeting and asked participants for ways that the meeting could be improved. All of the participants in this study felt that they had a negative initial IEP meeting. A majority of them also stated that they felt they had been blamed in at least one meeting for their child’s behavior or lack of academic progress. As far as improving the IEP meetings, the themes were that of parents educating themselves about the special education process and the special education laws, schools educating parents about the IEP process, and teams allowing parents to have more input at the meetings.

In the study by Stoner and Angell (2006), interviews were conducted with four families and the behaviors of those families were studied and categorized by how a parent fits into a type of role when they are involved with the IEP team. The roles were found to evolve over time and parents may be filling multiple roles at any time. The four roles which emerged

as themes were negotiator, monitor, supporter, and advocate. Again, trust, or lack thereof, played a central role in the families perceptions of the IEP team.

Although the researchers approached the studies in differing ways, they ultimately came up with similar findings. The findings indicated that parents experienced (a) a general feeling of negativity toward the initial IEP meeting, (b) issues of distrust toward the education professionals and (c) feelings of inconsistency between what special educators professed and what actually occurred at the IEP meeting.

Chapter 3: Method

The purpose of this research was to explore the extent to which parents felt they were an essential part of the IEP process for their children with autism. This analysis included an exploration of parental perceptions of the case managers who service these children.

A qualitative method was used for this study. Qualitative research typically emphasizes descriptive data and narrative. It is an attempt to gather meaning, in this case from purposefully selected participants. I interviewed four parents who had children diagnosed with autism spectrum disorder. All interviewees happened to be the mother. The parents represented four school districts in the state of Minnesota; Independent School District (ISD) 15 – St. Francis, ISD 742 – St. Cloud, ISD 477- Princeton and ISD 4142- STRIDE Academy charter school.

Procedures

In order to answer the research questions, data were collected via parent interviews from a variety of schools in different districts. All interviews were audio taped and the transcripts were analyzed by me and another special education professional. A system for coding, suggested by Bogdan and Biklin (1998), was used. First the interview transcripts were read in their entirety in chronological order. While reading through the transcripts a second time, descriptions of participants' experiences were written in the margins. These descriptions were then reread to determine categories of experiences. Categorizing involves organizing coded data units into categories identified through similar characteristics (Lincoln & Guba, 1985). Categories such as "misinformed by professionals" and "advocate" were identified and written as headings in separate notes. Then the transcripts were reread and examples of

experiences that fell within the named categories were listed underneath the headings. Finally, focused coding was used to combine and subdivide coding categories (Anzul, Ely, Friedman, Garner, & Steinmetz, 1999). This focused coding resulted in the themes that identified parent experiences in their child's IEP process. These themes are presented in the *Results* section and are illustrated with direct quotes so as to provide meaning in the words of the participants.

Validity of findings is increased through triangulation--using multiple methods of synthesizing data (Mathison, 1988). Triangulation was obtained through member checking. Member checking involved sharing my draft study findings with the participants to inquire whether their viewpoints were faithfully interpreted, whether there were gross errors of fact, and finally, whether the account made sense to participants (Lincoln & Guba, 1985).

Participants

Purposeful sampling was used to select parents for interviews with the intention of selecting participants who would provide "rich examples of the phenomenon of interest, but not unusual cases" (Patton, 1990, p. 138). The selected parents had at least one child with an educational diagnosis of autism who was currently enrolled in the public school system and had the diagnosis of autism for at least one year. Participants were selected by sending out letters which invited parents to participate in interviews for a research study. The letter was given to case managers of children with autism at three elementary schools and one middle school in St. Francis. Twenty-four letters were distributed in all. One parent response was received and that parent was interviewed. After receiving only one response, additional participants were recruited through contact with professors at St. Cloud State University; one of whom was aware of a parent who had a child with autism who chose to participate, and

another professor who had contacts at STRIDE Academy in St. Cloud. Two parents from that school responded and were interviewed.

Interviews

Interview transcripts were used as an analysis method to make meaning of participants' experiences. While many questions were individualized for each participant based on their personal experiences and recollections of specific situations, the aim was to elicit the same type of information from each participant. During the initial interview I intended to get information about the parent's experience with their child's special education case manager, and also attempted to understand parents' perceptions of their involvement in the IEP process. The questions designed for the first interviews were based on findings of extant research (see Appendix A for initial interview questions). In the second interview there were follow up questions for each interviewee based on the initial responses in the first meeting. These questions were intended to obtain clarification of previous information. In the third and final interview, participants were asked to reflect on their IEP experiences over time; how it may have changed them and their responses to case managers and IEP meetings.

All participants were informed that their responses would be completely anonymous and their signed consent to be interviewed and audio taped was obtained. Participants were informed of what the overall purpose of the interviews was, as well as the focus of each interview. They were also given an approximate time frame for each interview. Initial interviews lasted between 25 and 45 minutes. The interviews were conducted in a variety of locations, selected by the interviewees. These locations included the researcher's home, the

participant's home, and a restaurant. There was approximately a 2-week interval between the first and second interviews and a 3-week interval between the second and third interviews.

Chapter 4: Results

The aim of this thesis was to understand how the participants defined their experiences with case managers and the IEP team and also to understand their feelings about the IEP process. In analyzing interview transcripts, several ways of defining positive experiences emerged. From the parent perspective, a positive experience with the case manager and IEP team as a whole was based on the team's willingness to research options to enhance their child's education and develop a personal relationship with the parent. Parents described two main perceptions as key aspects of developing positive experiences: (a) feeling included and supported in the IEP process, and (b) the IEP team having an accurate understanding of the child as a whole.

Four parents were interviewed, three of whom had one child with autism and one of whom had two children on the spectrum. The following section presents a description of each child, the age at diagnosis, the current age, grade, and gender. A synopsis of the demographics can be found in Table 2.

Child Profiles

Darrin was a 13-year-old Caucasian male, currently enrolled in eighth grade. Darrin was given an educational diagnosis of autism in fifth grade at age 10, after his mother requested an assessment.

Evelyn was a 12-year-old Caucasian female, currently enrolled in seventh grade. In kindergarten the school referred Evelyn for neuropsychological testing, after which she received the medical diagnosis of autism.

Anna was a 6-year-old Caucasian female, currently enrolled in first grade. She received an educational diagnosis of autism spectrum disorder (ASD) in preschool, at age 4. At the same time, she received a diagnosis of attention deficit hyperactivity disorder (ADHD) and was prescribed medication to “help her attend to tasks”.

Michael, Anna’s younger brother, was a 5-year-old Caucasian male, currently enrolled in preschool. He initially received the educational diagnosis of autism at age 4 and began receiving in-home services at that time.

Grace was an 8-year-old Caucasian female, currently enrolled in second grade. While attending Headstart she was given an educational diagnosis of PDD-NOS. She later received a medical diagnosis of Asperger’s disorder at age 6.

Table 2

Family Information

<u>Participant’s name</u>	<u>Jeanette</u>	<u>Laurel</u>	<u>Melodie</u>	<u>Charlotte</u>	
Number of years attending IEP meetings for child	4	6	4	2	3
Child’s name and age	Darrin, 13	Evelyn, 12	Anna, 6 / Michael, 5	Grace, 8	
Age at diagnosis	10	5	4	3	5

Parent Background Profiles

At age 13, Jeanette’s son Darrin was the oldest child with an ASD diagnosis. Darrin was first diagnosed as speech-delayed at age 5, in kindergarten. It was not until fourth grade that teachers noted some atypical behaviors. He would withdraw and read constantly, no matter what else was happening in the classroom. At the same time, Jeanette was learning more about autism and the part of the spectrum called Asperger’s syndrome through trainings

she attended as a paraprofessional for the school district. She and her husband struggled as parents; they would see their 10-year-old son “melting down” on the floor because he had to brush his teeth or leave the house and they knew that this was not typical behavior. At that time Darrin’s mother requested an assessment from the school district.

Laurel’s daughter Evelyn was 12 years old. Laurel said that her daughter was speech delayed and initially started receiving speech services at age 3. At that time an occupational therapist noticed that Evelyn had some sensory issues, so she referred Evelyn for occupational therapy services as well. When the kindergarten teacher wanted to hold Evelyn back a grade, Laurel was concerned that there were more undiscovered issues with her daughter, so she actively started looking for information and took Laurel for neuropsychological testing. It was then that Evelyn was diagnosed with autism.

Melodie had two young children with autism spectrum disorder. According to Melodie, her daughter Anna seemed to develop typical speech, even being precocious in this area. Melodie’s concerns were based on the fact that Anna did not seem to understand any of the social skills children typically have at age 4, and had developed echolalia (repetition of words or phrases). Fortunately for Melodie, she had a friend who had a teenage daughter with autism. Melodie noted some of the same behaviors in her daughter and, knowing how important early intervention was, referred her daughter for assessment through the county’s early childhood program. Melodie was very vigilant when her second child, Michael, was born. She became alerted to possible issues when Michael was two years old and was only speaking one to three words. She called the county early childhood intervention program and her son began receiving in home services once he was identified as having autism at age 3.

Grace was Charlotte's first-born child. Because Charlotte did not have other children to compare Grace's development to, she turned to her sister-in-law who had other children, one of whom had a disability. Her sister-in-law suggested that Grace should be assessed and Grace was identified at age 2 with being speech-delayed. Shortly thereafter Grace was receiving not only speech services but also occupational therapy and physical therapy. The staff at Headstart told Charlotte that her daughter had "something called PDD-NOS." The unfortunate thing about this label was that it did not allow for any additional services for Grace, which Charlotte believed she needed. During this time, Charlotte was trying to learn what type of specific disability her daughter had. The family went to a few therapists before they received the current diagnosis of Asperger's.

There were two themes that emerged during the first phase of my interviews with these parents. The first theme was a perception of a lack of information from medical and educational professionals. The second theme related to negative experiences at the first IEP meeting.

Lack of Information

As previously stated, when Charlotte's daughter received the diagnosis of PDD-NOS there were no significant services provided to address her daughter's issues related to this disability. Charlotte stated that the school was very impressed with her daughter's knowledge base when they initially assessed her:

She knew all of her numbers, she knew all of her colors, she was starting to count and she was two! And I said well, that's great, but if you were to ask her a question she's going to hide under the table. So, really, knowing all that stuff is not going to do her any good from under the table. So they said that...well, we don't know what's wrong, we can't quite put our finger on it, but there's just something not quite right. That's a statement I heard over and over for *years*, from various people in the school...

Charlotte continued to be concerned about her daughter's development, seeking advice from her pediatrician. He encouraged her to "trust her gut" and take Grace for an evaluation.

Charlotte and her family spent a lot of time trying to determine exactly what was going on with Grace. It was frustrating for the family because they received different interpretations of Grace's behavior from different therapists. Charlotte explained:

...And then we had a neuropsych test for borderline, when she was about 4. We had another done when she was about 5 or 6...that therapist thought that she was shy. You know, so we got some missed cues too. We had several done. So we finally went to somebody who specializes in neuropsych testing and she said –yep, it's Asperger's.

Upon receiving the Asperger's disorder label, Grace was able to obtain speech therapy, occupational therapy, and physical therapy. Grace also received early childhood special education through Headstart.

Laurel had a similar experience when she was trying to find help for her daughter, Evelyn. It seemed everyone, including doctors and teachers, was in agreement that something was "going on" with Evelyn, but no one could clarify what that was exactly. Laurel explained:

They wanted to hold her back in kindergarten. I said ok, every different person I talk to is telling me something different, so I said who can tell me what's going on - once and for all what's going on and that's when I got referred for a neuropsych test and that's when she was diagnosed. ...the public schools were classifying her just learning disabled, she was attending parochial school and they felt she just needed to be held back, and then there was her occupational therapist who just *felt* there was something more. It was her therapist's remarks that got the ball rolling and got us to have neuro psych testing. I did not agree with what either of the schools were telling me, I also thought there was more to what was going on.

Jeanette and her husband were the first to suspect that something was developmentally atypical with their son Darrin. Their son had attended school all the way through fourth grade without having any teachers bring up concerns about academics or behaviors. Darrin was considered a very bright student and the only atypical behavior noted at school was that he

would withdraw and read all the time, even during the teacher's lesson. Jeanette worked as a paraprofessional for the school district so she had learned a lot about autism spectrum disorder. As she stated, "...all the year he was in fourth grade...it [his atypical behavior] did kind of almost hit me." Jeanette was able to recognize that some of Darrin's behavior difficulties resulted from a lack of understanding by his general education teachers:

Darrin looks normal. Darrin talks smart. And they don't understand the inconsistency in performance. I've been told he's manipulative, I've been told he just needs to try harder. Many of them just don't get it. That's where we need more education. Don't get me wrong, they're good teachers, most of them. Just like any profession, there's some that aren't and some that are. Most of them are. They just don't understand my son or other kids like him.

She went on to speculate about those teachers who understood her son, "It's interesting because the ones that get him a little bit better, he has better grades in those classes. And those are the teachers that come to the IEP meetings too." This situation ties into having an understanding of the unique needs of a student with autism and supports the idea of teachers having a vested interest in the educational process for the students that they serve.

Melodie, unlike some of the other parents interviewed, did not have a difficult time receiving a diagnosis for either of her children. She did, however, express disappointment in the lack of information provided to her about the meaning of autism at the time of diagnosis. She felt uninformed and unprepared to deal with what she was being told by the teachers:

Sometimes you... I mean my daughter...my big dilemma was when she was going through all this was, she seemed so normal and I expected her to be normal. ...they should tell the parent a little more directly what's going on. If it's your 'normal' autism or whatever, you know, they can tell you your child is gonna take a lot longer to learn things and that you need to have patience.

Parents interviewed had the common experience of (a) not getting accurate (or complete) information from medical and/or educational professionals, and (b) having a

feeling that things “were not right” but not getting agreement from the professionals with whom they consulted.

The First IEP Meeting

Along with parents’ frustrating experiences in trying to get diagnoses for their children, all parents discussed their negative early IEP meeting experiences. Parents interviewed shared that they had negative experiences of varying degrees during their initial IEP meetings. Typically, this first meeting presents the parent with the current level of functioning of their child which comes in the form of testing results. The types of evaluations vary, they could be many or few but they typically include an intellectual test, an academic assessment, an autism assessment (which looks at social skills among other things), large and small muscle assessment (gross and fine motor movements) and direct observations of the student’s current level of functioning compared to peers.

Melodie’s discomfort at the first IEP meeting was based on the fact that although she was given a diagnosis of Anna’s disability and what the school would be able to do to help her, she felt that the diagnosis was not thoroughly explained to her in terms of the common characteristics and what to expect from her child behaviorally. She was also not provided any tools to help her work with her child at home. Here Melodie explained what she needed from the IEP team members at that first meeting:

When I found out my kid had autism I just, like I said, started trying to find out what it was and I think half the time I didn’t even know what it was...I didn’t understand anything about autism. All I knew is that they understand things differently. There was a lot of time wasted because I did know that with autism they think differently but I didn’t understand how they thought.

Melodie felt that if she had been given some more concrete information and specific activities to do with her child, Anna's progress would have been even faster.

Jeanette felt that she was not given information as to what she should expect at the first IEP meeting. She did not even understand the purpose of the meeting and how it was different from a regular parent-teacher conference. She explained:

This is how much parents know, and I feel like I am fairly intelligent, but when my son was originally identified in first grade I went to an IEP meeting. And I'm sure I received a team notice saying it was an IEP meeting, I didn't get what that meant. Nobody had ever really explained what that meant. Sure, you get the Procedural Safeguards but that doesn't mean anything to you if you haven't been educated on it. It's just paper with some laws on it that really...you're like...what does this mean? I went to that IEP meeting, that meeting; to me it was a conference. It was also regular conference time with the classroom teacher. The principal was there. I didn't know why the principal was there, I had no clue. I knew that the speech pathologist was there because she was going to tell me why, you know, what Darrin's progress was. But I'm like, what did Darrin do wrong, the principal is at this meeting. It just shows what is not said, you know, too many things are assumed. And it's not that I'm not intelligent, it's just that I didn't understand the process. No one had ever explained the process.

Jeanette clearly felt that she was not given information she needed in order to understand an IEP meeting. She did not even understand the purpose of the meeting and how it was different from a regular parent-teacher conference. It seemed to her that while the school went through the motions of following protocol, no one made the effort to contact her personally and explain the process. In this case, this lack of information led to her confusion about why certain people, such as the principal, were even at the meeting.

Laurel and Charlotte expressed that the size of the first meeting and the considerable amount information given to them at this meeting made for a negative experience. It did not seem to them that the people at the meeting were being aware of and sensitive to their

feelings. Charlotte shared her first experience at an IEP meeting and the lacking spirit of collaboration which resulted from the principal single-handedly making a team decision.

...then I found a smaller school that we decided to go to and we changed our mind. Here they have a full-day and half-day kindergarten based on how you hit the lottery. And we went to an IEP meeting and I don't remember who the person was that came in but basically said, 'well, I don't care, I don't think she needs full-day kindergarten.' And I said 'my daughter has Asperger's--what's her number one problem? Socialization. And change. If you put her in a half-day this year, do you know how hard it's going to be for me to get her to go to full-day next year?' Because this head honcho, whoever it was said, 'no, I'm not gonna put it in her IEP that she needs to have full day', all the other IEP people were like, 'oh, okay, well it might be better for her if she doesn't get full time.' We didn't go to that school. So that was my only bad issue with IEP meetings...my very first one!

Charlotte felt that she had little or no input into the decision-making process. The IEP team seemed to be willing to consider full-day versus half-day kindergarten until the principal took a stand and said that full-day kindergarten would not be an option. The team then fell in line behind the principal's decision at the expense of including the parent in the process.

Charlotte summed up how she felt at her first meeting; she spoke of how she felt that she had no say in the decision making process because it was a "fight" between her as a parent and the school as to what would be in the best educational interest of her child.

... I gave up because I didn't feel it was a battle I could win. You shouldn't have to fight that hard, to get what you feel you need. I mean, that as a parent I think, this is a woman who has never even seen my child! Here, can I show you at least a picture of what my child looks like...this is the child you're referring to. But instead it's just, 'no, I won't put it in her IEP...no.' And it all had to do with budgets.

Clearly, Charlotte did not feel that the IEP meeting was a collaborative attempt to provide the best education for her daughter. More specifically, she felt that the educators had other interests and that was not a good message to send to a parent.

Laurel's experience at her first IEP meeting was that of feeling as if everyone at the table was overloading her with negative information about her child. Again, there appeared to be a lack of sensitivity to how she as a parent would perceive this information.

[I've] just been inundated with, 'your child can't do this, your child can't do this, your child can't do that.' A new parent just finding out feels like they're slammed - for lack of a better word. You've got ten people sitting there basically picking your child apart and you walk out of there just feeling devastated. I think initially it's hard enough for a parent to digest what they're being told about their child and I just don't think it should be handled in the way its handled, with, you know, every single person that has tested your child is now going to sit down and give you all this information. Like I said, it's hard enough for a parent to even hear that there's something different about their child much less then to go through two hours of hearing every little detail.

Laurel felt as if the team made no effort to consider her feelings in the way that they presented information at the meeting. The way the meeting was run made Laurel feel set apart right from the beginning; as if it were the educators versus the parent.

After these negative initial IEP meetings, these parents realized that they had to play a larger role in finding information about autism and providing it to the IEP team as well as learn how to advocate and participate during the IEP process. Just as the study by Stoner and Angell (2006) suggests, after feeling excluded from decisions, the parents took on a more proactive role in their child's education. The authors outlined roles that parents typically assume when they are working with the IEP team. It is important to note that the skills parents have in these roles evolve over time. These are not abilities which parents have when they walk into their first IEP meeting. The parents in my study fulfilled the role of *negotiator*, which is one who brings about desired outcomes through discussions, conferences, and compromise. All the parents took on the role of *monitor*, which describes actions that check the quality and content of their child's educational plan on an ongoing basis. To varying

degrees the role of *supporter* was also evidenced by the parents. The supporter role is one in which the parent encourages, assists, and advocates for the teachers. This typically occurs when the parent feels comfortable in the knowledge that their child is receiving an effective education. This seems to be a role that all of the parents in this study were filling at the time of my interviews with them.

There were three themes identified in the final interview. These were (a) parents' perceptions of the current IEP team, (b) recommendations for schools to improve IEP meetings, and (c) recommendations to other parents for improving IEP meetings.

The Current IEP Team

Although all of the parents shared negative experiences of their initial IEP meetings, they all expressed satisfaction with their current teams. This situation could be due to several factors. The parents may now be more comfortable in advocating and therefore find it easier to negotiate with the team members. It could also be the case that as the parents' knowledge base increased, they understood better what the team was proposing and discussing regarding their children.

Laurel, who had a difficult beginning with getting the special education diagnosis for her daughter, was especially pleased with the IEP team this year. When asked about her comfort level with the current case manager she said, "I don't know if she's as knowledgeable [about autism] as one's I've had in the past, but definitely very willing to look into things."

She went on to talk about the team in general:

I am very, very pleased. She's having a phenomenal year. She's got a good team this year and really...not that they haven't all been proactive but they're very much...they have a goal in mind and are working toward that goal; not just a day to day –ok, she

has to learn this, she has to learn that. They're prepping her for junior high next year. They're looking beyond just this school year, even junior high...life skills.

Laurel expressed her perspective on being a member of the IEP team in the following way:

I think for the most part, though, I have always been respected. Maybe they haven't agreed with the choices I've made or how I asked them to do things but they respect. They sometimes very strongly voice their opinion if they think I'm wrong but still respect that I have the final say.

Having recognized that she has the final say in her daughter's educational planning is indicative of how Laurel's feeling of empowerment had grown over time. The awareness that she knew all the intricacies of her daughter's autism, and that this knowledge was valuable to the educator's in her daughter's life, made Laurel feel much more confident in the IEP process.

Jeanette felt that she, too, was a valued member of her current IEP team. She and the case manager had developed a positive relationship.

She has learned an unbelievable amount this year and we are pretty much on the same page. [Working with her] has been really good. I talk to the case manager every week. I mean...we e-mail, we talk. And then we meet more frequent than just the typical. It probably took us six or seven hours just to get to the point where we had a finished IEP this time.

Jeanette's indication in this statement was that she felt she had a relationship with the case manager which went beyond that which the typical case manager may have with a parent. She highly valued the willingness of the case manager to spend as much time as necessary ensuring that the school was meeting the needs of the student and that the parent was involved. She also felt that the team made an effort to see if she agreed with the team's plans for her son's goals.

Charlotte felt that she was able to bring a lot of information to the IEP team since they were fairly new teachers and she was the one with the experience with autism. Despite the team's lack of experience, Charlotte clearly appreciated their consistent follow through:

If [the case manager] doesn't know something she will tell me straight up, 'you know, I really don't know that, let me find out some more, let me talk to the other girls...let me get more information and I will get back to you.' So they've always been really good about, you know, they will say, 'I don't know but I will find out'...and have always followed through.

The insight provided by Charlotte was significant. Although there was a lack of experience among the team who was charged with providing the best education for her daughter, she felt encouraged rather than disenfranchised because the team gave her the impression that they were willing to get information for her and were openly receptive to her ideas. She gained a sense of empowerment through her expertise in the area of autism and being able to actively contribute to the IEP planning process.

Melodie valued the level of comfort she had with the people at the meeting, which is something she had with her current team, "[I feel I am] treated with respect. I'm comfortable around them. I can speak freely around them if I have an issue or something." Regarding the case manager, Melodie said, "I feel I can talk to her. There is no secrets or anything. It seems like we're on a pretty open communication."

Melodie's comfort level had changed from feeling uninformed and viewing the process as intimidating, to trusting the people on the IEP team. She felt that, in contrast to her initial trepidation, the team valued her opinion and wanted to include her in the planning process, answering her questions and gaining her input along the way. Much of this transformation occurred because Melodie had a person attend IEP meetings with her, one who

had more experience with the IEP process and who understood what the role and rights of the parent were. Another element to the transformation was that Melodie engaged in intense self-education about her daughter's diagnosis and found that in many areas she was more knowledgeable than the case managers on the IEP team.

Recommendations for Schools

The parents interviewed all had suggestions on how schools, specifically case managers could improve IEP meetings. The majority of the comments were in regard to changing how the very first IEP meeting was conducted. Charlotte felt that the first meeting should be smaller so as not to be overwhelming for the parents, and she shared ideas on how the team could be more sensitive to a parent's feelings:

I think in the beginning, it would be nicer, if, say everyone's gotta be there, well, all 11 people don't gotta be sitting there for the whole hour. Why can't 2 or 3 people come in and talk, then they leave and the next 2 or 3 come in and talk? `Cuz I think that's another way that it would not be so overwhelming to someone new in the IEP process. Like I said, there's nothing worse than going in there and there's...you know, you almost feel like you're on trial...there's the jury. It's like...remember the good manager skills: start with a compliment, say something that needs to be worked on and end with a compliment. Rather than saying, 'you know, well she knows her ABC's, but all this is bad.' That's it...now that you have that horrible thought in your head I'll let the next person beat up on you.

Another area that Charlotte addressed was that of how teaching professionals speak to parents. She said that some of her best IEP meetings were when she was included in the dialogue and was asked if she had questions along the way, rather than at the end of the meeting. She explained:

I really felt like I wasn't being spoken *at*, I was being spoken *with*. And that is the big difference, I think, between a good and a bad IEP meeting. When they speak at you and say this, that and the other thing and when they're all said and done then they're like, 'now do you have any questions?'

Laurel echoed some of the same sentiments when asked how schools could improve IEP meetings for parents. In regard to the initial meetings, she stated, “I think it definitely should be broken up into smaller meetings, you know, a couple people at a time.” She went on to reflect how her perceptions changed with time and experience, “I guess I have been to so many that it’s...it’s not as hard now. Or even as you go on, the team is smaller. It’s me and four other people now.” Laurel had suggestions for what the case manager could do proactively to help the parents:

I think one thing they could do on a proactive...rather than, ok, you have your meeting and you sit down and they hand you this and you have 10 days or what it is to agree, sign it, and turn it back in; I think they should give that information to the parents ahead of time so that a parent can come to the meeting having read through everything that they’re suggesting. And rather than write it in the spot, trying to come up with changes or suggestions, I think a parent could come more prepared to know what they’re going to talk about.

It is important to note that according to some parents and educators, it may be best practice to send a draft of the proposed IEP in advance to the parent so that they can review it and then write the final draft at the meeting with everyone present. Unfortunately, this rarely, if ever happens. The most often cited reason is that case managers feel extremely pressed for time to get the IEP in its final form within the deadlines provided in federal IEP guidelines. The U.S. Department of Education, however, does not encourage or deny case managers to send out a draft IEP in advance. In fact, when the U.S. Education Department published the IDEA 2004 special education regulations, they included a commentary to address why specific regulations were chosen. In regard to having a draft IEP, the commentary states:

We do not encourage public agencies to prepare a draft IEP prior to the IEP Team meeting, particularly if doing so would inhibit a full discussion of the child’s needs. However, if a public agency develops a draft IEP prior to the IEP Team meeting, the agency should make it clear to the parents at the outset of the meeting that the services

proposed by the agency are preliminary recommendations for review and discussion with the parents. The public agency also should provide the parents with a copy of its draft proposals ... It is not permissible for an agency to have the final IEP completed before an IEP Team meeting begins.

In this statement it is clear that although case managers are not permitted to bring a final draft to an IEP meeting, the U. S. Department of Education is hesitant to have the case manager send out a draft copy in advance due to the fact that parents may be unclear that the information contained is preliminary.

Laurel's suggestion for the district was to treat parents equally *district-wide*, not based on how strongly the parent was willing to advocate for their child.

...that is the one thing that I find difficult in this school district is that they're not all...they don't handle things consistently between schools like that. Because what happened at [my friend's] IEP may not happen at another one. They aren't consistent across the board about how they handle [parent concerns]. Or just the way they're handled as far as [my friend's] information....because I feel very strongly that if that had happened at one of mine, and I would have argued the point, I would have won. That they would have listened to me. Because I've done that. When [my daughter] was in preschool I didn't...I had a problem with the director and I went to the assistant of the school district and we all sat down and it was resolved.

Laurel clearly felt there was a direct relationship between the assertiveness level of the parent and the willingness of the IEP team to accommodate the parent.

Melodie's recommendation focused on an alternative way to provide information to the parent and to any newcomers to the IEP team:

...I guess with Michael, the level of progress would be kind of cool to put on the IEP showing how much progress [he's] making as far as, I don't know how they would do that but I mean it would be interesting to see the changes on a graph or something. It's just typed out words and stuff. Like the [special education] director came in new and I'm not even sure if he knew that Michael couldn't talk at first. So he's coming in and he's at this different stage and nobody would even know... If I had moved like I was thinking I was going to move, then I would have had the information, you know, a running graph of what [the] improvements have been...

Jeanette discussed how the initial IEP meeting could be made more effective, bringing up ideas similar to those of expressed by Laurel and Charlotte:

I think case managers, especially the first time when they have a new student, need to explain the process to the parents. Some of them are probably doing that. The case managers I've had since then haven't needed to do that since I understand the process from working at the school. I've had a big advantage, I could ask anybody anything, but other parents don't have that advantage. I think that just showing parents that you're...that you want to communicate and just explaining the process *before* the meeting, you know, give them a call. Tell them there's going to be these people here. Sure, they've gotten the notice, but *why* is the occupational therapist here? *Why* is the psychologist there? Just to say those things.

Jeanette also cautioned case managers concerning the type of language they used in the IEP meeting; is the terminology in layperson's terms? Jeanette gave an example of how the team members could tactfully inquire of the parent if they understood what was being discussed:

...case managers have to be careful when they are doing the meeting and not assume everything they are saying is being understood. This particular meeting they were talking about fine motor and gross motor. And the parent didn't know what that meant in relation to her child at all. Someone finally asked, 'do you understand what we are talking about?' Sometimes you have to be careful if you know the parent well enough, can you ask them if they understand without them being offended. Or maybe just put it into the conversation [naturally] what it is without making a big deal about it too.

These are valid concerns which should cause special educators to take pause. In a teacher's preservice training there is emphasis on refraining from using terminology and language which a parent may not understand or which may be off-putting to that parent. It sounds like Jeanette, although well-educated, did not instinctively understand all of the inner workings of an IEP meeting. Special educators may forget these important pieces of the IEP meeting after having conducted meetings over a period of time. Just as case managers reflect on the effectiveness of their teaching, they also need to reflect prior to each IEP meeting as to whether the purpose and information will be clear to all participants.

Recommendations for Parents

There was no shortage of responses when asked for suggestions to help parents improve IEP meetings. I found it interesting that, once again, these four separate interviews yielded similar responses to this question. The answers focused on simple yet very effective ideas that the parents could put into place. Key points that were repeated were those of advocating for your child, having a plan prior to the meeting, becoming informed, and being open-minded.

Jeanette encouraged parents to ask questions and to do some independent research to become informed:

I think [that] they need to be not afraid to ask questions...I've been to several [IEP meetings] by now and it's gotten easier, but just don't be afraid to ask. And do research on your own. Yes, the case manager and the school district are responsible for some things but the parent is too and I think that as parents we need to get information. Know the basic laws and if you don't understand those procedural safeguards, then ask.

Along those same lines of "getting information for yourself," Melodie talked about the importance of learning about the child's diagnosis. She suggested that the parents utilize outside resources as well, which was echoed by Charlotte and Laurel, who both chose to bring an advocate/friend with them to the IEP meeting. Melodie also mentioned how parents should prepare for the IEP meeting.

...since each kid is different and each environment is different and [children] react differently to whatever, [the parent] could write down what's going on with their kid, you know. If they're having specific issues, write it down before they get to that meeting and address it."

On the subject of becoming informed, she stated:

I went to a lot of meetings. First I went to Parent's Time Out and I have intentions of going to them again to network. Seminars and stuff, you know, whatever I could take,

and reading and the internet. When you are first told your kid has autism, you're taken so far back that you just, you know, something's wrong with my kid! You know. And then you're not given the tools you need.

Laurel also discussed the topics of advocating, becoming informed, bringing someone to the IEP meeting and helping the team see the whole child:

[My friend] has been to numerous IEP meetings with me. To bring someone else with that can hear things too helps balance you because there's times when you just aren't in a position to hear what has to be...you know, they help carry that for you. I think that helps a parent.

When asked about bringing a notebook if they don't have someone who can attend,

Laurel said:

Yeah, but social workers or children's therapists, I mean...a friend, your mom...you know, just another pair of ears. A different insight. I think it's hard, parents tend to have a one way view of what it is so even having the other parent there, you are still coming from the same household so you still have the same view. Whereas, if you have somebody who's not emotionally as involved, it's easier to say, 'what about that or what about this?' Whereas the parents may not be able to think about it at the time or be able to see it. Or sometimes a parent wants to be defensive, 'well, my child *can* do that'...when they're saying [she] can't. Where [a friend] will go, 'no...she really *can't*.' It helps a parent. It just made me think that, yeah, a parent needs to advocate for their child and inform themselves if they don't know or if they agree or disagree, not to be afraid to step up and say that. They only see the child in the school setting. They need to understand the child as a whole. Like for skills, it has to be mastered across both settings before we consider it mastered.

It was very important to Laurel that someone who knew the family and the child be included in the IEP meeting. This person did not necessarily have to be a relative but he or she did need to be prepared to actively listen and offer input to the parent during and after the IEP meeting. She recognized that a parent could perhaps not be as objective as a person who is not so close to the subject being discussed. Laurel also noted that the process of having another individual attend the meetings helped her to feel more empowered in advocating for her child. Charlotte began by stating the importance of planning prior to the meeting:

Plan when you go in there, plan ahead. Make that hour before the IEP like you're studying for a pop quiz. What are points you need to think of, what are things you need to bring up? Like I said, have an extra ear, and it really doesn't matter if it's a seasoned person or not that's coming with you. Just having a second, you know. You can ask, 'did they say such and such?' 'Well yeah, they did.' Sometimes you don't even hear everything the way they said it. Or maybe you thought they said it one way, the intonation of their voice, but it wasn't that way at all, it was just how you were feeling and how you were perceiving it at the time.

Here it is evident that Charlotte wanted parents to be thoroughly prepared upon entering the meeting. Having thought through as many key points as possible ahead of time would enable a parent to better address the issues brought up during the IEP meeting. Like Laurel, she felt that having another person along to hear what was being said may help a parent's objectivity.

Charlotte went on to discuss how important it was for parents to realize that the child depended on them to act as the primary advocate in the educational planning process because no one knew the child as well as the parent knew the child:

The biggest thing I know is that...they need to have a sign that every parent should see before they go in that says, 'You are your child's biggest advocate!' You are not mean or horrible or any other derogatory remark. Because not only do they not know everything, but they can only know the standard of what is autism in the books. Well, we've learned that no diagnosis is the same, no child is the same, so therefore no IEP is going to be the same. These people at the IEP may be seasoned, 'we've done 4 billion IEP's'...but they've never done an IEP with *your* child. And your child might need something that sounds really ridiculous to them but, how often do I see them? How often do you see them?

Charlotte's reflection here was indicative that she had a mistrust of the educational professionals, not in the sense of their book knowledge regarding autism, but in that they could not possibly be as familiar as she was with her daughter Grace's needs, educationally and otherwise.

Final Reflections

The feeling of empowerment over time was apparent among the participants. There was a sense of feeling less intimidated and the realization that relationships among the team members were key to a successful meeting. When asked to reflect on how the IEP process has changed them, the participants discussed having more control over what happened in an IEP meeting and their increased self-reliance. In one mother's words:

I think the IEP process has definitely hardened me. Because you always have to look at what the needs are for your child. It has made me tougher to advocate as best that I can for [my child]. I have been through a lot of different IEP meetings and even teams. Having said that, I don't have a good impression of the IEP process, having been through so many case managers. I no longer depend as much on the case manager to cover everything that [my child] needs. I question that they have everything, or enough altogether; have they covered all the bases. An example is, next year when she moves to Junior High. We held her IEP staffing at the end of the year and I found out a week later that [the person] I thought was going to be her case manager, and whom I had met, had taken another position and now I have to start all over again. I don't think she would be as successful if I left her future solely in the hands of the educators!

And another participant had a similar response:

It has made me a stronger person. More able to speak up for myself as well as my child. I'm a little more thick skinned about the IEP process. Able to be more constructive and less reactive and not take every negative situation as a personal failure as a parent. I have no problems asking questions anymore. I feel like an equal with the others in the IEP team. My life experiences with my child make me more qualified [in the area of autism] than their schooling.

So, in this case, the parent moved from feeling it was a "me versus them" interaction to a more inclusive outlook. She had also become more confident in her abilities as a parent to express her ideas to the IEP team as to what would be in the best educational interests of her daughter. She came to the realization that living every day with her child with autism provided more pertinent experience than anyone could learn from a textbook.

It's interesting when I look back on my initial experience with IEP's and IEP meetings. I didn't know ANYTHING! As I said in our earlier interview, I didn't even know I was at an IEP meeting at one point. I probably didn't understand much about the goals and objectives either. I think more needs to be done to educate parents on the process. They need to be provided with the resources that will help them understand and advocate for their children. We need to teach parents to be advocates. At times the process is very frustrating because you don't feel like the IEP team is listening to what you're saying. They have their opinions and that is that. Learning about the process has made me a better advocate for my son. I also think more needs to be done to teach the student how to advocate for themselves and teach them how the IEP process works at a young age. They need to participate at an early age on a limited basis, increasing as they get older.

This parent came to understand that it was her responsibility to understand the IEP process in order to be as effective as possible when advocating for her son. She also believed strongly that it was the case manager's responsibility to ensure that parents knew what the purpose of an IEP meeting was, what the meeting consisted of, and what their role as a parent was. It was a shared burden of responsibility with both sides needing to take action to make the process as effective as possible. Darrin's mother concluded:

I still occasionally feel that they [the IEP team] do not "get" autism and that is frustrating. This is especially true with the general education teachers on the IEP team. My journey through this process has given me a passion to help others advocate for themselves and their children. Going through this process has given me more confidence to advocate, because when it comes right down to it, I know [my child] better than anyone does. I'm not afraid to ask for changes if I think they are necessary. The bottom line is: [my child's] success is by far the most important factor and I need to work with the IEP team and case manager to make it happen. Without collaboration between parents and teachers, it won't happen.

Here it is clear that this parent had moved forward through the cycle of effectively coping with a disability; that is, she was now in the role of advocate. Her focus had extended beyond just her own child with autism; she now desired to reach out and help other families that were experiencing what she had been through. She understood the important role she played as the number one advocate for her child's best interests.

Self-education, self-reliance, and the development of advocacy skills were the three recurring points in the parents' final reflection. The parents would all have liked to have been better informed at the beginning of the IEP process; however, when this did not occur, they chose not to give up and become compliant or apathetic, they all sought out the resources they needed; whether those resources were another adult, information on autism, or becoming knowledgeable about the mechanics of special education and the IEP process.

Chapter 5: Discussion

When I embarked on this endeavor to learn about parents' perceptions I was not sure what I would find. While initially I assumed that good, collaborative case managers would lead to increased participation by parents, the reverse turned out to be true for the parents in this study. The information gained during the interviews seemed to indicate that lack of informative professionals resulted in parents' active participation. At the outset, I believed that increased trust of the case manager by the parent *through the efforts of the case manager* would lead to an increase in collaboration. In fact, the collaborative piece seemed to stem from the involvement style of the parents as opposed to the style of the case managers. Two important unexpected findings were that: (a) case managers' lack of understanding led to increased parent involvement/advocacy, and (b) unknowledgeable case managers came to be accepted in situations where there was a "collaborative team" or involved principal.

It is important for parents to be involved in the IEP process to the point where they are comfortable, but that involvement should be achieved without negative initial experiences. Also, educators need to realize that parents will have varying levels or types of involvement. This concept ties in with what previous researchers have found: "Professionals should acknowledge the fact that parents may want to be engaged in their children's education in various ways and with varied intensity. Regardless of the extent to which parents want to get involved, education professionals need to welcome them, keep them informed, and allow them to participate as they desire" (Stoner & Angell, 2006, p. 186).

Are the findings from this study new? No, there have been articles written by educators on best practices for the IEP meeting. In fact, Mark Krug, a board member of the

Minnesota Council for Exceptional Children (MNCEC) wrote an article on the subject of IEP meetings in the January 2006 newsletter of the MNCEC. Herein he describes ways to have a “positive and productive” IEP meeting. His suggestions echo things that the parents in my interviews suggested: (a) develop an agenda and, if possible, send it out with the notice of the team meeting; (b) bring a draft document to a meeting clearly labeled “DRAFT”; (c) avoid jargon and euphemisms; speak in plain and simple terms; and (d) even if the parent seems to be in agreement with all that was discussed based on the draft IEP, they need to be provided time to digest the information and reflect on what was shared. Inform the parents that what was discussed will be incorporated into the final document and that [the case manager] will be mailing it/sending it out five to seven days after the meeting.

Here is a question for special educators: *Why* does it seem that we are not listening to our parents and colleagues such as Mark Krug? And questions for the special education system as a whole: What needs to happen to affect change? Should it be top down change from the administration within our schools? Would reformation of the Department of Education through an examination of its special education policies make the process work better for parents and special educators? Is ongoing teacher training needed to remind teachers whom they are serving and how to make the process understandable for all stakeholders? Or are there things that colleges and universities could do in preservice training that are not currently occurring?

I happen to believe a combination of these solutions would be effective. The administration of a school is ultimately responsible for how the staff is performing and how they serve the schools’ “customers,” which are parents and children. The special educators

and others on the IEP team need to feel that they are supported by the administration in their efforts to provide an effective IEP service. I feel that ongoing in-service training regarding how to provide the best possible services to families and to share ideas is essential to keep the idea of serving the whole child, including the family in the forefront of people's minds.

I also believe it would be helpful for the U.S. Department of Education to review some of the deadline mandates for providing service regarding IEPs. If the Department of Education could provide some guidelines rather than mandates to follow regarding deadlines and then allow the states and local school districts more control, the process may better suit the families and teachers involved. As it currently stands, many special educators may be tempted to take short cuts such as bringing the *final* IEP to the meeting rather than a working draft of the IEP. Perhaps a review of the maximum caseload a special educator may have could be determined by the individual school, based on the requirements, or needs of each student.

On the state level, there needs to be an assurance that the families are provided Parent Training and Information Centers (PTI), which are mandated in Part C of IDEA. When the states create this PTI, the information about its function needs to be highly visible to the public who may be seeking exactly the type of information and support the PTI's are supposed to offer. This way parents can readily have access to information regarding their child's disability, the inner-workings of the IEP process and additional resources to support the family system. This practice will benefit everyone involved in the IEP team decision-making: parents, case managers, local education authorities, and ultimately and most importantly, the student with autism.

Limitations and Implications

Although I sampled parents from different schools and their children were of varying age and ability, the size of this sample was quite small. Also, the families were all from middle income families with no significant cultural diversity nor was there racial diversity. The families were all from one Midwestern area of the United States and they lived within 50 miles of each other. The families' socioeconomic statuses were also fairly congruent. It is suggested that future research be expanded among parents of a variety of cultural and ethnic backgrounds and to include a more varied socioeconomic group.

The participants were all mothers of these children. It would also be interesting to get information and perspectives from a male head of household or persons with other types of guardianship. Further insight may also be gained from interviewing case managers of children with autism about their perceptions of parental involvement and the IEP meeting. This study could be broken down even further by the type or severity of the autism spectrum disability with which the child is diagnosed.

In order to continue to expand the extant body of literature, researchers need to continue to replicate these types of qualitative studies in a variety of locations throughout the United States and with as varied a sample as possible.

The collaboration process is critically important to the successful education of any child, but even more so in the delivery of specialized education for students with autism. Through consistent self-reflection on the part of educators and through parents becoming empowered early on in the IEP process, we can have the type of communication and collaboration that will meet the unique needs of children with autism and their families.

Researcher's Background, Experiences, and Biases

Prior to data collection, I noted my background, experiences, and biases in regard to the study. I am a parent of a 9-year-old girl who receives special education services for speech and Asperger's and a 7-year-old boy who receives special education services for autism. My daughter only recently received the Asperger's diagnosis as a secondary disability and I suspect that my daughter has a Nonverbal Learning Disability as opposed to Asperger's. I experienced some of the same difficulties as parents noted in the study. My son was given an ASD diagnosis by the school at age 3, but encountered a neurologist who stated that my son did not have autism. When I sought a second opinion, the psychologists confirmed the ASD diagnosis. I also experienced the various roles that the parents in the study filled.

I have been a general education teacher for 10 years. I recently obtained my Master's degree in special education, with a teaching license in Developmentally Cognitively Disabled (DCD). Holding the dual roles of parenting a child with a disability and teaching children with disabilities gave me a unique perspective into the IEP process.

I began the study with the belief that if special educators were to be more inclusive of the parent in the collaboration process, there would be increased trust on the part of the parent. It turned out that there were many other factors that contributed to the feelings of empowerment, trust, and collaboration from the parent's perspective. The parent may come to the initial IEP meeting having already experienced difficulties in obtaining the appropriate diagnosis and/or services. Each experience the parent has had affects the perceptions that parent has when coming onto the IEP team.

References

- American Psychiatric Association. (2000). *Autism*. Retrieved from <https://www.psychiatry.org/patients-families/autism/what-is-autism-spectrum-disorder>.
- Autism Society of Minnesota (2008). *Autism spectrum disorders*. Retrieved February 5, 2008, from <http://www.ausm.org/autismInfo/index.asp>.
- Anzul, M., Ely, M., Friedman, T., Garner, D., & Steinmetz, A. (1999). *Doing qualitative research: Circles within circles*. London: Falmer Press.
- Bogdan R. B., & Biklin, S. K. (1998). *Qualitative research for education: An introduction to theory and methods* (3rd ed.). Needham Heights, MA: Allyn & Bacon.
- Bowman, T. (1994). *Loss of dreams: A special kind of grief*. St. Paul, MN: Author.
- Bowman, T. (2001). *Finding hope when dreams have shattered*. St. Paul, MN: Author
- Center for Disease Control. (2006). *Prevalence of the Autism Spectrum Disorders (ASDs) in multiple areas of the United States, 2000 and 2002*. Retrieved November 17, 2007, from http://www.cdc.gov/ncbddd/autism/faq_prevalence.htm.
- Centers for Disease Control and Prevention. (2007). *Autism and developmental disabilities monitoring*. Retrieved March 19, 2008, from <http://www.cdc.gov/ncbddd/dd/addmprevalence.htm>.
- Fish, W. W. (2006). Perceptions of parents of students with autism towards the IEP meeting: A case study of one family support group chapter. *Education*, 127(1), 56-68.
- Friend, M., & Cook, L. (2003). *Interactions: Collaboration skills for school professionals* (4th ed.). Boston: Allyn and Bacon.

- Harrington, J. W., Patrick, P. A., Edwards, K. S., & Brand, D. A. (2006). Parental beliefs about autism. Implications for the treating physician. *Autism, 10*(5), 452-462.
- Iowa SCRIPT. (2000). *Family centered services guiding principles and practices for delivery of family centered services*. Retrieved from <http://www.iowaideainfo.org/vimages/shared/vnews/stories/56c742980ee0f/Family%20Centered%20Services.pdf>.
- Levine, P., Marder, C., & Wagner, M. (2004). *Services and supports for secondary school students with disabilities*. A special topic report from the National Longitudinal Transition Study-2 (NLTS2). Menlo Park, CA: SRI International.
- Lincoln Y. S., & Guba E. G. (1985). *Establishing trustworthiness. Naturalistic inquiry* (pp. 289-331). London: Sage Publications.
- Mathison, S. (1988). Why triangulate. *Educational Researcher, 17*(2), 13-17.
- Minnesota Council for Exceptional Children. (2006). *IEP meetings*. Retrieved November 17, 2007, from <http://www.mncec.org/>.
- National Association for the Education of Young Children. (1997). Retrieved February 5, 2008, from <http://www.naeyc.org/about/positions/dap4.asp>.
- National Institute of Health. (2007). Retrieved March 19, 2008, from <http://www.nih.gov/health/publications/autism/symptoms.shtml>.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage Publications, Inc.
- Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent

support group. *Focus on Autism and Other Developmental Disabilities*, 18(4), 228-237.

Stoner, J. B., & Angell, M. E. (2006). Parent perspectives on role engagement: An investigation of parents of children with ASD and their self-reported roles with education professionals. *Focus on Autism and Other Developmental Disabilities*, 21(3), 177-189.

Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities*, 20(1), 39-51.

Turnbull, A. P., & Turnbull, H. R. (2001). *Families, professionals, and exceptionality: Collaborating for empowerment* (4th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.

Turnbull, A. P., & Turnbull, H. R. (2006). *Families, professionals, and exceptionality: Collaborating for empowerment* (4th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.

U.S. Department of Education. (1990, 2004, 2006). Retrieved April 12, 2008, from <http://idea.ed.gov/>.

Appendix A: Interview Questions

Parent Interview Questions

1. Tell me about your child and the process of obtaining a diagnosis of autism.
2. Describe your relationship with your child's case manager.
3. How are you treated and perceived by the IEP team?
4. Describe the best IEP meeting you have attended.
5. Describe the least helpful IEP meeting you have attended.
6. What changes would you like to see regarding how IEP meetings are conducted?
7. What can school districts do to improve IEP meetings for families of children with autism?
8. What can parents of children with autism do to improve IEP meetings?

Appendix B: Interview Consent Form

Dear parent(s),

I am writing to ask for your assistance. I am a graduate student at St. Cloud State University and am completing my thesis project. I have chosen to interview parents of children with autism about their experiences with the elementary special education, particularly the relationship with the case manager.

For questions about the research, contact Donna Stromquist, graduate student in the Department of Special Education at St. Cloud State University. You may reach me at 763-213-1430 or by email at: stdo0601@stcloudstate.edu. Please feel free to contact me about any questions you may have about this study. You may also contact my faculty instructor, Dr. Julia Wilkins at jwilkins@stcloudstate.edu. This consent form explains the research study. Please read it carefully. Ask questions about anything you do not understand. If you do not have questions now, you may ask them if they occur to you later.

PURPOSE: The purpose of this research is to examine parents' involvement in the educational planning process for their children with autism. The results of this study should help to further the understanding of how vested parents feel they are in the planning done for their child. This knowledge will help teachers know how they can improve collaboration and inclusion of parents in the IEP process.

PROCEDURES: Four parents of children with autism will be interviewed. The interview will be audio taped for review afterwards.

TIME COMMITMENT: The interview should last between 15-20 minutes. There may be a follow up interview if additional questions come up when reviewing the audio tapes.

RISKS AND BENEFITS: There are no known risks to participating in this research, but it will help case managers learn the importance of establishing a family-centered approach when working with children who have autism and will provide them information on parent perceptions of the relationship with special educators.

CONFIDENTIALITY: You and your child's individual privacy will be maintained in all published and written data resulting from the study. Interviews will be tape recorded.

Interview tapes will be labeled with a code, known only to me, to conceal your identity. No real names will be used when typing up my interview notes. No one will have access to the tapes except me. The interview tapes and research notes will be kept in a locked cabinet during and after the study, and will be destroyed within one year of the date of the interview.

After my master's degree is complete, there is a possibility that my findings will be published. No real names of schools, students, or teachers will ever be used in connection with this study.

PAYMENT: There will be no cost or compensation for your participation in this research.

VOLUNTEERING FOR THE STUDY: Voluntary Participation/Withdrawal

Participation is voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Cloud State University, Independent School District 15, or

the researchers. If you decide to participate, you are free to withdraw at any time without penalty.

SUBJECT STATEMENT: I have read the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

I HAVE BEEN GIVEN A COPY OF THIS PERMISSION FORM.

Signature_____

Date_____

Audio Tape Release Form

I give consent to be taped during interviews in this study:

Please initial: Yes No

I certify that I obtained the consent of the subject whose signature is above. I understand that I must give a signed copy of the informed consent form to the subject, and keep the original copy in my files for 3 years after the completion of the research project.

Signature of Investigator _____

Date _____