



LOYOLA UNIVERSITY CHICAGO

MOTHERS' PERCEPTIONS OF SOCIAL WORK HELPGIVING PRACTICES:  
IMPLICATIONS FOR THE ROLE OF THE SCHOOL SOCIAL WORKER

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## ABSTRACT

The Individual with Disabilities Act has strengthened the role of parents in their children's special education. School social workers are one of the educational professionals in attendance at IEP staffings, yet their role definition continues to be poorly articulated. This qualitative study investigated school social work helping practices from the perspective of the mother with a child on the autism spectrum during staffings convened for the purpose of developing individualized education plans. As limited research exists regarding the activities of the school social worker during such staffings, this study served to understand practices mothers found helpful and essential to their participation.

Given that this study is aligned with an empowerment tradition of providing helping, backward mapping as a means of identifying school social worker practices was adopted. To achieve this end, a qualitative approach to gathering data from mothers was deemed the most aligned with eliciting this level of descriptive information. Through semi-structured, one time, in-depth, face-to-face interviews with 12 mothers, information regarding preferred school social work practices and how these related to increased participation and advocacy was elicited for the purpose of answering the following research questions: What helping practices do mothers associate with positive IEP staffing experiences? What are their perceptions of the role of the school social worker during the staffing? What helping practices do mothers identify as

being key to their increased participation and advocacy during the staffing?

Two independent coders, using open coding techniques, coded the transcripts of the interviews resulting in the identification of five themes. They include: (1) elements of the IEP staffing, (2) parent agency, (3) team climate, (4) child-centered focus, and (5) supportive functions of team members. A number of findings emerged after review of these themes. A synthesis of these themes revealed that mothers valued a family-centered approach to helpgiving. They also valued the profession of social work due to its strengths and systems perspectives and its focus on case management but found these social work functions missing from their IEP staffing experiences.

Findings from this study can be used to develop greater specificity in the role of the school social worker during IEP staffings. In addition, the findings offer some direction on the knowledge and skills to be included in a better definition for the school social worker.

CHAPTER ONE  
PROBLEM STATEMENT

**Introduction**

The focus of this dissertation was on the investigation of best practices of school social workers on behalf of mothers during the individual education planning (IEP) staffing. Examining the standards as put forth by social work accrediting and licensing bodies was a necessary first step in defining the framework for school social work, but was not sufficient for a fully developed one. The development of an integrated role definition for the school social worker benefitted from information gathered from mothers regarding the helpgiving activities of school social workers. It is this element that is missing in accounts of the school social worker's role during IEP staffings. This study was an attempt to fill that gap.

**Scope of the Problem**

As an outgrowth of the disability rights movement of the early 1970's, social work values and public education policy intersected in a significant way through the passage of the Education for all Handicapped Children Act of 1975 (Bye & Alvarez, 2007; Simon, 1994). School social workers could be able to find and exercise opportunities to make a significant difference in the quality of parents' involvement in their children's individualized educational plan as required by this Act. There is a large body of research into parents' involvement in the IEP process from an educational frame

of reference. Its purpose is to develop knowledge useful to promoting children's social and academic performance in the school setting. Research into the IEP process from a social work perspective has been minimal. Its focus on exploring and promoting issues of social justice was deemed valid given the history of discrimination that children with disabilities have experienced until recently.

Prior to enactment of this law, an estimated 1.75 million children with disabilities were denied a free and public education. Another 2.5 million of these children were receiving some form of education but not one sufficient to meet their educational needs (Freeman, 2003). Other estimates of the problem prior to 1975 suggest that up to 8 million children with special needs were not being adequately educated (Essex, 2008). Although public law enacted to rectify inequalities in educational practices was legislated 37 years ago, evidence exists that some inequalities in opportunities and access remain (Spann, Kohler, & Soenksen, 2003).

The fight to eliminate inadequacies in special education programs and services has not been abandoned. It has required, however, advocates to often exercise greater skill and stealth to address issues of a far more subtle nature on behalf of these children. Based on an historical trend of parent advocacy on behalf of their children with special needs, the promotion of parent activism has demonstrated strong promise (Ivey, 2004; Valle & Aponte, 2002). It is this strong "promise" or potential for more meaningful parental involvement that points to the importance of examining the thoughts and experiences of parents participating in IEP staffings for their children.

The movement to afford parents greater latitude in the planning of their children's

IEPs formally dates back to its beginnings over 35 years ago. Legal mandates have underscored the importance of parents' personal stake in their children's educational future within special education. Enactment of special education laws over this 37-year period provides markers for measuring overall changes in attitude and best practice beliefs.

One of the critical components of the Education for all Handicapped Children Act of 1975 (P.L. 94-142) was the mandating of an IEP document for all students in public schools eligible for special education services. The IEP became the document that reflected the cooperative planning efforts between parents and professionals with respect to each child's special educational needs.

The role of parent in the IEP process has been refined and strengthened through additional legislative action. In 1997, the Individuals with Disabilities Education Act (IDEA) Amendments called for parental involvement in their child's special education eligibility and subsequent placement processes (National Information Center, 1998). This has encouraged new interpretations of parents' rights in the IEP process. Valle and Aponte (2002) addressed their understanding of legislative intent by summarizing, "parents have the right to be informed, the right to be knowledgeable about the actions being taken, the right to participate, the right to challenge, and the right to appeal" (p. 470). Spann, Kohler, and Soenksen (2003) went further, declaring, "parents are now equal partners with school personnel, entitling them to access children's school records and participate in the design and evaluation of special education services" (p. 228).

Forward thinking and advocacy for greater parents' rights have been useful but



not sufficient in creating an optimal level of parental inclusion as envisioned by the law and its key promoters. A clearer understanding of mothers' perceptions in these processes was thought to allow for a more inclusive process in the future. It could also educate professionals and parents on how to more closely approximate legislative mandate and intent and develop best practice guidelines. Furthermore, given the central position parents have in advocating for the rights of their children with disabilities, achieving greater access to what a public educational system has to offer would promote greater social benefit.

Parents of children with disabilities have a proud history as effective advocates. Their efforts prompted the 1972 Pennsylvania court decision allowing children with mental retardation to a free and public education and to be placed with typical children rather than placed in segregated special education facilities (Allen-Meares, 2004; Essex, 2008; Raines, 2003). Parents also initiated action in Washington, DC, on behalf of children suspended or expelled from school for behaviors related to their mental retardation (Allen-Meares, 2004). The parental advocacy effort with the broadest consequences led to Congress passing the Education for All Handicapped Children Act of 1975. Children with handicapping characteristics were no longer permitted to be victims of educational discrimination. In recent history, parental advocacy has served generations of parents and children very well. Because of their successful efforts, it is presumed that new generations of parents will continue to advocate on behalf of their children.

This study afforded new opportunity to examine present and future roles of the

school social worker as parent-professional interactional patterns and outcomes were identified. This was deemed an important focus due to a present understanding that the school social worker role is generally poorly defined (Garrett, 2006; Kelly, 2008). This, to a large extent, is because school social work roles are strongly influenced by the larger educational community under which the social worker functions (Constable & Wolkow, 2009).

Additionally, due to their poor role definition, school social workers are made vulnerable to under-utilization (Garrett, 2006). This may often result from a limited recognition of the relational skill set professionally trained social workers usually possess (Bye, Shepard, Partridge, & Alvarez, 2009).

The lack of a more unified role definition may also lead to large disparities in function between school social workers in similar yet geographically different school settings. As a frequent consequence of poor role definition, the appropriate use of the school social worker is often restricted. In this era of reduced funding for non-essential personnel, the school social worker's position will remain vulnerable unless it becomes increasingly valued by educational administrators with fiscal responsibility over hiring practices (Allen-Meares, 2006).

The social worker must be pro-active in demonstrating his/her unique professional value in the school setting. S/he must repeatedly demonstrate his/her usefulness in meeting many identified social needs. Ultimately, it is up to the school social worker to inform school administrators on what the position is capable of relative to the individual needs of the school community (Constable, 2009).

The process of choosing a research study sample involved the following three considerations. A desirable sample should capture the interest of the social and educational research communities. The dynamic growth in the number of children being diagnosed on the autism spectrum has been alarming. The latest numbers indicate one in 88 children has the disorder (CDC, 2012).

A desirable sample would also contain enough complexity and variability to create important challenges for investigation and research. The population of children with autism is highly variable with regard to symptoms and the circumstances under which these symptoms present themselves (Wilczynski, Menousek, Hunter, & Mudgel, 2007). There are also a number of co-morbid conditions associated with autism such as anxiety, mood, psychosis, tic, seizure, and attentional disorders (Deprey & Ozonoff, 2009). Adding to its complexity is the vast difference in cognitive functioning amongst these children (Klinger, O'Kelley, & Mussey, 2009).

Finally, a desirable sample would provide and test opportunities for parents and professionals to work together to plan effectively for this population. Children with an autism related disorder seem a representative sample within the larger category of children in special education.

The National Association of Social Workers (NASW) (2002) has published standards for school social workers. School social workers are expected to provide services that are provided in a competent manner, which empower families to access and effectively use community resources. They are also expected to advocate for families. While these standards do not target interventions within the IEP conference directly, it

seems critical that in a meeting with school personnel and parents, the school social worker takes an active leadership role in ensuring these standards are met.

A unified vision for the role of school social worker is currently undeveloped. Data from mothers regarding which set of helpgiving practices they wish to receive from the school social worker during the IEP staffing was a first step in developing a well-defined role for the school social worker.

### **Purpose of the Study and Research Questions**

The Individual with Disabilities Education Act (IDEA) requirements put the burden on school personnel to ensure that parents actively and meaningfully participate in their children's IEP staffings. More specifically, they require that the educational professionals enlist parents as equal partners in the staffings' decision-making process. Having a clearer picture of how parents wish to participate in staffings will help identify most useful school social work interventions. This information can then be used to strengthen school social work function during IEP staffings.

This qualitative, exploratory study attempted to answer this overarching question: What are mothers' with children on the autism spectrum, perceptions of helpgiving practices of the school social worker within the individualized education planning conference? A number of sub-questions emerged which benefit from systematic exploration.

1. What helpgiving practices do mothers associate with positive IEP staffing experiences?
2. What are mothers' perceptions of the role of the school social worker during IEP

- staffings?
3. What helpgiving practices do mothers identify as being key to their increased participation and advocacy during the IEP staffing?

### **Definition of Terms**

This study took place within an educational system, which relies on a specific vocabulary. For the purpose of this study, the following definitions associated with the field of special education were adopted. The vocabulary governing special education tends to have been developed through case law and now consists of legal definitions.

*Autism* - Special educators use the classification of autism as it is defined in the federal regulations, a category making it eligible for educational services (Turnbull, Wilcox, & Stowe, 2002). The Department of Education recognizes the inclusion of the following under the autism umbrella: “autistic disorder, Asperger’s syndrome, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Rett syndrome” as defined in the Diagnostic and Statistical Manual of Mental Disorders (Illinois State Board of Education, 2008). Although these children have certain symptoms in common, they represent a wide range of skills and challenges. The following is the legal definition for use by special educators.

Autism means a developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age 3 that adversely affects a child’s educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences (34 C.F.R. 300.89(c)(1)).

*The Individualized Education Plan (IEP)* - The federal mandate defines the IEP as

“a written statement for a child with a disability that is developed, reviewed, and revised in accordance with this section,” meaning the requirements of the law (20 U.S.C. 1414). This document is required of each child between the ages of 3 and 22 who has been declared special education eligible by a combination of parents and school district personnel. The document consists of component parts spelled out in the IDEA. It is developed by persons holding specific positions; it is individualized to meet the needs of the student, and is valid for one year from the date of its origination. The school district is required to follow the stipulations in the IEP and cannot be held accountable for what is not written (Latham, Latham, & Mandlawitz, 2008). The IEP becomes official only upon parent’s signature attesting to agreement of the plan.

*The IEP Team* - The individualized plan is the product of the IEP team meeting process. The members of the team, as specified in the IDEA of 1997, are brought together to develop this plan. According to 34 C.F.R. 300.344, the school has the responsibility of convening a meeting to develop the IEP with the following in attendance:

1. The parents of the child.
2. At least one regular education teacher of the child.
3. At least one special education teacher of the child.
4. A representative of the public agency who:
  - i. is qualified to provide, or supervise the provision of, specially designed instruction to meet the unique needs of children with disabilities;
  - ii. is knowledgeable about the general curriculum; and

- iii. is knowledgeable about the availability of resources of the public agency.
5. An individual who can interpret the instructional implications of evaluation results, who may be a member of the team described in paragraphs (a)(2) through (6) of this section.
6. At the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate; and ... school social workers fall into any one of the latter three categories of attendees.

*Parents* - For purposes of this study and as supported by the IDEA Reauthorization of 2004, the category of parents refers to parents, grandparents, stepparents, or foster parents. It can also refer to the guardian who has assumed legal decision-making authority over the educational program of the child (34C.F.R.300.30(a)).

*Staffings* - The term staffing, as used in this study, refers to any one of three types of multi-disciplinary conferences to which both parents and educational personnel are expected to attend. The three types of staffings include: (a) conferences for the purpose of declaring a student eligible for special education, (b) annual review conferences at which time goals and objectives are developed for the following academic year, and (c) staffings for the purpose of developing and/or changing individual education plans.

*Related Services* - Related services refer to those services provided to students enrolled in special education but which fall outside the direct domain of the teacher. They are provided by specialized, ancillary staff within the school setting. The most common related services available to students on the autism spectrum while enrolled in special

education include psychological, social work, and speech and language services and physical and occupational therapies.

*Specialized Academic Setting* - As the term is used in this study, a specialized program refers to an alternative school program specializing in the education and treatment of children on the autism spectrum. These programs are funded on a per diem basis by their local education agency and are recommended when the staffing team determines the child's needs can be better served in a more intensive and therapeutic program. The parents must agree to this change in placement from public school to alternative setting before the transfer can be realized.

### **Assumptions**

This study rested on three basic assumptions. This first assumption was that parents and those who make the choice to work on behalf of children with special needs generally want what is best for their child (Childre & Chambers, 2005; NASW, 2008). Although there are always exceptions to any rule, the norm holds that most in the field of social work and many parents of a child with a disability such as autism, believe that with the right tools, participation in the educational planning for the child is possible (Able-Boone & Sandall, 1990).

The second assumption concerned what parents bring to the IEP conference. Parents have a wealth of information and can be considered experts on their children's needs and functioning (Knox, Parmeter, Atkinson, & Yazbeck, 2000; Van Haren & Fiedler, 2008). They require permission, opportunities, and at times specific types of support to voice thoughts, preferences, and objections to fully participate in the decision-



making process with education professionals.

The final assumption related to the role of the school social worker as responsible for understanding the parents' wishes regarding level of participation at the staffing. This assumption emerged from the accepted school social work function wherein the professional is expected "to repair the mismatches between school and family and in situations of potential difficulty to develop real partnership" (Constable & Walberg, p. 550). Given that partnerships are inherent in the conceptualization of staffings, it becomes incumbent upon the school social workers to provide the information, training, and resources necessary to meet parents' needs for participating at the level they wish.

## CHAPTER TWO

### LITERATURE REVIEW

#### **Introduction**

This chapter has two specific purposes. The first section provides the legal and historical contexts for understanding the role parents play in developing their children's individualized education plans. To this end, an overview of events and pieces of legislation leading to the creation of special education for children with disabilities are laid bare. In addition, the legal mandates for IEP and Individualized Family Service Plan (IFSP) development are explicated with a focus on the role of parents in this process. This research was imbedded in a distinct historical context. For this reason, seminal sources of information highlighting these moments in history are included in this chapter. They illustrate some of the injustices mothers of children with disabilities endured. While recognizing that scholarship is critical to studies of this type, it is equally relevant to include documentation of the professional and cultural trends which acted as precursors to parental advocacy on behalf of children with disabilities. Figure 1 provides a visual display of the most significant historical moments, which culminated in the passage of legislation providing school age children with special needs the right to a free and public education.

The second section of this chapter includes outcome research on parental participation in the IEP process. This is reviewed with a focus on the shifting trends

from professionally to family- driven practice approaches. A helping model within a family-centered approach and its application to social work interventions in IEP staffings is then discussed. Empowerment, being an integral component of helping within a family-centered practice approach, will be offered as a theoretical and philosophical framework to the issues investigated in this research endeavor.

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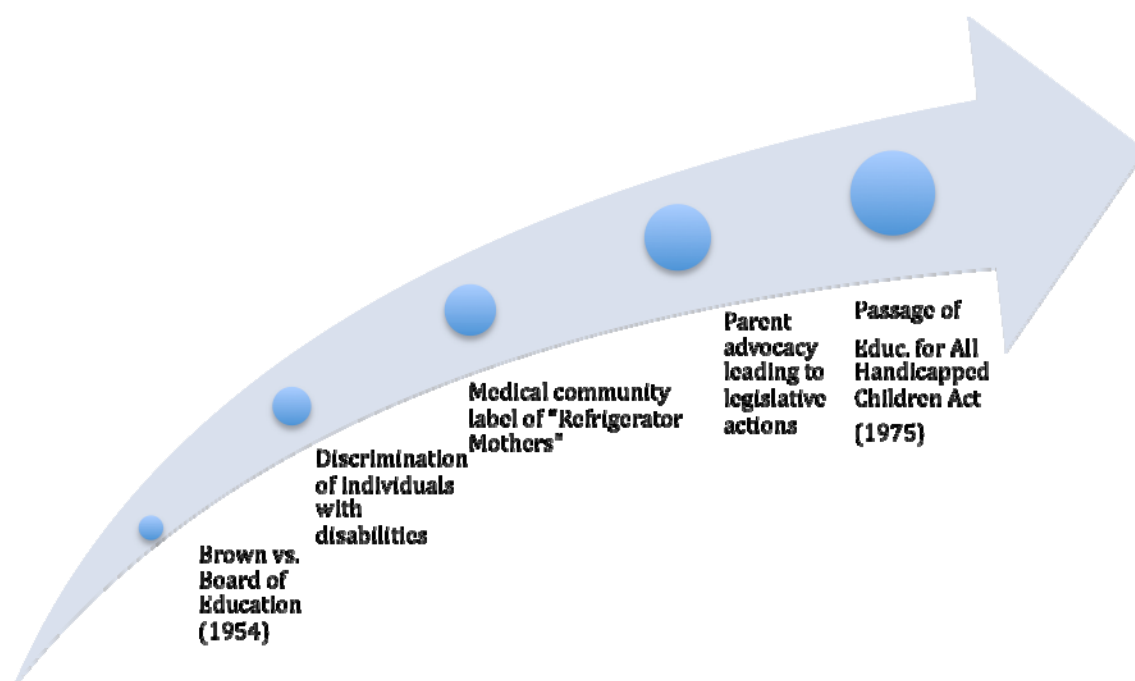


Figure 1: Historical and Cultural Influences Culminating in Passage of EAHCA in 1975

### **Historical Perspectives**

*Brown v. Board of Education Topeka* was a landmark piece of legislation, which impacted students with disabilities well after the case was brought to the Supreme Court in 1954. In a unanimous decision, the Court declared that students, regardless of race, were to be granted the right to an integrated education. The former doctrine of ‘separate

but equal’, referring to the segregation of students by race was found to be unequal by law, although individual states delayed taking action in accordance to the new law (Massat & McKay, 2009). While this law did not apply directly to students with disabilities, its ‘separate but equal’ doctrine would become relevant in the education of students with disabilities.

During this same period in United States history, individuals with disabilities were being subjected to laws limiting their rights to vote, marry, and drive. Over half of the states had laws, which called for their sterilization (Osborne & Russo, 2007). Within this climate of limiting the rights of persons with disabilities, advocates for this population began to speak up. Included in this group were the parents of children with disabilities (Ivey, 2004; Valle & Aponte, 2002).

Legislation responsible for the creation of special education was a direct result of advocacy that led to judicial actions. As with *Brown v. Board of Education of Topeka*, these cases are considered landmark decisions as they led to protecting the equal opportunities for one group of students.

In 1971, the case of *Pennsylvania Association for Retarded Citizens v. Pennsylvania (PARC)*, initiated through parent advocacy, declared that Pennsylvania children with mental retardation were entitled to a free and public education. In addition, these children were entitled to be educated in schools for typical children rather than in segregated special education facilities. The concept of ‘separate but equal’, which was outlawed as a result of *Brown v. Board of Education Topeka*, was applied here. Parents were given the right to due process if school districts attempted to exclude

or change educational placements for their children (Osborne & Russo, 2007). This provision has stood the test of time and has become an integral part of the Individual with Disabilities Education Act.

In *Mills v. Board of Education of the District of Columbia* (1972), the parents of seven students with disabilities filed a class action suit on behalf of 18,000 students with disabilities who had been denied an education appropriate to their needs. The court ruled in favor of its litigants, mandating school districts to provide funding ensuring that all students would receive an education meeting their specific needs and abilities. In addition, the suit provided due process safeguards in the event students were excluded from or received alternative educational placements. Both of these cases set precedents for the conditions set forth in the federal legislation that followed (Allen-Meares, 2004; Freeman, 2003; Osborne & Russo, 2007).

Section 504 of the Rehabilitation Act of 1973 was the first of these federal legislations and is considered one of the four federal statutes affecting special education. It protects the rights of any individual with a disability from discrimination if involved in a program or activity receiving federal funding (Osborne & Russo, 2007). For the public school student, it allows for accommodations to be made if there is evidence of some impairment limiting her/his participation in school programming. This benefits the child who has a level of impairment but not sufficient enough to declare her/him eligible for special education. Unlike the requirements of IDEA, Section 504 does not require a written service plan. While a number of public schools take the initiative to meet with families and develop an agreement collaboratively, it often falls upon the parent to

advocate for the initiation of accommodations on behalf of their child.

The Americans with Disabilities Act of 1990 is another federal civil rights act, which plays a role in special education. The act “prohibits discrimination of persons with disabilities and guarantees them equal access to employment, public services, transportation, public accommodations, and telecommunications” (Fitzsimons, 2009, p. 199). It augments Section 504 of the Rehabilitation Act by extending protections to individuals with disabilities who are participating in programs or activities in the private sector without federal funding (Osborne & Russo, 2007). While this Act tends to be more applicable to school employees than to students, schools are expected to know about and implement accommodations providing full student access to school activities.

The most recent federal statute governing special education is the No Child Left Behind Act (NCLB). Passed in 2002, it concerns itself with system-wide outcomes of student achievement. Two of its many provisions are relevant for students in special education programs. First, in situations where local education agencies are unresponsive to the needs of parents, improved choices regarding educational programs are made available. Additionally, the local school system is responsible for taking reasonable measures to recruit, hire, train, and retain highly qualified school personnel to provide special education services to children with disabilities (Osborne & Russo, 2007).

The Individuals with Disabilities Education Act, the final of the four federal statutes effecting special education for children with disabilities, has direct relevance to this study. Its development from its inception in 1975 to the more recent amendments of 2004 will be discussed. The expanding role of parents is explored as it relates to the

individualized education plan of the child with disabilities.

Parental participation in the planning for their children's specialized programs in public schools continues to evolve. Roles for parents in their children's education can be traced back to the War on Poverty of the 1960's. This period saw the rise in funding and development of multiple programs providing economic, social, and educational opportunities for children considered to be "at risk" (Rappaport, 1981).

One of the best-known programs to have its origins in this era was Head Start. Authorized in 1966 with the passage of the Economic Opportunity Act Amendments, this was the first program for children at risk for developmental delays. It addressed a role for parents. The Head Start Model was designed with the goal of involving parents in the development of educational plans and services for pre-school children (Wehman, 1998). It was to become the template for the development of the Individualized Education Plan for students with special needs (Gallagher & Desimone, 1995).

During this time, children with disabilities were frequently placed in institutions on the recommendation of the medical community (Wehman, 1998). Children on the autism spectrum were particularly susceptible to institutional placements.

Professional thinking of the time held that mothers were deficient in attachment and bonding capacities with their child (Gabovitch & Curtin, 2009). This blaming of parents by professionals led to the label of 'refrigerator mother', a commonly used term laden with stigma (Danesco, 1997; Hanley, 2006 [Motion Picture])

Aligned with this notion that parents needed to improve their skills in meeting the needs of their children with disabilities, the focus on programs prior to 1975 was on

viewing parents as partners in the teaching of professionally designed child-centered programs in the home. There was an implied attitude that parents were expected to be compliant with professional recommendations. Professional staff offered parents training to help them conform to professionally established goals (Wehman, 1998).

During this same period, Congress published findings on the issue of educating children with disabilities. These findings were to provide the rationale behind new legislation effecting school aged children with disabilities. They included the following:

- Over half of children with disabilities were not receiving an education sufficient to affording them equal opportunities as children without disabilities.
- One million children with disabilities were excluded from public schools.
- Children with disabilities attending public schools often did not receive an appropriate or successful public education due to their disability going undetected.
- Children with disabilities were not receiving adequate services in the public school system, thus forcing parents to secure costly and often poorly accessible services. (Jasper, 2004)

In 1975, the Education for All Handicapped Children's Act (EAHCA), also known as PL 94-142 was enacted. This was considered a landmark piece of legislation as it provided all children with disabilities between the ages of 3 and 21 the right to a free appropriate public education (FAPE). It also required the development of an individualized education plan for each student to ensure s/he received an educational program appropriate to her/his special needs (Christle & Yell, 2010).

With the passage of PL 94-142, parents were invited, for the first time, to participate in their child's staffing convened for the purpose of developing an individualized education plan for their child (Wehman, 1998). Notions of parental



involvement and participation were initially poorly conceived concepts and vulnerable to individual school system interpretation. Parental wishes for the programming needs of their children often went unsolicited and unheard (Childre & Chambers, 2005; Pruitt, Wandry, & Hollums, 1998). This often led to parents' dissatisfaction with the way they were treated by school professionals (Fish, 2000; Sheehey, 2006).

The authorization of Part H of the Education of the Handicapped Children's Act Amendments of 1986 (PL 99-457), created a more fully developed role for the family in the care and treatment of their child with a disability within the early intervention community (Espe-Sherwindt, 2008; Minke & Scott, 1995; Sabatino, 2001). The Individualized Family Service Plan (IFSP) became the cornerstone of P.L. 99-457. This mandate was based on the assumption that meeting families' wide range of needs would in turn enhance the child's developmental growth and sense of well being (Epley, Summers, & Turnbull, 2010; Mahoney & O'Sullivan, 1990). The service plan, designed for the birth to three population was based on the IEP and served a similar function. It provided the blueprint for the description of services offered and the manner in which they were to be delivered (Fish, 2006). There are differences however. While the IEP focuses on services for the child, the IFSP focuses on services for the family.

Additionally, there is an explicit adherence to a family-centered practice philosophy within the IFSP system, which has not been formally adopted in the IEP process. As a result, the level of family involvement in the development of each type of plan varies.

In 1990, the EAHCA was retitled the Individuals with Disabilities Education Act (IDEA). It was amended in 1997 and again in 2004 (Osborne & Russo, 2007). A

number of provisions included in the initial legislation were expanded upon and strengthened in subsequent amendments to Part B of IDEA. One concerned the role of parents in the decision-making process on issues of child assessment, placement, and intervention for the school aged child. This legislation was developed as a result of research linking student educational success with parental school involvement (Turnbull, Rutherford, Wilcox, Brennan, & Stowe, 2002).

Strengthening the role of parents was stressed even further in the IDEA, Part C, enacted in 1999, whose focus is on children prior to their entry into public school. Part C of IDEA required parent-professional collaboration and gives parents key decision-making authority over their child's overall services (Dinnebeil, Hale, & Rule, 1999). This legislation, geared to infants and toddlers, assumes a family-driven rather than professionally-driven approach to service planning and decision-making

The IDEA mandates governing children with disabilities accord the family equal power in the planning, decision-making, and evaluation of services (Wehman, 1998). However, there is evidence that this does not occur to the extent it should for both the school age child and for those enrolled in early intervention programs (Bruder, 2000).

Significant efforts have been made to provide children with disabilities an education commensurate with that of typical peers. Not having a voice due to age and at times due to the severity of their disability, parents of these children have been accorded a role in the process of educational planning.

Influences on the role definition for the school social worker will be discussed. The following sections will also review evidence for actual participation in light of the

role granted parents through the federal mandates.

### **Influences on School Social Work Role Definition**

The development of a more clearly defined role for school social workers, particularly in IEP staffing settings, necessitates an investigation of the various influences impacting it. The following are a number of such influences. While not an inclusive list, the categories targeted below are in line with what the literature has consistently identified as having a bearing on the a more comprehensive definition of school social work.

### **Model of Helpgiving**

While a number of helpgiving models have been explicated in the literature, one seems particularly well suited to the activities of school social workers within IEP staffings (Brickman, Rabinowitz, Karuza, Coates, Cohn, & Kidder, 1982; Vetere & Carley, 2006). Dunst and Trivette (2002) proposed a model of helpgiving imbedded in a family-centered framework. Family-centered care, also referred to as family-centered practices, family-centered services, and family-centered helpgiving, assumes "...an approach to working with families that honors and respects their values and choices and which includes the provision of supports necessary to strengthen family functioning" (Dunst, Trivette, & Hamby, 2007). Although originally emanating from the health care field, it has become a valued approach in early intervention for children with disabilities (Dunst & Trivette, 1996). It is just beginning to find a role in special education for children ages 3 to 22, although more prevalent in programs for the younger child (Dunst, 2002).

Until recently, there has been limited consensus on how the concept of family-centered care has been both understood and operationalized (Trivette, Dunst, Boyd, & Hamby, 1995). This is in part due to a lack of research efforts into identifying the helpgiving elements and conditions that define family-centered care.

One research effort attempted to identify various levels of family-oriented services within the human service field. The classifications consisted of professionally-oriented, family-allied, family-focused, and family-centered models. They represent a continuum of helpgiving services to families, which are entirely determined by professionals on one end of the continuum and determined by the family on the other end (Dunst, Boyd, Trivette, & Hamby, 2002; Trivette et al., 1995). Using these categories, Trivette et al. (1995) sought to find support for two hypotheses: “the more family centered the programs, the more empowering the helpgiving practices” and the “use of empowering practices would be related to the degree of control parents indicated they had in terms of procurement and provision of services and resources from a target helpgiver” (p. 239). Using a sample of 298 families with children aged birth to 5, data found support for their first hypothesis. Families receiving services from programs with a family-centered orientation were more satisfied with the helpgiving practices of their assigned workers. In addition, parents acknowledged greater sense of personal control when the helpgiving they received adopted empowering practices. What became clear in this study was that the program and its services influenced the degree to which family-centeredness was practiced rather than being due to family characteristics, such as the nature of the child’s disability, in influencing the manner in which helpgiving is

provided (Dunst et al., 1995).

Another study attempted to find support for the identification of specific dimensions of helping within a family-centered approach. Data from families recruited from 22 helping programs was collected to determine the extent to which two specific helping practices were related to level of family orientation of programs. The two specific practices included relational and participatory efforts on the part of helpers. The researchers referred to relational practices as those involving the clinical skills often associated with human service worker activities such as active listening, empathy, warmth, etc. Participatory practices, on the other hand, were related to behaviors and activities associated with promoting feelings of empowerment in helpseekers. These activities include helping families find their own solutions to their problems and for developing those skills serving to improve their situation (Dunst et al., 2002).

Findings of the study were similar to the former study in that it found that the level of family orientation to helping influenced parents' ratings of the helping they received. The more professionally-centered the helping, the lower the ratings. Conversely, the more family-centered the program, the greater the ratings. In addition, the elements of relational and participatory practices varied according to program type. Hence, families claimed they achieved a greater level of desired outcomes when a more participatory style of helping was offered to them. In a second investigation within the same study, it was determined that the participatory practices employed by programs were more closely associated with a family-centered approach. Relational practices did

not have a discernable effect on the level of family-orientation of programs (Dunst et al., 2002).

The significance of both studies lies in the benefits of knowing the specific elements of helping practices most positively influencing families' locus of control and satisfaction with services. Programs invested in promoting family ability to define and successfully manage their problems are now advised, through the literature, to adopt participatory practices among their helpgivers. As participatory practices are closely aligned with an empowerment ideology, empowerment as a theory undergirding preferred helping for families with children with disabilities is worthy of further explication.

### **Empowerment Theory**

Empowerment as a concept achieved popularity in the 1960's with the emergence of the civil rights and feminist movements (Simon, 1994). The focus on empowerment was also a response to traditional social work practice of that period with its focus on clinical interventions targeted to the intrapsychic conflicts inherent in individuals seeking treatment. Simultaneously, there was a beginning exploration into the effects of power within the social work literature (Solomon, 1987).

As with the concept of family-centered care, the concept of empowerment has had vague definitions and has been used to mean different things to different people and in different contexts (Bartle, Couchonnal, Canda, & Staker, 2002; Gutierrez, 1990; Gutierrez, DeLois, & GlenMaye, 1995; McWhirter, 2001; Simon, 1994). It has been alternately described as a theory, framework, goal, ideology, process, and philosophy

(Cochran & Dean, 1991; Gutierrez, 1995; McWhirtier, 2001). For purposes of this study, empowerment is examined as both a philosophy guiding social work practice within a family-centered practice model and as a process by which people and organizations can assume control over their own problems and challenges.

According to Solomon (1987), “empowerment refers to the reduction of an overriding sense of powerlessness to direct one’s own life in the direction of reasonable personal gratification” (p. 80). It has also been described as “a process of increasing personal, interpersonal, or political power so that individuals can take action to improve their life situations” (Gutierrez, 1990, p. 149). Both definitions address the element of power being critical in the transformation from being a victim or recipient of services and interventions to one where individuals can assume control over their own lives and the challenges confronting them.

While empowerment theory and process have been associated primarily with women, people of color, and the gay and lesbian communities (Gutierrez, DeLois, & GlenMaye, 1995; Simon, 1994), it also has relevancy to those individuals with disabilities and their families based upon their discrimination by major institutions such as schools, the medical community, and places of employment (Gabovitch & Curtin, 2009; Osborne & Russo, 2007; Valle & Aponte, 2002). As has been referenced previously, attempts to ameliorate discrimination practices were initiated by the federal government through the enactments of the American with Disabilities Act of 1990, The Education for All Handicapped Children Act of 1975, and Section 504 of the Rehabilitation Act of 1973 (Bye & Alvarez, 2007; Osborne & Russo, 2007; Simon,

1994). Despite these efforts, there continues to be evidence of more subtle forms of discrimination. IEP staffings are one of the settings where discrimination has been identified through the professional literature (Spann, Kohler, & Soenksen, 2003).

To understand the role of empowerment in IEP staffings, its convergence with an ecological systems approach is useful. A systems approach posits that people are to be viewed in transaction with their environment (Germain, 1991; Germain & Gitterman, 1996). For the purposes of this study, examination of environmental influences in the school setting is highly useful in understanding the parents' perspectives of their participation in IEP staffings.

Either assuming power over individuals or denying individuals' power promotes oppression. Each type of negative transaction encourages a sense of disempowerment on the part of individuals (Germain, 1991). In the IEP setting, the hierarchical nature of the school's organizational structure lends itself to both the withholding of power to families and at times to the abuse of power in disavowing a parent's voice in the decision-making process. Such practices have repercussions to families and by extension to their children who are being denied a more thoroughly planned educational program.

There are numerous outcome studies supporting parents' sense of powerlessness in relation to educational professionals. One set of studies has explored the locus of control over the decision-making process in educational programs for children with disabilities. Much of the evidence points to educators being in charge of this process (Turnbull & Turnbull, 1997; Vaughn, Bos, Harrell, & Lasky, 1988).



In one study, IEP staffings were cancelled due to parents refusing to attend as the professionals had completed the educational plans without their input (Goldstein, Strickland, Turnbull, & Curry, 1980). This finding was supported in more recent studies, suggesting ongoing disparities in the assumption of power within staffings (Childre & Chambers, 2005; Fish, 2006; Sheehey, 2006). Similar findings have emerged from research on the IFSP process, which has a more explicit role for parental involvement in decision-making. In a larger scale study with a sample size of 290 parents, findings suggested that service plans for their children were not developed with their input (Able- Boone, Goodwin, Sandall, Gordon, & Martin, 1992). As a result, their preferences for services and programs were not given sufficient attention.

Studies have also reported on parents' perceptions that their thoughts and observations concerning their children were not elicited, listened to, or taken into consideration by educators in the development of the IEP (Childre & Chambers, 2005; Lo, 2008; Petr & Barney, 2001; Pruitt et al., 1998). Comments from a study by Pruitt et al. (1998) offer some examples of parents' thoughts on this issue:

...Teachers must remember that there is a lot of value to what parents say—even through they are hysterical or not rational—because they really do know the child, or,

Some professionals believe that since they are the ones with the degree that they know everything and believe that the parents are inferior and don't know what they are talking about (paragraph 11).

Having significant information on their children and being thwarted from sharing it with persons responsible for developing individualized educational plans can be extremely frustrating for a family. The ensuing transactions between family and staffing

environment can have one of two results. It can promote a sense of disenfranchisement with motivation for participation in the decision-making stalled, leading at best to passive engagement in the process. It can also lead to the adoption of hostile and defensive attitudes, which in turn inhibits openness between parents and professionals. Neither approach benefits the educational interests of the child.

Examples of lack of fit between family and education professionals are found in the negative characterizations of families (Shannon, 2004), being labeled as unreasonable for requesting services the school district did not find appropriate (Fish, 2006), and feeling criticized, blamed, and labeled as non-compliant (Petr & Barney, 1993).

The behaviors reported in these studies reflect the mistrust engendered between parents and professionals. From a transactional perspective, the devaluation of parents by staffing professionals is oppressive, disempowering, and leads to defensiveness and disenfranchisement. Mutual engagement and effective joint decision-making do not occur.

As parents familiarized themselves on special education law, parents reported they became more successful in advocating for the educational needs of their children (Fish, 2006; Fish, 2008; Gilliam & Coleman, 1981; Goldstein et al., 1980). This in turn, increased respect by professionals, transforming what was once a negative staffing experience to one which was more productive and where parents felt more in charge of the process (Fish, 2006). This repeated finding in the literature suggests the need for encouragement and assistance from professionals in meeting parent need to be fully

informed, in acquiring the skills necessary for effective self-advocacy, and in receiving help navigating the special education system. These functions are well aligned with empowerment practices utilized by the school social worker.

### **Role of the Social Worker**

The roles that social workers are asked to perform in this era of post-modernism appear more complex than at any other time in the history of the profession. The evolving direction of social work education over the past few decades illustrates this trend. The texts currently used in the education and orientation of potential social workers to the profession of social work offer information on the issues, values, and perspectives that shape our understanding of how social workers should perform in the varied and complex workplace settings they inhabit.

A significant source of controversy exists over what being called a professional social worker ought to mean. This long-term debate centers on whether professionally prepared social workers choosing to enter into private practice should be considered social workers in the same vein as workers in public or private-not-for profit settings who serve more disenfranchised populations. Career choice, professional identity, and even long-term personal financial success all play a role in the decision to choose a clinical or more generalist approach to the profession. This has direct implications to school social work. While some school settings embrace a role for social workers that are wholly clinically oriented, others support a range of social work skills (Kelly, 2009).

NASW, the body setting standards for the profession, assented for inclusion of private practitioners into the family of social workers. This occurred in 1957 and by

1985, the number of social work private practitioners rose to represent nearly a third of NASW's overall professional membership (Specht & Courtney, 1994). Against this rising tide of clinically focused training which generated an ever-increasing number of social work psychotherapists, has emerged a significant grass roots movement.

Practitioners and academics behind this movement have exerted pressure to shift the trend from a strictly clinical approach to social work with its emphasis on study-diagnosis-treatment model, to one focused on client strengths, client as expert, and client as driver of his/her own problem solving (Dybicz, 2010). Whatever side of the fence one chooses to stand, it is clear that the profession struggles on with the split over this issue. This is clearly being played out in the school setting, where the majority of states rely on clinically oriented practice modalities while those in leadership positions in the field and supported by current research efforts of academics promote a range of modalities which are not embedded in a traditional clinical orientation (Kelly, 2009).

Social workers have often differentiated themselves practically and philosophically based on roles and practice principles rooted in either the "Settlement House" or "Charity Organization" service models of the 1900's (Gitterman & Germain, 2008). Characteristically, Charity Organizations functioned in the community by possessing expertise in helping people who traditionally are seen as being unable to help themselves. This has long been considered a conventional view of social service delivery (Mullaly, 1997). Progressives and critics, however, often consider traditional practice a static effort due principally to its hierarchical structure and more rigid role expectations as well as the pathological view of people engendered in this approach.

Settlement House models, more egalitarian by design, place social workers in the role of social activists, impacting social systems at multiple levels. This role demands a more progressive and critical stance on the part of the social worker. The social worker must see and understand how social service institutions fall short of adequately meeting human need and actively seeks to change these institutions and the environments in which they exist. Settlement House models, aligned with current post-modernist thought, guide social workers to view the experience of individuals as specific to them and eschew any one specific way of thinking about them or doing for them. Furthermore, there is the belief that groups of people are entitled to a unified voice (Mullaly, 1997). This has a direct impact on the group of parents with children on the autism spectrum. It is this non- traditional approach to social work that will acknowledge each family's unique experience while allowing this group of parents to have a voice regarding their shared interactions with the multiple systems involved in their lives.

However, as the literature has validated, this is not the consistent experience of parents with a child on the autism spectrum. Nor is it their consistent experience with social workers in the public school setting. A more current interpretation of the original philosophy and function of Charity Organizations place social work practice into a neo-conservative paradigm. This promotes the belief that it is the individual's responsibility to improve his/her condition. The failure to do so is the result of personal weaknesses and reflects clear deviance from the norms of society. Social welfare is thus seen as temporary, abnormal, and residual. By extension, the nature of social work practice

under this umbrella therefore imbeds control and coercive elements into its treatment approach with people (Allen-Meares & Garvin, 2000; Mullaly, 1997).

The generalist social work practice model provides some synthesis of elements from both the Settlement House and Charity Organization models. Functions described in the generalist model run the gamut from more clinically oriented roles, such as consultant, enabler, and facilitator, to more action-oriented roles such as planner, monitor, teacher, and trainer. This practice model may most accurately define the social worker as resource manager who optimizes his/her use of the broad range of helping tools at his/her disposal (Miley, O'Melia, & DuBois, 2004). It is important to credit correctly the generalist social work model, as its functions go well beyond traditional mental-health psychotherapist paradigms and have applicability in a range of community settings, including schools.

Fraser, Randolph, and Bennett (2000) discuss the placement of prevention as another framework for practice, along with restoration and rehabilitation, all directed towards enhancing quality of life. These themes, like generalist practice themes, give recognition to the importance of promoting change through understanding each person's connection to the environment. This supports a unique perspective of the social worker; that of an ecological-systems approach (Gitterman & Germain, 2008). Focus on the fit between person and environment is particularly suited to the school setting. The family of a child with special needs comes into contact with numerous systems and their behavior in IEP staffings will be affected by the fit between family and the specific system they are in relationship with. This perspective, unique to the social worker, can

lead to interventions on multiple levels on behalf of the family, and by extension, the child. This practice approach affords the social worker a source for additional understanding of human relatedness in both social and natural realms. It does so in its ability to explain the confluence of forces impacting human suffering, development, and adaptation.

Empowerment, a concept related to personal and/or social change, is well used in a number of social work contexts.

To be meaningful in describing emerging forms of practice, the term, empowerment must be defined in a political sense as enhancing the skills, motivation, and knowledge that vulnerable people have relevant to changing oppressive systems; these skills are also used when people join with each other in groups to strengthen the effectiveness of the actions they take. (Allen-Meares & Garvin, 2000, p. 86)

In the social work practice setting, empowerment can be summarized in the following ways. First, empowerment requires the worker to establish a dual focus on both people and their environment. Second, empowerment gives preference to working with the most disadvantaged, oppressed, or stigmatized individuals or groups. Third, empowerment requires the worker to understand how people learn, grow, and adapt. Fourth, empowerment guides the worker to engage people collectively, share power, and raise consciousness (Cox & Parsons, 2008). The social worker's use of empowerment strategies is likely the most powerful tool in his/her arsenal for promoting positive and sustainable change. For that reason, the skill in the uses of empowerment strategy is central to being an effective social worker.

The role of social work practitioners in various settings is often strongly, if not almost, entirely influenced by organizational mandates, priorities, and the personalities

of key leadership figures (Abramson, 1993). Social workers in private practice, functioning within an almost exclusively clinical model, have different freedoms but also different systems of accountability than have their clinical counterparts in private-not-for profit or public sector settings. Clinically oriented practitioners, by the nature of their work, often have a much narrower spectrum of function than social workers who must perform non-clinical tasks much of their work day. It follows that the more varied the social worker perceives the demands of the work, the more generalist their skill set will likely need to be for the worker to feel competent. Community based social workers, outreach workers, and school social workers would seem to be categories of professionals who need to practice with a broad range of skills in order to manage their time and work efficiently. Such a method of practice may also produce additional benefits. Exposure to such varied work may leave the worker well positioned to employ perspectives and practices based on empowerment, ecological perspectives, strengths based practices and systemic thinking in efforts to promote change on multiple levels. These perspectives and practices are deemed essential to a family-centered approach to working with families in IEP staffing situation.

### **Role of the School Social Worker**

The role of the school social worker in IEP staffings is not referenced in the professional literature. There are, however, descriptions of the tasks and activities of social workers within the IFSP process (Mahoney & Wiggers, 2007; Sabatino, 2001; Shannon, 2004), descriptions of the school social worker's role in the implementation of the Education for all Handicapped Children Act (Alderson, Krishef, & Spencer, 1990),



and of school social work roles in transitioning children from early intervention programs to special education (Rosenkoetter, Hains, & Dogaru, 2007).

There does exist a body of research concerning the functions of the social worker in using empowerment practices, which can be applied to his/her work in the school setting (Boehm & Staples, 2002; Itzhaky & Scharz, 2000). Additionally, recommended practices for human services in general (Gutierrez, DeLois, & GlenMaye, 1995), counseling (Fine & Gardner, 1991; McWhirter, 2001), and psychology (McWilliams, Maxwell, & Sloper, 1999; Rappaport, 1981), are represented in the literature.

The standards for school social workers have been made explicit by two key associations governing social work practice in the school setting. As early as 1978, The National Association of Social Workers (NASW) recognized the need to refine the role of school social workers to meet requirements emerging from the new federal and legislative mandates related to special education (NASW, 2002). Three of the 28 standards put forth have particular relevance to the school social workers' involvement in the IEP process. The three standards for school social work related to the IEP process elaborate the themes of empowerment, advocacy, and cooperation. They are expected to "help empower students and their families to gain access to and effectively use formal and informal community resources" (p. 12), are expected to advocate for families, and finally, are expected to work collaboratively with the school to mobilize the resources necessary in meeting the needs of families (NASW, 2002). These uses of empowerment and advocacy are consistent with the general literature on empowerment practices (Boehm & Staples, 2002; Gutierrez, 1990; Solomon, 1987). The School Social Work

Association of America (SSWAA) largely echoes earlier themes developed by NASW when they describe needs for social workers to mobilize school resources, provide advocacy, and liaise between family and school (SSWAA, 2009).

Specific helpgiving practices within an empowerment model are varied. There is some agreement in the theoretical literature that work with families should consist of a shared conceptualization of the problem and how it may be perpetuated. Upon establishing consensus regarding problem dynamics, the social worker is responsible for promoting greater parental autonomy. S/he consequently promotes the requisite skills beneficial to successful management of problems and issues independent of professionals (Gutierrez, 1990; McWhirter, 2001). Some examples of skill promotion are teaching social skills, decision-making, skills, and assertiveness skills.

In one study examining elements to social work empowering practice, three types of helpgiving activities were identified. These were education, as in skill building, participation, which included activities enabling a family to take an active role in decisions and process, and use of a strengths perspective. These were viewed as essential by professionals (Gutierrez, DeLois, & GlenMaye, 1995).

In a study specific to helpgiving practices on behalf of children with disabilities, data from parents indicated that active participation in the decision-making process had the most significant impact on their ability to deal effectively at all levels: family, school, community (Itzhaky & Schwartz, 2000). This lends support for school social work efforts engaging in the promotion of such behaviors through both cognitive and behavioral efforts (Boehm & Staples, 2002; McWhirter, 2001; Thompson, 1997).

Increased awareness, skill acquisition, and opportunities to actively participate in decision-making provide families with a sense of mastery and control. While the school social worker cannot make families feel empowered, their professional activities can engage families in a process whereby they become empowered.

### **Role of the School Social Worker in a Host Setting**

The lack of clarity regarding the identity of the school social worker was recognized soon after the development of school social work as a field of practice more than a century ago (Shaffer, 2006). This lack of clarity has persisted despite the evolving role of school social work (Kelly, 2009). ‘Visiting teachers’, as school social workers were referred to at the beginning of the 20<sup>th</sup> century, were considered the liaison between home, school, and community. In addition, they were advocates for students in their quest to become educated in the public school system. These same functions are accepted for school social workers today. Confusion arises on how the functions are translated into practice. Contributing to this confusion is school social work’s role within the complex organization of the educational system.

School social workers practice within a host setting (Bronstein, 2003; Dane & Simon, 1991; Janson & Simmons, 1986; Lee, 1983; Link, 1991). This poses a number of challenges to the role definition of the school social worker. Primary is that the host organization represents the discipline of education with a mission, values, and set of priorities effecting decision-making which do not represent those of the profession of social work.

School social workers in the host setting of the school system are relegated to a

token status when their numbers make up 15% or less of school personnel (Dane & Simon, 1991). Given that schools employ primarily educators in the role of teachers and administrators, one can easily assume that school social workers are viewed as support rather than essential personnel and easily fall within that 15% cutoff. Being of minority status within an organization opens up their vulnerability for marginalization unless the social worker can carve out a highly visible and indispensable role for him/herself. Only in this way can school social workers keep from being professionally isolated, ignored in the flow of information and decision-making, and misunderstood in their role, professional capabilities and expertise.

Being employed in a host setting also contributes to role ambiguity for the school social worker (Dane & Simon, 1991). This is evidenced in the primary source of referrals to the social worker. Educators assume primary control over who gets referred and what the focus of the intervention should be (Link, 1991). Thus, the social worker in the school setting becomes the agent of the organization rather than operating out of the values and practices promoted by the profession of social work.

Compounding this dilemma of being expected to work in a manner defined by educators, is the fact that most school social workers are supervised by someone outside of their profession (Garrett & Barretta-Herman, 1995; Kelly, 2009). Being supervised by persons with different professional identities, set of values, and priorities subtly influences the school social worker to conform more with the objectives of the host agency rather than to those aligned with the perspectives and values of the social work profession.

School systems, like the majority of organizations in the United States during the beginning of the 21<sup>st</sup> century, are concerned with budgetary decisions and their impact on the allocation of resources. Schools are also concerned with measurable outcomes as mandated by NCLB and IDEA. Schools are pressured to provide services to the maximum amount of students in the most efficient manner possible as a means of containing costs. While this may reflect sound practice on the part of educators, social workers may consider this as being in conflict with the best interest of students and their families. Role ambiguity emerges when school social workers have to decide how to provide a service in line with the values, thinking, and practice of their profession that may run contrary to practices of the host organization.

The challenges to school social workers elicited by working within a host agency should encourage workers to approach their role with more thought and attention to ethical concerns than might a worker in a predominantly social work agency. A more fully defined role, at least in one practice arena, might serve the school social worker better in navigating the role discrepancies brought about through practicing within a host setting.

### **Conclusion**

The enactment of the Education for all Handicapped Children Act of 1975 was significant in that it called for the provision of a free and public education to all students with special needs. In addition, it mandated the development of an IEP for each child determined special education eligible. The role of families in its development was a key feature of this Act. Unfortunately, there is some evidence that this does not routinely

occur. While we must accept that not all families may wish to participate fully in such a process, they are nonetheless to be afforded the opportunity to do so if they wish it.

Families of children with special needs are as varied as their children. Not all families are equally equipped to participate fully in staffings. In addition, elements in the staffing environment may provide barriers to their full participation. It is then incumbent on someone to offer families the appropriate intervention strategies enabling greater involvement as is required by law. The school social worker seems well positioned to provide such assistance.

While no formalized or unified role for the school social work role is explicated in the literature, general social worker helpgiving practices have been described. The literature emanating from the field of early intervention supports a family-centered approach to families with its undergirding empowerment ideology. This approach is gaining acceptance within the special education system. Literature on the general role of social workers aligns itself with this view.

The family-centered approach supports specific helpgiving activities to families, which promote a sense of empowerment among families. These activities include advocacy, skill training, and opportunities for participation to families. These are all activities that could fall within the school social worker's purview. This information, coupled with the information from families regarding the helpgiving practices they find most useful, can assist in the development of a more defined and unified role for the school social worker within the IEP staffing. A better explicated role definition for the school social worker can then serve to better navigate the challenges inherent in working

within a host setting. This in turn will afford the social worker more opportunities to offer their specialized perspective and associated practices to both families and school as a whole.

## CHAPTER THREE

### METHODOLOGY

This exploratory study investigated and described school social worker helpgiving practices from the perspective of the mother with a child on the autism spectrum during the individualized education planning staffing. As limited research exists regarding the activities of school social workers during IEP staffings, this study was considered a beginning attempt to identify those practices mothers identified as being helpful to their role as a fully participating team member. Knowledge of effective helpgiving practices would be helpful in developing a more informed role definition for school social workers.

Exploratory studies tend to employ qualitative methodologies and was thus chosen for building further understandings of the parental perspective in IEP staffings (Salahu-Din, 2003). Through individual interviews with mothers, information regarding their preferred school social work practices and how these related to their increased participation and advocacy were elicited.

The following research questions were explored:

1. What helpgiving practices do mothers associate with positive IEP staffing experiences?
2. What are mothers' perceptions of the role of the school social worker during IEP staffings?
3. What helpgiving practices do mothers identify as being key to their increased



participation and advocacy during the IEP staffing?

A qualitative research methodology was adopted as it was believed to offer the most useful means of gathering data supporting the research questions of this study. This methodology has been shown to be effective when the research is attempting to:

- Expand understanding of phenomena from the perspective of participants
- Develop a richer and deeper understanding of the experience of the participant
- Interact with participants in a face-to-face manner (Salahu-Din, 2003).

The purpose of this study was to identify which helpgiving practices mothers found to be most beneficial in effectively navigating the IEP process. This methodological approach offered participants the opportunity to fully describe their individual staffing experiences. In addition, it offered some flexibility to the researcher in her effort to get a more complete understanding of the participant's experience and expectations for the staffing situation. From these descriptions, school social worker helpgiving practices of value to mothers were identified.

Given that this study is aligned with an empowerment tradition of providing helpgiving, backward mapping as a means of identifying school social worker helpgiving practices was utilized. Backward mapping is an analytic strategy relying on consumer driven opinions, perceptions, and descriptions of experiences which influence desired changes in policy and supports (Walker & Koroloff, 2007). A backward mapping approach focuses on descriptions of conditions and experiences from those individuals most affected by them. This is in contrast to a forward mapping approach often utilized by complex, hierarchical systems such as educational institutions where desired changes

are determined by those most removed from their effects and influence (Walker & Koroloff, 2007). Consumer-driven information elicited from in-depth interviews focused on the activities of IEP team members and school social workers is deemed of particular value as it is the consumer, in this case the mother, who is most affected by the helping efforts, or lack thereof, within the staffing situation. The “closer one is to the source of the problem, the greater is the ability to influence behavior in the desired direction” (Fiorino, 1997, p. 253). While many school policies are developed from a top down, forward mapping paradigm, this approach encourages the mothers’ opinions and desires to be considered in the development of practice decisions. It intersects with an empowerment tradition in that it allows the consumers to give voice to their experiences in staffings and to suggest approaches facilitating a greater sense of inclusion and collaboration within the IEP process.

As this study was an initial effort to identify school social work helping practices in IEP staffings, future research efforts, using other methodologies, can be undertaken to include other stakeholder perspectives. However, this effort of having the mothers’ perceptions identified and examined insured that they had an opportunity to voice their opinions and to have these considered in the recommendation for services that might benefit families attending staffings in the future.

This chapter describes a number of methodological considerations. They include the following: (a) sampling procedures (b) inclusion and exclusion criteria (c) data collection methods (d) data organization and analysis (e) ethical considerations and (f) researcher bias.

## Participants

The 12 participants involved in this research were all mothers who had children on the autism spectrum who were between the ages of 5 and 22. Five of the 12 parents interviewed had children placed in one public school district although in different schools and academic programs. The remaining seven parents had their children placed in one, private, not-for profit private day school specializing in the education and treatment of students on the autism spectrum.

The pool of respondents reflected significant sample homogeneity. Table 1 offers a visual account of the basic demographic characteristics for each mother interviewed. Mothers shared similarities of race, socio-economic status, and educational background. The first five mothers represented those who had a child in a neighborhood public school. The final seven represented those whose children attended the specialized program. Because the parents with children enrolled in public schools were from one district, their demographic characteristics tended to be slightly more homogeneous than were those of parents with children from the specialized program. The latter program drew students from a seven county area and some differences in demographic characteristics can be accounted for by the variability of geographical residence.

The first five mothers resided in one suburban school district within a large, Midwestern, metropolitan area. The area is known for its affluence and high quality schools. The area's property tax base is strong with its local residents generally very active in school and community affairs. Individual demographic survey data gathered were consistent with these assessments. Mothers tended to be highly educated, most

having earned at least a Master's degree, and having family incomes greater than \$100,000 per year. All were white and married.

Table 1. Parent Characteristics

Family	Sex	Race	Age	Marital Status	Highest Educ Level	Level of Income	Number of Staffings Attended
01	F	W	49	M	B.A.	\$100,000+	200
02	F	W	--	M	M.B.A.	\$200,000+	60
03	F	W	47	D	Ed.D.	--	59
04	F	W	40	M	M.A.	\$100,000	15
05	F	W	47	S	B.A.*	--	12
06	F	W	46	M	B.A.	\$110,000	10
07	F	W	44	M	B.A.	--	30
08	F	W	34	D	Some College	\$25,000	13
09	F	W	45	D	B.A.	\$50,000	10
10	F	W	32	M	H.S.	\$78,000	3
11	F	W	41	D	B.A.*	\$61,000	18
12	F	W	58	M	H.S.**	\$55,000	20

*Note:* W=White; M=Married; D=Divorced; S=Separated

\*Has taken courses beyond the B.A. level but not sufficient to earn a Master's degree.

\*\*Has taken some college courses.

The second group of respondents consisted of mothers from a wider geographical area as their children were bused to the specialized school program usually located outside their community. While the first group of parents lived exclusively in single-family homes in suburban communities, this group was comprised of condominium, town home, suburban, small town, and rural dwellers.

While there was some variability among respondents whose children attended the specialized program, most were attributable to one or two outliers. Only one parent had

an income under \$50,000. That same parent was the sole respondent under the age of 40 and was only one of two with less than some college education. These mothers reflected similar demographic characteristics as the second group except in the area of marital status. In this latter group, the majority of women were either separated or divorced.

Table 2 offers a breakdown of student characteristics. Most children were of middle or high school age. There were two exceptions. One mother had a child, a kindergartener, new to special education. The second was a mother of a student about to transition out of special education and into adult services. The children averaged 9.9 years in special education and their parents had attended an average of 37.5 IEP staffings.

Table 2. Child Characteristics

Family	Age of Child	Years in Special Education	Number of Spec. Ed. Schools Attended
#01	21	20	4
#02	18	15	6
#03	13	08	5
#04	13	08	2
#05	15	09	3
#06	13	08	3
#07	13	08	2
#08	11	09	4
#09	4.5	03	2
#10	13	11	3
#11	12	09	3
#12	15	11	2

## **Sampling Considerations**

### **Recruitment Efforts**

The initial recruitment effort involved connecting with an area Special Education Director for the purpose of coordinating the piloting of a brief demographic questionnaire and a series of guiding interview questions. With this first step, one mother was initially contacted and served as pilot. This mother, in turn, connected via email, to other local mothers of school-aged children on the autism spectrum. Her coordinating effort identified other mothers willing to participate in the study. This first group of study participants represented those mothers with a school age child in the public school system. A benefit was the enthusiastic response of mothers encountered in this initial process. All five voiced interest and hope in promoting improved IEP staffing processes, as their motivation for agreeing to participate in this project. Two of the five interviewees expressed interest in reviewing the study results.

The recruitment of respondents from the specialized program proceeded as initially planned. The school's principal managed the distribution of recruitment materials to teachers and parents. No further contact was permitted between researcher and school, a boundary established by the principal. The researcher had to rely on return receipt of 'intent to participate' forms from interested parents. Eventually, ten 'intent to participate' forms from interested mothers were received.

It was the principal's desire to keep the research interviewing effort totally separate from the ongoing IEP function at the school. As a consequence, all interviews were conducted at locations other than the school. Ten forms with contact information

were returned to the researcher. Of these ten, two mothers did not respond to follow up efforts. One could not agree on a suitable interview site. In the end, seven mothers agreed to be interviewed. Of these seven, six identified their homes as the most suitable interview site while the final mother identified her local public library as suiting her best.

### **Sampling**

A nonprobability sample was adopted for the purpose of this study.

Nonprobability samples have been found to be useful when the goal of the research is to understand a particular social process rather than to generalize the findings (Monette, Sullivan, & DeJong, 2005). As this study sought to more fully understand mothers' perceptions of helping practices, this sampling approach seemed well suited to this goal. Of the various nonprobability samples available to researchers, purposive sampling was considered the best fit. A population of mothers with children on the autism spectrum and who were enrolled in special education was the only population targeted in this study.

The most efficient means of securing the targeted population involved enlisting participants from one school specializing in the education and treatment of students on the autism spectrum. This school, located in a suburb of a large midwestern city provides social-emotional services and special education to approximately 125 students between the ages of 5 and 22 who have an autism spectrum disorder. Students come from a seven county area to the west, northwest, and southwest of the Chicago metropolitan area. They represent approximately 60 public school districts located in a mix of rural, suburban, and urban areas and represent racial, ethnic, educational, and economic diversity. All of these

students have been referred to this private, not-for-profit educational facility by their referring school district due to behaviors, which were considered too challenging for the public school to appropriately manage. The decision to place the child outside the school district was determined at an IEP staffing with the inclusion of parents. Some parents requested this school placement while other parents were given school options from which to choose. This private program is free to the family due to its contractual relationship with the students' families' home public school district.

### **Sampling Procedures**

The study employed a convenience sample to recruit a specific group of mothers willing to share perspectives of their IEP experiences. One mother was designated the primary interviewee during the piloting of the survey instrument and interview. This mother offered to recruit other mothers in a snowball fashion. This was not the initial methodological intention but proceeded due to her enthusiasm for the project.

A specialized school program was then targeted as the key school source for the main body of interviews, a purposive sampling approach. Both samples were self-selecting. Only mothers with high interest in the study became subject volunteers. This self-selection process led to two issues needing explication when discussing results: sample homogeneity and mother's capacity to advocate.

### **Sample Size**

For this study, 12 participants made up a sample size sufficient to fully describe the helpgiving practices valued by mothers in staffings. Sample size has this requirement. Qualitative studies, rather than their quantitative counterpart, permit



smaller sample sizes, as the intent is to describe and understand phenomena rather than to generalize findings (Anastas, 1999). The 12 respondents used in this study fall well within the range of recommended interviews required in studies of a more descriptive nature (Kvale, 1996). For this study, the 12 face-to-face, in-depth interviews were of sufficient size to provide data to satisfy the research questions. There was consistency in mother identified helping practices and this suggested some saturation of the topic. The option to conduct additional interviews was rejected, as it seemed unlikely new information would be forthcoming.

### **Inclusion and Exclusion Criteria**

Mothers were considered eligible for participation in this study if they met two criteria. The child had to be enrolled in a pre-determined specialized education program and had to have a diagnosis or symptomatology consistent with one of the autism spectrum disorders. The potential participant had to be willing to be interviewed for approximately 90 minutes and to meet outside of the physical school facility. All mothers who expressed an interest in participating in this study were contacted. Of the 15 who expressed interest, 12 met the established criteria and were interviewed.

### **Data Collection**

Two methods were used to collect data. The first consisted of a demographic survey, which was used to collect background information on both the child and the parent (see Appendix F). Mothers were instructed to complete the survey only to the extent comfortable. They were given verbal permission to leave questions blank if they wished or to refuse to complete the survey altogether. The survey tool had a numerical

identifier in lieu of name, which allowed for the maintenance of confidentiality for the parent.

Items for the survey were chosen to provide some context to the descriptive data offered by mothers. Knowing the number of schools attended and years enrolled in special education was helpful in determining mothers' level of experience with staffings and with different IEP teams. Basic demographic information helped determine the level of homogeneity of mothers along those factors. Given that the results of the survey did reveal homogeneity among participants, findings had to be strictly applied to this narrow parent population.

The second method for collecting data was through face-to-face, in-depth, individual interviews. A semi-structured interview format was deemed the most beneficial for the purposes of this study. This interview structure relied on guiding questions or topic areas, which were provided in a pre-determined order. The interviewer had the flexibility to probe further to elicit greater elaboration of responses (Berg, 2001; Kvale, 1996). The guiding questions (see Appendix G) attempted to elicit two types of information. Some of the items related directly to the research questions, such as describing a positive staffing they had attended and describing the elements in the staffing contributing to this positive feeling. These relied on more concrete responses, which were based on observations and behaviors. Other items attempted to elicit more of the mothers' thoughts, opinions, and wishes. Both were intended to provide a complete picture of what mothers were experiencing in staffings juxtaposed against what they wished they were experiencing. There was no formula for the length of time allotted an

interview (Berg, 2001). For purposes of this study, 90 minutes were offered to parents.

### **Pilot**

The piloting phase of the study took place in one public school district known for its services to students on the autism spectrum. The site was different from the one chosen for the subsequent phase of the study, but shared some important features. Both programs educated children on the autism spectrum and both encouraged parents to attend the IEP staffings.

The initial recruitment effort involved connecting with an area Special Education Director for the purpose of coordinating the piloting of a brief demographic questionnaire and a series of guiding interview questions. With this first step, one mother was initially contacted. The piloting effort resulted in only minimal changes to the guiding questions and to the structure of the interview. An additional item was included in the interview as it came up in the first meeting with the mother; that of number of staffings attended on behalf of the child. Not only did it provide data useful to this study, but it also seemed to ease the mothers naturally into a discussion of staffings, their level of involvement, and some of their experiences. Although 90 minutes were allotted to the interview, this parent was able to answer the questions within a 45-minute time frame and this time frame was then offered to the other participants as part of their informed consent.

### **Semi-Structured Interviews**

The in-depth interviews were structured specifically to provide mothers time to adjust to the novelty of the interview situation. Each interview followed a prescribed format which consisted of: (a) introductions and small talk, (b) explanation of the

research project, (c) review of informed consent procedures, (d) introduction of the brief questionnaire, (e) initiation of the audio-taping, and (f) introduction of the guiding questions.

The seven semi-structured guiding questions followed a developmental format with items considered the least threatening preceding those requiring greater self-disclosure. That mothers would be increasingly likely to disclose information of a self-reflective nature once acclimated and more at ease with the interview format was an assumption made by the researcher.

The guiding questions were developed directly from the research questions. The professional literature was referenced in developing items related to parent participation and advocacy. Specifically, qualitative studies focusing on parent participation in Individual Family Service Planning meetings were helpful as parents' experiences with helping within early education has been well documented (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Dempsey & Dunst, 2004; Dunst, 2002).

### **Data Organization and Analysis**

Data analysis in qualitative research involves multiple researcher activities, the first one being the organization and subsequent reduction of accumulated information gathered during the in-depth interviews (Berg, 2001; Marshall & Rossman, 2006). A voluminous amount of data was accumulated as a result of the 12 in-depth interviews conducted. Gathering and analysis activities occurred simultaneously (Weiss 1994).

Given that each interview was audio recorded, the first step in the process was transcribing all interview material verbatim. Problems with the interpretative quality of

some of the transcriptions arose. After review of the written accounts, it was clear that some meanings were distorted. Also, many interviews contained significant amounts of professional jargon as well as names of experts in the field of autism.. Due to the need to correct these problems for purposes of reliability of data, all audio-recordings were re-submitted for another transcription process. Each digitized interview was compared to the final transcription to insure the verbatim content was transcribed accurately. This was a lengthy process but a necessary step as the transcriptions served as the database for this study. An accurate record of what the mothers described was critical to this research endeavor.

### **Data Organization**

There were four major types of data collected on each of the 12 parents: (a) the digitized, verbatim account, (b) the verbatim transcription, (c) the demographic survey, and (d) the written field notes written immediately following each interview. Each form of data was provided a numeric code, identifying which grouping of four belonged together. These were all stored in a locked file cabinet.

Codes were created after the data was collected and transformed into written texts. Open coding, the activity involved in conceptualizing gathered data, was the primary approach to the data analysis in this study, as it is unrestrictive in numbers of codes permitted to be identified (Strauss, 1987). Open coding entailed reviewing the transcribed data from interviews with great attention to detail. This inductive approach to code creation emphasized the descriptive element of the parent experience rather than an interpretation of that same experience (Miles & Huberman, 1994). Familiarity with the

data as a result of multiple readings facilitated the recognition of emerging patterns, and codes could then be revised or eliminated. This was undertaken by two independent researchers, both in the profession of social work but with no relationship to the participants. Each coder applied their own codes independently of one another. The codes were then reviewed by the researcher to determine their labeling consistency. Multiple codes were identified and as they tended to be descriptive, there was less opportunity than with interpretive codes, for disagreement. Repeated readings and data immersion resulted in the identification of five themes, which seemed to predominate and were linked to the questions asked by this study. Each theme was examined individually and matched with supporting interview data.

### **Ethical Considerations**

Informed consent and confidentiality were the primary means of protecting disclosed data and the research participants who provided it. Both were fully reviewed with potential participants prior to their agreeing to participate in the study. In addition, approval of activities and forms related to the research were submitted to the Institutional Review Board of the University prior to proceeding with any recruitment activity.

### **Confidentiality**

A parent's right to privacy is linked to the manner in which the researcher manages the confidentiality of data (Folkman, 2000). Two sources of privacy emerged in this study. The first related to the brief questionnaire requesting demographic information on each participant. The second related to the rich accounts of parents' participation in IEP staffings, which were digitized and transcribed into text.

Prior to any data collection activity, each mother who expressed interest in participating in this research study was informed of the parameters of confidentiality. They were provided with a 'consent to participate' form, which explicitly described the researcher's efforts at maintaining participant confidentiality (see Appendix B). Each mother was informed that the survey they filled out in the first phase of the study would be identified by numeric value in an effort to hide the identity of the participant to any person interacting with the data. They were also informed that all interviews would be recorded, the audio tapes kept in locked cabinets for the duration of the study, and that all audio and text information from parents would be destroyed and disposed of upon completion of the research project. Given the potential for breaches of confidentiality via the Internet, contact between researcher and actual participants was maintained primarily through telephone, mail, and in person.

Every effort was made to insure the interviews were conducted in ways to insure privacy. On two occasions, however, once during the piloting of the data collection tools and once during the interview, interviews were conducted in public libraries. While it was possible to secure a private room for one of the in-depth interviews, the pilot interview was held in the main library room where a number of individuals were using the facility. This was discussed with the parent, and she acknowledged the situation and insisted she had no issue with sharing her personal information in this setting. She in fact had arranged the site.

**Informed Consent**

An informed consent form was mailed to each participant who expressed interest in participating in this study. In addition, the information contained within the informed consent document was reviewed verbally with each parent to insure its content was understood and consent freely given (see Appendix B).

Voluntary participation extended to parents' understanding that they could withdraw from the study at any point in time. They were also permitted to refuse to answer any question, either in the brief questionnaire or during the interview. This was addressed in the 'consent to participate' letter each mother received and was reviewed verbally to insure full comprehension. Two mothers did decline to answer questions regarding their level of income. It was further explained to each participant that their participation in this study would have no influence over receiving additional services or preferential treatment from their children's school programs.

**Role of the Researcher**

Because of the researcher's background in the field of autism, and specifically with parents of children with autism, the potential for bias was an issue needing to be addressed. The concern was in coding the data and then developing themes without a biased overlay. While the researcher's familiarity with autism was helpful in understanding what parents were attempting to describe, it could also be a hindrance as biased interpretation can be introduced when the descriptions are either unclear or somewhat ambiguous.

As a way to protect against researcher bias, multiple coders were used and



compared. While both had similar professional training, neither had prior work experience with this specific population. As a final attempt at minimizing bias, the researcher reviewed her level of projection and bias at regular intervals through self-reflection and in consultation with other professionals.

## CHAPTER FOUR

### RESULTS

#### **Introduction**

The purpose of this study was to investigate mothers' perceptions of helpgiving practices in IEP staffings. While it was important to explore all helpgiving efforts within staffings, special attention was given to the helpgiving behaviors of school social workers. Once identified, this information was used to carve out a more comprehensive role for the school social worker in IEP staffings. This information also provided some direction on how to better align team attitudes and behaviors with a more family-centered approach to educational planning that is equally inclusive of mothers and educational team.

Five themes emerged which serve to organize the flow of the results section. The themes developed here are generally distinguishable from each other but have some inevitable overlap. The themes are as follows: (a) elements of the IEP staffing (b) parent agency (c) team climate (d) child-centered focus and (e) supportive functions of team members.

#### **Theme One: Elements of the IEP Staffing**

First, the respondents identified a number of elements, which impacted their participation in IEP staffings. Coding outcome clusters identified staffing size, seating arrangements, staffing length, and IEP document as the most frequently mentioned issues

to surface in the interview process.

### **Staffing Size**

Nine of the 12 mothers identified staffing size as having a significant influence on their staffing experiences. Most of these respondents recalled between 10 and 12 professionals typically attending the staffings in which they participated. With this many people, mothers often described themselves as feeling “intimidated” and “overwhelmed”. The mothers, in describing their discomfort, responded in their own unique ways. One mother stated, “There’s like ten people and me, and... I feel like they look at me like I’m crazy.” Another explained, “it can be intimidating when you’re walking in and you’ve got all these people sitting there. And the more people there, the more intimidating it is.” One mother, who had consistently positive experiences throughout her involvement in special education, used metaphors to describe her experience. She stated:

You know there are so many people [in the IEP staffing] it’s kind of like being at a wedding reception...I mean it’s kind of like giving birth. You think you’re going to have the doctor and maybe a nurse and there are like 12 people in the room. It’s like I have no idea what all the different people are doing.

One mother, with a long and varied professional life in special education, provided an additional perspective. She expressed the belief that staffing size, as reflected in the number of professionals attending staffings, is dependent on staff assessment of the difficulty a particular parent might create in the meeting. She described assertive, contentious or generally difficult parents, as perceived by school staff, as “PITA” or “pain-in-the-ass” parents. She related that, in her experience, the number of school professionals attending staffings is often increased when the team

expects a “PITA” parent to attend the staffing. She went on to describe “PITA” staffings, “A typical staffing is when no less than 10 to 12 people are around the table because anytime a “PITA” parent is involved, they pull all staff in. It’s fully staffed. It’s not a handful skeleton crew.” This mother additionally expressed her belief that staff exercised more care and better procedural compliance under such circumstances.

The circumstance of mothers not really knowing the school personnel attending their staffings was cited as a problem. Combining this situation with a typically large staffing size, parent discomfort was likely to be high. Parents commented in the following ways: “The number of people were a lot - we were outnumbered greatly. They were strangers. And maybe it felt that way because they were strangers to us, so that felt intimidating.” Another stated, “Because staffings are not always easy to attend when you have a bunch of people sitting around the table. And then people, all those people you don’t know, yeah, it’s a little overwhelming.”

In summary, large staffing size was viewed as a source of discomfort by the majority of mothers interviewed. As one mother explained:

I don’t mind public speaking. I took public speaking and some college courses, college prep English. I can talk. I can sit in front of a group. I have no problems. So, no, that was not intimidating for myself personally, but I have heard from other people that, yes, it is a very intimidating experience.

Some mothers offered solutions to the problems of staffing size. One parent suggested that school personnel and parents make introductions prior to the formal staffing. As one mother put it, “As long as I know a handful of people in the room, then I feel pretty good about the group.” A second parent solution involved reducing the

number of staffing participants. The mothers generally considered three to five school professionals in attendance to be an optimum number. One mother saw this arrangement as possible if staffing attendees would share staffing outcomes with other key staff not in attendance. She said: “I really think if you limit the staffing to the core people, then they can work with everybody else in the school, specials and whoever else.”

It was clear, then, that smaller staffing size made for better staffing experiences from the mothers perspectives. Also, when they have met and know at least some of the professionals attending their staffings, they seemed less likely to succumb to negative thoughts or feelings or to experience discomfort.

### **Seating Arrangement**

Some parent respondents found certain seating arrangements to impact their staffing experiences. One particular seating arrangement was a significant barrier to the mothers’ sense of inclusion in the process. The barrier was sensed when parents were seated directly across from school professionals at a conference table. Subjectively, these across the table seating situations often raised a sense of personal vulnerability. One parent described it this way. “In previous staffings, it was like all the staff was seated on this side and here you were, the parent, on one side and you feel like you’re in front of the judge and jury.”

It is interesting to note that many parent respondents indicated they preferred to seat themselves at staffings in a more random, family-style way. This style of flexible seating seemed to minimize what some parents perceived as adversarial or judgmental stances on the part of school personnel.

### **Staffing Length**

The length of staffing time was the third element identified in parent interviews. The range of time spent in IEP staffings for this group of mothers, spanned from 20 minutes to four hours. While most agreed that 45 minutes was an adequate time frame to successfully meet the purpose of the conference, not all did so. Variations in staffing time seemed more evident when comparing public program staffings to specialized program staffings. Of particular concern and frustration to some mothers were memories of public school staffings lasting for as long as three or four hours. One mother related that staffings of this length occurred when she found herself providing training information at great length to school personnel. Some felt that the school's procedural rigidity also added time to the staffing process. Another mother recalled school staff taking extra time and in her estimation, acting overly cautiously. She said, "[staff ]were pussy-footing around explanations".

Some parents indicated that a 45-minute time frame did not work for other reasons. One mother talked about her sense of constraint in trying to do a year's worth of programming and planning for her child in such a short time frame. This parent, adamant that 45 minutes was an inadequate amount of staffing time, said this:

They set these IEP's for a 45-minute block of time. Give me a frickin' break! Like you can like plan a whole year's worth of goals and objectives and have it all done in 45 minutes? Well eventually, and I think I had a large part of this process. I don't know they will give me credit for it. But I would also—give me the stuff beforehand. Give me your goals, give me your drafts, and let me have at this because when I get to that table, I'm not going to sit there for two or three hours because my brain is fried and so is yours. It makes me crazy though because they put these meetings on a 45-minute block of time and they always go over. Even with stuff done beforehand, we always go over because there's too much

blah, blah, blah about things that just really aren't important.

This same mother voiced frustration and criticism over the school district's cutting off IEP meetings to keep to their schedule. As a parent and parent advocate, she voiced the perspective that many parents will often fail to re-schedule an IEP staffing if it is cut short. She explained:

Most parents would not call another meeting because they don't want to go through that process again—it's exhausting. But because I have the endurance of an iron man, I'll be like, 'no, we're gonna meet again, we're going to finish this'.

### **Short and Long Term Goals for Child**

Two distinct elements surfaced in the parent interview data. Both are more difficult to describe, as they have a more subjective flavor than most other elements discussed.

First, there seemed to be a sense of difficulty mothers felt in merging their expectations for their child's school success with the goals advanced by school program staff. The nature of these difficulties, more than anything else, may be embedded in the contrasting relational experiences of being a mother versus that of being a teacher of a child on the autism spectrum. One mother briefly addressed her differences with school staff in this arena. Her comments seemed to convey a real underlying pain and disappointment. As she expressed, her initial goal, or hope, was that the school would assume, with her, responsibility in helping her child "make it to adulthood so he can have a successful life." Over time, she grew to believe that school staff had more shortsighted plans for her son. Commenting on a primary school experience, she expressed the following, "[The school just wants] "to get my son out the door and into fifth grade".

This mother was able to acknowledge the school's goals and perspective. She knew the school was limited in meeting the overarching need she had identified for her child. In so doing, she went on to comment, "So our goals are different, you know. I guess we don't have the same focus." In this instance, her realization and disappointment led to diminishing participation in the staffing process and a turning way from school staffings as a potential source of ongoing support.

The second element was a mother's recognition of having competing goals with the school. This disparity, again, seemed rooted in the distinct identification and perspectives that mothers and school professionals each maintained and then brought to the table.

The majority of mothers, who found their goals for their children at odds with the school's position, were seeing the conflict focused on placement issues. Mothers interviewed shared a range of placement issues varying from class mainstreaming to pursuit of private placements and maintenance or relinquishment of private placements. For many of those interviewed, these decisions and the emerging differences inherent in the process were very emotionally laden. Some mothers talked about taking the step to hire advocates or lawyers specializing in the field for support.

Also significant for some mothers was the issue of deciding on or agreeing on "related services." Interviews generally reflected that conflict or agreement over these aspects of service seemed very much dependent on the individuals involved in the process. One mother described how this process could lead to acquiescence and dissatisfaction with the staffing process:



Typically parents leave [the staffing] feeling very angry and frustrated and feel like they have just been, you know, run over by a bulldozer, and the services that are being given to them are services given to them because everybody else agrees on it and the parent does it. And yes, we know that we can come back to the table. But it's a wearing and draining process. So, the meetings are typically—it's just a colder meeting.

### **IEP Document**

A final IEP staffing element concerned the actual IEP itself. Two distinct issues about the IEPs surfaced in the interviews. First, some parents strongly objected to the drafting of an IEP before the formal IEP meeting. It should be noted that this was not found to be a universal practice. Some parents knew this was not legal and have commented, as well, on the highly dismissive nature of this practice.

A second concern was the IEP document form, itself. As its use is mandated and standardized, it became a very overwhelming and confusing tool for many parents. One mother, also a professional parent advocate, described her take on the overall confusion as follows:

I think the forms are intimidating too. And they keep changing the darn forms so they're even more difficult even for the school personnel to navigate through that parents don't end up reading it. I have so many parents that come to me and they'll say, something that they want or they need for their child. And I'll say, "How did the IEP go? What's in your IEP? You already have this accommodation, how is that being implemented?" They'll be like, "Well, I don't know."

There was general consensus that IEP forms can be difficult and confusing. One additional concern to some was that once signed, any change required additional staffing time. A few parents noted the potential for problems with this situation.

## **Theme Two: Parent Agency**

The term *parent agency* is intended to convey a variety of ways that mothers define their personal experiences in learning to act as advocates for their children. As advocates, their underlying goal, in the staffing context, is generally to insure the best special education programming for their children. To explicate the findings, it is useful to identify three different focus areas that comprise parent agency in this context. These focus areas are: (a) preparation for staffings, (b) education of team members, and (c) developing relationships with team members.

### **Preparation for Staffings**

The data reflected a consensus among mothers that they were initially quite unprepared to function in the IEP staffing environment. They frequently described themselves as having felt poorly equipped to navigate the special education system. There were different reasons. Some key reasons identified were ignorance of special education law and limited knowledge of what their child's educational programming options might be. The mothers also commonly expressed a sense of feeling peripheral to the process. In other words, just being present in the staffing with an expectation of agreeing to whatever the staff had planned for their child, was not acceptable. As one parent reflected, "I was really at the beginning of a learning curve and I was desperately trying to get a grip on what was going on". Another mother spoke of her initial staffing experience with insight and regret. "I wish I would have done better. I think I could have done better, but I didn't quite know how to argue the system." Another parent comment addressed what seemed to be her overall confusion with the process. She

stated:

I just knew that I'd have to agree on whatever plan we came up with, but I think that when the behaviors came to the point where I even didn't quite understand or know how to intervene or what kind of things to put into place, that's where the problems started happening, because I didn't know.

From these initial experiences and expressions of frustration, mothers drew motivation to learn. They talked about organizing their learning efforts in a number of different ways. Many mothers sought information on a variety of topics related to their children's disabilities. Mothers took on personal missions to become self-informed. Their primary actions included personal research, networking with other, more experienced parents, networking with professionals, and attending workshops and conferences.

The mothers interviewed consistently talked about having to learn the ropes to become effective special education parents. This meant taking the initiative to engage resources outside of school professionals and the IEP process. The mothers were also consistent in relating that they sought help early on as parents of children within special education. One mother summarized it this way,

It [information] did not come from anybody in the IEP staffing. It all came from me going out and seeking out information from doctors or workshops or autism organizations.

Another stated, "I did some research. I used my nursing background, read on the Internet and thought, this looks like what my kid has here."

Other ways of preparing for IEP staffings surfaced in the data. One mother discussed the help she found through an online group. She referenced using that resource to find additional reading materials. She said: "I was a member of OASIS online support

group and they also have a book that I have that has very detailed chapters on what to do in IEPs.” Another mother referenced her access to reading materials as being very helpful. She said, “I became more well read and more knowledgeable of my rights and her [child’s] rights and the disability.”

A final parent referenced the value she experienced in connecting to a support group. She said:

I guess from talking to other parents and hearing – I’ve heard stories of people having really rough times. We used to go to a support group out there. When he was younger, I would try to go to support groups ... for parents with special needs kids, and you would just hear different things like that.

The data revealed that mothers interviewed carried a consistent message. The message was that accessing and gaining knowledge and information in preparation for staffings was powerful. It, most importantly, afforded the mother opportunity to successfully advocate for her child in the IEP staffing context. As one mother put it, “when you have a child that has a disability, you can either curl up and feel sorry for yourself and pretend it’s not there, or you can get over it and start advocating for him.”

Also, the relationship between parent effort and outcome portrayed in the data was instructive. In order to advocate, one needs to be informed. One mother described the value of proper information as it related to advocacy. She stated:

I’ve heard on my own, I heard that I actually can intimidate people at the table. And I don’t mean to because I really try to be a soft person. But I want them to know I’m educated and I’m going to educate myself. And if I don’t agree with what they’re saying, I’m going to look it up. So don’t spit the law out at me because I’m going to write that down, and I’m going to go look it up. And if what you’re telling me isn’t true, I’m going to say “lets get back together.”

The data revealed that with sufficient knowledge and information, mothers felt empowered by having choices. Choices included taking stances that involved legal actions when rights' violations occurred or seemed likely to occur. Getting legal support took on different forms but in this data, most commonly involved the enlistment of mediators or special education attorneys. Having knowledge and ability to pursue legal options seemed effective leverage strategies to use with school administrators. One parent described her conversation with her child's principal at the staffing:

Listen, we've talked through things before. We've been able to be on the same page. I'm coming to you. I do not want to get a mediator involved. I do not want to get a lawyer involved. But I have been in contact with both. I know my rights and I am pursuing...

The interview data revealed an array of efforts and strategies mothers employed to gain a sense of agency in their dealings with the system. Not all mothers seemed to have the resources to hire an attorney. Some chose to seek out and network with support persons to help them out financially when the need arose. One mother stated, "I think whatever happens, if we go to the IEP staffing and it doesn't go [the way I want], I'm sure my parents would even be willing to help me with whatever it took – if that's what it took to get a lawyer." One mother described the confidence she carried from the pre-staffing preparation in the following summary. "I do feel when you have knowledge and education behind you, you're bound to get somewhere, and you're not trying to be mean about it, you're just trying to do the right thing."

Building confidence and exercising agency in the staffing context was found to be a process that developed over time. Parents were consistent in voicing their beliefs that the self-education necessary for good staffing preparation was an extensive, long-term

endeavor. Confidence in their advocacy in this context came after years of practice.

### **Mothers' Responsibility for Team Education**

With one exception, all mothers interviewed described themselves as educating or training IEP team participants on aspects of dealing with children diagnosed with an autism spectrum disorder. The range of teaching and training varied. One parent formally trained staff with her school principal's participation. Other parents described their efforts as more informal, usually providing bits of teaching in the context of the staffing itself. Some parents were resentful of having to assume a teaching role with staff, feeling that productive planning time became lost. One mother said of her experience:

In the public schools you have to worry about the teacher every fall and it was this grueling process. You had to explain what "Asperger's" was. You had to explain how he was impacted by it, and you hoped and prayed that they'd read the packet from the previous year, which they didn't always do.

As a consequence of her experience, this mother took the initiative and developed a staff informational packet, which she disseminated at the start of each new academic year. She described the primary benefit being a better-focused effort on IEP planning. Other mothers remarked on their recognition that their teaching time for staff was needed because of high staff turnover. One parent stated:

I gotta tell you, here I am at the tail end [of my child being in school], just ready to go out and I am educating all of these newbies because the school district has cut, cut, cut and we lost good people and now we've got a bunch of part-timers. And they're either young, fresh out of school and don't have the background and experience, or they're actually more seasoned but they've been brought into a different role than they're ever been in before. So, that was really frustrating, just trying to get them up to speed. It's always like a three-hour meeting that didn't need to be. It was

exhausting.

A similar sentiment was expressed by another mother:

Because we have newer people at the table. When you have these constant cuts and things in the district, and they're switching all these people around and you're bringing new people to the table and it's not a constant, you know, person working with your child, you know, for at least a bulk of the time all the way through, you stop and you take ten steps backwards so you [educate].

Some mothers expressed an understanding of why it was important to fall into a teaching role with school staff. Usually the mothers tied this to the belief that they, as parents, "know their children best." Aside from this, parents frequently expressed what is often an unmet need: to be well-informed about what the school can and will offer their child. One mother put it this way: "Parents need to be educated on what's appropriate for the school to be working on with the child and offering the child."

A sense, by mothers, of having to do more than their share in the staffing process was common. Some parents also seemed to find staff too uninformed and consequently identified the staffing process as losing its intended focus.

Mothers often became not just teachers but also helpers. A number of those interviewed talked about providing updated resource lists and other such information to team members. Some of the mothers intimated that staff often appeared quite unfamiliar with important information. Some of them noted that one aspect of the problem was manifested in their having to repeat themselves when sharing information with staff. This seemed to reflect a certain sense of dismay as mothers described the apparent ignorance of some staff.

Some of the mothers described going to great lengths to make it easy for staff.

One parent described developing a resource file for her personal use, which she shared with her school social workers:

I have a resource file that I developed on my own without any help from anybody, and I've given it to social workers at my school when there's problems with the students or they need information. I've tapped into my resource file to give them that, or try here at the website. That information should be right at hand.

In summary, mothers interviewed were consistent in describing their IEP staffing experiences as unbalanced. Generally, they felt they gave much more than they received. In spite of such frustrations and disappointments, many mothers approached their situations pragmatically. Some were extraordinarily giving, maintaining very helpful attitudes and behaviors towards staff. Although most mothers wished school staff had been more helpful, they recognized their need to adjust to the realities of each situation. Finally, it is important to note that the mothers identified the critical need for staff support upon their entry into the special education system.

### **Responsibility for Developing Relationships**

Mothers interviewed uniformly felt that developing positive relationships with all team members was extremely important. They viewed their success in this effort as increasing the likelihood that their children's needs would be met by the system. Additionally, mothers recognized their need to identify and reach those persons with power in their staffings.

Mothers generally described themselves as demonstrating pro-active qualities in forming staff relationships. They described a variety of ways used to gain the attention and connection with staff. Some mothers offered tangible gifts ranging from food to



therapeutic games and toys. They mentioned verbal praise as another way to build connection.

Mothers also discussed the importance of forming relationships both prior to and outside of the staffing setting. Collateral efforts like these were seen as ways to improve levels of collaboration and cooperation in the staffing setting. All of these strategies tied into a general thrust towards fostering warm exchanges with team members. One mother stated:

I would validate everybody who was on my child's team somewhere throughout the year, you know. It could have been a note to them or it might have been – social workers were my favorite because I give them games and things.

Another mother described her behavior at staffings:

I always brought food. You know what, there – and it was a way to validate people, you know, at the table. You know, they're busy and I'm busy too. I'm a professional, you know. I've been a working mom but I've always tailored my work around my girls so I could be available and accessible to them. But I always brought, typically chocolate, because, you know, chocolate makes the world go around. And I think it kind of softened them up a little bit towards me.

Another mother described her behavior quite similarly. She stated: "I bring them cookies. I'm of Italian descent, so I feed people. I just do that. But I certainly, I'm unaware that it didn't help – I know it helps." Other mothers shared a broad assortment of items with staff such as flowers, information, literature, and various foods. In general, mothers described the benefits of pro-active giving as easing relationship tensions through promoting a more human, less adversarial environment.

Mothers interviewed generally reflected an awareness that positive connections with staff worked in favor of their child. Many of these same mothers also recognized

that contentious or adversarial relations with staff could not always be avoided. They preferred, however, to establish strong, positive, connections from the outset. One mother described both conditions:

I'm not shy and I pretty quickly – and I've always tried to express to everybody that I consider them as all members of the same team, until they give me reason to believe otherwise. And I think, talking to some parents, that's not always the case. Some parents approach it as an adversarial thing and I give people the benefit of the doubt.

Another mother spoke of having tried both collaborative and adversarial approaches:

I'm a natural relationship former, so that is important for me because I think I always - I like to feel out and maybe it's just a natural way of being. If you want what you want, you have to know who you're asking it from and the best way to do it. I have tried the approach of just going in and demanding, and that doesn't work.

Some mothers discussed the risks of being “adversarial.” At least one mother mentioned having fears of staff retaliation towards her child's siblings enrolled at the same school. This parent's views are as follows:

I was very afraid of how I approached things in regards to my child because I do have two other children that need to go to this school. So I was needing to pursue things to get him the best education I could, because I knew at the time, and I still know, public school system is not the best place for him. And I knew I had to do something, but I didn't want to be the nasty nuisance, like “Oh God, it's that Mrs. [name], here she comes”. I didn't want that on my kids, the other two, because I have two that have to go through that school district. Can't pay for private school, there's no way. So, yes, you had to make sure that you formed a good relationship.

A number of mothers stressed the importance of building key staff relationships early on and prior to the emergence of problems or other difficult issues, if possible.

Some said just one trusting relationship could prove very helpful if and when things

began to “fall apart.” Mothers described this early process as foundation building and that a good foundation continues to serve an important purpose over time. One mother made her point philosophically by saying: “It’s like anything you do in life; it’s the foundation that you build.” This same mother attributed a positive high school staffing experience to the efforts she put into building trusting, collaborative relationships during her child’s early years in school. As she stated, “This shouldn’t be that hard.” One mother, after much thought, came to a more disappointing conclusion and expressed considerable regret over having to work hard to connect with team members. She summarized her view this way:

It took a really long time to build a relationship there. And I gotta tell you, I shouldn’t have to do that. My energy shouldn’t have to be focused on building a relationship with everybody at the school. It should have been them building a relationship with my daughter and us working together for what was best for her.

In summary, mothers interviewed, exercised what is termed here as *parent agency*, in a number of different ways. Most, after initial contact with special education systems, began systematic efforts at self-organization. Their efforts typically involved various forms of research, self-education and networking. Most mothers discussed interacting with staff in a teaching capacity. Some found this uncomfortable, but most mothers were ultimately pragmatic and assessed their efforts as benefiting their child. Mothers were highly consistent in recognizing the importance of pro-actively engaging team members to develop strong, positive connections with their children’s school programs. Many freely discussed their unique approaches to relationship building and most mothers felt reasonably satisfied with the results of their efforts.

### **Theme Three: Team Climate**

Mothers' views of how they were able to join into their IEP staffings and how they were received and treated were essential to their overall experience with their schools. These views, as expressed by respondents, seemed highly dependent on staff attitudes and conduct. Thus, it stands to reason that effective teams would rely on a climate of safety wherein members were able to engage fully with one another (Kahn, 2005).

Mothers in the study described their experiences with inclusion in the staffing process as falling along a continuum from very high to very low. What most mothers identified as most significant were: (a) feeling welcomed (b) feeling safe and (c) being treated in a proper and professional manner.

#### **Welcoming Efforts**

Many mothers identified that being welcomed early on, during their first years of involvement with special education programming, was of critical importance. In general, mothers identified common and effective staff welcoming behaviors. Most frequently mentioned were name recognition, eye contact and physical proximity to known staff in seating. All of these actions were acknowledged by mothers and considered inviting. To explicate further, many of the 12 mothers interviewed identified a staff's welcoming tone of voice as setting the meeting mood. Voice tone, together with a warm manner of introduction, were key to establishing a welcoming meeting climate.

Mothers mentioned that when they experienced a combination of welcoming behaviors, such as being recognized by name, being afforded eye contact, and being

invited to have a seat at the staffing table, they relaxed and got more comfortable, then became more engaged and productive. One mother offered an example of how she wanted to be brought into the staffing room. She stated simply having one team member invite her into the staffing by offering, “Here, please, come sit by me,” would have been well received. She believed that with that sort of support, any anxiety entering a new situation of this nature would have been significantly reduced.

There were other welcoming behaviors described by mothers that seemed to put them at ease. When staff expressed initial excitement talking about the child, it made a positive connection with the parent. When staff was able to articulate or reflect a parent’s understanding of a child, the parent made a positive connection. When staff simply asked the mother questions about the child, a positive connection was also made. It is important to mention that mothers’ experiences of being made to feel more welcomed and having a stronger sense of belonging seemed to occur with greater frequency in specialized programs than in public school programs.

Conversely, there were a number of problematic situations described by mothers. One centered around a mother’s struggle with the manner in which team members introduced themselves. Normally, a staffing starts with team members introducing themselves to the parent(s) present. When staff insisted on adding their terminal degree to their self-introduction, some mothers reacted poorly to this and identified these additional qualifiers as distancing and intimidating. As one mother stated:

When they say I’m a Ph.D., and I’m this and I’m that, while it’s great that we might have all this knowledge and expertise at the table. If you have a parent who just graduated from, you know, just has a high school or college diploma, it’s intimidating to them. You don’t know what’s going

on inside their head.

### **Safety Generating Behaviors**

In the data, mothers identified characteristics or qualities of team behavior related to establishing and maintaining their safety in staffings. What emerged were five characteristics, two positive and three negative that seemed to have the greatest impact on mothers' feelings of safety.

Mothers commented that a sense of being respected by staff and in turn, being able to trust staff were most important to their sense of safety. Ongoing respect and trust were seen as promoting higher levels of staffing participation and greater amounts of satisfaction with the overall staffing process. On the negative side, when mothers sensed they were being blamed, patronized, or treated condescendingly by staff, their sense of safety diminished.

Of the types of dismissive staff behaviors mothers identified, being patronized was one most frequently mentioned. Mothers described picking up on this through staff tone of voice. Patronizing behaviors, observed by the mothers, often took the form of staff presenting themselves as sole authorities or experts. Mothers also felt patronized when they experienced staff placating them and their situations. They often saw these personally insensitive assessments as failures to understand and appreciate their circumstances. The mothers consequently felt too managed and too controlled and sensed little regard for their personal investments in their children. At the extreme, mothers described incidents where team members looked at them as if they were "crazy" or "idiots." One mother spoke of a staffing experience where she felt the staff was out of

touch with what she was going through as a parent:

Even the very decent teachers, who were not bad people, did not have a passion for the kids as individuals, not just my kid. I mean, it's not that they didn't like the kids or didn't care about them, but it was, I always felt that, as a family, we were sort of being patted on the head. And, "there, there, it's going to be alright", when you know, we have big gaping wounds and blood pouring out.

Another mother spoke of the issue of expertise:

They [team members] were always very condescending, and there were numerous times in staffings I would tell any of them, "you don't speak to me that way". They had a tone, just very condescending and very-almost in a roundabout way of saying, "you don't know what you're talking about". And numerous times I would, you know what, she's with me 365 days a year. She's with you six hours a day, sometimes five, out of eight months, nine months, so don't tell me you know my kid better than I know my kid. Numerous times I've said that.

One mother, feeling patronized in her school staffing, described writing her school's principal as a means of communicating her needs. She did not want to be placated. She stated, "They ask you what you want, and you tell them, and they say okay, and it doesn't really happen." Some mothers reported taking a more direct route to these situations by confronting offending staff in the staffing itself.

Mothers reported being most incensed and outraged when they were blamed for aspects of their child's diagnosis by staff. In the data, they described experiences where their children's challenging behaviors at school were attributed to poor parenting. These painful attributions were repeatedly evidenced. As one mother described this:

And then a lot of times the parents feel like it's [the IEP staffing] a condescending experience, that the team looks at the, like "well, your child has this because you're dealing with something." And there had been enough innuendos or comments that have been made over the years that I – I mean, I can't even begin to tell you...

One mother related her experience with teachers in the staffing. She stated, “A lot of times it felt as if the teachers were blaming us for her behaviors. “She’s spoiled, we’re not disciplining her enough, we’re not understanding.”

In staffings, issues of abusive behaviors in the home surfaced more frequently than might be assumed. According to the data, staff raised questions of abuse with about one in four parent respondents. One mother described her experience:

The very beginning...they accused my husband of beating us because my son was acting out and they were trying to figure out why and they said, “no kindergartener would have this behavior, it must be learned at home. You are in a safe place right now, you can tell us, right, that your husband is beating you.” And so that is when I went and got a psychologist and then he came with me to the next meeting and it was much better after that.

This particular mother was appalled that staff would make this kind of allegation of abuse in a staffing, and furthermore assume that the setting was “safe.” In her mind, trusting relationships between herself and staff had not yet been established. Finally, related to *Safety Generated Behaviors*, it is important to state that while positive experiences seemed to occur in both public and specialized school settings, more negative parent experiences were described as occurring in public school settings.

### **Professionalism**

Professionalism was identified as one of the important qualifying factors influencing team climate. Mothers in the study generally agreed that when staffings were professionally oriented, they had order and predictability. Meetings started on time and followed an agenda. The business at hand was important. This is not to say that softer elements were not equally valued. Some mothers preferred mixing personal, anecdotal



sharing with the business of setting goals. One mother related how she preferred a business-like, responsible focus:

[A really pleasant staffing experience] would be one that you'd get a little more professional of a meeting. So it's not done in a classroom or done in a trailer where it's just little tables or whatever. So it's a little more professional, that they mean business, and your time's important, and to just sit around sometimes and people were late and you had to wait for them. "Oh, I thought she was coming. Is she coming? Could someone call her and find out where she's at? That type of thing. When I have kids and I have to be there, or my husband's missed work to be there. Professionalism. If you're on time or you're early, you would expect the same in return. I don't show up late. Never showed up late. That's just how I was raised. So yes, so it's a sign of respect. Your time is important. Professionalism is a big thing. And they want to come off like they're your pal, your buddy, and everybody's your friend. That's fine and great too, but there has to be professionalism that you need or require. And somebody can be a really nice person, and I'm not knocking them for being a really nice person, but I can see how things are run and you need to be a little more on top of things.

Most mothers viewed professionalism, in this context, as inviting. Mothers wanted questions. They wanted dialogue. They often viewed these behaviors as respectful. One mother described it this way:

Good teams will continue to address the parents...Invitational teams, effective teams continue to draw the parents into conversations about their child. They will address by name, "Mr. and Mrs. So and So, how do you feel about?" or "We're considering this, Mr. and Mrs. So and So. Do you have ideas about...?"... But effective teams, regardless of which member it is, will continue to address the parents and allow it to continue to be invitational even if the parent has acknowledged that this would be difficult for them.

Some mothers shared the belief that working to achieve mutual respect was a staff quality that defined the "professional." This was seen when staff were able to accept differences in perspective with parents or even other staff. As one mother indicated, "There was mutual respect whereby, what does it hurt to try it, you know what I mean, to

see if what this person with her years of experience has suggested would work.”

The issue of trust was addressed earlier under *Safety Generating Behaviors*. It has a place again in the context of *Professionalism*. As mentioned, trust and respect were identified as required elements in order to achieve a sense of safety. It is important to note that parent respondents differed in their assessment of the prevalence of the two qualities. The data revealed that mothers universally experienced respect from the team at some point in their special education involvement. The occasions wherein mothers were feeling trusting of staff did not appear as prevalent.

There were three primary barriers that mothers identified as impeding trust of professional staff. The first was their perception of a lack of transparency, that is, honesty and openness, in the staffing itself. Mothers talked about sensing this early on in their staffing experience. The second barrier was poor follow through on tasks, goals and objectives developed in the staffing. The third barrier was a general negativity toward mothers engendered through school grapevines and rumor mills. It often took the form of labeling parents in hostile or highly unfavorable ways and often circulated back to parents by both school staff and other mothers.

In some instances, mothers talked about their efforts to mitigate the impact of trust barriers. They reported that having contact with staff outside of formal channels was helpful. They related that these sorts of sustained efforts, over time, improved trust.

Some of the mothers interviewed were quite aware of their own lingering distrust and suspicions of school staff. One mother described her caution and suspicion of team behavior this way, “They didn’t tell me of this change because they knew I wouldn’t

agree to it. So they were sneaky and they just did it, so now I'm stuck." Asked whether staff could have made an unintended error, the mother further explained:

But as a parent, you're going to think the worst. That's what you're going to think and there goes that trust again. And to be successful in this whole process, we have to trust you guys. There's no other way around it. To be successful, there's got to be a trust element.

This mother's comments seemed to capture the bind common to other mothers sampled. As they sought higher ground, they could not ignore past obstacles giving them cause to move forward with caution. Another mother talking about the impact of school rumors, stated:

You never knew if they were-you know, that forked tongue. They're talking to you this way because you're a parent, but then, in the next breath, they may say something else as soon as you walk out the door.

When questioned about her suspicions, she added:

Because when you have other staff members who aren't involved in the staffing come up to you and tell you, "Oh, you should have heard what they said when you left." Or, " You should have heard them walking in the hall saying, Oh geez. What a piece of work. Do they even know what they're talking about?" You know that. You know that's going to happen. Yes, those staffings were horrible, horrible.

This mother's remarks were not dissimilar to those of other mothers interviewed. They seemed to confirm that malicious rumors and parent labeling aside from reflecting poor professional behavior, could be a formidable barrier to the formation of trusting parent-team relationships.

For most mothers, levels of professionalism encountered in their child's specialized program proved to be uniformly higher than their public school counterparts. They found staff to be more non-judgmental and respectful. As a result, mothers were

generally more satisfied with these staffing experiences.

#### **Theme Four: Child-Centered Focus**

Mothers in the study uniformly reported valuing staff attitudes and behaviors that emphasized their children's strengths, demonstrated commitment to their children's growth and success, and which offered communications that were clear and timely. The extent to which each was demonstrated seemed correlated to the mothers' levels of satisfaction with the overall staffing experience.

#### **Strengths Perspective**

Parent respondents consistently valued team members who emphasized their children's strengths in staffing discussions. A strengths perspective formed a context, constructively framing a child's growth and progress. It afforded a softer exchange between team members and mothers and benefitted all staffing participants by creating a warmer, more congenial, and more collegial atmosphere.

In the interview data, mothers discussed positive experiences from teams employing a strengths perspective. In other portions of the data, mothers discussed less positive experiences when staff failed to employ such a perspective.

It is relevant to begin with some of the more difficult staffing experiences where staff criticism appeared to dominate. One mother, reacting negatively to staff critical comments, described her experience this way:

It was more of "your son is a bad kid." And you know, "we need to do this to protect myself", basically is how she [team member] put it. It was all "your son is a horrible, aggressive kid" and then she said that at the meeting. "Not smart, you know, below average, very aggressive" and then he is like the opposite of those things.

This same mother had an opportunity to speak up at her staffing and counter staff criticisms of her child. She felt unprepared to do so. She felt, at that point, too unsafe to share her thoughts and feelings on the matter. She recalled her sense of this by commenting, “I was a little bit overwhelmed.”

Another mother described her painful experience listening to staff depict her child in a negative manner. She recalled the staffing as being a time when “you basically are given an opportunity to sit there and have the team tell you what’s not going right with your child”.

An additional mother felt disrespected in a staffing when she was directed to take certain actions rather than being asked to collaborate and jointly develop goals with the team. Exasperated, she stated:

Pretty much all but one staffing with the public school was a horrible experience and I think probably the worst one was four hours long and it was just prior to the district agreeing to private placement. And it was a deluge of negatives, just non-stop.

Some mothers described themselves as walking into staffing situations already stressed. Sometimes they were dealing with other life issues and hoped for support and balance in the team’s approach towards them and their children. Two mothers recounted the difficulty they had hearing negative descriptions of their children’s school behaviors while simultaneously experiencing intense emotional burdens. One discussed being in the process of a divorce and the other related dealing with her mother’s terminal illness. In addition, one of these mothers pointed out that the negative staff appraisals contributed to her losing a grip on the optimistic stance she normally took in staffings. Both of these parents were angered. They blamed the respective teams for what they considered to be

insensitivity to their family situations.

All mothers with children enrolled in the specialized program and some parents in public school programs had positive, strengths-oriented staffing experiences. With these experiences, mothers recalled staff talking about their children's strengths at the beginning of the staffing. Later in the staffing, problematic issues would be introduced. Mothers related this as feeling balanced and thus tended to see team members as viewing their child more holistically and objectively. Mothers, of course, recognized that as a result of an autism spectrum diagnosis, their children exhibited problematic behaviors, but in spite of this, they also sought out and appreciated a balanced overall assessment. They felt this often happened when their children's significant, positive attributes were acknowledged, explored, and factored into a broader view of the child. One mother with a child in the specialized program described her positive take on a staffing experience and compared it to proceeding ones:

Everybody goes around and gives the report and they share the positives and the things they're working on, but they never address the behavior negatively, and I appreciate that. I will say staffings from the other [public school], when they are so focused on the negative behavior, it can skew a parent's point of view.

Another mother expressed a similar appreciation:

You actually felt like they were listening to your input as a parent and there were positive things that were said. It wasn't all the negative things. It was okay, well, there's this, but there's also that. A negative, maybe something that she would be struggling in, but then there was always something that was positive that she did. And it wasn't like it was scripted positive. There was always something. There was always something good when there was something maybe not so good.

This mother valued the balanced account of her child's school activity and appreciated

the staff's spontaneous manner of discussing her child's strengths. In this instance, the spontaneous and unrehearsed nature of the staff presentation was viewed as genuine and trust enhancing.

One mother was very impressed with staff efforts to keep a positive stance when sharing her child's difficult behaviors. She said, "They [team members] put a positive twist on even some of the most horrendous details, so it was always an upbeat meeting for the most part."

Mothers often recognized and appreciated when staff made extraordinary efforts to identify strengths amidst the constellation of problem behaviors associated with autism spectrum diagnoses. One mother summed up what many other parents desired. She said, "Everybody has something good about them and a strength that you can draw from...and then you could build the IEP based on those strengths not the weaknesses. I think you build the IEP on strengths."

All of the mothers expressed the desire for IEP staffings to maintain a strengths focus. This did not mean avoiding discussions of a child's difficult behaviors. Rather, the mothers wanted clear and honest accounts of their children's performance in school; ones that were balanced and genuine and could lead to the development of IEPs that considered the whole child rather than just the disability.

### **Commitment to Child**

It was apparent from interview data that mothers gauged staff commitment to their children in a number of different ways. Two very distinct commitment factors surfaced repeatedly. The first was that the team or team member conveyed an

understanding of the uniqueness of the child. The second was that the team or team member communicated this understanding to the parent with enthusiasm and appreciation.

The research data supported that satisfaction with staffings was highly correlated to staff demonstrating commitment to the child as judged by the mothers. Another finding was that levels of perceived commitment to the child was mixed in the public school settings but consistently high in the specialized setting. A number of mothers also attributed lowered commitment to children as resulting from factors outside of the child. Some of these factors included concerns over budgetary constraints that became more of a focus than the actual child, leading to competing educational priorities, and team member educational bias.

As mentioned, commitment to the child was demonstrated in a variety of ways. A number of mothers described one member of the team, often the teacher, who best conveyed his/her sense of commitment with statements such as, "I am so excited about having your child in my class next year," or, "I've had many students with Asperger's. I'm familiar with it. I embrace it. I wish more people had it because I think it's a quality that's blah, blah, blah..."

Mothers appreciated those occasions when staff identified with the whole child and not principally with the disability of the child. One mother stated, "It's embracing. It's being committed to your child." Mothers also seemed to value staff displays of positive affect. It was this emotional connection to their child and the empathic understanding that mothers noticed and appreciated. One mother stated:



I really felt they loved him and there were tears when he was having a bad day and there were hugs when he had a great day. And it was like concern, not like we don't love your child, but we love him so much, it's hard for us to see him like this.

The mother, in this instance, seemed to sense that staff connections to her child mirrored, in some important way, her own valued connection.

What was also known and shared in the data was that mothers were highly sensitive to the quality of connection displayed by staff. They were sensitive to whether staff verbal expressions were congruent with their non-verbal behaviors. The mothers indicated they were more readily able to trust the genuineness of staff communications when a positive staff-parent relationship existed prior to the staffing. One mother described her experience connecting with the teacher around her child. She captured the essence of what most mothers interviewed seemed to desire and described her positive experience in this way:

The teacher said, "I am so excited about having [student] in my class next year." She said, "I just wanted to let you know that if there's anything that you would like to give me or you would like me to read". She said, "I would even love to visit you this summer and get to know her [student]". And she said, you know, "if there's anything that I can do, please just let me know because I really want to make it a good experience for her." And immediately the walls went down. So, there was no preconceived notion on either part and so I knew that we were going to have a good year. You know, did [student] achieve some of the goals, we wish she could have? No. But the fact is, is that because the teacher embraced the parent, the teacher embraced the student, we didn't face any of those issues when we got to the table.

In the IEP staffing, when mothers detected genuine concern and caring for children, their attitudes frequently softened. They became less guarded and less reactive. Their willingness to hear and absorb painful aspects of their children's behavior

increased. They better tolerated difficult assessments, setbacks, and limitations. As a consequence, staff and parents merged in their understanding of the child. They increasingly found common ground and were more consistent and congruent in the way they dealt with the child.

### **Team Responsiveness**

Mothers viewed staff responding to their informational needs in wide-ranging ways. They generally recognized that staff differed in their abilities and willingness to respond to them. There were usually two types of staffing informational responses that concerned parents: first, information that concerned the child directly and dealt with the child's school progress and behaviors and second, information of a less direct nature that dealt with services and programming for the child.

Mothers desired a steady flow of information from staff and they wanted it to be current with what was going on. Generally, they voiced objections to being flooded with information in staffing situations, not wanting to be "dumped on" and left feeling overwhelmed. Additionally, mothers objected to receiving dated information. They became suspicious when staff withheld or delayed revealing something of significance. Mothers expressed wanting to be kept informed around issues with their child that really mattered in a timely way. One mother shared a positive public school experience in which a team member contacted her prior to the staffing to inform her of some of the information that would be shared at the staffing. She described:

The following year when she [team member] diagnosed him autistic, she actually called me and said I want to talk to you before the IEP, and she didn't tell me about the autism until we had a phone conference call. She faxed me the report and told me before the IEP... It was very helpful to

me because I need time to digest that, because for me it came out of left field...I have so much respect for her because she knew that was going to be hard and that I needed time and she did not want to blindside me in the IEP with it, and for that I'll always be grateful.

Children on the autism spectrum are not always able or willing to be communicative about their daily school experiences. Mothers often appreciated staff addressing this issue with them. A mother of an adolescent with Asperger's Syndrome shared her perspective:

You know he's not going to tell me anything, nothing happens. He never has homework, nothing's ever happened. I mean he could go to school and murder someone and if I came home he wouldn't tell me, "Oh by the way, I killed someone". You know? I mean it's just, nothing happens. So it was cute to hear that the very first day not only did he participate, but he was the only one of the whole group willing to do so. You know, but so that's positive in that you definitely like hearing staff embrace the issues and stuff.

In summary, mothers valued staff communications that had breadth and balance. They appreciated staff efforts to share information that was current and timely. They also welcomed staff efforts to present material in manageable doses. All of these qualities added to the positive experience this group of mothers desired in IEP staffings.

### **Theme Five: Supportive Functions of Team Members**

There was agreement among respondents that supportive efforts by IEP team members were valued and appreciated. Mothers varied in their descriptions of "support", and each mother was specific in her unique characterizations of these activities.

Support, as the term was used by respondents, had two manifestations. The first was that mothers viewed staff support as addressing their emotional needs. The second was that parents viewed support by way of staff sharing information and resources in

ways that addressed their competency needs.

Most mothers in this study shared the notion that school social workers could be more helpful in staffing situations. In the broadest sense, this meant that social workers could and should be more useful in assisting mothers to cope more effectively in staffing situations.

### **Emotional Support**

Many mothers first engaged, then re-encountered school personnel at times when they were carrying complex personal burdens. These burdens were often related to personal or family health problems, financial strains, or other losses or changes within families stemming from death, divorce, and other matters of this magnitude. Some mothers identified finding support for their personal burdens outside of the school setting. Many mothers, however, expressed regret and disappointment that school staff failed to be sensitive to their burdens. One source of difficulty noted was when schools placed more demands on mothers' time and emotional reserves than they felt they could manage.

One mother described earning support from school personnel. She found that an increase in staff support resulted from her diligence in developing strong relationships with staff over the years. Prior to these efforts, she recalled relying on her religious faith and her church community for help. Her need and efforts to seek support really began when she moved to the area where she currently lives. She described the experience in the following way:

When we moved into the suburbs, I truly had nobody, nobody here. My husband worked an hour away from home. I got a, you know, a first grader and a second grader. And you know, I was waiting to get into our house. We lived on the other side of town within temporary housing. And

so, and I'd actually had a miscarriage earlier in the year, and so, we were-I was dealing with my own little baggage so the last thing you wanna do is like spill your guts out to all your new neighbors. And so, it was very difficult to find that support. So, for me, it came from a church perspective and really getting into my faith. And I gotta tell you, that's what got me all the way through. Because even when I didn't get what I thought was best for my child, or what was most appropriate, I was at peace with it because I knew that I invested a lot of my own prayer time in it. Because I really want what's best for her.

This same mother described her efforts to transform her relationships with school personnel. She said the following:

I would get support at the school because I took a lot of time to hone and develop relationships at the school. But isn't that the way it is with anything in life? When you think about it, you get the support when you engage yourself and you start working alongside of somebody for a common goal. And when the chips are down for you, then they come in and they help you out.

A few mothers did not expect support from the team for their personal issues.

They indicated a preference to use friends or family members for those purposes. They preferred the efforts of the staffing team to be focused on meeting their child's needs.

These mothers identified this child-centered focus as being supportive in its own right as it confined itself to the child's school issues.

### **Information**

The mothers viewed receiving information and knowledge concerning resources as an essential element of support in the staffing process. Most of them wanted more of this kind of information conveyed in staffings.

Most mothers initially felt quite overwhelmed with their staffing experiences. They were unfamiliar with how they were supposed to behave. They felt ignorant of many aspects of what was often discussed, such as diagnostic, special education, and

legal information practices and processes. All mothers recalled asking for individual team member or team support in these areas. One mother offered her ideas on what might be helpful to a new parent. She said:

Probably what I could see for other parents being really helpful is at the beginning, like when a parent is first starting to do IEPs, is maybe having somebody that works one-on-one with them to help them get prepared for the IEP, to know what to expect...Maybe even have some sort of resources on-I don't know if there are any resources, but on how to most effectively approach the IEP. Now the big issue is, especially with the Internet and everything, the people have some-we're over-informed. And it gets to the point where you don't know what to read and what not to read. So it would definitely-I would recommend definitely having something that was simple. Maybe even an audio thing they could listen to. But something to hold their hand and help them get the best foot forward on that first IEP.

A few mothers who had children enrolled in early intervention programs recalled a drop in the amount of informational support received as they transitioned into special education programs. Once in special education, they described themselves as feeling unsupported, generally cut off from all forms of prior informational support they had previously relied on. A few mothers felt fortunate to have some support in managing this change. These mothers had early intervention workers accompany them to their initial IEP staffings, easing their way into new relationships. One mother framed it this way by saying, "we actually had the woman who worked with us from early intervention come with us to the first one [IEP staffing], to be an advocate, which was great because we didn't know what we were getting into."

The few mothers who had the support of an early intervention worker found the experience to be very beneficial. They expressed doubts over how they would have managed without this sort of help. Mothers transitioning without this support reported

initially feeling confused, overwhelmed, and very alone in the process. Mothers commented to the effect that, “there was no one there to help me.” One mother stated, “you have to do it all on your own,” which seemed to summarize the information gathering tasks that initially fell on parent respondents.

### **Resources**

Respondents used primarily peer and professional sources outside of the school to gain a foothold in their adjustment to being a parent of a child in special education. A number of mothers privately hired psychologists, psychiatrists, and neurologists to help them get grounded in the situations they faced. They also frequently used autism networks, as well as tools from the Internet to identify new resources. Most mothers, fairly early on in the process, reported learning that IEP team members do not provide them with needed help.

Mothers often reported taking initiatives to help other parents. They organized resource data for themselves and others in similar situations. They did this in the absence of efforts by school professionals, who, they claimed, did not provide significant help in this effort. Many parents expressed disappointment with the lack of effort made by school staff in this area. They felt that at least one member of the team should have related expertise and shared this to help them navigate the complex fields of autism and special education. One mother made this observation about how resources could be offered at staffings:

[It would be helpful to learn about] places that you can go, people who can help you, especially when it comes to sitters. If they know somebody that works in the school that’s a sitter, “here, this is somebody I know personally.” Give somebody an outlet. Just saying, “Oh, have you joined

a support group?” doesn’t work, and we haven’t joined a support group and we can’t. We don’t do it because he works and when we’re not doing that, we’re doing outside therapy and I have support through my family. It’s something that we probably should do, but it doesn’t really interest me enough to do it, so just saying there’s support groups, where’s the support groups? There are support groups, but where?

This mother went on to say that effective resource identification needed to be specific. She stated, “Resources have to be very specific. Web sites. If there are fees involved. Let people know if there are fees involved. All different types of things.”

Mothers identified needing different types of resources, depending on where their children happen to be on the special education continuum. Early in the process, mothers desired information that would help them become competent in understanding and participating in the IEP process. As their children moved forward, parents stated they wanted information related to their need to plan for their children’s futures. This could include information on adult services as well as legal issues that might impact reaching the age of majority. Mothers also expressed concern about the aging children’s social opportunities. Regardless of the type of information and resources desired, parents identified the school social worker as the key team member to work with them on these issues.

### **School Social Worker**

All respondents acknowledged that the school social worker attended the IEP staffings. Parents did not readily identify these social workers with the same clarity of function and purpose as they did the psychologists, nurses and teachers attending the same staffings. Most mothers maintained some sense of school social workers as being “nice” and “likeable” but found them limited in their knowledge of autism. As one



mother stated, “I think there’s a lot of them [school social workers] who don’t understand it (autism) and are afraid of it.” Another mother stated, “ I, myself, have had very little use for the social workers because I don’t think they are trained to understand what the needs are for our kids who have special needs, and not just autism but special needs in general.” Another mother recognized the helpful intention of the worker but the lack of expertise to act on it. She stated, “ It was really sad because he (social worker) really wanted to help, but he didn’t know how.”

Mothers reported that school social workers play a number of different roles in staffings. Principals and administrators seemed to determine what these roles would be. Social worker roles seemed to vary somewhat from setting to setting.

While mothers consistently identified social workers as in attendance at IEP staffings, they viewed them as being relatively inactive and participating minimally if at all. When they did participate, it was usually confined to sharing developmental study findings, updating social work service progress and providing behavior management advice.

Most mothers expressed beliefs that social workers could play a more active role in the staffing process. It is thought that role confusion or lack of role definition seemed to inhibit social work functioning in staffings. One mother offered this observation:

They’re good people and they have the right intentions but they don’t know where they fit in, I think a lot of them. I don’t think the role is clearly defined. I don’t know if that’s at the education level or when you get into the system.

Another mother mirrored a similar sentiment. She stated, “I think the social workers need to have a bigger voice, but they can’t get a bigger voice until there’s a level

of understanding of what the social worker's role should be in the IEP process." Another mother attributed the lack of "voice" on the part of the social workers to the lack of power they have in relation to the building principal. This mother explained:

If the directors of the programs decide whether or not they're hired or fired, what power do they have to speak up? If they are going to be worried they are going to lose their jobs. I mean, there's always a certain amount of manipulation-you kind of have to join your own-but I mean, let's be honest, it's in any job. If the boss is going to can you, you're not going to speak up.

This mother noted that speaking up is less risky when simply reporting on progress or offering some behavioral insights. Power differentials can become an issue when workers are expected to advocate, as efforts with advocacy might not always be consistent with an administrator's agenda.

Mothers generally wished that school social workers would advocate more frequently. Some acknowledged the risk a team member might take in doing so. One mother provided an example of how the social worker had to be very guarded in how she framed her ideas at staffings:

I have a particularly contentious ongoing situation. It's an administrator that is really strong but negatively strong, autocratic, authoritarian. The staff is delightfully supportive and they are very committed. They meet all of those other things but this administrator just makes it such a negative experience in general that I think most of the staff feel somewhat gagged and unable to speak freely for fear of political retribution...He charged the social worker with "find this out for me" and she wasn't delighted, and she had lots of really positive things to say but you could tell that she really felt like she needed to couch it and that she didn't feel as though she had the ability to speak freely in those meetings and that was really frustrating.

Besides having little voice, parents viewed school social workers as holding little influence with other team members. The social worker's low status among peers

naturally impacted their level of participation. One mother shared her observation concerning social work staffing involvement. She said, “I think they are intimidated because I don’t honestly think the social workers are given enough respect to have the level of input that they should.” While mothers tended to view social workers as minor participants in IEP staffings, they also viewed social workers as having potential to contribute much more.

Positively, some mothers perceived the school social worker as being “the voice for your child.” They were perceived as having been trained in advocacy, in case management, and in identifying referral sources and resources in the community. They were not necessarily experts on autism, a trend witnessed by a number of mothers, but they appeared to be trained to listen at different levels and to communicate empathically. They were also perceived to be skilled problem solvers who had the ability to think systemically while adopting a simultaneous strength perspective. Because of their knowledge and training, mothers viewed school social workers as capable of facilitating staffings, assuming case management functions, and training other team members. Some stated that training efforts could be geared to improving team collaboration and helping team members gain more sensitivity and understanding of the unique emotional ties they have with their children. One mother addressed this when she said:

Teach these people, explain to these teachers and these therapists that you don’t know best. Just because you are a professional, listen to what these parents are saying, because they are making sense. It may not be in your technical terms, but if you really listen to them on what they want for their child, you’ll get where you need to be.

Respondents were resolute about their need for support during the IEP staffing.

They recognized that in order to ramp up their competence, they need timely, accurate and relevant information from team members. Mothers also recognized that their needs changed over time.

Generally, once mothers gained a firm grasp of the autism diagnosis, educational, legal and resource issues, they seemed ready to advance and participate fully in planning for their children's future. Most mothers sought some level of support from staff for themselves and their children. A fewer number of respondents used private sector professionals for emotional, informational and resource related support.

All mothers acknowledged that the school social worker attended IEP staffings. They offered mixed assessments of the social worker's level and type of participation. Many viewed the social worker as a minor participant in staffings. They reported that when they do participate, their input is often prescribed and limited to discussions of factual information about their contact with the child, social developmental history findings and sometimes their behavioral observations of the child.

The mothers in the study wanted social workers to become more active in staffings. They wanted social workers to train other team members to improve their grasp of parental perspectives. They also hoped social workers would train other team members to learn to really partner with them in constructing collaborative educational plans for their children.

### **Conclusion**

As the demographic data exhibited in Table 2 indicated, the sample tended to favor well educated, financially secure, married mothers with a median age of 44. The

mothers interviewed revealed that as a group, they tended to value the development and use of advocacy skills. They viewed this as critical to procure the services and programs necessary to their children's successful academic, emotional, and social development. They attributed this ability to advocate to both the formal education they pursued and to their commitment to conducting research through online resources, available literature, professional networking, and through connections with similarly situated families.

The data revealed these mothers tended to have had both satisfactory and dissatisfactory IEP staffing experiences. The former were primarily a result of specialized educational program experiences, while the latter occurred primarily but not exclusively in the public schools.

As a group, the respondents revealed uniformity in expectations of team member behavior and attitudes during IEP staffings. They also shared many similar viewpoints on the potential professional strengths of the school social worker and how they would like to see these strengths translated to staffings.

The most significant finding in the data was the value all parents placed on their active participation in IEP staffings and specifically, on their ability to speak up on behalf of their children. They indicated they would do whatever necessary to insure their children received the best individualized educational programming possible. Many mothers indicated a willingness to fight the educational system when they perceived a conflict emerging between legally mandated and educational systemic constraints. This is one area of many in which mothers expressed a need for support. They identified the school social worker as being well positioned to provide this to them.

## CHAPTER FIVE

### DISCUSSION

#### **Introduction**

The purpose of this study was to explore mothers' perceptions of school professionals' attitudes and behaviors in IEP staffing contexts and how these affected their level of participation and advocacy on behalf of their child on the autism spectrum. Mothers were asked to reflect on their experiences with one specific education professional, the school social worker. This information was considered valuable in developing recommendations for increased specificity in school social work functioning within IEP staffings.

There was a broad range of staffing experiences encountered by mothers interviewed. There was also a large variation in the number of years mothers attended staffings and the number of different settings where these staffings were held. While it is important to note that the sample of mothers was relatively small, it is also important to note that most staffing concerns and complaints occurred in public school settings

The data from this group of mothers suggested that helpgiving practices inherent in a family-centered approach were highly valued. Mothers' levels of satisfaction increased when family-centered practices were present and decreased when more professionally-centered approaches dominated. This supports research conducted on parental perceptions of helpgiving within early education conferences (Dunst & Trivette,

1996; Dunst et al., 2002).

Mothers in the staffing process, as the data suggested, valued professional school social work orientation and practices. They identified a systems orientation and strengths perspective as having potential to improve staffing climate and heighten collaboration in the staffing environment. In addition, they believed social work advocacy could assist them in securing the best programming for their children. By mothers' accounts, social work functions that parents identified were generally missing from their IEP staffing experiences. They commonly held the belief that school social workers could act skillfully in the manner described above yet contended that social workers did not usually exhibit these skills and perspectives in the IEP staffing context.

The 12 participating mothers in this study were enthusiastic respondents, eager to be involved in the project. A common motivation stemmed from their frequent sense of isolation and historical difficulties in multiple staffing situations. These same mothers stated that an effort to make staffings more consumer-friendly in the future would be well worth their time. They expressed hope that their stories would be helpful to this end.

Interviewees were generally quite open in sharing what at times was painful and humbling material. Some were forthright in recounting their mistakes and shortcomings. They welcomed the researcher into their homes, taking pride in introducing their children with disabilities. Many of the respondents provided background on their child's special education experience. Often these stories included the mothers' personal growth and success in challenging and engaging IEP team members in their schools.

This chapter discusses the findings through the lens of a family-centered practice

paradigm. Data from this study is offered to provide support for the need of relational and participatory helpgiving practices found to be critical to a family's sense of satisfaction in staffings held on behalf of their children (Dunst et al., 2002). Also included in this chapter are the following: (a) policy and practice implications (b) strengths and weaknesses of the study and (c) recommendations for future research.

### **Family-Centered Practice**

Helpgiving within a family-centered framework is correlated with parental satisfaction of staffing experiences and with positive outcomes achieved in staffings (Dunst & Trivette, 1996, Dunst et al., 2002). Dunst et al. identified two specific helpgiving practices as necessary components within a family-centered approach. The first, relational practices, refers to those clinical skills often associated with human service worker activities. The second, participatory practices, refers more to those behaviors and activities associated with promoting feelings of empowerment. Relational practices standing alone are not sufficient to define a family-centered approach. They require a simultaneous set of participatory practices, which encourages a sense of empowerment on the part of parents (Dunst et al., 2002; Trivette et al., 1995). The data provided by the mothers in this study supported these findings.

The 12 mothers in this study were very clear in identifying the attitudes and behaviors contributing to their sense of satisfaction with regard to both process and outcome of the staffing. The themes developed from the data distinctly fell into each of the two types of helpgiving categories defined by Dunst and his research team (2002).



**Relational Factors**

The mothers identified concrete issues inherent in current staffing structure, which served, in their opinion, to interfere with the development of collaborative relationships amongst team members. They cited difficulties participating in staffings with ten or more professionals in attendance. They described being intimidated and overwhelmed. This situation was exacerbated when they had no opportunity to develop relationships with key staff prior to the IEP staffing.

Staffing seating arrangements created another difficulty for mothers. Many of the mothers indicated that being seated in chairs directly across from school professionals seemed to create a psychological barrier. The face-to-face approach at such meetings seemed discomfiting. Mothers viewed these structural considerations as having significant impact on their subjective experiences of the meetings. Consequently, they behaved in a more guarded and inhibited manner.

Formal school staffing processes traditionally bring together school professionals from requisite disciplines. Seating arrangements are often rigidly proscribed and tend to embody the hierarchical order of the school culture. In this culture, the staffing chairperson often acts autocratically. Other school staff and parents consequently feel unimportant. They also feel disempowered and fail to fully engage in the staffing process. Relational and interactional barriers such a model fosters inhibits the benefits that could be gained from more inclusive efforts which runs counter to the family-centered approach (Dunst et al., 2002; Trivette et al., 1995). This climate appears rigidly professionally driven and fosters a disempowering and thus more dissatisfying staffing

experience for mothers.

Some mothers in this study suggested ways to improve the traditional staffing climate. They suggested that at least one professional team member connect with the parent prior to the staffing. This person could then welcome the parent to the staffing and offer to sit beside her in a gesture of support. While alterations to seating configurations could be seen as an easy fix, beneath the surface, real change may need to reflect some relinquishment of rigid status and control mechanisms which appear well-rooted traditions in many school settings.

Mothers described attending staffings where they felt disconnected from professional team members. Their descriptions included not being listened to, being patronized, ignored, and generally made to feel unimportant. This experience is supported in the literature (Able-Boone, et al., 1992; Childre & Chambers, 2005; Turnbull & Turnbull, 1997). It runs contrary to the relational practices inherent in a family-centered approach (Dunst et al., 2002).

The mothers unanimously agreed that one of their principal roles as a parent with a child in special education was in taking the initiative for developing and maintaining relationships with team members. In addition, they felt compelled to find ways of nurturing the academic professionals. They provided gifts, food, verbal affirmations and reinforcements as a means of appearing sympathetic to the team.

Needing to develop relationships with professionals as a way to be taken seriously as a parent of a child with special needs was a burden these mothers emphatically stated they did not want. They were already dealing with the day-to-day needs associated with

their children while simultaneously attempting to manage the other aspects of their lives. They desired less not more responsibility. What they did want, however, was to be taken seriously, listened to, and treated with respect and without judgment. They preferred working with professionals rather than against them. This tended not to be their experience and they thus felt compelled to develop personal strategies which served to bind parents and professional into an increasingly collaborative relationship. This experience was not novel to this group of parents and is well documented in the literature (Fish, 2006; Petr & Barney, 1993; Shannon, 2004).

Mothers recognized that there was a lot of material to be covered in each annual review staffing. Team members worked diligently to get all mandated topics covered in the limited amount of time allotted for each staffing. They did so successfully most of the time. What appeared to get lost, from the mothers' perspectives, was the relational component. Mothers were not made to feel welcomed into the staffing, they felt material was reviewed rather than discussed with them, and their input was not solicited. Rather than being engaged in a process of developing a plan, they were asked to agree to a plan that had already been developed without parental input. This too reflects structural issues within a rigid, hierarchical organizational system. School personnel are focused on meeting the myriad mandate requirements and in so doing seem to lose sight of the relational issues inherent in a process involving people with potentially varying agendas. It is at this juncture that the assistance of a school social worker might be useful.

## **Participatory Practices**

Participatory practices have been identified as essential components of an empowerment based approach to family-centered helpgiving (Dunst et al., 2002). From an empowerment perspective, helpgiving practices in the IEP setting refer to those worker directed activities, which assist in parents' development of personal, interpersonal, and/or political power. This power is then directed at improving the academic outcome for children who have highly individualized learning needs. The literature suggests three categories of helpgiving activities fitting within such an empowerment paradigm. They are activities directed at enhancing motivation, skills, and knowledge (Allen-Meares & Garvin, 2000).

The data suggested the mothers in this study had the motivation to actively participate and advocate for their children. The question remains whether all parents of children on the autism spectrum have an inherent motivation to participate or whether this is solely attributable to this particular group of mothers who self-selected to participate in this study. The mothers did admit, however, that they lacked the requisite skills and knowledge to effectively and confidently navigate the IEP process when first introduced to special education. Being unable to speak the same language as educational professionals, not having a thorough understanding of their rights, and being uninformed on special education in general, contributed to their sense of powerlessness. The mothers did not feel they had the tools with which to discuss and negotiate for programs and services. The data indicated that this sense of powerlessness coupled with the mission of securing optimal programming for their children, engendered a tension between parent

and professional. This tension between parent and team can lead to destructive, verbal exchanges not conducive to long term collaborations. These mothers expressed desire for relationships to be collaborative rather than contentious.

The mothers identified lack of motivation and effort on the part of team members to fill this informational void. They admitted they felt fortunate they had the personal resources to become sufficiently self-informed enabling them to compete with educational professionals on an equal footing. Some mothers expressed concern for those parents who did not have access to support and resources outside of the school system. However, they felt that the burden of resource sharing was to be shouldered by team members who should provide all parents with the information required to navigate special education in an informed manner. Team members already possess some of this information. Lacking is both an organizational sanction and professional initiative.

Consistent with the literature, the data revealed that IEP team members in public schools often promoted a sense of disempowerment amongst parents (Childre & Chambers, 2005; Sheehey, 2006; Turnbull & Turnbull, 1997). Often, individualized education plans were prepared without parental input, the IEP team met privately prior to a more formal meeting to which the parent was not invited, and the IEP document was excessively cumbersome rendering it an ineffective conduit for discussion and review. Relegated to a peripheral rather than integral role in the brainstorming and decision making process rendered mothers feeling powerless and insignificant. This resembles a more traditional, professionally-driven approach to staffings, which is in contrast to the mandates of IDEA around parental participation. Some of the barriers to shifting from a

professionally-centered to family-centered framework in school staffings may relate to the constraints imposed by organizational structures.

Staffings facilitated by autocratic school administrators diminish opportunities for mothers to share important thoughts and observations concerning their children. From a transactional perspective, these disempowering behaviors discourage support and collaboration between mothers and professionals, causing them to feel excluded from the process. They either tend to become defensive and withdraw or become angry and act out their frustration towards school professionals. Mutual engagement and effective joint decision-making cannot occur in such tension filled environments.

The hierarchical nature of the school's organizational structure reinforces a system where power is held by one or a few rather than broadly distributed among attendees. To operate differently would require a managerial paradigm shift. Many factors mitigate against parent power and influence over programmatic and service decisions. However, schools are now in a position of having to consider how to meld their operational constraints and their traditional structure with a philosophical shift in team definition and functioning. A paradigm shift has already been established in early education through the mandates of the IFSP where parents have been given a decision-making partnership role (Dinnebeil, Hale, & Rule, 1999; Wehman, 1998). It is being considered in the IEP process and some school districts are attempting to fully incorporate the parent into their team as full members (Spann, Kohler, & Soenksen, 2003). It is well documented that greater and more equitable parental inclusion is just beginning (Childre & Chambers, 2005; Pruitt, Wandry, & Hollums, 1998). Mothers in

this study seemed to reiterate this desire for greater inclusion.

### **Policy and Practice Implications of the Study**

The mothers in this study recognized that the school social worker is well positioned to affect team functioning in significant ways. They also believed that social worker efforts could be in concert with existing public school organizational structures. The data suggested that mothers would generally welcome movement towards more functional school social work role definitions.

The role of the school social worker in IEP staffings is not referenced in the professional literature, despite indications of their consistent attendance in staffings. They tend to be silent team members. The majority of mothers observed the worker maintaining a predominantly passive role, only participating when asked to share progress from work with the child or in disseminating social developmental study information. In fact, a number of mothers expressed difficulty remembering the social worker by name or face, in contrast to their memory of other school professionals such as nurse, psychologist, or teacher.

Not only does the role of school social worker in the IEP staffing suffer from a lack of definition, but its function tends to be determined by the special education administrator for each building (Kelly, 2009). For the schools that adhere to a rigid hierarchy and rely on formalized functioning, the school social worker seems to have a more ambiguous role. More forward thinking settings tend to adopt more inclusive staffing leadership styles. Under these circumstances the school social worker can perform with a larger and better-defined role. However, regardless of the type of school

setting or organizational structure, there seems to be inconsistency and some level of confusion regarding the school social worker's role. This ambiguity seems to apply to team members, parents, and the social worker herself. Data from this study has the potential to begin to address some of these problems with school social work role definition. This could aid both the schools and parents.

The standards put forth by both NASW (2002) and SSWAA (2009) target school social work functions but do not address professional expectations specific to IEP staffings. The standards, do however, have relevance to worker participation in IEP staffings, as they encompass activities aimed at helping families access resources, providing advocacy, and liaising to promote greater cooperation and collaboration with school personnel. According to this group of mothers, school social workers have not provided these functions in their IEP staffings.

The mothers succinctly articulated the types of information they needed at various points in time in their role as parent to a child in special education. During the early years they wanted information on their legal rights, support navigating IEP staffings, and general special education information. They believed this would enhance their participation and advocacy. This has been validated in the literature (Fish 2008; Gilliam & Coleman, 1981). Upon entering high school, the mothers became more concerned with legal, financial, and vocational planning for their children. They expressed interest in receiving information and resources that reflected this shift in need.

The data suggested that while school social workers should be able to provide valued information and resources to parents, they often did not. Mothers voiced their



frustration that the burden for acquiring the requisite information and resources was shifted to them rather than remaining a social work professional responsibility. The mothers viewed this inability to provide specialized information and resources as a deficit in social work knowledge of autism and autism-related services. While there might be this gap in knowledge stemming from academic failures within school social work curriculums as the mothers hypothesized, there might also be alternate explanations.

Alternative explanations for the seeming lack of school social worker specialized knowledge are worth exploring. School social workers are experiencing large caseloads (Allen-Meares, 1994), directing professional activities towards child-directed practice and away from more research-oriented activities. In addition to time constraints, some school social workers may be experiencing computer access difficulties which impede local resource identification. Poorly defined job descriptions (Garrett, 2006) can prevent school social workers from engaging in those information and resource sharing tasks valued by both the mothers in this study and by the profession of social work as a whole. This might be compounded by job descriptions defined by persons outside of the profession of social work (Bye, Shepard, Partridge, & Alvarez, 2009), creating conflicting professional job expectations. The data from the mothers in this study identified the issue of parental need for specialized knowledge and their sense that school social workers failed to meet this need. Further research would need to be conducted to gain a clearer understanding of the barriers to school social work functioning in this area.

Statistically, one in every 88 children is now determined to have an autism spectrum disorder (CDC, 2012). This would suggest that most social workers employed

in public schools will, in some way, interface with the disorder. This will most likely occur in the IEP staffing. School social workers will increasingly be called upon to assist parents concerning facets of the disorder, its related set of evidence-based supports and accommodations, and in identifying and accessing the appropriate community resources each individual family may require. The mothers in this study made it abundantly clear that they expected the school social worker to have the necessary knowledge and skills to help them become more educated in the domains of special education, autism, and related case-management. Again, the mothers voiced their beliefs that school social workers' lack of specialized knowledge reflected the failure of social work education and training.

It is tempting to critique the curriculum of Master of Social Work school social work programs but the reality is that given requirements from the Council on Social Work Education as well as individual state requirements for school social workers, there may not be room in the curriculum for education about highly specialized populations. This leaves the individual school social worker in the situation to seek continuing education on their own and often at their own expense. Another factor in school social work, different from agency work, is that often supervision is lacking for school social workers or administrative supervision is provided by someone from another discipline (Garrett & Baretta-Herman, 1995). Thus, a source of further education and training is compromised.

One major policy implication can be drawn from this study. Based on the data provided by this group of mothers, school social workers tended not to participate at the same level as other team members during IEP staffings. The mothers saw this as a waste

of their unique skill set; one that set them apart from all other disciplines represented at staffings. Their systems and strengths perspectives of school social workers were highly valued by parents. Poorly defined job descriptions, lending confusion to the school social worker role in IEP staffings might be one contributing factor. Being expected to assume an active leadership role within a host agency might also affect school social work functioning. This, coupled with the need to function within a generally rigid, hierarchical organization where educational values rather than social work ones prevail, can create additional professional performance strains. Improved school social work functioning in IEP staffings would benefit from the development of a more clearly articulated set of school social work functions specific to the IEP staffing setting. If these are then included in the standards governing school social work, social workers will be provided with the sanctions necessary to promote their unique professional behavior. This could serve as a guideline to others in the educational organization, providing a clearer and more comprehensive understanding of the role of school social worker as related to her work with parents and team members in IEP staffings.

A practice implication also emerged from this study. Professional school personnel attending autism spectrum related IEP meetings need to better understand what it is like to be a mother of a child with an autism spectrum disorder. This would likely enhance the sensitivity, respect and non-judgmental nature of family-directed interchanges, all elements valued by mothers in the study. This learning could be promoted in team trainings led by the school social worker. This might also encourage the team to view the family through a different lens. The social worker seems uniquely

qualified to undertake this effort because of her group work training, systems perspective and strength-based perspective. Ultimately, the training might be useful in reducing staff-parent tensions; tensions that negatively impact planning and programming for the child.

### **Strengths and Weaknesses of the Study**

A number of strengths and weaknesses emerged from this exploratory study, all of which are directly related to its methodology. While the benefit of a qualitative methodology is in the richness of elicited data, sampling issues can render the findings limiting.

### **Self-Selection Process**

The study employed a convenience sample to recruit a specific group of parents willing to share perspectives on their IEP experiences. Mothers recruited from the public school and specialized program self-selected to participate in this study and thus only those with high interest in the study became subject volunteers. This self-selection process led to two inter-related issues needing explication when discussing results. They include sample homogeneity and mother's ability to advocate.

A convenience sample was employed as a way to recruit respondents with a wealth of experiences in IEP staffings. Due to the self-selection process that ensued, the mothers volunteering to participate in the study represented a relatively homogeneous group. They tended to be financially secure, educated, and able to advocate on behalf of their children. This does not represent the entire category of parents who have children on the autism spectrum, but rather a small subset. The findings remain specific to this group of mothers and cannot be generalized to all who have a child on the autism

spectrum.

Another limitation emerging from the use of a convenience sample is related to the type of data provided by the mothers. The 12 mothers described their personal staffing experiences during the interviews. Their recollections may have held biases and distortions that may not accurately reflect the actual transactions taking place in the staffings. For a more balanced overall perspective of staffing proceedings, other team members would need to be interviewed. It is likely that special education administrators, teachers, and social workers will each have their own unique perspective. For purposes of this study, however, which is an initial, exploratory review of a mother's perceptions of the IEP process, this is sufficient to make a few recommendations for the types of helpgiving school social workers can offer mothers and school professionals.

### **Researcher Variables**

While bias and distortions undoubtedly exist given the level of dedication mothers express towards advocating for their children, the fact that all of the respondents recognized an underutilization of the role of the social worker in staffings lends support to this being a finding of value. Additional strengths emerge from the methodological approach to this study. Two are related to researcher variables: researcher knowledge and researcher employment history.

The researcher had an employment history working with both school age children on the autism spectrum and with their parents. In addition, the researcher was knowledgeable of current evidence-based interventions for these children and was familiar with the professional community specializing in autism. The mothers spoke of

programs and interventions by name and acronym. They also shared anecdotes and opinions about autism specialists from the fields of psychiatry, neurology, speech and language, and psychology. They appeared to appreciate the researcher's ability to recognize and understand the specific language and professional network mothers were speaking of. One of their frustrations about the social workers' lack of knowledge of autism-related information and limited awareness of the professional community supporting these children, these frustrations were not replicated during the interview. On the contrary, the mothers appeared relieved to speak with someone who possessed familiarity with the field. This seemed to encourage their more expansive and detailed portrayal of experiences parents were describing. It is believed that because of this commonality, connections between interviewer and interviewee were more quickly established.

Given that the data reflected the perceptions of one small, relatively homogeneous group of parents, from a limited geographical community, generalizations of the findings cannot be made. The findings reflect a beginning exploration of an area of social work practice previously overlooked by researchers.

### **Recommendations for Future Research**

Four recommendations for future research emerged from the data collected from this sample of mothers. One has to do with the issue of gender and its effect on the IEP staffing transactions between parent and professional. Another has to do with the role of the school social worker and her potential to actively engage in professional activities within a host setting. These and other potentially useful recommendations are discussed

in an effort to lend direction to future efforts aimed at better role definition for the school social worker in IEP staffings.

The self-selection of mothers volunteering to participate in this study led to a homogenous sample. While these mothers were able to fulfill participatory and advocacy functions in IEP staffings, they did so despite some team attitudes and behaviors challenging such functioning. Some of the mothers in this study indicated that they received a more inclusive and respectful response from team members when accompanied to the meetings by either their spouse or psychologist. It should be noted that in both examples, the accompanying figure was male. This data raises the potential for a new line of research. To what extent is the way one is treated in IEP staffings influenced by gender? Do fathers identify similar helpgiving needs as do mothers? Are mothers' levels of participation and advocacy influenced by the gender of the staffing facilitator?

Research efforts directed at such issues of gender might offer mothers information on how they can increase their personal power in staffings, either through efforts at self-education or in knowing whom to bring with them as support persons. Future research on fathers' perceptions on helpgiving might inform school social workers on how to individualize their professional role to accommodate the specific needs of fathers. Issues of gender may also affect the school social worker in his/her transactions with parents and team members. Any of these avenues for future research could increase our understanding of the interpersonal dynamics inherent in IEP staffings. This information can then be used to promote a more family-centered approach to helpgiving in staffings.

Mothers in this study provided data on school social work functioning in IEP staffings. Mothers perceived them as under-performing. According to these mothers, school social workers participated less than did their team counterparts, they rarely expressed their professional opinions, and rarely met the mothers' needs for knowledge and resources. The mothers recognized that this under-performance was in stark contrast to the education and training they believed school social workers received prior to their employment in the public schools.

School social workers who engage in effective practice within a host setting such as a public school system can offer specific expertise that has the potential to enhance the IEP process. However, mothers saw little evidence of this. Future research, directed at indentifying the barriers to active participation in IEP staffings might be helpful in encouraging a shift in this trend.

Working with this homogeneous sample, the staffing experiences of those parents with fewer financial, educational, supportive, and personal resources available to them could not be addressed. A similar research approach with this other population sample might identify additional helpgiving activities. Again, increased specificity of the needs of a population of parents who have children on the autism spectrum helps to inform the behavior and activity of the school social worker.

According to the data in this study, one quarter of the parents were reported by school personnel to the Department of Children and Family Services (DCFS) for physical abuse and/or neglect. The school policies and procedures pertaining to the reporting of abuse and neglect create tension between parents and professional team members. It is



recommended that further research investigate the percentage of parents of children with an autism spectrum disorder reported to DCFS. How does this percentage compare to reports made of a general population of children? Findings might be helpful in training school social workers how to more accurately make reporting decisions.

As this study assumes an initial exploration into the perceptions of parental experiences in IEP staffings, many avenues exist for continued research. Four such ideas have been suggested as ways to arrive at information useful in augmenting what is the beginning of a role definition for the school social worker specific to IEP staffings.

### **Conclusion**

The Individuals with Disabilities Act has strengthened the role of parents in their children's education. While this role has been steadily evolving, parents are not yet being fully included in the planning and decision-making processes on behalf of their children as required by law. Parents with a child in special education will interface with the public school in unique ways. However, all of these parents share one thing in common. They each attend an annual review staffing where their child's IEP is discussed and developed. The IEP is a process by which a team made up of parents and school professionals are meant to review the child's school experience from the preceding year and then together develop new or updated goals for the upcoming academic year.

The experience of mothers in these staffings was the focus of this qualitative study. In depth interviews were conducted as a means of identifying the factors facilitating or hindering mothers' participation and advocacy efforts. They were asked to identify specific attitudes and behaviors of team members influencing their participation.

In addition, they were asked to share their perceptions of school social worker functions during the staffing experience and the nature and quality of their collaboration.

There is abundant social work literature on school social work functions, but very little literature exists on the role of school social worker in IEP staffings. This study is an attempt to fill this gap in the current social work literature.

Many program decisions are made using a top down model, where individuals far removed from the day-to-day functioning of the organization are placed in positions of designing program components. This study was concerned with understanding mothers' ability and opportunity to provide a voice for their children around school related issues. It was also important to provide mothers a voice in describing how established helping practices in staffings either facilitated or hindered their active participation. A backward mapping approach was chosen, where the mothers, who were directly affected by these established practices, could inform others of their experiences.

This study can be used as a springboard for future research into related school social worker functions. School social workers, functioning within a family-centered perspective, engage in activities directed at enhancing motivation, skills, and knowledge (Allen-Meares, 2000). Studies investigating the experiences of mothers possessing a different set of personal and environmental resources might shed additional light on the set of helping practices the school social worker should be prepared to offer. In addition, understanding how issues of gender may impact the participation of both parent and school social worker might be useful in designing an expanded role for the school social worker in staffings. Greater specificity of the knowledge and skill required of the

school social worker is essential to a better -defined role definition. This information can then be disseminated to parents, team members, and school personnel as a way to minimize role.

APPENDIX A  
LETTER TO PARENTS

Current Date, 2011

Dear Parents:

As a doctoral candidate at The School of Social Work, Loyola University Chicago, I have the opportunity to conduct a study on parental perceptions of the types of helpful activities provided or desired from social workers during IEP staffings. The findings from this study are hoped to offer recommendations for an improved role for the school social worker during staffings. I am looking to this school program as a source of participants as the study will focus on families who have children on the autism spectrum and are involved in IEP staffings.

I am looking for parents with a child on the autism spectrum to participate in a one- time interview, lasting approximately 90 minutes. The date, time, and location of the interview will be scheduled with your convenience in mind. If your are interested in participating, please either contact me by phone at (630) 217-5180, by completing the enclosed form and mailing it to me in the self-addressed, stamped envelope, or by attending an informational session scheduled for April XX, 2011 at the school.

I hope you will give this serious consideration, as I believe your thoughts and opinions can help us better understand what types of help you would like to receive in IEP staffings. I am happy to discuss any question or concern you may have regarding this study or your potential participation in person, by email, or by phone.

Thank your for your consideration and I hope to hear from you. All participants will be given a sensory toy as a token of my appreciation for your involvement.

Sincerely,

Kristina Lind, LCSW, Type 73  
Doctoral Candidate, Loyola University Chicago klind@luc.edu  
(630) 217-5184

APPENDIX B  
CONSENT TO PARTICIPATE

## CONSENT TO PARTICIPATE IN RESEARCH

**Project Title:** Parents' Perceptions of Social Work Helping Practices:  
Implications for the Role of the School Social Worker

**Researcher:** Kristina Lind, LCSW, Type 73, and Doctoral Candidate  
Loyola University Chicago

**Research Assistant:** Priscilla Brinkman, LCSW, Community in Schools  
Michael Dentato, Clinical Professor and Doctoral Candidate,  
Loyola University Chicago

**Faculty Sponsor:** James Marley, PhD, Associate Dean for Academics, and  
Director of the Doctoral Program, Loyola University Chicago

### **Introduction:**

You are being asked to take part in a research study being conducted by Kristina Lind for a doctoral dissertation under the supervision of James Marley, PhD in the School of Social Work at Loyola University Chicago.

You are being asked to participate because you have a child on the autism spectrum attending a special education program. We are looking for parents who are willing to share their perspectives on the specific types of help they are currently receiving and wish they were receiving from social workers during IEP staffings. Please read this form carefully and ask any questions you may have prior to deciding whether or not to participate.

### **Purpose:**

The purpose of this study is to identify those social worker practices parents find helpful to them during IEP staffings.

### **Procedures:**

If you agree to be in the study, you will be asked to be involved in the following:

- A 1-hour interview scheduled at your convenience, facilitated by Kristina Lind
- Audio recording of the interview
- Completion of a brief questionnaire with items of a demographic nature

### **Risks/Benefits:**

Although there will be no direct benefit to you from participating, your information will be helpful to us in developing a fuller understanding of what parents perceive as being

helpful social worker provided activities during IEP staffings. There should be no risk to you as a result of participating in this study.

**Confidentiality:**

- Your names and identifying characteristics will only be known to the researcher and will not be shared with anyone else.
- Anecdotal information may be included in the written study but will not be attributed to the participant by name. You will be provided the opportunity to review all anecdotes prior to their inclusion in the study at your request.
- The interviews will be audio recorded. Only the research team will have access to these tapes and transcriptions. The tapes and transcriptions will be stored in a locked file cabinet for the duration of the study. Once the study is completed, the tapes and transcriptions will be destroyed.

**Voluntary Participation:**

Participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free to leave questions unanswered or to withdraw from participation at any time without any consequence to you.

**Contacts and Questions:**

If you have questions about this research study, please feel free to contact Kristina Lind at [klind@luc.edu](mailto:klind@luc.edu). You can reach the faculty sponsor at [jmarley@luc.edu](mailto:jmarley@luc.edu)

If you have any questions about your rights as a research participant, you may contact the Compliance Manager in Loyola's Office of Research Services at (773) 508-2689.

**Statement of Consent:**

Your signature below indicates you have read and understood the information provided above, have had an opportunity to ask questions, and agree to participate in this research study. You will be given a copy of this form to keep for your records.

---

Participant's Signature

Date

---

Researcher's Signature

Date



APPENDIX C  
LETTER TO TEACHERS

April 23, 2011

Dear Teachers:

Enclosed you will find an envelope with an attached “recruitment flyer”. I would appreciate your assistance in placing one in each of your student’s backpacks.

I am conducting a study on social work helpgiving practices during IEP staffings and am looking for parents to participate in this study. These letters will allow me to get the word out to families about the project and to encourage them to participate.

Due to issues of confidentiality, I am having potential parent participants mail back forms to me. In the event a parent returns it to you, please place the unopened, self-addressed envelope in a mailbox at the front office designated for this purpose.

Thank you for your cooperation with this recruitment effort.

Sincerely,

Kristina Lind, LCSW, Type 73  
Doctoral Candidate  
Loyola University Chicago

APPENDIX D

INDICATION OF INTENT TO PARTICIPATE

I am interested in participating in a one-time interview that will run approximately 1 hour at a date, time, and location convenient to me. I understand the topic will be on my perceptions of social work helping practices during IEP staffings.

I would like to receive more information. The following is my contact information:

Name:

Phone:

Email:

APPENDIX E  
RECRUITMENT FLYER

Parents:

Research on Parental Participation in IEP staffings  
needs YOU!

Do you have a child on the autism spectrum? Do you  
attend IEP staffings?

Would you like a chance to talk about your  
experience in IEP staffings?

If yes, please see attached envelope for further details  
on how you can become involved—Thank You!

APPENDIX F  
SURVEY ON DEMOGRAPHIC INFORMATION

**INSTRUCTIONS:** Please indicate your response to the following items by circling the response that most closely reflects your current status. Completing this questionnaire is completely voluntary and there will be no consequence to you should you not wish to complete it or parts of it. Your responses will be helpful in understanding demographic trends in our research findings.

**THANK YOU FOR YOUR TIME AND COOPERATION!**

**1. My relationship to the student attending this school is:**

Mother/father	grandmother	grandfather
Foster parent	guardian	other

**2. Number of adults in the home:**

One	two	three	more than three
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**3. My age as of today's date is:**

20-29	30-39	40-49	50 or over
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**4. My ethnic background is as follows:**

Hispanic	White Non-Hispanic
American Indian or Alaskan Native	Pacific Asian or Pacific Islander
Other	

**5. My educational background is as follows:**

Non High-School Graduate	High School Graduate GED
Some college, but no degree	Associate degree
Bachelor's degree	Graduate Degree

**6. The community which best describes where I live is:**

In a large city (>50,000)	In a suburb near a large city
In a mid-sized city or town (2,500-50,000) but not a suburb	
In a rural area or town (<2,500)	





APPENDIX G

SEMI-STRUCTURED INTERVIEW GUIDING QUESTIONS

## Semi-Structured Interview Guiding Questions

1. How many IEP staffings do you think you have attended for your child?
  - a. Can you describe some typical experiences you have had in these staffings?
  - b. Can you remember one example of a really positive staffing experience?
  - c. What did people do or say to make the staffing a positive experience for you?
  - d. Can you remember one example of a difficult or dissatisfying staffing experience?
  - e. What did people do or say to make it a difficult experience for you?
2. Have you attended IEP staffings with a school social worker in attendance?
  - a. Can you describe what the social worker's involvement looked like during the staffing?
  - b. Can you remember a time when a school social worker was very helpful to you during an IEP staffing? What did he/she say or do that was helpful?
  - c. Can you remember a time when a school social worker was unhelpful or unnecessary during an IEP staffing? What did he/she say or do that you found unhelpful?
3. How would you describe the "ideal" staffing experience?
  - a. How would you want participants to behave?
  - b. What would you like the participants to focus on?
  - c. What can participants do to assist you in making the staffing a satisfying experience for you?

4. On a scale of 1-10, with 1 representing no participation and 10 being extremely active in IEP staffings, where do you think your participation falls?
  - a. Can you describe what this level of participation looks like?
  - b. What level, using the same scale, do you wish it to be?
  - c. Are there any staffing conditions that have contributed to your rating score?
  - d. Are there any personal characteristics that you feel contribute to the participation level you have identified?
  - e. In your opinion, what do you believe the school social worker can do to help you get from the level you indicated to a 9 or 10 level?
5. Has your participation level changed as your attendance in staffings has increased?
  - a. Can you describe how your participation has changed?
  - b. Can you describe what has contributed to this change in participation?
6. Where do you see your advocacy skills in IEP staffings? On a scale of 1 to 10, with 1 being no advocacy skills and 10 being extremely effective in advocating for your child, where would you put yourself?
  - a. If you rated yourself between 1 -5, can you describe how this number translates into the level of skill you believe you have?
  - b. If you rated yourself between 6-10, can you describe how this number translates into the level of skill you believe you have?
  - c. Who or what has contributed to the advocacy level you currently have?
  - d. Where on this scale would you like to be? How could the school social worker get you from your current rating to where you would like to be?

7. Families with children on the autism spectrum benefit from support. What are some sources of support for you and your family?
  - a. Who helps you find the resources, supports, and information you require or desire?
  - b. Is there anyone in the school who helps you with this need? Can you list the personnel who have been most helpful in this regard?
  - c. What has the school social worker done to assist you in getting resources, supports, or information?

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## VITA

Kristina S. Lind has taught social work for the past 12 years at both the University of Illinois, Circle Campus and at Loyola University Chicago. Her primary teaching responsibilities have been at both the graduate and undergraduate levels. Her areas of preferred teaching are in School Social Work Practice and Policy, Group Work, and teaching the Capstone course to undergraduate students in their senior year. She has presented workshops on topics related to group work and autism both nationally and internationally.

Prior to pursuing her doctorate, Kristina held a number of administrative and clinical positions in social work agencies. She was the Director of Program Services at the Lund Family Center in Burlington, Vermont. She oversaw the clinical and administrative components of the Adolescent Maternity Residence, The Children and Family Services Program, and the community based Teen Pregnancy and Parenting Programs. While in this position, she was a member of the Governor's Task Force on Teen Pregnancy Prevention. She then was Unit Director at St. Vincent's Center of Catholic Charities in Timonium, Maryland where she ran a residential program, serving children in State's custody with histories of sexual and physical abuse and neglect. Upon moving to Illinois, she became the Clinical Coordinator at Krejci Academy of Little Friends, Inc. The program's focus is on children and adolescents who are on the autism spectrum and their families. She remained in this position for 15 years and retired after

completing the first two years of her doctoral program.

Kristina received her Ph.D. from Loyola University of Chicago. She earned her Master of Social Work from the University of Chicago's School of Social Service Administration and her Bachelor of Arts from Northwestern University in Evanston, Illinois.