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The View from across the Table: A Qualitative Study of Parent Experiences with the School Psychologist During Initial Evaluation Feedback Conferences

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THE VIEW FROM ACROSS THE TABLE: A QUALITATIVE STUDY OF PARENT EXPERIENCES WITH THE SCHOOL PSYCHOLOGIST DURING INITIAL EVALUATION FEEDBACK CONFERENCES

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Dissertation Approval

This is to certify that the thesis presented to us by Katherine Scipioni on the 22 day of May, 2014, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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“Listen to the “mustn'ts”, child. Listen to the “don'ts”. Listen to the “shouldn'ts”, the “impossibles”, the “won'ts”. Listen to the “never haves”, then listen close to me... Anything can happen, child. Anything can be.”

-Shel Silverstein

Abstract

This qualitative study focuses on the experiences of 11 parents whose child received an evaluation at school by the school psychologist. By using a semi-structured interview, the author examined the initial evaluation process, or the first time a parent had his or her child evaluated by a school psychologist. A special focus was placed on the meeting in which the parent received results from the school psychologist. The results indicated that there is a lack of connection between parents and the evaluation process. This disconnect becomes wider over the course of the evaluation and at the end of the process, these parents are still searching for help for their children. This dissertation will discuss ideas for an improvement in reframing this process around a cognitive-behavioral framework; this will include developing a therapeutic alliance using empathy, learning the existing schema that a parent has for his or her child, and treating the evaluation feedback conference as an activating event for thoughts and feelings. Finally, practice guidelines for school psychologists to use during the evaluation process with parents will be suggested.

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Chapter 1

Introduction

School psychologists perform various roles in schools, but the primary role of most school psychologists is completion of psychoeducational evaluations. Although school psychologists are members of an evaluation team and multiple team members may contribute to an evaluation, the responsibility to interpret and explain the results to parents frequently belongs to the school psychologist. Psychoeducational evaluations are multi-faceted, comprehensive, and serve as determinants in learning the child's needs and in prompting educational placement decisions. Parents will provide input into the assessment and will be one of the primary recipients of the results. Legislation such as the Individuals with Disabilities in Education Act (IDEA) mandate that parents be informed of the results of the evaluation and that parents participate in the educational planning process after the evaluation results have been distributed to the team. Parents will receive results of an evaluation at the assessment feedback conference, during which the evaluating school psychologist reviews the results with the parent. This conference provides school psychologists with an opportunity to involve parents in their child's education.

Presently, there is a variety of research available on how students benefit from parent involvement (Henderson, Mapp, Johnson, Davies, 2007; Esler, Godber, & Christensen, 2008). As a result, many articles and publications discuss the importance of relationships between parents and school psychologists. The literature outlines information that speaks to the importance of the relationship between a parent and a school psychologist (Miller & Kraft, 2008); the National Association of School Psychologists (NASP) provides many ideas for ways in which school psychologists can build partnerships with parents in a systemic manner in *NASP Model for Comprehensive and Integrated School Psychological Services* (NASP, 2010). A school psychologist's capacity to participate in parent involvement activities varies (Pelco, Jacobson, Ries & Melka, 2000); however, completing evaluations is consistent throughout the profession. Thus, the assessment feedback conference can be a common opportunity for school psychologists to involve parents in school matters.

Flanagan (2011) published an article that has provided specific ideas for skills that school psychologists should use during the parent feedback session, but the author notes that minimal additional research is available, which directly measures this exchange between a parent and a school psychologist. Additionally, a collaborative assessment approach has been outlined by Tharinger, Finn, Hersch, Wilkinson, Christopher & Tran (2008). This approach incorporates the therapeutic elements of providing assessment feedback to parents and highlights the importance of the relationship between the assessor and the parent during assessment feedback conferences. Thus, a therapeutic element to this relationship should also be considered (Norcross, 2010). This approach includes many notions that should exist in any assessment feedback conference; however, it makes no specific mention of using this model in schools. Additionally, there are many steps to planning the assessment feedback conference, which may create practical limitations, given the time constraints and various other responsibilities held by the school psychologist. There is a definite need for further study in this area, given the lack of evidenced-based recommendations for ways in which a school psychologist should communicate evaluation results to parents.

Statement of the Problem

A review of the literature reveals and highlights the importance of parent involvement, of how schools should establish parent-school partnerships, and of how parents should be involved in the pre referral and referral process when a child is suspected of having a disability. The combination of research and policy reveals that school psychologists should play a role in parent involvement activities (IDEA, 2004; Esler et al., 2007; NASP, 2010). However, the practices of most school psychologists do not allow for adequate opportunities to be involved with parents (Pelco et al., 2007) and in many situations, the evaluation process is the only opportunity most parents will have to engage in parent involvement activities. There is minimal research that examines how school psychologists should facilitate the initial assessment feedback conference with the parent; this includes a lack of guidance about how evaluation results should be relayed and how to ensure that parents understand the results and also understand their child's disability. This poses a problem for a variety of reasons, given the enormous number of children who will go through evaluations in their lifetimes.

There is research from other branches of psychology that outline how to structure assessment feedback properly so that the consumer understands the results. The collaborative assessment approach (Tharinger, Finn, Hersch, Wilkinson, Christopher & Tran, 2008) provides steps for use by a psychologist when planning the feedback session and when executing the feedback session. This model stresses the therapeutic element of the assessment feedback conference by focusing on the therapeutic relationship between the assessor and parent and how this will subsequently support the parent during the process (Tharinger et al., 2008). Thus, the therapeutic relationship becomes important, and certain critical elements of effective therapeutic relationships should be carefully considered; these elements include empathy, listening to clients, involving clients in the therapeutic process, and requesting feedback from the client (Norcross, 2010).

Although both the collaborative assessment model and building an effective therapeutic relationship certainly provide a starting point for any school psychologist who needs guidance on how to deliver evaluation results to parents, several limitations are present. First, the model has not been directly studied for effectiveness. Second, the model has not been intended for use in schools; the school psychologist performs a variety of duties and may not be able to have time to develop an effective therapeutic process for delivering results (Pelco, Ries & Melka, 2000). Last, the model did not take input from parents into consideration when developing the theories and techniques. Taking feedback and input from clients is considered a key element to building effective therapeutic relationships (Norcross, 2010), thus this limitation is deemed critical for further study. Parent input about how a school psychologist should relay evaluation results is crucial, given the fact that parents will be one of the primary consumers of the evaluation and considering even further, the numbers of children in schools who will receive an evaluation.

Purpose of the Study

The purpose of this qualitative study is to examine the perceptions and reactions that parents have when reviewing initial evaluation results with the school psychologist during an assessment feedback conference. This study will seek to gain deeper understanding about a parent's experience during this interaction. Data obtained from the parents will be used to develop a model for ways in which school psychologists should conduct evaluation feedback conferences to relay the results of an evaluation to parents. This model will include not only direct input from a parent, but will also be specific to the school setting. Additionally, the feedback session is one of the more common opportunities that school psychologists have to involve parents in schools. Therefore, the model generated from the data obtained in this study will provide guidance on how school psychologists can use this opportunity to improve parent involvement in schools. In sum, the present study will seek to understand the perceptions and reactions of the parent during the initial assessment feedback conference and from these perceptions, the researcher will develop a theory or model of how school psychologists should provide evaluation results to parents.

CHAPTER 2

REVIEW OF THE LITERATURE

Parent involvement in schools has been examined and studied in various aspects of research on education. The definition of parent involvement varies, as do the recommendations for the ways in which parents should be involved in schools. Wandersman, Motes, Lindsay, Snell-Johns, Ford, & Amaral (2002) conducted a review of the literature and concluded that parent involvement is defined as those times when parents participate in activities across the home and school environments that promote the development of students. Parent involvement spans many dimensions, including the behavior of the parent, the parent's attitude toward involvement, barriers to involvement, and how parent involvement is facilitated in a specific school (Miller & Kraft, 2008).

Henderson et al. (2007) proposed a model that included five different kinds of parent involvement roles that parents should play in schools. The authors define parents' first role as that of *partner*, in which the parents perform the rudimentary operations needed for the development of their child's academic and social skills. When parents are asked to act as *collaborators*, they work with the school teams to support problem-solving efforts for their child. Parents take on the role of *audience* when they support the various productions that occur in the school that their child attends. When parents volunteer assistance to teachers, to parent organizations, or to other parents, they take on the role of *supporters*. Last, parents act as *advisors*, or participants in decision-making about school policies (Henderson et al., 2007). The role of the parent spans many different functions and affects different components of the school system. Their roles can be direct or indirect, and parents can become involved for all students, for a specific class, or for their individual child. Despite this multi-faceted definition of involving parents in schools, the authors indicate that traditionally, parents perform supportive roles such as fundraising or volunteering as chaperones on class trips. This is a very limited scope of parent involvement (Henderson et al., 2007).

Although there are various methods used by schools to involve parents, there is consensus regarding how much a children benefit from having their parents involved in their education across a variety of outcomes. Henderson & Mapp (2002) conducted a review of available research studies on parent involvement and its effect on the student's education. The results demonstrated the fact that when parents are involved in their child's education the following outcomes can be predicted: students' grades and test scores will increase; grade retention will decrease; school attendance will increase; social skills will improve; the student will likely graduate from high school; and it is likely the student will pursue postsecondary education. Pelco et al.'s (2000) research notes that it is difficult to draw conclusions from the benefits of parent involvement because of the various models and definitions of parent involvement. Although it is unlikely that any one model can account for all the benefits, it is clear that when parents are involved, students perform better in schools (Pelco et al., 2000).

Legislation and Parent Involvement

The importance of parent involvement is reflected in many pieces of legislation. Laws that affect and regulate education often outline specific roles for parents and include a variety of rights that parents have. These laws include procedures for parents of students in general education and students with disabilities who receive special education services. A monumental Act that has affected parent involvement was No Child Left Behind (NCLB) (US Department of Education, 2001). Title 1 of this Act stipulates a school-parent compact that delineates specific duties that a parent must follow to support their child’s learning. Examples include ensuring that homework is completed and that parents send their children to school. The compact will also describe how schools will work to provide highly qualified educators who deliver high quality instruction. Last, the specific method for communication with parents is outlined by requiring schools to develop a written parent involvement policy and holding an annual meeting for parents (Tableman, 2004). These pieces of legislation bring parent involvement to the forefront of focus for many teachers and school administrators because these laws insist on monitoring schools about how well they involve parents.

The Individuals with Disabilities in Education Act (IDEA) (US Department of Education, 2004) is another piece of federal legislation that mandates parent involvement. This bill outlines the rights of a parent when a child is suspected of having a disability and what additional rights the parent will have if his or her child is subsequently placed in special education. The parents’ rights will be presented to them in written form, called a procedural safeguard manual. The intent of these safeguards is to ensure involvement from those parties who know the child the best (parents) and intensively incorporate parent input into the Individualized Education Plan (IEP) (Johnson, 2003). This dense and seemingly overwhelming document is given to parents at every step in the special education referral process and at every IEP meeting. Some examples of parent involvement rights outlined in this document include ensuring that parents provide consent before an evaluation is conducted, including a section of the IEP for parent input, and providing a parent with prior written notice of the action that the school district would like to take with his or her child's education, prior to any change being made.

A study conducted on the readability level of the parent rights document was conducted by Fitzgerald & Watkins (2006). The authors point out that it is assumed that when parents participates in the evaluation process that their rights have been explained to them and that they understand their rights. However, other studies have shown that communication does not always happen with parents and schools, particularly when working through the IEP process (Johnson, 2003). Fitzgerald & Watkins (2006) noted that the recommended reading level for public documents should be between the seventh and eighth grade reading levels; in their review, the researchers found that only 4-8% of the documents were written at this level. Their study, conducted by obtaining copies of parents rights from 49 states and the District of Columbia, revealed that the average length of this document was 1,334 words, 24% of which were deemed words that would be unfamiliar to an average reader; additionally, more than one half of the documents were written at a college reading level (Fitzgerald & Watkins, 2006). Their study also examined the amount of jargon that was used; the number of acronyms used ranged from 0 to 47, with 90% of the samples containing 21 or fewer acronyms (Fitzgerald & Watkins, 2006). The number of pages of each document varied significantly, suggesting that the breadth and depth of information being explained to parents varies from state to state (Fitzgerald &Watkins, 2006, 506). The parent is a member of the child's team and is expected to provide meaningful information to the school on how to meet the child's needs. It may not be clear to the parent how he or she is to participate in this process if schools do not communicate these rights to the parent, especially given the noted issues in the readability of procedural safeguards. Thus, navigating parent responsibilities typically occurs without any formalized training. Research by Valle (2011) found that parents who have children involved in the special education process feel as if they are often forced into the role of an advocate without necessarily understanding or wanting this role. The procedural aspects of special education certainly can overwhelm any parent who is going through the process (Valle, 2011).

In addition to IDEA, the National Joint Committee on Learning Disabilities (2005) has identified some key points that schools should be considering in order to ensure adequate parent involvement. Schools need to understand how parents are included in the planning of the response to intervention (RTI) model at the state and district levels and they need to understand clearly how parents are involved in all stages of the RTI process. Parents need to have information provided to them in written form, describing the steps they can take to request an evaluation for special education services, which is one of the rights that are outlined in IDEA. Last, schools also need to provide parents with copies of information explaining how their child may be found eligible for special educations services under the various disability categories (National Joint Committee on Learning Disabilities, 2005).

These laws certainly create good intentions for parent involvement, because they make sure schools are aware of the importance of having parents properly involved in their student's learning. They place parent involvement at the forefront of the schools' focus and ensure monitoring of how schools get parents involved. These laws also delineate many rights that parents may possess. In fact, a parent's rights are so dense and so loaded with jargon that a legal or communications experts needs to break them down in laymen’s terms so that a parent would be able to understand. Evidently, these laws demonstrate the importance lawmakers have placed on parent involvement in education; however, the actual execution of this involvement according to these laws may create a barrier (Valle, 2011).

Parent Involvement for Culturally and Linguistically Diverse Students

If a student is considered to be culturally or linguistically diverse, then additional barriers to establishing the parent-school partnership occur, and additional considerations should take place during the pre-referral and referral process. The “culture” of special education is mandated by IDEA (2004), which was developed through a congressional process in a democratic country (Turnbull et al., 2006). An immigrant family from a country that does not practice democracy or a family from a culture that does not value participation in the legal process may not be equipped for the role of the parent of a child who receives special education. The language used in this legislation may also pose some barriers. In some cultures, the term “disability” does not mean the same thing as the English translation. In many Native American languages not only is there no word to represent “disability”; disability is a concept does not even exist in their culture (Turnbull et al., 2006). When a parent comes from a culture that does not hold the same values, such as participation in the process, this may create another barrier to getting that parent involved in his or her child’s education. Understanding that a parent’s culture may not assume the rights outlined in IDEA can help school teams plan for how best to involve parents in the IEP process without increasing their discomfort (Lo, 2012). It is also important to consider that immigrant families may be accustomed to a different special education process that occurs in their home countries, and walking into a meeting with a table filled with school professionals may be extra intimidating. School teams may have to take on the additional responsibility of educating culturally and linguistically diverse parents on how to take on the roles outlined for them in the law (Lo, 2012).

Another consideration that school teams must address is how to give parents meaningful access to the information being presented on their child when the primary language of the home is a language other than English. Many times schools may attempt to find any staff member in the building who speaks the native language of a parent to interpret or translate. A problem with this option is that the nature of the language being interpreted may require formalized training. It may not be possible for a person with basic interpersonal language skills in both in English and in another language to adequately translate certain terms that exist in special education. It is imperative to ensure the use of interpreters who are adequately trained to translate this information, considering the fact that many of the key terms in special education may not even exist in another culture or language (Turnbull et al., 2006).

Schools need to remember the culture of working class families and ensure options for working parents to participate appropriately in this process. Parent-teacher meetings are typically held during working hours, which can create an extra challenge for parents needing to get time off to attend conferences. It could be possible that only one parent can attend, which adds an additional burden of one parent having to relay the school information to his or her spouse or partner. In some situations, such as times when psychoeducational evaluation results are shared, this can create discord particularly when the results are difficult and unexpected (Turnbull et al., 2006).

Payne (1998) discusses the impact of generational poverty and its impact on parent involvement in schools. In her landmark book, *A Framework for Understanding Poverty*, Payne highlights the differences between the culture of schools and the culture of families living in poverty. The author discusses how schools operate from a system that was formed on middle class values, which conflict with the values of families living in generational poverty (Payne, 1998). Families in generational poverty place more emphasis on activities that provide enjoyment, whereas middle class families tend to place more emphasis on activities that advance themselves or uphold obligations. It can be said that assumptions may be made about an individual's intelligence or decision-making simply because that person's values may not be consistent with that of the middle class. The attitudes that parents bring with them cannot be ignored and schools need to be sensitive to their backgrounds when including parents on making decisions (Payne, 1998). As mentioned previously in this article, the readability of parent procedural safeguards varies significantly and they are often written at a higher than recommended reading level. Parents living in generational poverty likely did not finish high school, thus the gap between the communication of their rights and responsibilities and their reading skills may be wider than that of parents in a middle class family. The study conducted by Fitzgerald & Watkins (2006) examined the readability of parents' rights documents written in English; the variability in the findings can cause the reader to pause and wonder what the variability may be for a document written in Spanish or a language other than English (Fitzgerald & Watkins, 2006). Understanding that additional practices must be put into place for families who are not only culturally and linguistically diverse but who also maybe living in poverty is imperative for the establishment of appropriate communication and trust in parent-school relationships

Parent Involvement and School Psychologists

According to NASP, there are ten functional competencies that school psychologists must possess in order to best meet the needs of students; these are outlined in *NASP Model for Comprehensive and Integrated School Psychological Services* (2010). One domain, Interpersonal and Collaborative skills, identifies how imperative it is for school psychologists to share information effectively with a variety of audiences in a variety of contexts (NASP, 2010). When a school psychologist possesses adequate communication skills he or she becomes more effective at promoting change, particularly with individual students. These skills become of particular interest when school psychologists establish working relationships with parents. The working relationship between parents and school psychologists can be integral for solving student problems, because parents are considered the most influential people for promoting change in their children (Henderson & Mapp, 2002). In fact, NASP (2010) acknowledges the importance of school psychologists working with parents by identifying “Home/School/Community Collaboration” as another competency domain of school psychologists that highlight the importance of collaborating with parents to create better outcomes for individual students. “Diversity in Development and Learning” is also identified as a foundation of school psychological service delivery to stress the importance of being prepared to work with families who are culturally and linguistically diverse (NASP, 2010).

In addition to the training model outlined by NASP (2010)*,* Turnbull et al. (2006) explains a model for establishing partnerships with parents of students who are identified as having special needs. The authors highlight the fact that educating children is a primary function of a family unit, so parents' involvement in school should be assumed (Turnbull et al., 2006). Additional care needs to be taken when working with students who have a disability and also with their families. The Turnbull et al. (2006) model is relevant for any professional working in special education and is an example that school psychologists should follow to establish effective partnerships with parents of children with disabilities.

In the model outlined by Turnbull et al. (2006), the authors identify seven principles of an effective partnership (communication, professional competence, respect, commitment, equality, advocacy, and trust) that will allow for mutual support to link parents and school staff. *Communication* reflects the principles of providing parents with quality information. Parents deserve truth and information should be provided to them in a clear manner. This principle is important, because communication initiates the partnership and will be needed in all aspects of parent involvement (Turnbull et al., 2006). The principle of *professional competence* highlights the importance of maintaining high expectations for students and providing all students with a quality education. *Commitment* is demonstrated when school staff are available and accessible to parents and maintain sensitivity to emotional needs. *Respect* and *equality* are principles that foster sensitivity to the culture and role of a parent. When the school staff show respect for cultural diversity, identify strengths, treat students and families with dignity, share power, and foster empowerment, they are adhering to these principles. *Advocacy* is performed when school staff works to prevent problems by demonstrating concern when systemic problems are present, and also when they seek alliances with parents. Finally, *trust* is identified as the “keystone” to the seven principles of family partnership (Turnbull et al., 2006). Trust needs to be present in every principle of an effective school partnership in order for both parties to work together.

It is clear that specialized training is required to achieve all principles of an effective partnership as outlined by Turnbull et al. (2006). Esler, Godber & Christensen (2008) posit the idea that school psychologists are ideal practitioners to facilitate building partnerships between schools and families, given their specialized training. Additionally, Pelco et al. (2000) discuss how school psychologists’ training in other domains such as assessment, consultation, and development make them experts and key players to carry out the role of developing a partnership. The study conducted by Pelco et al. (2000) specifically examined how school psychologists view their roles of facilitator for parent-school partnerships across a variety of variables by surveying 400 school psychologists. The results found that 90% of respondents agreed that parent involvement was important in order for students to succeed; however, 40.5% said school psychologists do not have time to participate in this activity (Pelco et al., 2000). The results of this study showed that there were three activities that school psychologists rated as being important and also as activities in which they are involved for significant periods of time; these include: consulting with families about ways to support learning and behaviors at school; teaching families about child development, discipline or parenting, and facilitating conferences as a means to increase cooperation between parents and schools. Eighty percent of the participants in the study reported that they had engaged in the latter activity during the previous year but it was unknown how effective schools psychologists were in that role (Pelco et al., 2000).

The results from Pelco et al. (2000) highlighted the discrepancies that may exist in the training of school psychologists and the practical applications of working as a school psychologist in the school setting. Research conducted by Pelco et al. (2000) provided evidence that the role of facilitator of partnerships between schools and families often takes a back seat to other responsibilities that school psychologists must carry out; this is unfortunate, given the benefit parent involvement has on student performance at school. When the complexities surrounding parent involvement are considered in conjunction with the training of school psychologists, it becomes clear that the specialized training given to school psychologists can be utilized to facilitate parent involvement in schools.

Parent Involvement during the RTI process

IDEA (2004) attempted to make parent involvement less procedural and more substantive by allowing schools to use a Response to Intervention (RTI) process (US Department of Education, 2004). This process occurs within general education and provides support to any child suspected of having a learning or behavioral issue in school. This practice can prove to be more proactive as it tries to have schools identify student learning needs early, thereby providing interventions before the problem manifests itself as a disability (Miller & Kraft, 2008). When schools use an RTI process, parents become involved in a manner similar to the model purported by Henderson et al. (2007) because their input will be used in the data collection steps to the problem-solving process.

When a student starts to experience academic and behavioral issues, the family-school partnership becomes much more imperative. Principles outlined by Turnbull et al. (2006) and NASP (2010) are effective methods for use by school psychologists; these will ensure positive school partnerships with an additional benefit of adherence to federal statues for parent involvement. Becoming proactive with parent involvement means using techniques and practices that not only welcome parents into the school setting but they also assist school staff with establishing effective home and school partnerships. Schools will be better equipped to understand the strengths of the student and the family when a partnership includes the family in the pre-referral process (Turnbull et al., 2006).

Miller & Kraft (2008) highlighted ways to communicate with and involve parents through various tiers of RTI. In Tier 1, all students are provided with high quality instruction and interventions, and data are collected on their progress (Miller & Kraft, 2008). Communication practices in Tier 1 should focus on communicating to parents the academic and behavioral expectations of their child's school. Parents should also be told how schools are addressing state and federal mandates for assessment, curriculum, and instruction (Miller & Kraft, 2008). School staff should consider methods for teaching parents about the expectations for their school. Examples of ways to involve parents at this level include parent organization groups, such as parent-teacher associations, and providing various parent workshops and training around certain topics of interest (Miller & Kraft, 2008). These recommendations for parent involvement tie in nicely with the way Tier 1 supports are provided, because these supports are given school-wide to all students to promote learning. In addition, if the principles of communication and respect are being utilized (Turnbull et al., 2006), a family should be informed of the concerns as early in the process as is possible. Another benefit is the prevention of unnecessary evaluations; if school staff and families share information about changes at home and school, and collaborate on ideas to support a student, thus solving the problem before an evaluation is warranted (Turnbull et al., 2006).

When students present with problems that persist beyond the typical interventions that are put in place for all students, new sets of communication and involvement practices must occur. In Tier 2, students who demonstrate a failure to respond to the interventions provided in Tier 1 are now provided with more intensive support. Different interventions for targeted groups of students who did not respond to Tier 1 supports are implemented and additional data collection techniques are utilized (Miller & Kraft, 2008). Parents require direct communication about the goal of Tier 2, which is prevention and provision of a higher level of support to address their child's concerns (Miller & Kraft, 2008). The school team should explain to the parent how decisions will be made, based on this process and consider methods to communicate information between home and school (Miller & Kraft, 2008). In terms of involvement, schools need to examine how best to provide more targeted interventions so that the parent may become involved in supporting his or her child's learning in the best ways possible. This may include reaching out personally to parents when training opportunities occur or providing the parent with training and materials to execute certain interventions at home (Miller & Kraft, 2008). This will allow parents to stay involved in the intervention process and may serve to make the data that are being collected regarding their child's interventions more meaningful.

Special Education Referral Process and Parent Involvement

When schools use an RTI process that incorporates the steps to effective communication and involvement outlined by Miller & Kraft (2008), parents should be prepared for the subsequent referral for a special education evaluation that may need to occur in Tier 3. Interestingly, in Sec 1414 (a) through (c) of IDEA (2004), the evaluation requirements are stipulated and these do not state explicitly that a child's parent should participate in the evaluation process. The authors suggest that the school psychologist should be sure to include parents in the data collection process by asking questions, by conducting interviews, and by allowing parents ample time to review questions being asked of them so that they feel prepared (Turnbull et al., 2006). In order to ensure that the partnership continues to focus on trust and shared decision-making, Turnbull et al. (2006) also recommend that the school psychologist explain to the parent those forms of data that will be collected, including the reasons for this. Last, the school psychologist should continue guiding the team by linking assessment data to a subsequent intervention plan, ensuring that the student's needs are being addressed through implementation of specially designed instruction (Miller & Kraft, 2008).

Parent Feedback Conference

A child's initial assessment feedback conference occurs after the culmination of the evaluation process; this is the time when the evaluation results will be reviewed with the parents. This conference is considered a key moment in the collaborative relationship between the parent and the school psychologist. Gimpel & Huebner (1994) conducted the first study that examined parent perceptions of the school psychologist during the parent feedback conference. This study surveyed parents with children who had disabilities; for this study, participants were recruited from a local school district and from a state sponsored, parent organization for children with disabilities. The participants of the study completed questionnaires containing items that were organized into the six domains of practice by the school psychologist: assessment, consultation, counseling, research, liaison services, and program development (Gimpel & Huebner, 1994). Psychologists completed a similar questionnaire so that their responses about their job perceptions might be compared. Parent responses revealed that consultation was perceived to be the most important role of a school psychologist, followed by assessment and counseling. Comparatively, the school psychologists ranked assessment, then consultation, then program development as the three most important roles. The overall variability in responses in the parent sample indicated that parents see the importance for a wider variety of school psychological services.

Responses to items that assessed problems experienced during the multidisciplinary team procedures were tabulated. The parents of the school district rated "lack of appropriate follow-up" as the most concerning problem, followed by insufficient time devoted to discussion of methods to help the child. The third problem was poor explanation of the evaluation results; comparatively, the state parent group rated "poor explanation of evaluation results" as the biggest concern. The parents' concerns in the school district were closely aligned with the primary concern of the psychologists; i.e., that there was a lack of appropriate methods for follow up with a parent regarding the results of an evaluation (Gimpel & Huebner, 1994).

One of the most significant findings in this study was how the number of parent contacts correlated with overall satisfaction of services. The average number of parent contacts in the school district sample was smaller (M = 3.97) than that of the state organization sample (M = 6.32). Additionally, the range of parent contacts showed a similar pattern. The range of parent contacts was 0-25 for the school district sample and

0-52 for the state organization sample (Gimpel & Huebner, 1994). Parent contacts showed a significant correlation with overall satisfaction r (122) = .31, p< .001, but the state organization sample's correlation with overall satisfaction was non-significant.

Studies that examine the experience of the parent during the initial feedback conference demonstrate important practical implications for school psychologists. This is a moment that is stressful and can cause parents to reconsider their perceptions of their children (Vaughn, Bos, Harrell, & Lasky, 1988). Many places in the literature noted that when students are considered to have a disability many parents wonder if they are to blame or if they are "bad parents". When interviewed about the parent perception of the IEP conference, a variety of emotional responses were reported. The majority of the sample (69%) felt positive and appreciative, but 23% reported feeling "nervous" and "cautious", and 8% reported feeling "confused" and "overwhelmed". The parents in the study were also asked to provide a definition for "learning disability" and to report upon the amount of time their children would be receiving special education services. Although the majority (68%) of the sample reported that the amount of time their children would receive special education services was the same as that discussed in their IEP meeting, there was significant variance in how a parent defined a learning disability. Twenty-three percent of respondents could not explain the term or their responses were unrelated; 8% stated that it was "just how their child was"; 12% percent thought it meant that their child had a physical problem, and 27% stated it meant that their child was "slow" (Vaughn et al., 1998).

The study concluded by asking parents about any additional questions they might have had after attending the conference. Twelve percent of the sample stated that they would like more explanation of the scores; 8% wondered how their children would react to the placement; 4% wondered what they could do to help more at home, and 65% said they had no questions. What is concerning about this finding is that the conferences reviewed a wide breadth of information, including the results of the students' psychoeducational assessments; changes in the students' educational programs that were being implemented, and assigning the students with a disability category (Vaughn et al., 1988). Witt, Miller, McIntyre & Smith (1984) found that the variables that were most closely aligned with parent satisfaction after the initial placement were making sure the meeting was not rushed; the fact that the parents were not made to feel "blamed" for the child's disability by the school personnel, and the number of people who took on an active role in planning their child's educational program. The studies conducted by Vaughn et al. (1998) and Witt, Miller McIntyre & Smith (1984) indicate that parents need better understanding of evaluation results and that parent satisfaction will improve if the school uses care and time when providing results. Furthermore, the emotional reactions felt by the parent during this complicated and undoubtedly stressful process in our schools warrants support from school staff.

A Therapeutic Process

Parent feedback can be a therapeutic intervention (Ackerman, Hilsenroth, Baity & Blagys, 2000) and effective parent feedback will optimize outcomes for students, including future success of interventions (Pollack, 1988). Pollack (1988) outlined "effective parent feedback" to include empathetic understanding, relevance of the information, clarity of the information, and respect of the parent and family. Norcross (2010) reported that 80% of psychotherapists indicate that the relationship between the client and the therapist is the most important factor in the success of therapy. Likewise, clients identify the therapeutic relationship with the therapist as being more effective than the techniques used during therapy (Norcross, year). Positive therapist characteristics, included warmth, understanding, and affirmation, but minimal use of attack and blame, were central to the effectiveness of therapy interventions.

Additionally, Norcross (2010) identified empathy as one of the essential elements of therapeutic relationships. Empathy is not only considered to be a function of a positive therapeutic relationship, but it will also serve to allow the client to facilitate change in his or her emotional experiences and promote creation of new meaning. The difficult notion of empathy is that an appropriate empathetic response will vary from person to person, thus there is no universal empathetic response (Norcros, 2010). The author also mentions that listening to the client is a key element to developing any therapeutic relationship, and that the voice of the client is missing from many texts concerning ways to develop a therapeutic relationship (Norcross, 2010). Additional practical implications to building an effective therapeutic relationship include using the client's experience with change and readiness to collaborate to build the relationship. The therapist should also ask the client what has worked for him or her during therapy and also the therapist should request feedback on the therapeutic relationship (Norcross, 2010). The implications of how to build an effective therapeutic relationship should be considered when providing evaluation results in order to support the parent and increase the likelihood of intervention success for the student.

Collaborative assessment approach. One particular assessment feedback approach focuses on the relationship between the parent and the assessor. Although there are no current models for delivering feedback to parents whose child receives an evaluation in the schools, Tharinger, Finn, Hersch, Christopher, Wilkinson & Tran (2008) discussed this particular model for providing assessment feedback with parents and pre-adolescent children. Their approach, the *collaborative assessment approach*, is also known as the “information-gathering” assessment model. In their model, the psychologist avoids trying to instill truths about his or her client based on the assessment results. Rather, the psychologist focuses on trying to offer insight and allow for new truths to enter into a parent’s existing schema of his or her child (Tharinger et al., 2008).

Schemas provide a sense of identity and emotional security (Swan, 1996) and schemas determine how an individual makes sense of prior experiences and of the world. The schemas held by a parent for his or her child are intricately connected to emotional states, so the process of changing a parent’s existing schema about his or her child will become an emotional process (Tharinger, et al. 2008). The assessor can promote the parent’s accommodation of new information into the existing schema and can help the parent navigate the emotional responses when there are data that severely conflicts with the schema around their child. Thus, Tharinger et al. (2008) highlight the fact that the assessor must be supportive of the various emotional reactions the parent may experience (relief, guilt, anger, hope, grief, anxiety) as they accommodate the new information about their child. The collaborative approach emphasizes the use of the collaborative relationship between the psychologist and the parent during the assessment feedback conferences so the parent may “co-edit” and revise his or her schema with the support and guidance of the assessor (Tharinger, Finn, Wilkinson, DeHay, Parton, Bailey & Tran, 2008). When the parents collaborate with the assessor in revising their schema, they will be more likely to accept the new information that has been provided about their child and will remember it (Tharinger et al., 2008). A therapeutic process that helps parents view their child's challenges in an accurate, compassionate, and useful way can happen by collaborating and supporting parents (Tharinger et al., 2008).

Prior to the conference. In order to prepare for the feedback conference, the authors stress the importance of preparation for the assessor. Each assessment feedback conference should be tailored to the parent and child, and it is recommended that the assessor ask himself or herself, "If I were this client, what would be the best way to approach me about these results?" (Tharinger et al., 2008, page 604). The assessor should then consider the following variables. First, he or she must determine whom to invite to the assessment feedback conference. To answer this question, the assessor must have a good understanding of the family make-up, including the number of parents; the role each parent plays in parenting, and any other significant family members who live with the child or who assist with parenting the child (Tharinger et al., 2008).

Next, the assessor needs to determine how to present the results. The importance of ordering the way in which the findings are relayed to parents was determined from research conducted by Shroeder, Hahn, Finn, & Swann (as cited in Tharinger et al., 2008). The authors illustrated the fact that assessment feedback should be presented in a process that mirrors the existing narrative that parents have for their child. In order to do this, the assessor must examine information that parents provide, such as in interviews and rating scales; these clue the examiner into how the parent perceives their child. Then, the examiner can order that information across three levels, ranging from information that is most similar to the parent's existing narrative to information that is novel and discrepant from the parent's usual ways of thinking about their child (Shroeder et al. as cited by Tharinger et al., 2008). Initial information that is presented will be findings that are close to how the parents currently perceive their child (Level 1). The bulk of the information relayed during the assessment feedback session should occur in Level 2. This information will be information that serves to modify slightly or reframe the parents' perceptions of their child (Tharinger et al., 2008). Last, Level 3 findings will be information that conflicts with the way in which the parents perceives their child. When considering this information, the assessor should get a sense of the degree to which the parents' current perceptions of their child maintains their own self-esteem (Tharinger et al., 2008).

After the assessor has planned and analyzed how to present the information, he or she will next need to decide what the major findings and recommendations are. To do this, the assessor will need to identify those findings that will best address the parents' presenting concerns and answer their questions. Additionally, the assessor will need to identify that information which is important so that the parents' schema may change. It is important in this step that the researcher does not deter from relaying information that maybe difficult to hear or that the assessor may become anxious in telling the parents (Tharinger et al., 2008). Next, the assessor should ensure that he or she uses language that is accessible and easy for parents to understand. To do this, the assessor needs to pay attention to the language the parents use and needs to be mindful of the parents' culture (Tharinger et al., 2008). Then, during the assessment feedback conference the assessor will need to ensure that he or she is using an appropriate tone, paying attention to the parents' responses and whether or not the parents are overwhelmed; it is also necessary to assess the level of anxiety felt by the assessor when he or she goes into the feedback conference (Tharinger et al., 1998).

Limitations. This model certainly encompasses many of the components of an assessment feedback conference and highlights steps that the assessor needs to make to ensure that the parents will accept the information and comply with the report recommendations. However, the authors did not indicate if this assessment model could be used in the schools. The steps that need to be taken to deliver the assessment feedback results in this manner are detailed, and may not be feasible in the school setting, given the volume of evaluations that school psychologists need to complete and the variety of other duties that research has shown tend to take precedent over collaboration with parents (Pelco, Ries & Melka, 2000). Other obstacles that may occur include district procedures and policies that delineate who should be invited to the feedback conference. The school psychologist may not have the power to set up the meeting according to this model. For example, some districts may require the local educational administrator (LEA) and other team members need to be present when results are given. This would impede the school psychologist’s skills for ensuring the therapeutic connection needed in this approach. Additionally, a variety of research was reviewed and integrated into the various components of this model; however, the researchers did not include data directly from parents who have gone through this process with their children. Norcross (2010) highlighted the fact that data should be taken in any therapeutic relationship to ensure effectiveness. Although this approach is certainly a reasonable starting point for determining how evaluation results can be delivered in schools, there is a need for further investigation to ensure that an appropriate method is utilized.

Conclusions from the Literature

A review of the literature exposes a gap between research and practice in the field of school psychology in regard to relaying evaluation results to parents. There is no specific technique, approach, or outline available that is evidence-based for school psychologists to follow when presenting information to parents. Schools are unique systems and environments. Extrapolating research based procedures for presenting results from other environments is a start, but these may overlook specific experiences held by the parents in school settings, including the complicated procedural aspects (Fitzgerald & Watkins, 2006; Vaughn et al., 1988; Valle, 2011) and the pre-referral process during which student concerns are first identified (Miller & Kraft, 2008). Research from Norcross (2010) highlights the importance of the relationship in compliance and treatment outcomes, and models of parent involvement from Turnbull et al. (2006) indicate that parents will better foster trust when they share power with the school staff; this is similar to the way in which parents collaborate with the assessor in the collaborative assessment feedback approach (Tharinger et al., 2008). The emotional responses that may occur during initial assessment feedback conferences (Gimpel & Huebner, 1994) require support, empathy, and care in order to improve parent satisfaction and to increase the likelihood that the child will benefit from interventions (Tharinger et al., 2008). Last, the input of clients and review of client feedback in therapy improve the therapeutic relationship and the effectiveness of therapy (Norcross, 2010). The direct input of parents is deemed crucial in order to study effectively how school psychologists should deliver evaluation results to parents. Therefore, the relationship between parents and school psychologists during this critical and sensitive exchange should be studied.

CHAPTER 3

Method

Participants

The participants of this study included parents of children who had been evaluated for special education in a school setting in the state of Pennsylvania. A “parent” was defined as the guardian or caregiver of a child with a disability according to IDEA 2004. The parent must have been responsible for the child’s educational decisions during the initial evaluation for special education (consistent with IDEA Sec 300.20). The parent included biological parents and stepparents or grandparents, as long as they were caring for the child and they were legally responsible for the child’s welfare at the time of the initial evaluation (IDEA 2004). If a foster parent met those requirements he or she could have been included in this study. However, surrogate parents were not included. The definition of a surrogate parent according to IDEA (2004) is an adult who is appointed by local educational agencies (LEA, or the school district) for students who have no parent and/or the parent’s whereabouts were unknown. The responsibilities of a surrogate parent are to represent the child in matters relating to identification, evaluation, and placement of the child, and the provision of a Free and Appropriate Public Education (FAPE) (IDEA 2004). Examples include children who are “wards of the state” according to the laws of that state or “an unaccompanied homeless youth” according to the McKinney-Vento Homeless Assistance Act. The relationship of a surrogate parent to a child is purely to represent him or her in procedural matters relating to their needs, but surrogate parents do not provide any additional caregiving or support for the child; therefore, they were not included in this study.

The child needed to attend a public, nonpublic, or charter school in Pennsylvania during the timeframe of his or her initial evaluation. Participants were limited to Pennsylvania in order to best control for differences across states in regard to the role of the school psychologist. Participants who resided outside of Pennsylvania and whose child was evaluated outside of the school setting were not included. There were no exclusionary criteria regarding any other family variables, such as race, ethnicity, type of school the child attended and socio-economic status. Additionally, there were no exclusionary criteria regarding the child's age at the time of the initial evaluation or the amount of time that had elapsed since the child's initial evaluation; this was done in order to analyze the long terms effects of this conference and to determine if there was something significant about the age of the child at the time of his or her initial assessment. Participants volunteered for this study; the sample is considered a convenience sample. A convenience sample was utilized because there is minimal research available that discusses the significance of the initial assessment feedback conference and therefore it was difficult to discern "where to start" in regard to developing a sample for this project. Using accessible participants was determined as an adequate starting point to collecting information. Additionally, the participants in this study needed to share personal and detailed descriptions about an experience involving their child. Therefore, using a convenience sample was beneficial in connecting participants who were willing to disclose this level of personal information with the researcher because the researcher was someone who was loosely connected to them.

Participants were recruited through personal networking, word of mouth, and through eliciting support from other school psychologists in Pennsylvania. In the latter method, an informative flyer was provided (Appendix A). The flyer encouraged prospective volunteers to email or call the researcher to express interest. When participants contacted the researcher, a brief screening interview was conducted to ensure the fact that the parent met the inclusionary criteria. If the parents did not meet the inclusionary criteria they were informed that they could not participate in this particular study. If the volunteer met the criteria, that individual was provided with information regarding the study. Participants were recruited until saturation occurred. Saturation occurs when the information being elicited from participants no longer provides further insight into the parent experiences (Strauss & Corbin, 1998). In the event that saturation could not be attained, participants would be recruited until the limits of using a convenience sample were exhausted.

The database for this research was collected and analyzed over the duration of three months. During this time, the primary researcher recruited participants through networking with personal contacts; local agencies that support parents of students with disabilities; state agencies that support parents with disabilities; Internet-based distribution lists; networking with other school psychologists; and through local chapters of parent organizations in Pennsylvania.

A total of 22 parents volunteered to participate in this study; however, only 11 continued to participate in the study. One potential participant was not included because her child was older than age 21. Two participants were excluded because their children had disabilities but had never been evaluated by a school psychologist. One participant was screened, an interview time was arranged, but they did not arrive for the interview and did not respond to a follow up contact for rescheduling by the researcher. Four potential participants expressed interest in participating but did not respond to attempts made by the researcher to complete screening interviews. Finally, one participant expressed interest but declined being screened because she did not feel she could commit to the time that it would take to complete an interview.

The 11 participants agreed to complete a demographic questionnaire and engage in a semi-structured interview with the primary investigator. Ten of the interviews were completed over the phone and one was conducted in person. A confirmation email was sent prior to the interview. Time was spent establishing rapport during the screening interviews and prior to the reading of the interview prompt. Additional time was allotted at the end of the interview for debriefing and feedback, which was always positive. Most often, the parents expressed the fact that they were glad to share their stories in the hope that sharing their experiences could make things better for other parents. Throughout the study the primary investigator maintained a journal. In this journal, the primary investigator took notes after each interview about the parents' impressions, the comfort levels of the interviewees, and the potential themes that were emerging. In particular, the primary investigator used the journal to ensure that objectivity on behalf of the researcher was maintained while conducting the interviews and reviewing them.

Overview of Research Design

In qualitative research, the experiences and stories of the participants are examined and integrated so that a topic or phenomenon can be better explained. The purpose of this study was to examine the experiences of parents when they meet with school psychologists in order to review evaluation results of their children for the first time, with the goal of developing a theory or model based on this meeting. Therefore, a qualitative study based on systematic grounded-theory research was utilized in order to best answer the research question. In this approach, the researcher captures the perceptions of the participants and codes them into data in order to build a theory (Strauss & Corbin, 1998).

Barney Glaser and Anselm Straus developed grounded theory research in 1967. This approach allows theories to be based upon (or “grounded”) in the experiences shared by the participants (Corbin & Strauss, 1998). Researchers select the grounded theory method when they want the perceptions of the participants to lead to the development of a theory surrounding a process, action, or interaction (Creswell, 1997). There are two common approaches to grounded theory qualitative research, and for this study the systematic approach was selected. This approach was developed by Strauss & Corbin (1998) and is used when the researcher systematically develops a theory. The intention of this study is to systematically use the perceptions and experiences of parents who have children with disabilities in order to develop a theory about the parents’ experiences when they receive evaluation results from the school psychologist for the first time.

Measures. This study utilized two different measures. The first measure was a questionnaire that was used to gather demographic information about the parents and their children (Appendix B). The second measure was a semi-structured interview designed by the researcher and her dissertation committee. (“Parents and School Psychologists”) (Appendix C). The interview was composed of several, broad, open-ended interview questions that served as the primary source of data collection. Clarifying probes were utilized as needed.

Procedures

Interviews lasted between 30-60 minutes and participants were allowed to opt-out at any time. Interviews were conducted in-person at a mutually agreed upon location or over the phone. When the interview commenced a brief introduction was provided, according to the script in Appendix C. The demographic form was provided to the participant after the interview was conducted. In order to protect confidentiality, each participant was provided with a pseudonym that was used to label the demographic form and audio recording. The interviews were recorded using a digital hand recorder, and when it was not in use by the examiner, it was kept in a locked cabinet.

Participants were notified that the interviews would be audio recorded and later transcribed. When the interview commenced, the participants were reminded that the questions were about the initial assessment feedback conference with the school psychologist. A definition of the initial assessment feedback conference was reviewed with the participant. The participants were reminded that they could stop the interview at any time and that they could decline responding to any questions that they did not feel comfortable answering. The participants were given the opportunity to ask additional questions of the researcher prior to the start of the interview, and those questions were addressed before the interview began.

The interview protocol consisted of four questions. The first question asked the participant to briefly describe his or her child. The second question asked about the parent’s experience when the child was being evaluated (in other words, the process that occurred prior to the feedback conference). The third question asked about the parent’s experience during the initial assessment feedback conference. For this question, specific follow- up probes were used. First, the researcher asked what the parent was thinking during the initial assessment feedback conference. Second, the researcher asked what the parent was feeling during the event. Last, the parent was asked if there was anything else that he or she would like to share regarding the experience that day. Open-ended follow - up probes were asked, as needed, to any questions.

At the end of each interview the participants were asked if they had any additional thoughts to share, comments, or questions they wanted to ask. Participants were then thanked for their participation and were asked to complete a demographic form (Appendix B). The demographic form was provided to the participant after the interview was conducted in order to limit bias by the researcher during the interview. Parents were provided with phone numbers for local parent rights' groups upon completion of the interview (Appendix D).

The researcher then transcribed the interviews. When the researcher transcribed the interviews, these were transferred from the digital recorder to the researcher's personal computer. The researcher used secure transcription software to have the interviews transcribed from audio recordings to text. When the interview was successfully transcribed, the audio recording was deleted. All interview files were password protected when stored on the researcher's computer.

After the interviews were transcribed they were read numerous times by the researcher, who took notes on the information. The information provided by the participants was coded for themes and categories to be used for future analysis. Additionally, the researcher wrote in a journal after every interview. The purpose of journaling was to ensure that any emotional reactions experienced by the researcher remained separate from the content of the interview. It was intended that participants would be recruited until saturation had occurred, or when the information being elicited from participants no longer provides further insight into the parent experiences (Strauss & Corbin, 1998). In this study, the researcher recruited participants until all recruitment efforts that could be utilized in convenience sampling were exhausted.

Data Analysis

A three-step coding process was used to code the data from the transcribed interviews. First, the open-coding stage began. In this stage, the researcher began to dissect data collected from interviews to examine those categories that emerged from the data. A category is described as a unit of information about an event, situation, or occurrence (Strauss & Corbin, 1990). A validation team was utilized to assist the researcher with this step by reviewing the transcripts and discussing the salient themes. This team consisted of five people, including the researcher; more specific information about the validation team will be discussed in subsequent sections.

Categories were broken down into subcategories (called properties) that allowed for a smaller set of themes to take precedent for exploration (Creswell, 2007). This process narrowed the information down to the main themes and ideas that were central to the study (Creswell, 2007). The researcher selected one category as the main phenomenon to analyze further. This central category was discussed often by the participants or is a particular concept that is of interest (Creswell, 2007). After the central category has been identified, the database was revisited to understand the categories that relate to this phenomenon.

The categories were interconnected in the second stage, called the axial coding phase, in order to provide further insight. During this phase, a visual model will be generated that identifies the core category relating the phenomenon of interest. This model allowed the researcher to explore the conditions that influence the phenomenon (causal conditions); interactions that result from the central phenomenon; the narrow and broad conditions that influence these interactions (called context and intervening conditions) and the outcome strategies (or consequences) of the phenomenon (Creswell, 2007). In the third phase, selective coding was used to tell a story that integrates the various categories of information obtained from parent interviews (Creswell, 2007). Upon completion of the three phases to data analysis a theory will emerge relating to this study.

Data Analysis and Interpretation

In this study, the data were analyzed and interpreted throughout the data collection process. The analysis and interpretation process began after the fourth interview was completed. Each interview transcript was read several times by the primary investigator. During the first read, the primary investigator sought to gather a sense of the information that was shared, and began to identify categories. As data were identified for categorization, the primary investigator began to code the data in order to organize the information. After the data were organized into categories and coded, topics that emerged were further analyzed for themes.

Additionally, a validation team was created to assist the primary researcher with reviewing transcripts. The validation team was utilized in order to further examine themes and reduce any bias held by the examiner. The validation team consisted of a parent of a child with a disability (who was also a school psychologist); a Psy.D. candidate in school psychology with qualitative research experience; a qualitative researcher who was also a school psychologist; and the third committee member of the dissertation committee (who is a parent, a school psychologist, and has conducted qualitative research). The panel reviewed and discussed transcripts in order to continue to discuss categories and themes.

CHAPTER 4

RESULTS

Findings

Discussion of findings. The research findings were divided into two sections, demographic findings and descriptive findings. The demographic section described responses generated by participants via completion of the demographic form. The descriptive section provides summaries of responses to questions asked about their child, the initial evaluation process, and the initial assessment feedback conference, including the thoughts and feelings felt by the parent during this conference. In addition to the questions that were asked, the parents expressed suggestions and recommendations from their experiences that can contribute to this research. A discussion of the categories that emerged from the parents' experiences was also included. Additionally, this section includes an analysis of how the various stories told by the parents related to their experience of going through the evaluation process with their child who has a disability. Each participant was assigned a pseudo-name that was used throughout the discussion to protect confidentiality.

Demographic findings. The participants in this study were 11 parents, each of whom has a child with a disability. Table 1 reports the descriptive findings of the participants.

Table 1

Pseudo-names of participants and factors relating to the child

Name	*Number of Kids*	*Number Kids/SPED*	*Age of child with Disability*	*Years since initial Evaluation*	*Child Still in SPED*
Susan	2	1	13.6	3	Yes
Holly	2	1	17.6	15	Yes
Lydia	3	1	20	12	No*
Marisa	1	1	12	8	Yes
Hayley	1	1	14	8	Yes
Pete	4	1	8	3	No
Donna	3	1	15	12	Yes
Patti	3	1	11	4	Yes
Victoria	2	2	17	12	Yes
Jill	3	1	12.6	8	No**
Colleen	3	1	16	10	Yes
Median			14	8	

Note. * Parent reported student is in college and is receiving services

**Student is enrolled in a private school for students with disabilities

Each parent reported the number of children in his or her family. Each parent had from one to four children. In one of the families, both of the children in that family receive special education services. Ten of the participants in this study had only one child with a disability in their families. The child with a disability ranged in age from 8-20, with a median age of 14. The participants indicated various amounts of time that had passed since their child's initial evaluation, ranging from 3 years to 17 years with a median of 8 years. Last, 8 of the participants indicated that his or her child continues to receive special education services. Of the three respondents who said their children no longer received special education services, one respondent indicated that his or her child is in college and receives some support services. Another of the respondents indicated that his or her child is in an approved public school for students with disabilities. The third respondent indicated that his or her child is enrolled in Catholic school.

Additional demographic information regarding relevant educational factors of the participants is reported in Table 2.

Table 2

Parent Characteristics as a Percentage of the Sample

Characteristic	*Percent of Responses (n=11)*
Educational Level Completed	
High School	18.2
Bachelor's Degree	27.3
Master's Degree	45.5
Doctoral Degree	9.0
Age of child when disability identified	
Birth-3	18.2
Age 3-5	36.4
Elementary School	36.4
Middle School	9
High School	-
School Psychologist contact before feedback	
Yes	73
No	18
Not Sure	9
School District Description	
Rural	9
Urban	36 *
Suburban	63.6*
Disability of Child	
Learning Disability	36.4
Intellectual Disability	9 **
Autism	63.6**
Other Health Impairment	9
Hearing Impairment	9 **
Emotional Disturbance	-
Traumatic Brain Injury	-
Visual Impairment	-
Multiple Disabilities	-

Note. *One participant identified her district as both urban and suburban

** One participant identified her child as having Autism, Intellectual Disability and Hearing Impairment.

In this study, 54.5% of participants hold at least a Master's degree. The majority of the participants' children were identified as having a disability in the schools from ages 3-5 (36.4%) and during the elementary school years (36.4%). None of the participants' children was identified in high school. The majority of the participants (73%) indicated they had contact with the school psychologist prior to the initial assessment feedback conference, and one participant could not recall speaking to the school psychologist prior to the assessment feedback conference. Additionally, the majority of the participants (63.6%) indicated that their children are involved in suburban school districts, with one parent describing their school district as both urban and suburban.

When asked to indicate the child's disability, the parent was provided with nine choices, which are taken from the possible disability categories in IDEA. In this study, the majority of the parents have children with Autism (63.6%). The second highest group was Learning Disability (36.4%). One parent indicated his child was identified as Other Health Impairment. Additionally, one parent indicated that her child has numerous disabilities, including Intellectual Disability, Autism, and Hearing Impairment. There were no participants involved in this study that had children with an Emotional Disturbance, Visual Impairment, Orthopedic Impairment, or Traumatic Brain Injury.

Descriptive Findings. The semi-structured interview began with one question that asked the parents to describe their child briefly. This assisted with understanding the child, including how the parent viewed the child. The information from this question was integral in understanding how the parent conceptualizes his or her child.

Parent description of their child. All of the parents who were interviewed were able to provide multiple details about each child, including strengths and interests of the child in addition to mentioning his or her disability. The responses to this question revealed the first theme that emerged from the data, which was how the parents viewed his or her child. In their descriptions, participants included many different aspects of their children, including: strengths, weaknesses, pre-existing medical concerns, descriptions of their personalities, and some mention of their children's disabilities. Most of the participants provided additional input about the child as a person, and most of the participants reported at least one area of strength they observe in their children. The significance of this information was that it demonstrates the lens with which the parent views their child. The parents in this study provided examples of the different aspects of their children- their strengths, who each one is as a person, their medical needs, *and* their disabilities.

Lydia stated,

> Um, she is an outgoing, um, good sense of humor, um she is resilient; she is persistent, she loves photography, she is dyslexic, and I love her. She has difficulty with auditory processing; she has difficulty with reading; she has difficulty with her short-term memory; she has trouble with receptive language

> um, so I guess, she has difficulty with sequencing and categorizing; so it's a pretty broad, um, affect in all of her learning; it's a pretty broad range disability.

Marisa shared,

> Um David is a fun kind fun loving kid; he’s very, he has a pleasant personality that most part endears him to other people. Um he’s a very smart kid; he’s very determined when he needs to be, borderline on stubborn. On the negative side, he has a trouble handling frustration when things don’t go as planned. Emotionally, he’s still probably even more, even though he’s almost 13 emotionally, he’s more like a nine year old; um intellectually he is pretty much on par as high or higher than his peers. He made gold honor roll twice so far this year. I would say he really enjoys… he loves Legos. He loves… he’s singing, I think, I think he’s getting a solo in chorus; he loves music, loves singing, has a good ear, and he will be testing for his black belt in karate.

Hayley reported,

> OK, he um, he is very much into sports at the moment. Um, he likes basketball, he plays on a rec league; um, he is extremely intelligent, um, probably (laughs) a little bit too much because he tends to think he knows the answers to everything (laughs). Um, he is, if I might say, he’s cute, um and um he’s just an all around great human being.

Pete indicated,

> James is a relatively normal, precocious eight-year-old boy, UH and he loved to play anything that is related to science or building anything at all with his hands; he's a super avid Lego guy, loves to run. I am won some awards this past year

> with cross-country team, and am at the same time he likes quiet activities, enjoys reading and that has to be forced into, that that will definitely get into that once you get him going, and he likes video games as well. Pete: Yeah, so he tends to, you know, sort of self-engage into whatever is interesting him at the moment; so once he does that, for instance if he's engaged in playing Legos and building something, it's very hard to pull him away from that. So there's lots of negotiations and lots of "O, but let me just finish this"; you know I haven't done that yet; just one more thing, you know that once you can finally pull him away from something like that, and get a book in his hands and get him reading a book, he will then become equally as engaged in that as he was in the Legos will.

Colleen's description included specific medical information, when she stated,

> When Jill was born she um was in the NICU for 4 ½ days on full oxygen because she acquired pneumonia at 2 hours old. So she could actually have a much more significant disability than she does have, um so that's where the disability came from, that she was oxygen deprived for a short period of time and ya know, experienced brain damage from it.

Protection. Many of the parents presented with a desire to protect their children. This was evidenced either through direct statements or indirect statements that parents made when describing the child. A parent's desire to protect his or her child became related to the schema parents held of the child. The view the parent had for their child's disability included a need to protect the child, either through downplaying the child's issues or having concerns about the future.

Holly explained,

> First of all I'm black and I was 18 years old and also knew the statistics for young black males in the city where I'm at that time in Harrisburg; their life outcome wasn't very promising… and the more I learned about Autism, the more those fears became more and more like, okay, how do I take care of this child so he doesn't get hurt? And the more I thought about those concerns, about how will he not get hurt. He is nonverbal and walking around, babbling with some of the needs children with Autism have. How was I going to be able protect this child in society?

As Holly continued to tell her story, she described how her desire to protect her son progressed into thoughts of wondering how he was going to take care of himself when she was no longer around. She described this idea through an interaction she had with her caseworker.

Holly explained,

> They had, and then all these flags like went off in their heads that I was suicidal and I was going to kill my child and I was then gonna kill myself, and that was totally not what I was saying, but it got me help; it got me some waivers; they said you are too stressed; you need some help. I was like, okay, we'll take the help. Really I'm not suicidal or anything and I was worried about his future and leaving him one day. I had to mention that because if I hadn't had that reality, I don't think I would've had done anything to prepare him for what life was good to be like without me.

Marisa and Donna reported a desire to protect their children by downplaying their children's behavioral needs.

Marisa explained,

> Sometimes… often times it's involving um schoolwork; for example, if he gets a problem wrong and he has to repeat something, or if he doesn't want to do this; like today he shoved the chair out. Sometimes, well one thing we are working on is he grabbed my hand and bit my hand, and he does that sometimes. In the past it involved um banging his fists, kicking the floor, kicking the chair. When he was in elementary school there were a few…incidental situations where he, he ended up kicking someone else and when I say incidental, he kicked due to frustration and someone happened to be in the way. He wasn't trying to, he wasn't trying to aim for a person; he was just mad, so his hand went out and like and like another kid's leg might have got into a way. So got into trouble once or twice, but this was in elementary school. But, ya know, he's not a bully though; he doesn't go around bullying other kids.

Hayley reported,

> I knew that he didn't interact in the same way as other kids, um, but I, ya know, and of course, kind of looking back, I don't know if I was being sort of, ya know. Was it a coping skill? I guess that um, ya know, I really framed it as a way that "Well he's just smarter than the other kids so he's not going to want to do the same things that we do." Um and that's just how I sort of, I guess made it ok in my head.

The evaluation process. The parents were then asked to describe their experiences during the evaluation process. Three notions arose from this discussion. First, most of the parents reported that they knew something was going on with their children and they suspected something was wrong. This seemed to be related to how parents view their children. Because parents view all the details about their children, they are aware of the deficiencies and differences that may exist. Each parent's connection to his or her child makes it difficult to ignore the problems. Some parents had friends and family members who made conclusions about what the problem was with the children, and the parents would acknowledge something was wrong but it was not what the family was suggesting. This highlighted the fact of how well the parents know their children, and although they may not have been able to name what was going on, they knew there was a problem. Holly best summarized this notion when she stated:

> I believe there really isn't parent who doesn't know in their heart that something is wrong.

Colleen reported,

> And so I always kinda had it in the back of my mind and then, then the oxygen thing, you know I always just had on in the back of my mind that there was some, there were some deficits somewhere.

Patti indicated,

> At school they had approached us about a reading issue and put her into, um, what they called, Reading Recovery program. Um, but they didn't, they didn't identify any math issue until later when we, um, brought it up to the to the teacher; then she started to notice there was a math issue.

Further, Hayley reported,

> And, um, it was the first time anybody actually put a name on it because I had only suspected that there was something unusual with my child, but I couldn't, like, I couldn't identify what it was, and to be honest, I thought that it was just, he was extremely smart and that he was just sort of thinking past the typical behaviors for that age.

Lydia indicated:

> I know in kindergarten she couldn't do, um, sound letter combinations, um, and then, at that time I don't even know if I knew exactly how significant that was, but she couldn't hear two syllables, she couldn't hear a /j/; she would learn her math facts but then she couldn't retain them, I mean, and so, you know, you thought it was something wrong with the teacher or whatever; so I worked with her over the summer and she had them all down with these games and all that. But then you go over them with her month later and it was like she, you would think she never learned them, so there was trouble um retaining memorization. Um, she would have trouble with, um, when he had to talk about seasons of the year and, um, you would ask her what one was a fruit or a vegetable and things like that, um. And she would have troubles with categorization and things. She could do the math facts and she could get them; she would have trouble retaining them. Um, word problems were, you just, you know, impossible.

Holly shared that she knew something was not right, but she received misleading feedback from her family and friends.

Holly elaborated,

> There was a lot of people telling me they thought he was deaf and they kept saying, "He's deaf." And I was, like, no way he's not – and I thought they were trying to put all these labels him just because he wouldn't do what they want. So then the second pediatrician says, "Well, we need to try to figure some things and rule some things, just between me and you." And she was and I was like, okay. So he first got a speech test and, and is well with, with that the hearing test, he passed with flying colors and that for me that was, was a huge relief for me. I was, like, I kept trying to tell them that my son is not deaf.

Asking for the evaluation. As each parent's schema of his or her child began to include information that indicated something was wrong, the parents began to look for answers and seek help. The second theme that arose from this question about their experiences during the evaluation process was that the parents were aware that something was not right and, therefore, they advocated for the evaluation by talking to teachers or formally requesting it.

Colleen explained,

> I picked up on it. I pursued it. I was the one who initiated the concern, I guess you would say, for lack of a better word.

Colleen went on to describe how she made numerous attempts to initiate an evaluation over the span of a few years.

Colleen mentioned,

> I was very open, um, from kindergarten up until second grade; each year saying, ya know, let me know; let me know; let me know. I'm not going to be one of these parents who wasn't going to be ready to hear "not my kid" kind of thing.

Susan also discussed making multiple attempts to start an evaluation.

Susan reported,

> Um, I had started pushing for an evaluation when he was in fourth grade and still wasn't able to copy from the board, or and was still reversing letters. And that was the first time we met with the school psychologist at the school, and she told me that it was completely normal for him to not be able to copy from the board and reverse letters, and that he would just learn cursive and that everything would be fine. In fifth-grade we pushed for it again and I formally requested it. We met multiple times a year.

Lydia indicated,

> Um, so she was screened at the end of first grade for auditory processing problems and they said, "yes", so I pushed up a full-scale evaluation, which was how we got to the psychologist. So, um, we were just trying to understand why school was hard for her and what the, what the other implications were. We found out what the rules were and you would call and follow up, and ask some things and you hand-delivered things, and you had get them stamped to make sure things had been received. It was very proactive, which I'm not always, but, um, you know, but I would say you had to, you know, be on top of it, as opposed to just kind of hoping that everything would come together.

Patti further reported,

> Um, well, it was, I felt like it was something that we needed to keep pursuing, um, and, it was when she was in first grade, we got testing done.

Elusiveness of the evaluation process. Third, several parents commented on the elusiveness of the evaluation process. The parents' need for help was what led them to requesting an evaluation. However, many parents discussed poor understanding of the evaluation process. It was clear that the evaluation process was a mystery for many of the parents, but it was pursued as a mode to get the parents help. This theme of poor understanding of the evaluation process persisted, regardless of how the evaluation was conducted. The parents viewed the evaluation or the evaluation occurred at the child's school when the parent was not around. Regardless of how the evaluation was carried out, the central theme of this study emerged during responses to this question. There is a disconnection between the parent and the evaluation process that occurs in schools. Parents do not understand the relevance of what is going on, and experience confusion about how the evaluations will assist with their primary concern, which is how to help their children.

Hayley explained,

> I guess the best way to say it was that it was bit of a mystery to me because, um, I knew he was "being evaluated", but I didn't really know what that was going to entail, um, because that's the first time anybody had ever evaluated my son, so, I didn't really know what to expect. So, um, they told me they were going to do it and they had me sign the paper and they did it at his school in his school environment. So it wasn't like I was there and I didn't have a meeting with the

> psychologist prior to, so it was still sort of felt like they were going to do something with him, but I don't know what it is or what it is going to mean kind of thing**.**

Jill stated,

> Um, the developmental pediatrician had done some further evaluation but no straight testing; I didn't really know what testing involved. I thought at that time the psychologist just came out to observe him and then say, "He has Autism." I don't want to be… you know, with um, blinders on here but, she was, this was NOT enough; this was not an evaluation; they didn't test him; they didn't DO anything; they just looked through a window for 20 minutes. That's just, that's not TESTING. She walked out of the observation room and said, "He's got Autism; I'll talk to you about it later". She said she would talk to me later when we had our meeting.

Holly described,

> Because, like I was not focused on anything y'all are saying right now; I am looking at him thinking about him and what's happening, and how I was reacting to it. And I was more focused on him than anything they were saying at that meeting because I was his voice and they say there can't be other mothers like me, but that's the best way I can put it; that those two parts should not go hand in hand.

Donna further reported,

> Oh my goodness, just time-consuming things that seemed almost…that seemed almost ridiculous (laughs). Like why do we need to see if he can stack blocks? I

> mean it all makes sense now; he never stacked anything; he never played anything; he just sort of lined everything up.

Finally, Pete described his son's assessment in the following words,

> They had a whole host of people interacting with him over the course of a couple of hours, you know, different types of evaluators; one of them was a psychologist and they ended up doing the normal five year old, like, hey, stack these blocks up as tall as you can. You know the fine motor skill, up to the simple playing games. One lady I remember did a scavenger hunt with him where she would give him more and more complex directions. You know, two steps to three steps to four steps and so on, and you know he definitely did not do as well as we thought he would. Do you know, I don't know if it was all the transitions between activities or what it was, but he definitely had trouble. The lady actually who gave him the more difficult instructions, well, she had to she had to repeat the directions several times and then even make them simpler for him to be able to do it.

Initial evaluation feedback conference. The parents were then asked to describe their child's initial assessment feedback conference during which they received the results from the school psychologist. Several themes emerged from this question. Primarily, the parents reported how the language used to explain the evaluation results was problematic. The jargon used to explain results and the lack of context between the scores and day-to-day life made it difficult for the parents to understand how to help their child. Additionally, there was no definitive summary presented in most of the situations, which resulted in the parents having more questions about their child. In general, the parents needed to understand what was going on with their children and how they could help them, which were the reasons why the parent pursued an evaluation in the first place. The interviews revealed that, ultimately, the evaluation did not meet the parents' needs.

Use of jargon. Overwhelmingly, most of the parents made several references to the jargon used when explaining the results. This included the language itself, the scores, and how little the results related to real life. The use of jargon emerged as a theme that widened the gap between the parent and the evaluation process.

Holly provided extensive detail about this aspect of her experience, stating that, she continued to report upon her experience with jargon and how it affects her.

Holly elaborated,

> There have been times where I just wanted to get up and walk away, like when you are ready to make this in a language I would understand I will come back to the table. Um, there are times where I cried a lot; I cried a lot because I mean the progression of where they should be, and when they start using numbers and percentiles. I don't want you to use percentiles, just tell me the big picture; don't use these long words and numbers, um because they are doing what I have done all my life (starts to cry). I don't compare him to anyone else and you compare him to a bunch of people, ya know, there are a lot of parents who don't want any label on their child.

When describing the language, Colleen stated,

> Um, I didn't need to at the meeting because, I mean, the other people on the team obviously knew, ya know, understand that language and everything the way I explained it to her father. I would basically describe; I would give analogies

> between things that her brothers could do at certain ages. Um, because you do have to do quite a bit of deciphering and translating.

Hayley explained,

> That part that says “OK, this is what this is” and “This is what average is” and “This is what above average is”, and “Below average is”, um I didn’t have that, that I can remember at least; it wasn’t called out to me, um, saying, OK, that this is a test and this is what the test said; it was sort of like I had this assessment, um, and this is what I concluded from it, but I didn’t remember something more analytical, I guess, and for someone like me that was important, so um, and so I thought it was a little subjective, I guess I was trying to say.. The testing, the testing was subjective; I felt like it was a little like subjective; it was like based on observations and things like that which were, which were important but I needed something that said, ya know A+B=C. So I felt like my personal experience I didn’t get that, but I feel like maybe someone else would have gotten that.

Victoria reported,

> I mean for example, um, in the, in the middle of the elementary years, so my sons both have Autism and they have commensurate, ya know, impairment in social ability, and engagement or connectedness, and there was never any interest in evaluating that area, like, um, ya know, they would evaluate their speech and they’d say something like, “O they are beneath the 1st percentile for expressive speech”, and I would think, well, thank you for slapping us across the face with some useless information. Like, what does that, what information does that give us that allows us to write IEP goals that would make any sense? It gives us no

> information that would allow us to write IEP goals. It just, ya know, and I don't think they did it for spite. I think they only know how to give certain tests and they don't know how to do others.

Context. In addition to the clinical jargon being problematic for parents, the information presented was not relevant for many of the parents. Many parents reported the fact that they did not receive real life examples or any context to understand what the scores meant, and this perpetuated a lot of feelings of confusion for parents.

Pete explained,

> Ya, we got kind of, from the psychologist, "Well, sometimes for fidgety children, like your son, we have this weighted vest that they wear, to make them aware of their physicality and help them to stop moving." And, ya know, and I had never seen one of these weighted vests, but the, um sort of visual, I got of it right away was sort of , ya know, fisherman, that orange fisherman's vest with lots of pockets (laughs) and I'm thinking, "MY KID IS NOT WEARING THAT IN CLASS!" (laughs).

In Lydia's interview, the lack of context began to challenge the schema she had for her child. As with most of the parents, Lydia knew something was wrong with the way her child was learning to read; the lack of context in the report findings caused her to forget her child's strengths.

Lydia reported,

> I think that's the thing that really bothered me about the whole thing the most, looking back on it; they don't give you enough information in context, um, and and you don't know what to do with all the information you have, you know, that

> you got, and you didn't really; it's not concrete when you are done. I think we were kind of lost. I think just because they give you stuff, but they don't give you the context of which it is, you didn't feel like it gave you a lot of answers; you felt like it gave you some more flags. I had no, I had no understanding. I thought she was broken and you know, difficulties and her struggles created a lot of stress for me and for her and for our home life. Um, I don't, I don't, I mean I know that there are some things on strengths, but I don't think, I think they could spend a little bit more time on that and how those strengths can play out, and I do think they should give you more practical information and ways to connect and, ya know, ways to put some of this information into context and what that's going to look like.

Poor summary. The lack of context and lack of understanding of the evaluation findings connected to a theme of poor summation of the information. Many of the parents did not receive a conclusive answer, which exacerbated feelings of confusion and furthered the difference between the parent and the evaluation process.

Jill further reported,

> Do you give the parent a report? The parents who read it are going to sit down and discuss it and you're going to sit there, and let's discuss this report, thinking they understand the report and the parent is probably too embarrassed to say they don't understand the report. That sort of thing is huge so parents, they're going to read that report and they really don't; all the words are going over their head; that's really for lawyers and things like that, um, it's really just trying to give them, like if I am going to give a diagnosis to your child, I want them to explain

> how I am coming up with that diagnosis and its not jut because he's in the 25th percentile. You're seeing the things he's actually doing at home; here is what I have observed him doing and here is what a typical kid would do. That's huge.

Patti reported,

> The one thing that stands out for me and it goes along with what I said earlier was that I asked what this is, and they specifically told me that they do not need to give the diagnosis; that they do not program for diagnosis. They program for learning profiles. I think that, and I don't know; I don't know a lot about the intricacies of working in the school district, um, but I think that they, the school psychologist and everyone in the school can do more than just hand you the little blue pamphlet that says, "Here's your safeguards, your procedural safeguards." They could say, for our purposes, we only need to provide you with this information; if you want more additional information you need to go find a private evaluation.

Marisa described,

> I wish there was a nice executive summary (laughs) or just like, um, well I think they do have summaries, but a lot of them are written in jargon too. Um, on a scale of 1-10 he's doing BOOM and that's where he's at. Sometimes I wish it could be simplified a little bit. It's just, it doesn't help parents; that's how therapists think, but it's not how parents think. Parents think, "Is he going to do well at school; will he get kicked out; will he get beaten up?" Ya know, that's how parents think. Ya know it's like, ok, is he gonna flunk; is he gonna get beat up; is he gonna kill himself; is he gonna get expelled? No? Then ok! (laughs)

Parent needs not met by evaluation. Many of the parents reported that the reasons they wanted the child referred, or what they were seeking to obtain from the evaluation, was not met. As mentioned previously, parents sought out this evaluation process in order to receive help for their children. Their needs were ultimately not met, due to a lack of explanation about the evaluation process, the use of jargon throughout the evaluation process, and lack of context for what the evaluation data means for their children. Another theme that emerged was that the evaluation teams did not know the referral question, nor did they know the reasons why the parents wanted the evaluation in the first place.

Susan explained,

> Well, during the first one, it was very, that was when she identified him as gifted and it was extremely negative. I was very focused on getting him support, and they were, like, she was very focused on how. “Well you have to look at the fact that he is bright.” I wasn't really concerned about him being bright; I was not really concerned about gifted programming, like I really couldn't have cared that he had been gifted, and she was so focused on that that she didn't pay attention to anything we said.

Holly further indicated,

> Someone made a comment about how with the diagnosis you can get money, and I wanted to scream at them because some people just want to know what is wrong with their children. I can speak for myself because he has never got a dime of SSI, but if you are in a position that you’re in and that’s where your mind set is at and that parent

> doesn't want that diagnosis, when you give a diagnosis, don't just think about the child but think about the parent too.

Victoria shared the following experience, regarding an evaluation she had requested on her son, Daniel. Daniel was initially identified as having Autism and Victoria requested a re-evaluation later in his life to determine if he also had an Intellectual Disability (which he does).

When describing this evaluation, Victoria shared the following details,

> If parents request IQ testing for the purpose of accessing state services, it means they know that their kid is probably retarded, so don't… pussy foot around it. I had written, like I had written it almost exactly in those words; I had requested IQ testing for the purposes of accessing state services. Does that sound like I'm really afraid that they are going to find out that my kids are retarded?! No, it doesn't, I don't think! But when the guy who evaluated them was talking about it, he made it sound like it was such a difficult thing to talk about, so he was all full of all this, ya know, consolation and sympathy, and I thought it was very misplaced. I mean probably it's true for people who have no idea or they're, ya know, they're gonna be upset or freaked out about it, but I guess it kind of bothered me that he was treating it like its some terrible shame and we were pretty much like, GET IT ON THE PAPER MAN, because we are trying to get our kids protection (laughs) And also, some MONEY for them! Because we know about the ID waivers; in this case I wanted the psychologist to recognize that if I requested the testing I was probably prepared for the results of it and not give me like this "Oh I gave them every chance to be NOT retarded"; that's basically the speech he was giving us.

Concerns about the future. After hearing these results, the parents revealed a variety of concerns about the future, including lack of certainty regarding long term prognosis, not understanding the next steps, and difficulties understanding how to proceed. These concerns about the future emerged as a result of parents not receiving answers that they could make sense of about their children's needs; this was coupled with the fact that their referral questions were still not answered.

Lydia articulated,

> That's what I think the bottom line is, is what, ya know, I mean, for the short term or the long term. What does it mean, and, ya know, that's probably what comes out the most; what do you do with this information, um, is a big question um, and I don't think you get kind of that either.

Susan explained,

> And then we left and I had to re-explain everything to my husband that I didn't agree with; so it was like, we really were just like "Okay, will public middle school be the right option for us? Should we be looking into private school? Should we be cyber-schooling him? I mean, what should we do?"

Marisa reported,

> Don't say the kid will never do this or the kid will never do that, or you will have to adjust your expectations. That pisses me off

Patti described,

> Um, but um, I well, this I don't want to say turned around but she could, ya know, like this could all still be just a catch up process and then, she'll be in a regular classroom, um, you know, for math because that was all that was being pulled out

> for at first. Patti: And then reading, the following year, ya know. They never gave me the impression um; they never closed the loop on the conversation, you know, and I know that you can't; you can't say where a child is going to be.

Sense of hope. At this point in the process, parents were left with insufficient information to answer their initial referral questions and were still wondering how to help their children. Additionally, the parents received new information about their children that they could not fully grasp, but knew it pointed to information that something was wrong with their children. The theme of how the evaluation feedback was related to a parent's sense of hope for their child emerged. Some parents reported being hopeful but some parents left feeling hopeless that things would improve for their particular child. Susan explained,

> Yes, I think it got worse, I think when they finally agreed to evaluate and that was such a long road getting there, that when they finally agreed, I at least had hope like, "Okay he's going to get the supports", because he's was moving into middle school and into a teenager and I was very frustrated that I was doing all the instruction and education at home, and I was doing all the accommodations, and it was a really frustrating time to be his mother and trying to teach, and it was nonstop battles and I was tired of that. Susan: And just the feeling of hopelessness because she just wasn't listening. I think just because I was angry, I know that I brought a lot of "Okay let's just get this over with, I just want to get out of here. You're not listening to me anyway, so like, why are you wasting my time, like let's just move on."

Pete described,

> And, ya know, we were really hopeful that not only would all of this help James, but it would also sort of help the whole classroom environment, because you know, we were sort of concerned about, ya know. I mean he is still in this school; ya know, three years later now, and we were hoping it would sort of have an impact on his socialization and his friend-making, and then none of the accommodations that were put in place were really used to help in that way.

Lydia explained,

> Um, but you're talking about getting tested and I think that it's an ongoing struggle to keep remembering that this person with a learning disability, she is not defined by her learning disability. That's just one piece of who she is, but that's a fight and when you are going to these psychologists and they are putting all these things on you, and you see this special ed., and you know all of these things that aren't right, and you don't, maybe you can't, envision there can be a bright future afterwards.

Lydia also discussed how it was important not only for herself but also for her daughter to have a sense of hope as well.

Lydia further explained,

> What you are going to do to help them and to give them a sense of, you know, a sense of hope and how things can change? I think that should be done at an early level, um, that it should be done for the parents as well the child.

Holly discussed how she realized her hopes for her son changed after his evaluation.

Holly elaborated,

> It's part of that shock. I don't think I got shocked until later when I started reading about it, but knowing what I know now, I probably would have been in shock; it can be a death sentence. Ya know when you are pregnant you think, I just want them to have 10 fingers and be healthy, but be careful what you are wishing for. My hopes for my son haven't died, but they had to be rearranged a little bit, but from what I started out with. I just had to rework and rework; my hopes and dreams for what I wanted for him have just been reworked.

Donna described,

> SO I guess, I kind of felt like, not really lost, I guess sad (starts to choke up) Like ya know, this is, this is the rest of my life (sniffs), but ya know, it turned out, it turned out quite differently, but (sniffs) I remember feeling like, ya know… almost despair (cries). It's almost like, this is going to be like, a painstaking life (sniffs and laughs) I know. I have no idea what it, what it would have been like if I had known, ya know. I'm having a hard time wording it, but like if I knew what it would be like now, I have, I have no idea what that would have been like, do you know what I mean?

Pre-existing medical diagnosis. The parent's schema of their child included many different aspects of the child as a whole person. As described previously, many of the parents reported significant medical history for their children and as a result, many had received some form of a diagnosis before the school evaluation. This seemed to influence how the parents received the results of the school evaluation.

Marisa reported,

> They didn’t tell us too much; they didn’t tell us a whole lot of what we didn’t already know, in terms of, yea, I mean the initial autism diagnosis was done by the developmental pediatrician. I mean it was, ya know, by that point we had, ya know, worked through most of the feelings that come with the Autism diagnosis by then, and we had worked, I think both of us worked through a lot of that. Ya know it wasn’t very emotional; it was more practical at that point. Ya know, my, it might have been harder for us if the first time the Autism thing was brought up was during the school evaluation; there might have been more emotion involved.

Donna described,

> Um, I was trying to think, I mean the evaluation by the doctor was stressful and this one wasn’t because I already had the diagnosis. I guess, it was so very, ya know, shocking at the doctor’s office, that I don’t… it was still so sad when we got the school evaluation, just, ya know, as I was realizing he needed to go into Autistic Support, but, um, it still wasn’t as shocking as the doctor’s evaluation was to me. I mean that, that’s probably the best way I can describe it.

How to help. All of the parents reported they wanted to get ideas and information about how they should help their children. Seeking help for their children was reported to be the primary reason why the parents pursued the evaluation process. Sadly, most of the parents did not achieve this result. Parents were left with more questions about their children’s needs after the evaluation process concluded, and thus their need for help and desire to know how to help their children increased. The lack of help emerged from the poor explanation of evaluation results, including lack of a conclusive diagnosis, and this lack of help persisted through a need for more information to answer the additional questions that emerged. Along those lines, some of the parents expressed the fact that the process ended with an apparent lack of desire to help their children, both in learning but also in coping with the emotional side of having a disability. In some instances, parents also discussed the fact that the recommendations from the evaluation did not make sense. Jill explained,

> If the psychologist had taken the time to explain and, ya know say, "Hey here's some things you should read up on; here's something about Autism to read up on." That I think would have saved a whole lot.

Victoria explained the following from her experience, regarding how she sensed a lack of interest about how to help her child.

Victoria explains,

> Ya know my understanding is from a parent's perspective that, we're here to talk about my kid; we're here to try to figure out what's going to help my kid make progress, my kid learn and that never, I mean I always feel like, me and maybe a teacher, um, if I'm lucky, there is an interested teacher that, that's as good as that gets.

Patti reported,

> One thing I asked from the very beginning was, "What is this" You know, what can I actually look up that will explain to me what this actually is? And the only thing I was ever able to get from them was weak executive functioning, weak working memory, and that was it. Ya know I mean, I asked that questions over

> and over again, and was never able to get a real diagnosis that actually would be helpful; no one told me what this really was.

Hayley described,

> Ya know I have to be honest, I don’t know and I and I can’t really say to this moment that anybody ever said to me that this is an Autism Spectrum Disorder. Um, and, it was sort I got to the end of it and it said that word again, Asperger’s’. And there were things in there that sort of talked about social deficits and so when she and I met and sort of talked about it, I remember feeling like I still don’t know what to do about the fact that he, that he has this social deficit.

Lydia further explained,

> It’s not like anyone gave you a handout or gave you resources or gave you suggestions of people you could talk to, to, um, to confer about it with. I think people should have handouts I mean, ya know, I, people if you are going to tell people they have a problem with something, it would be nice for them to give you more information about on what it means, um, you know, as opposed to giving you these tasks and dry things and “They’re weak in this and they’re weak in that”. And I also think that they could refer you to resources. I mean there is certainly, I know now, I know there's a lot of resources on websites and in books for your kids to understand because my daughter knew she was struggling, and you know, there were times where she would become completely frustrated with it all. I mean for her to hear an adult talk about things and be dyslexic or read a book about someone who has learning problems, um, whether with anything from

> that Mr. Falker book, Patricia Polacco or anybody else. I think that those are huge to help with the emotional aspect rather than just this dry, ya know, testing thing.

She continued to highlight how the inability to receive help from the school evaluation made it difficult for her to help her daughter cope with her disability.

Lydia continued to describe,

> I think that they don't look at that part of how to help you help your child, um, as well as how can you put it into context, but how do you help your child put it into context?…but that for me was a huge piece because the kids are frustrated; they know they're not learning like other people and they don't have any information and the psychologist did not touch that ANYWHERE, about how to help my daughter understand what was going on with her, and so she, the psychologist, didn't help ME understand it. I couldn't help my DAUGHTER understand it. I didn't receive any suggestions for how I can help my daughter to cope with this and help her understand it and help her understand what was going on with herself. So, I think those are some pretty huge pieces, just that that frustration of dealing with your child when you still don't have more information and you watch them. I mean, that's, the part of, that's the downside to all of this; I mean you're told some things about it, but you are never really told how it's going to work or how it's going to work out, ya know, and you still see your child struggling and getting frustrated, um, and that's something that kind of went on for a long time.

Holly discussed,

> But then for me I just wanted to know what was wrong and then it led to the opening of, like what did we need to do for them, taking him to the specialists in wanting children to do for him and saying, "I just I need you to help me", and in my case I was looking for help specifically with how he was not communicating

Pete reported,

> There were definitely, ya know the weighted vest thing, ya know I was confused by that suggestion because it didn't seem like it, ya know, that it didn't really fit. Um, as a classroom teacher, my wife is a classroom teacher and neither one of us has ever had a kid in our classroom wear a weighted vest. So ya know, we were thinking, or I was thinking, ya know, this seems… odd. (laughs) If putting a bunch of weights on a kid with ADD, ya know, for lack of a better term, fixes the problem, then ya know, I've been in classrooms where (laugh) I should have had DOZENS of weighted vests in my closet! (laughs)

Feelings. Specific probes were used to ask the participants to describe their feelings and thoughts during the assessment feedback conference. Overall, most of the participants provided examples to explain their thoughts and feelings, as opposed to articulating specific thoughts and feelings. Additionally, the participants expressed a variety of feelings that appeared to be related to their specific experiences. The parents expressed feelings of relief, anger, frustration, shock, confusion, disbelief, sadness, overwhelmed, upset, validation, excitement, deception, and a sense of isolation upon hearing the evaluation results. In many cases, the parents recalled having multiple feelings, some of these all at the same time.

Holly explained,

> When they said he was “Autistic”, I cried tears of joy. That’s because my son wasn’t a bully; I had a label; I had somewhere to work from; I didn’t know what was going on; that explained why he wasn’t progressing with other kids.. So for me it was a sense of relief; he’s not a bully; he’s not deaf; there’s something wrong.

Holly further explained,

> They just make you feel really inadequate about your child because I remember this one time I did cry. I know my child is not where you think he should be, but I am doing the best I can, so it was like make a person feel ok, because I didn’t go to school and I didn’t get a degree in that you are making me feel like I am not able to care for this child.

In Hayley’s response, she also expressed some relief along with feelings of being scared.

Hayley reported,

> Um, and um, it was, it was, it was sort of a I guess a relief in a way because it had a name, like things that I felt had a name, but at the same time it was a little scary because I didn’t know the bad things.

Feelings of anger were expressed, in addition to feelings of being stunned and frustrated in some of the other participants.

Jill reported,

> I was stunned; I was just stunned and I was furious and I remember the anger came later because I was more stunned. Um, and it just felt very, I felt very talked down to and afterwards, ya know, I just I questioned a lot.

Susan reported,

> So I left completely frustrated and started the next year completely frustrated because it was like the same thing all over again… I just felt completely frustrated and disgusted and let down and when I had to go into the next year then to go into the next year at middle school, and at the very first meeting I get told by the principal that “Well, we don't do SDIs”, like I was ready to cry; I was so frustrated, like I thought here we go; it’s going to start all over again….. They were rigid and not flexible. I think disbelief also.

Victoria also reported feelings of weariness, along with her frustration.

Victoria shared,

> I didn’t know whose benefit all of this pussy footing around was for; it didn’t make sense to me. So but I just did what I usually do ,which is keep my mouth shut because I don’t want to spend any more time at these meetings than necessary…we’re just confused, like why would you give this test and why wouldn’t you give, I mean he didn’t fucking give a standardized test; it was like… I guess he just didn’t get the message; maybe he’s not the smartest guy on earth, he didn’t get the message, I don’t know, just weariness.

Confusion was indicated in both Hayley and Lydia’s responses.

Hayley shared,

> Um, I, I think I think that I really um, the most that I felt was sort of confused and a bit, um, like I said, there was a level of relief but there was also some confusion about what does that mean for the future kind of thing.

Lydia described a variety of feelings in her response:

> I would, you know, I think you are just overwhelmingly sad. Confused (laughs) Ya, you know, and frustrated. I would say all of those are good descriptions of how I felt. And so you have this sense of isolation in terms and then you also think that your child is more unique. You feel frustrated and concerned and overwhelmed. Because you don't understand any of it.

Donna also expressed feelings about being overwhelmed in regard to what she needed to do next.

Donna explained,

> I just really remember feeling like… ya know, I just, just wanted someone to snap their fingers and fix things, so I wouldn't have to do it.

Patti stated,

> Um, well it was a long time ago, but um I remember being upset that this was happening to my daughter, although ya know my daughter and that my daughter had to experience this, ya know. Pretty much I was concerned about how much should I be doing about this.

Colleen reported,

> Just that I was excited that it was identified. And that um, ya know that we would just, ya know, keep moving, moving forward, really. Was it just that I wasn't thinking or seeing something that wasn't really there. Just confirmation that I pretty much knew what was coming anyways and uh, ya know, just I, ya know I feel that um, I'm grateful that I saw a need for, ya know, an intervention or whatever.

Finally, Patti shared an experience of feeling deceived by the school psychologist.

Patti mentioned,

> Do you think maybe they knew she had a nonverbal learning disability and they just didn't tell me? I believe that she knew and she chose not to tell me.

Thoughts. Similar to the feelings, a variety of thoughts were expressed by each parent. Many of the parents expressed multiple thoughts that they had experienced at the same time. And, as discussed previously, many parents expressed having more questions after the evaluation process, so many of the thoughts recounted by the parents were the questions that were present in their minds after the evaluation concluded. Most of the questions were related to the idea about what to do next, and the previously mentioned theme of being concerned about the future.

Jill explained,

> And I remember talking to the speech therapist and saying what am I going to do? Do I change everything that I am doing? What do I do?

Patti reported,

> How were we going to help her, um; how much should I really be concerned about this. Is it something that she's going to play catch up with and then be able to be, um, not have special ed. support**?**

Susan reported,

> I mean, I just kept thinking "I don't know. What am I going to do?" and thought "What in the world am I going to do next?"

Hayley and Lydia both recalled thoughts of "What does this all mean"?

Lydia described,

> What does it all mean?! I mean, um, you think your kid is the only one, with this problem.

Similarly, Hayley reported,

> Um, I mean I guess I was thinking what does this mean? Or my son's lives, like how is this going to, ya know, impact his life? I do remember her making reference in the evaluation to , it was like famous people that had had it, ya know, Bill Gates, Einstein, and all, so, I felt like if it's, if it's a problem, (laugh) with all these famous people having it? There's, ya know, a disconnect there (laughs) Um, I, I guess I mean, just, the one thing I thought that was, do I need to talk to someone else about it? Do I need to? Do I need to hear from someone else? Like do I need to go to a doctor, another person, another, ya know?

Impressions of the school psychologist. In the parent's recollections of the evaluation process, the parents recalled specific details about the school staff involved, particularly the school psychologist. Many of the respondents reported their reactions and impressions regarding the school psychologist. What emerged in their responses was that the parents recalled specific details about the school psychologist who conducted the evaluation. The parents recollections ranged from recalling personal details about the school psychologist to how focused the school psychologist was on their children. Also, many parents reported that they believed the school psychologist wanted to help, but that the school psychologist was limited in what ideas were allowed to present to parents. The parents reported that it seemed the school psychologist was not speaking openly for fear he or she would recommend something that the district would frown upon, presumably due to the cost of the recommendation on the district. In one case, Patti, reported that the school psychologist was representing the school district more than the needs of her daughter.

Marisa reported,

> A couple of them I was like, OK who is evaluating you? Some of them were pretty goofy.

Victoria explained,

> During the meeting, she did seem kind of child centered and I remember her saying something… maybe she just laughed at something I had said. I think I had made a joke, ya know they were kind of the special ed. supervisor was giving me a little bit of shit for moving to Pennsylvania like, umm, ya know "O well you're just shopping around for the best district" (laughs) or something like that…I said something like "Ya know if things were much better on Mars I would try to go there; I have two special needs kids!" Like of course I'm going to try them the best education I can find them. I just made kind of a joke about whatever she was saying and I remember the psychologist laughed and I remember her looking at the psychologist with the most nasty glare, like you're not supposed to, ya know, reward this kind of behavior (laughs). But, um, and you know it was kind of funny because I noticed immediately this kind of tension between the administrator special ed. supervisor who is supposed to make decisions about placement and the psychologist who was kind of understanding about, ya know, Daniel having a very unique profile. And, the administrator who just seemed like

> she just wanted to slot him into a spot without much… concern about what kind of individual attention he'd need.

Jill specifically mentioned how she noticed staff members needed to go “off the record” in order to truly express their thoughts and recommendations about her child.

Jill described,

> I've been to due process, and I can tell that they have to be very careful with what they say. And she kind of went off the record and said, ya know, there's a private person I think you want to see.

Patti reported a similar experience in regard to deferring to the school psychologist relative to whether or not she should receive a private evaluation.

Patti reported,

> Um, I feel like, I told the school psychologist that I was going to get a private evaluation, that I was thinking about getting one and I was, um really relying on her for her information because she was the expert that I had available to me, and I really thought she was an expert who was working with me. And so I feel like, I feel like talking to a school psychologist now or talking to anybody from the school. I now realize that it is like talking to someone else's lawyer. They are not working with you, they are not representing you; they represent only the school district.

Lydia shared this experience and recalls receiving a direct answer from school staff regarding the legality of making this kind of recommendation.

Lydia explained**,**

> I don't think that I understood because I kind of all thought that, you know, we were part of the same team and then I started to realize the legal, legality side of all that. Um, so there was, um, I think it was at a point, I think in Third grade I asked a teacher what they thought she, that she would be better off in a school for kids with learning disabilities and she basically laughed in my face, and said I couldn’t possibly tell you what I thought about that, and I was shocked And I was also kind of angry and disappointed, um, because if you can't get good information from the people who are teachers who have all this information and the therapists were the best sources of knowledge about your child, um, then I don't know how you get it, which I think that is a why we eventually went outside of the school for, um, private testing, which is a luxury.

Experience with re-evaluations. Many of the parents shared information regarding their experiences relative to the subsequent re-evaluations their children received in schools. For most, their children received special education services throughout their schooling and continue to receive special education presently. Therefore, the participants have gone through the re-evaluation process multiple times with their children. A theme emerged from this additional input that was shared by the parents. Overwhelmingly, the parents reported how after the initial evaluation they felt that the re-evaluations were pointless and that there was no desire for new information to be obtained about their child.

Jill described,

> Um, trying to always look at the case with a fresh set of eyes even if it's nothing, especially if you are speaking to a school psychologist; you are going to start to see a lot of the same thing and I think it can be very difficult to look at things with a fresh set of eyes.

Victoria continued to discuss this theme when she mentioned the re-evaluation she requested for her son to determine if he had an intellectual disability. The previously mentioned theme of school psychologists not being cognizant of the parent's referral question and of the disconnection between the parent and the process emerged in one of her reported experiences.

Victoria further explained,

> And that's treated like, they keep saying stuff like, "Your son still qualifies for special education" (laughs) and I often feel like (laughs), ARE YOU OUT OF YOUR MIND? HOW COULD HE NOT QUALIFY?! Ya know he has Autism and an Intellectual Disability. Is he gonna, ya know, is he going to be ineligible? Ya know they stuff they say is kinda of insane and I don't, I don't get it.

Later, Victoria continued to discuss her disappointment with re-evaluations.

Victoria continued to discuss,

> I've learned is, once they do, maybe at least my district, maybe their strongest evaluation is the initial evaluation because that's the only time they are interested in finding anything out. Other than that it's a bunch of people who are really trying, I mean they got my kids pegged as super needy, so what so what more would we wanna know?

Conversely, Hayley described a very positive experience she had with a re-evaluation. In this circumstance, Hayley reported confirmation of her son's strengths, as well as concrete examples of what the results meant. There were feelings of hope for the future, feeling as if her child was going to receive adequate help for his disability, and feeling as if she was partnered with the school. All of the details of this experience are contrary to what most of the parents, including Hayley, reported during their initial evaluation experience. As a result, Hayley recollected many positive feelings and thoughts from this experience.

Hayley reported,

> Um, it was that whole idea of that validation of that whole thing I knew about my son that was outstanding, and it just made me feel like it wasn't a deficit, like, it wasn't a problem. Um, that he had this because he, there's so many good and positive things that he has going for him, um, and they were able to say to me when I got to the public school setting, they were able to say to me, "Well this is what we were going to do; we are going to put him in these, ya know, he is going to have a social skills class and this is how we will sorta help build those skills." SO I got concrete: We are going to do X Y Z to help that improve. I felt better, I felt like he was in the right place then, um, because, I felt like they had a strategy for, um, working on this thing that they were telling me were challenging. Um, it was ,it was comforting, and um, I was I was very, happy at that point because I felt like, ok I don't have to figure this all out myself; somebody is going to help me figure it out, and that, that was very comforting. I felt like: They got this! They are going to be my partners!

Parent advocacy. Prior to the beginning of the evaluation process, most of the parents advocated for an evaluation in order to obtain understanding of their children's learning needs and to acquire help for their children. As previously discussed, the parents concluded the evaluation process with more questions, diminished hope for the future, and were still seeking help for their children. As a result, the parents continued their quest to obtain help for their children, and they accomplished this through advocacy efforts. A number of participants developed their own expertise in dealing with their children's disabilities. Many of the parents sought and obtained information, implemented interventions and accommodations themselves, and began some sort of work in the field relating to their children's disabilities. This theme highlighted how much the parents sought help and the lengths to which the parents were willing to go to get help for their children. Interestingly, none of the parents reported feeling burdened by needing to take on the extra work of finding help for their children. Their advocacy efforts went hand in hand with their job as a parent. Holly best stated this when she was recounting how she had to learn how to cut her son's hair (because the places that specialize in cutting hair for children with Autism did not know how to cut his kind of hair):

> Of course I had no choice; that's my baby!

Jill stated,

> I wound up working as a teaching assistant in a specialized school so I have seen children on the spectrum of all different abilities.

Susan described,

> They didn't really give him any of the supports unless I was going to put them in place as a parent. We provided all of his technology; I provided all of his graphic

> organizers, I taught him how to use everything because they weren't really willing to put a lot in place at school.

Hayley elaborated,

> Um, but, he would tantrum, and I, so I didn’t really know how to navigate that, so I started looking, I started reading, so I was reading all of these books, um, at her suggestion, and I still, I found a lot of information was similar, um, and gave me some ideas about how to change that or how to help that.

Lydia discussed,

> I run an adult dyslexia education now and I would have just died to have something like that, attend a program where I could listen to, I mean this is one of the parts that have come out over time. As an example, just having people who are dyslexic speak; I mean I've never heard of kids when they talked about special ed., I thought of people who are retarded. I know from our work, talking to people at work, I know people whose kids have over-the-top anxiety problems and school phobias, and um a lot of other things. So you know I think that it might be valuable to have that piece of the puzzle.

Additional suggestions. Finally, several of the parents made specific recommendations they wanted to share, based on their experiences. Donna discussed how the parents needed to feel as if they were part of the process. This suggestion relates to the central theme that emerged from the data, which is that the needs of the parent are not directly connected to the evaluation process. Along those same lines, the need to demonstrate empathy was discussed by several participants, and how showing empathy to the parent would help parents feel included in the process.

Donna explained,

> That, ya know, um, I think parents should definitely take in what the professionals tell them, and what their recommendations from the report are, but they ultimately, parents need to know the decision is theirs and not psychologists or they, ya know, parents need to know that they are part of the process.

The idea of culture emerged as a theme in Holly's experience. Holly specifically shared insights about how the labels that are placed on children are perceived by people in her culture.

Holly reported,

> First of all I'm black. And this may not affect everybody but especially in my culture, you know, in my culture for whatever reason we don't really accept labels.

Finally, Jill, Susan, and Marisa reported specific notions of what can be done to improve the process for parents.

Jill discussed,

> Ok, uh, I would say empathy is huge: And you can never have too much of it, which I think that's hard because you get burned out as you get older (laughs). Ya know now that I have worked with children; I've worked in the classroom; it can be hard; empathy is huge.

Empathy was indirectly referenced by Susan, who shared,

> Um, I think that sometimes when results are being given, no one, they don't, like school psychologists don't always think about what it's like for the parents who are receiving the news and how they are emotionally feeling, and I think that's

> what creates feelings within the parent And I know, I mean, it gets hard because I give results a lot, but I think until I went through it, it's so hard to think about what the other person is feeling, and I just think that that's forgotten a lot, that we forget that these are parents that we are talking to, and that we're talking about their kids, and it’s, it's just not always taken into account.

CHAPTER 5

DISCUSSION

Summary of the Findings

The purpose of this study was to understand the perceptions and reactions of the parent during the initial assessment feedback conference, and using this information to develop a theory or model concerning the way in which school psychologists should provide evaluation results to parents. In the literature, there is evidence that supports how parent involvement promotes better outcomes for children. There is some evidence that highlights barriers to parent involvement. When considering parents of children with disabilities, some of these barriers include daunting amounts of paperwork; language that is difficult to discern, and a lack of regard for the parents' culture. The studies examining how school psychologists should provide feedback to parents are limited, and there is no model that is specific to the school setting regarding how school psychologists should provide results to parents. It was determined that there was a definite need to explore the experience of a parent going through the evaluation process in the hope of developing a model for ways in which school psychologists should provide results to parents.

A total of 11 participants completed interviews for this study. All of these participants were parents who had children with disabilities. Their responses generated several common patterns and themes. The process of evaluating a child ultimately begins with the parent, because each has significant amounts of information about his or her child. Also, each parent has a certain schema for his or her child. Therefore, it is important, initially, to understand how each parent views his or her child who has a disability. Although the length of the descriptions to this question varied, not all parents immediately mentioned that his or her child had a disability. The ones who did may have been primed to do so, given their understanding of the purpose of this study.

Parent schema of their child. As one can imagine, the schema each parent holds for his or her child encompasses the whole child and not just the parts of the child that are impaired. This data afforded some connection to how understanding the schema held by the parent for his or her child could assist school psychologists when providing evaluation feedback to parents through connecting with the parent. Lydia described this notion succinctly when she stated,

> I think it's important for everyone to focus on the whole child and that this is only one piece of her.

She described the lack of "whole child focus" in detail.

Lydia described,

> It was very hard to continue to, to struggle to see, that she wouldn't, um that she could be seen as a whole person and to see that this is only one small part of who she was, and that's a long, that's s process that you really have to struggle with, um when you get all the information, struggle in trying to get all the information and to try and understand what the information means.

Holly also made a comment that highlights how the parent's view of each child and the views of the evaluation are different. The parents take a human lens to look at each child. She stated,

> There is a human here; the humanness of this is lost.

These descriptions provide the first piece of evidence for the overall theme that emerged from this study- there is a disconnection between the parent's needs and the evaluation process in schools.

Disconnection between parents and the process. For schools, the purpose of an evaluation is to complete child find obligations, or to identify children with disabilities and to determine if the disability warrants special education support. Most parents do not lead with the notion that their children have disabilities. They lead with what they know about each child as an overall person, and what they know the child is good at.

Victoria indicated,

> Um in terms of the disconnect um, ya I think they need to be reminded that… give me new information that will not just tell me that, "O, your kid is in this percentile, " but that will tell me, " Given that your kid CAN do this, this is where the energy should be going in terms of his IEP goals"

In this study the majority of the parents knew something was "off" with each child and therefore they began a journey to seek answers and help for their children. Hence, each parent began this evaluation process under the premise of wanting help for his or her child.

Help. The theme of wanting and seeking help was reported by almost all of the parents, and many of the parents in this study advocated for an evaluation for their child, some even on multiple occasions. Ultimately, as best stated by Holly multiple times, parents are looking for the "bottom line": What is wrong with my child, and how do I help them?"

Holly elaborated by saying,

> I guess the biggest piece is that I say this all the time- I understand, you got a degree; you use big words; I need you to bottom line it; write it down make it simple. When you give the definition of the big words find the little word, you explain one thing, bottom line it, something else, bottom line it, go and tell that parent there is something wrong with their child. I need you to **bottom line it,** Write it down; make it simple, when you give the definition of the big words find the little word, you explain one thing, bottom line it, something else bottom line it!

Lydia also shared,

> I think everyone is trying to be professional and, um, dry and academic and. um ,I think that most people, the **bottom line** is they want to know is what does it mean and what are we going to do about it and how can I help my child?

When parents were reporting concerns with the way in which the results were presented, their concerns included the fact that a summary was lacking from the evaluation and the jargon that was used made it impossible to understand what the results meant. Issues with jargon were prevalent throughout the interviews. As mentioned previously, the use of jargon isolated the parent from the process. It is interesting to relate this theme to existing research on the use of jargon in special education proceedings.

Fitzgerald & Watkins (2006) reported research findings on the readability of procedural safeguard manuals that parents are provided when they go through the evaluation and the IEP process. Their study indicated a variety of concerns with the procedural safeguard manual, which is intended to inform the parents of their rights and explain the evaluation process to parents.

The use of acronyms, the use of words that would be unfamiliar to most readers, especially readers having readability levels less than an eighth grade reading levels were findings reported in their study. The results of the current study and the results from Fitzgerald & Watkins (2006) highlight the significance of language used in reports and in feedback conferences. Procedural safeguard manuals and assessment feedback conferences are intended to further involve parents at school; however, it appears that they actually continue to isolate parents from the evaluation process. Additionally, the parents entered into the evaluation process without an explanation of what was going on and why. It is unfortunate, because if the process is not directly explained to the parents, they would likely not be able to find the information they need in the procedural safeguard manual because of the language used in the document.

Overall, the evaluations were not deemed to be helpful by the participants. This was because the disconnection between the parents' reasons for pursuing an evaluation, and the disconnection became wider as the evaluation process continued. As reported by many parents, the evaluation process was not explained to them, and as a result, the reason why the psychologists were doing some of the things they were doing was confusing. Additionally, the parent did not have the context to connect the process to ways in which it would relate to each child's life.

Process. Other factors that continued to expand this gap between the parents and the evaluation process included the jargon used in reports and the paperwork used throughout the process.

Jill mentioned,

> Ultimately, all the parent wants to know is "What's wrong with my kid, and why is my kid this way?" It's almost as if you don't need to go through line by line through the report; it's almost like take the summary of your report and put it into average language.

Holly stated,

> A lot of the stuff they did, they talked off my head. When it came time for evaluation time that all paperwork come together all at one time and I got tired. I got tired of all that paperwork at that time. I was really sick of his life being all about paperwork. I was faking it, I was thinking like I was thinking of o.k., I will sign this, and you use this terminology. Now put those words down in English and maybe act like English-speaking people, I don't speak that language and I understand that you got a do what you got a do, but you got to understand I gotta live my life too and I didn't go to school for all of that.

Marisa reported,

> It becomes just a more of an endurance exercise, endurance and paperwork exercise at a certain point (laughs) And it never ends! It's a, it's a long process so it's kind of like an endurance test to get all the services, but it's something you gotta do.

In this particular sample, it is important to note that the majority of the sample holds at least a Master's degree (54.5%). The jargon and language used in the evaluation process was still misleading, despite the level of education that was attained by the parent, and a Masters or Masters-equivalent is a degree similar to what any entry level school psychologist must have attained in order to enter the field. Holly was very open in sharing the fact that she did not hold a degree comparable with that of a school psychologist; the frustration she felt from the use of language that she didn't understand in her interview was palpable. Regardless, this data show that even if she did hold a degree equivalent to that of the psychologist, she still would have had difficulty discerning what was being said.

Interestingly, despite how disconnected the parents are from the process, as Holly and Marisa mentioned they still tolerate these aspects of the process because of their desires to achieve help for their children.

Holly further explained this theme when she stated,

> If I had not been determined to get him the help that he needs, I mean those first couple of times I was thinking, I am not even going to deal with you and your diagnoses and your clinical talk. I might not have come back. I'm thinking this is the farthest thing from family-driven but they are making us come into your environment, take a part in your process and sometime you're using these big words, mom can't even understand. How I am supposed to help him understand when I don't get it? I would have kept him at home, kept him in a bubble, I woulda kept him in this world, ya know. Basically the one thing that I remember about the whole process is that unless I get a psychologist that understands "This is what I am saying" vs. what they have been taught to say, then they are trying to make me feel inadequate about taking care of my child.

Much like the parent's existing schema for his or her child is a human schema, versus the evaluation "schema" of finding a problem, these conflicting schemas also seemed to continue throughout the evaluation process in regard to the paperwork and language used to describe a student's learning.

Holly said it best when she shared the following,

> Life is not lived by a piece of paper.

Results. Because the parent's journey continues to the day that each parent receives the results from the school psychologist, the parents proceed through the evaluation feedback, with an expectation that he or she will receive the "bottom line" by receiving a summary indicating what to call the problem with his or her child; indicating what is going on with the child, and suggesting how to help the child. However, this does not occur in the assessment feedback. The theme of seeking help and the subsequent lack of help that emerged was explained directly by Susan.

Susan shared,

> So when they finally said, "Okay we're going to evaluate", I said, "Oh my gosh, finally someone is going to help me, I'm finally going to get support", and then we went to the meeting and they were like "Nope, there's nothing we're going to do", even though everyone, the teacher, the counselor, everyone is sitting their going, "Well ya, but look at what he does, he cannot write."

Contrary to Susan's experience, Hayley reported an evaluation in which she felt she did receive what she needed, and reported a very positive and emotional response.

Hayley described,

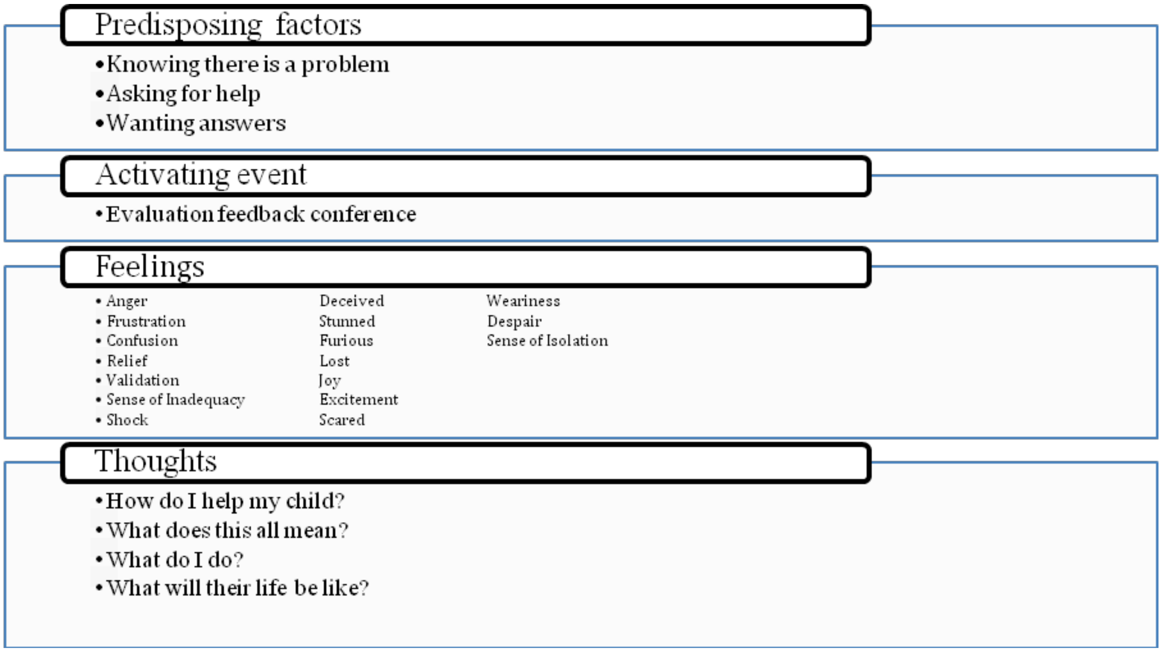
> And, and to this, to this day, I will never forget that evaluator who evaluated him in first grade, because she, she just was an amazing human being, so, (tears up) I mean, you know, you know when somebody really needs something right in that

> moment and ya know someone wants to give you what you need, like needed to hear, needed to know, (cries) it really makes a difference (sniffs).

The parents' journeys seem to climax at this point, and it is no surprise that a variety of thoughts and feelings arise after hearing results. In this study, parents were asked to use retrospective recall to remember their thoughts and feelings. This moment can be conceptualized as similar to an "activating event" in cognitive behavior therapy. An activating event is an internal or external factor that triggers a person to activate schematic structures (Hyland & Boduszek, 2012); in this study, the schematic structures surround the parent and how each one views his or her child. The parent then experiences a range of thoughts and feelings. What determines whether or not the person experiences positive or negative thoughts and feelings around an activating event depends on his or her beliefs about the activating event (Hyland & Boduszek, 2012).

In this study, the parent walks into the evaluation feedback meeting with expectations, or perhaps even a name for what is going on with his or her child, and recommendations for how to help the child. They *believe* these results will help. As evidenced by these parents, this does not occur, and what happens next is a myriad of thoughts and feelings. The participants' recall about what happened varied from thoughts to feelings, but for many, the feelings of being frustrated and angry, as well as feelings of despair jumped to the forefront of their recollections. Accompanied by these feelings were thoughts that represented confusion and thoughts that expressed worry over the child's future. Figure 5.1 presents a visual depiction of this process.

Figure 5.1: Cognitive-Behavioral Model of Parents Experience during Initial Assessment Feedback Conference



What was important to report was that the median length of time that had passed from the initial assessment feedback conference for parents in this study was 8 years, and 73% of the sample continues to have his or her child placed in special education. Throughout the interviews a significant number of details could be recalled regarding the initial assessment feedback conference; also, the parents could still remember many of the thoughts and feelings they experienced, which highlighted the significance of this event. The thoughts presented in this stage of the process relay another important theme that emerged. Parents are seeking hope for the future and want assurance that their children have a future. Many of the parents mentioned being shocked and some even started a process of grieving the future for their children, mentioning what a hard life they envisioned for themselves and for their children.

Holly stated,

> Autism itself can be difficult enough as it is; it can be a death sentence and you're not thinking about that, that you have to deliver it with some tact when you are commenting about a child's mental state or talking to a parent who is fearful about their child's future. You should think about how you are going to tell that parent and if that parent doesn't understand, do NOT give them a look like they are dumb, because they might just be in shock. Ya know when you are pregnant you think I just want them to have 10 fingers and be healthy, but be careful what you are wishing for. My hopes for my son haven't died, but they had to be rearranged a little bit but from what I started out with. I just had to rework and rework; my hopes and dreams for what I wanted for him have just been reworked.

Lydia reported,

> I mean I really do think that the psychologist and the system can do a better job, putting all of this information into perspective. Um, to help you, to help you see this in a bigger picture that, you know, to put it in the right place.

Lydia's report of the "big picture" highlights another notion: many times the parent envisioned a dismal future but now, looking back, his or her child is doing much better than was originally anticipated.

Hayley described,

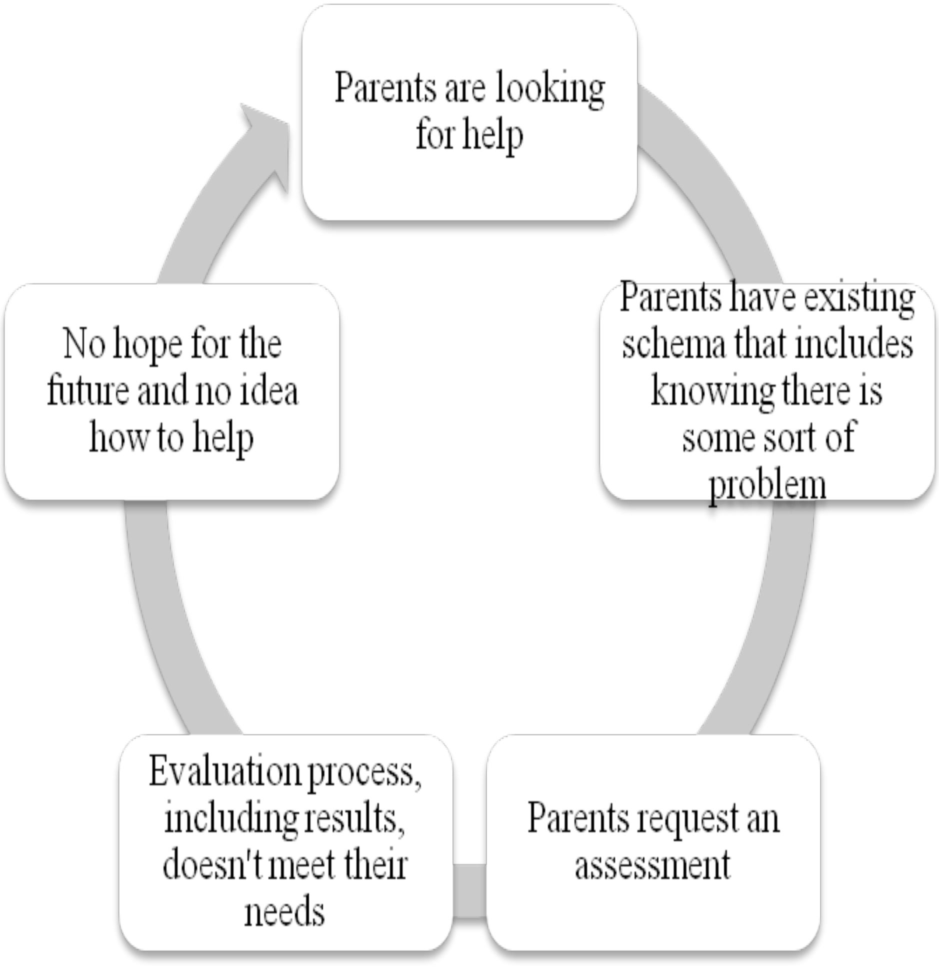
> I don’t know that that’s the best thing anybody ever gave me was, um allowing me, I guess, to really say, um, there’s this super positive things about your son---are so super positive about your son, and if you knew him today vs. what he was when he was diagnosed, he’s just a totally different person; um, he’s just, he’s just gained so much and picked up so much along the way and, um, its just amazing to see; he does sports, and he, ya know, that whole thing and now he’s a superstar who loves basketball and loves every sport; it’s just, ya know, I guess its always, like give people hope; that’s what people need to hear.

Holly stated,

> So we have to be reminded my son used to do that and people would be like, HE DID? So there is hope, there is definitely hope.

When the evaluation feedback concludes, the parents are left with a variety of different thoughts and feelings; they are still left wondering about how to help their child. In addition to the desire for help that parents held, prior to the evaluation, parents now have the various thoughts and feelings and lack of hope for the future. Essentially, parents are back at square one, so to speak, with more layers of concern and more questions about their child than they had before they started the evaluation process. They sought out and embarked on this process to obtain answers, to find help for their child, and to identify what was wrong, and by the end of the process they still had not received the help that they needed. Figure 5.2 represents a summative model of the parents experience during the initial evaluation process.

Figure 5.2: Summative Model Depicting the Parent's Needs during an Evaluation



Coping mechanisms. As a result, parents continue their quest for help and continue looking for information regarding how they can help their child. This occurred, using a variety of methods for parents in this study, including going to conferences, reading books, finding parent support groups, seeking a second evaluation from a private evaluator, and for some, pursuing careers in the field of special education and working with people who have disabilities. This theme also exemplifies the parents' continued roles of advocacy for their children even after their first attempt (requesting and/or consenting to an evaluation) did not have the result for what they ultimately hoped.

Throughout the interviews, the parents used humor to explain their experiences and in various points of the interview they expressed appreciation for this work and for an opportunity to share their stories.

Hayley stated,

> I want to tell you I think what you are doing is great (laughs).

Holly reported,

> Thank you, because you brought back the memories I had like, OH, I needed to bring that back because I forgot about that.

Patti described,

> I mean the reason I saw your posting, you know, I'm always checking out different areas to find out information, so when I saw your posting I thought, um, you know this is an opportunity for me to let my experience be known to someone who maybe this could help somebody.

Victoria stated,

> Oh good, I am glad. My pain can be gain for someone else- (laughs) I'm kidding.

And finally, Jill stated,

> You're very welcome I'm glad I could help.

The idea of using humor and sharing their experiences emerged as a way that parents used to cope with this experience. Their desire to help emerged in a way not only to help their own child, but also to help themselves and other parents who may be going through the process with their own children.

Cultural implications. Finally, the research provided a multitude of ways that the culture of a family can impact parent involvement in schools. Particularly, Turnbull et al. (2006) discussed how the values held by parents from specific cultural groups may create another barrier when involving parents in schools. Lo (2012) also reported how school teams need to involve parents in the various special education processes. The method used to involve parents' needs take place without increasing their discomfort. In the present study, culture was not specifically questioned from each participant, aside from the demographics of their school districts and highest levels of education completed by the parents. The aspect of the family's culture emerged in Holly's interview. It was important to take a moment and to examine how culture impacted her experience in ways that relate to the findings in this research about cultural factors' effects to parent involvement.

Holly described,

> (sigh) Okay well first of all, we're black and the hardest part that I've dealt with is accepting; I can see it with some other cultures, but this diagnosis just doesn't take away from who he is you know; it doesn't make him any less of a person and it doesn't mean by any means that my son is stupid. I think that's the worst fear that makes a lot of people maybe not get the help they need for their child…they ran from it and so I saw lots of kids in my culture not being as far as they could be,

> not progressing as far as they could be, not get the help they need because people weren't accepting of their needs.

Significance of the Findings

This study provided a variety of significant benefits. First and foremost, this study exemplified the experience of the parent who has a child with a disability by understanding his or her direct experience. By understanding the parent's desire for help and realizing that the evaluation process does not ultimately achieve that result, the schools can start to develop awareness for what the parents want and how to better provide this for them.

This information would be useful to share with other parents whose child is suspected of having a disability or who are just beginning the evaluation process. The data obtained in this study can show parents that they are not alone, and that there will be many stages to this process. It can show how the parents' lives will change if their child is found to have a disability and will be placed in special education. Hopefully, this can prepare parents for the frustration, anger, and confusion that many of the parents experienced when they began this process. Of greatest importance, however, it can give these parents hope as they venture into this complicated and foreign territory called special education. The parents shared how difficult everything was in the beginning, but no one has continued his or her feelings of despair to the current time.

On a personal level, as a school psychologist this was a fascinating self-study. Upon review of the journal kept during this research and of the notes taken, it is clear that listening to this feedback will change this researcher's ability to provide results. One of the purposes of this present study was to develop a model for school psychologists to provide results, and this researcher can attest to the way her view of the evaluation process has changed as a result of this study. During the validation team meeting for this project, fellow school psychologists explained how helpful this research would be for review by any school psychologist, particularly school psychology students or students who are new to the field.

Susan articulated this notion in her interview. Susan is a practicing school psychologist who also is a parent of a child with a disability and who mentioned this idea in her interview.

Susan explained,

> Um, I think it's made me a better school psychologist. I think sometimes it's still hard because there are times where I am doing a report and I think, “Okay I know as the school psychologist what I should say and what needs to happen, but I know the parents are not going to take this very well”. Now when I give test results back to a parent, like I always, try to go through it in my head and think, “What am I going to, like what would I react if this was said about my child?” Or, like, before I even do test results, like I try and get a better understanding from parents about, “Where do you think your child is at? What do you think the main concerns are? Like, what are you expecting to get from this evaluation? ” Sometimes, they don't seem to have any clue when it is school related but sometimes it’s just that they're really just frustrated and they just want help for their child, and even if they don't qualify, I’m really thinking about, “Well, how are we going to provide supports in the school even if the child doesn't qualify?’ And so, instead of making it all about a final diagnosis, I really try harder to make

> it more about the child and about how we're going to support them whether they qualify or don't qualify.

Practice Guidelines for School Psychologists. As mentioned by Jill in her interview,

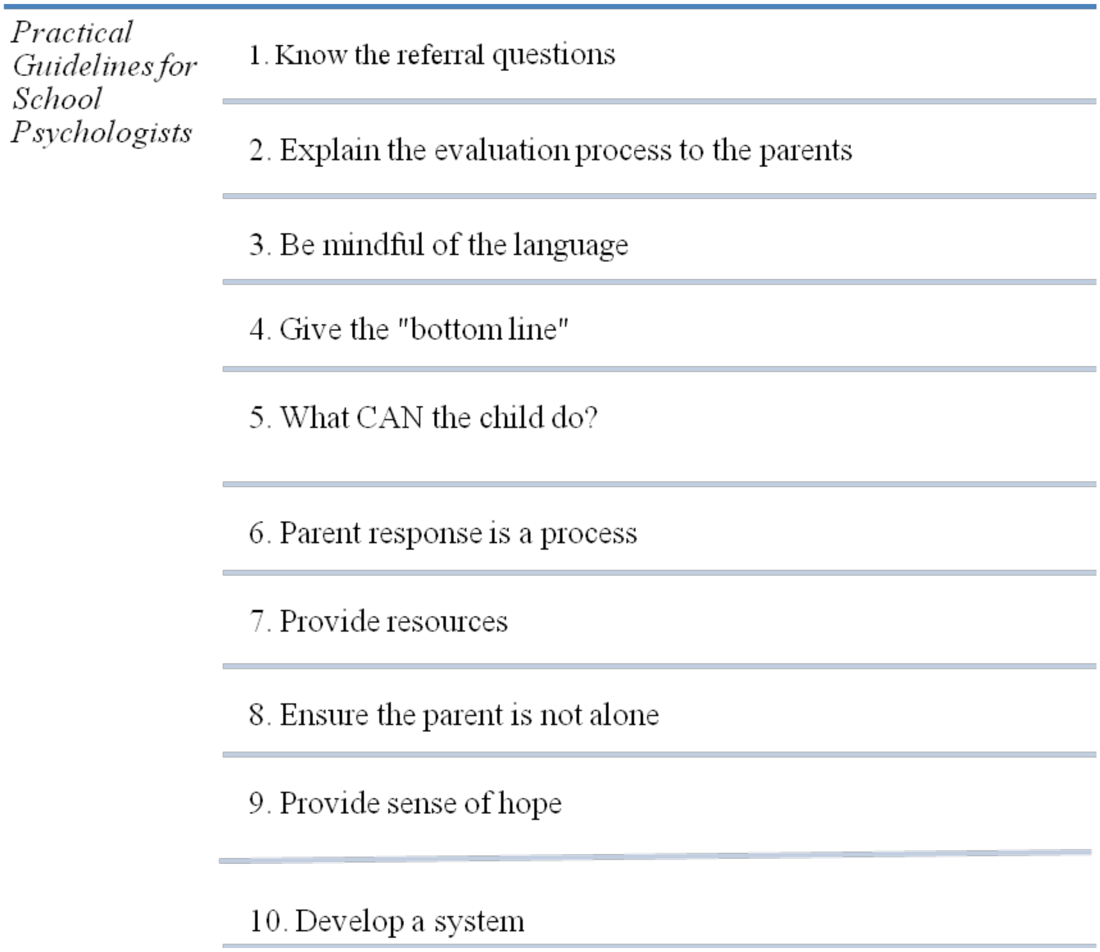
> Empathy is huge.

In Norcross (2010), empathy was reported to be integral to this therapeutic relationship, and part of having empathy in this process is knowing the parents' experiences and understanding the variety of emotions, both positive and negative, that will emerge. This reinforces the necessity of forming a therapeutic alliance with the parents during the evaluation process in order for the gap between the parent and the process to decrease. The school psychologist should also remember that the "bottom line" is that parents are seeking help for their child.

Additionally, understanding a parent's schema of his or her child seemed to relate to the overall theme of wanting help for the issue(s) parents identify in their child. This lends some support to the Collaborative Assessment Feedback Approach (Tharinger, Finn, Hersch, Wilkinson, Christopher & Tran, 2008). Using what parents know about their child to help them rewrite their schema, and using the assessment results would be appropriate. However, feasibility for practice in a school would largely depend on the amount of time school psychologists can allocate for parent contact prior to the assessment feedback. In this study, 73% indicated that contact was had with the school psychologist prior to the evaluation feedback. Whatever this contact looked like, it was not significant for establishing a therapeutic relationship based on empathy for the help that the parent was seeking for the child, nor for fully understanding the parent's schema for the child. Therefore, at this point the model for practicing school psychologists should focus on overall practice guidelines that emerged from themes tabulated from this area of research.

Figure 5.3 explains practice guidelines that were generated from the parent experiences.

Figure 5.3: Practice Guidelines for School Psychologists when Delivering Evaluation Results to Parents



Practical Guidelines for School Psychologists	
	1. Know the referral questions
	2. Explain the evaluation process to the parents
	3. Be mindful of the language
	4. Give the "bottom line"
	5. What CAN the child do?
	6. Parent response is a process
	7. Provide resources
	8. Ensure the parent is not alone
	9. Provide sense of hope
	10. Develop a system

Know the referral question. School psychologists should ask the parent specific questions such as, “What are you hoping to get from this evaluation?” and “What are you expecting from this evaluation?” Then school psychologists can use this information to individualize the evaluation by connecting the parents’ needs with the tools used in the evaluation. The focus should be on understanding the parents’ views of their children and forming a connection with the parents in order to provide them with the sense that they are receiving help. Knowing the parents’ referral questions is the first step to understanding the schema that parents hold of their child; this will be pivotal as the evaluation process moves on, especially helping the parent rewrite their schema for the child (Tharinger, Finn, Hersch, Wilkinson, Christopher & Tran, 2008),

Explain the evaluation process to the parent. It is necessary to take some time to discuss the evaluation process with parents and to explain the paperwork and the purposes of the assessment. It is also necessary to assess how foreign this process will be for the parent. For example, a parent who has had no experience with the evaluation process (particularly the emotional response when each one hears the results), their experience will likely vary from the parent who has had some form of evaluation conducted by a doctor or at a clinic. The use of empathy is vital at this step, because the process is very foreign to some parents. They are likely experiencing a variety of thoughts and feelings around this process. In this step, explaining the process adequately to the parents by using empathy as a means to establish a therapeutic alliance (Norcross, 2010) is recommended.

Be mindful of language. Being mindful of language is closely related to the subsequent guideline, to give the "bottom line". As mentioned previously by Fitzgerald & Watkins (2006), the readability level of public documents should be no higher than an eighth grade reading level; however, most documents that are made available to the parents during this process are inundated with jargon and foreign acronyms. It is important to acknowledge that the jargon used to describe scores and the statistics of the scores will be foreign to the parents, regardless of their educational backgrounds. With this in mind, it is beneficial to provide contextual information whenever possible to explain what the results mean, and if possible, to use "real-life" examples that the parents have provided. It also helpful to take the time to explain, generally, (in verbal or written form) what some of the technical language means.

Give the "bottom line". Somewhere in the report, it is necessary to summarize what it all means. This summary becomes "parent friendly" by avoiding the use of jargon and encouraging the use of layman's terms. It may also be helpful to check the readability level of what has been written by using a readability test in a word processing program. Harvey (1997) reported that psychologists need more than an awareness of how to make reports more readable; rather, there are specific suggestions that can be implemented. Some of these suggestions include: shortening sentence lengths; minimizing the use of difficult words; reducing the use of jargon and acronyms; omitting passive verbs; and increasing the use of subheadings (Harvey, 1997).

What CAN the child do? It is necessary, regardless of the results of the assessment, that time be spent to focus on the child's strengths. Ideally, it is important to use the input provided by the parents during their initial interview to confirm and validate what they already know about their child to be true. This information should also be included in the feedback conference. As Finn & Tonsager (1997) report in their research on therapeutic assessment, focus on the opportunities for intervention that assessment information can provide. As with planning any intervention, knowing and identifying the strengths of the child are necessary steps to planning interventions.

Parent response is a process. It is necessary to ensure that there is enough time in the feedback conference to answer the parents' questions, and also to understand that it will take time for the parents to understand fully what is going on with their child. When it looks as if a parent is not able to understand fully what is being shared, it is vital to use empathy and a shared understanding of how difficult this new information may be for the parent. Using the therapeutic alliance established with the parent and using empathy (Norcross, 2010) helps the parent accept the results.

Provide resources. It is beneficial to develop lists of local, state, and national resources for parents to learn more and understand what is going on, and also to provide websites, articles, and book recommendations for the parent to review. Reichman, Corman & Noonan (1997) noted in their research that there are numerous resources available through multiple programs that support children with disabilities. School psychologists may be able to locate these resources in their local communities and provide contact information to parents; this is in addition to any additional resources that help explain the disability, how to help, and/or the special education process.

Ensure they are not alone. Besides the resources that parents can review in order to learn more about their child's disability, it is also a helpful to provide options of support groups and parent groups. The idea is to connect parents to other parents who have been through this process, in order to decrease feelings of isolation and provide parents with other parents who can relate to their experience. In order to conceptualize this step of the process as a way to emulate the principle of *commitment* in the model presented by Turnbull et al. (2006) it is important to be available to parents and to maintain sensitivity to how this process has affected them.

Provide sense of hope. Faso, Neal-Beevers, & Carlson (2013) reported that hope is a resiliency trait for parents who have children with disabilities (specifically, intellectual disabilities and autism). Hope has been found to reduce feelings of stress, depression, and anxiety that parents of children with disabilities experience. Additionally, hopefulness allows the parent to think about their child's potential to attain life goals (Faso, Neal-Beevers & Carlson, 2013). Ensuring that the parent has hope for the future will improve their outlook for the future and decrease their maladaptive emotional responses, which will in turn have a positive effect on the child's well being. Thus, it is important that school psychologists provide parents with a sense of hope for the future, regardless of the evaluation results or disability. This can be delicate and tricky, as Colleen has reported; the manner with which a school psychologist explains the needs of child's can easily be misconstrued if not communicated properly. It is important to discuss realistic expectations for the child, given what is now known about the child's skills. It is also important to acknowledge that the assessments are not ultimately predictive of any child's future; however, they do provide a snapshot of how the child is functioning in this particular moment in time. As Holly worded it, the parent may need to re-work their visions for their child’s future, given the child’s disability.

Develop a system. Research conducted by Pelco et al. (2000) identified how school psychologists acknowledge the importance of participating in parent involvement, but that these activities do not take precedence over the evaluations and other responsibilities. For all of the previously mentioned guidelines, if it is not conducive for the school psychologist to perform these duties based on their existing obligations and responsibilities, it is imperative to designate another person to perform these roles. Perhaps another staff member or perhaps a parent who has been through the process might work with and support parents as they go through the evaluation process. Consideration might be given to training the staff member identified to perform these duties in practices that school psychologists would do, so that there is someone providing this service to parents.

As noted previously, Hayley shared how much her experience improved when she received what she needed (help) and when she had a sense of comfort with the process. When asked about additional comments and suggestions, Holly discussed how feeling cared for, being relaxed, and the use of empathy by the psychologists towards her changed her experience with a second evaluation that occurred after her son’s initial evaluation.

Holly described,

> Once I got to that point, once they met with me and sent me to Dr. NAME, I met with her, and she had a whole different process with it. She put him into his own little room with toys; he knew I was down the hall, and I was able to focus a lot

> more on what she was saying and what she was telling me about, and I could focus, and it made me comfortable enough for me to sit there and talk to her, and she was like asking me all these questions, and I think for me, the part that was hard was that I have always been a very private person so a lot of the questions that she asked were, I thought they were intrusive. I had to sit there and answer them, so I was able to focus more on the information that she needed.

Later, Holly compared this experience with the school experience.

Holly further explained,

> That process was a lot different; it wasn't like it was just another, like it wasn't like a robot; like let's get this kid in for another evaluation and all that; it was more like ok, let me talk to you about your child; let me show you your child is in the room having fun. In the other one it was just testing, and he wouldn't play in the correct way, but this one, however, he would play, was fine. SO I was able to answer and give her what she needed and listen to what she was saying, what she was telling me, why the diagnosis, what the diagnosis meant, the label, you know. So she was able to talk to me, like ok, some of the delays were, well he should be doing this or that, and saying this is why these are considered delays; this is why we are calling it this. I mean that was what I needed from the start, like from the I/U; tell me first, like I really needed it broken down that much.

Finally, she recounted how these details improved her overall involvement with the evaluation process.

Holly further explained,

> Well, to compare it to when I went to Dr. NAME, I mean the atmosphere was so much more relaxing with Dr. NAME; like I said, when it was with her the test that she did with him, I was allowed to sit there and have a cup of coffee and just chill for a minute. I didn't have to see him being tested; I could just know he was in a room trying to play, but then at the I/U, I was distracted.

Ultimately, it is imperative that school psychologists apply empathy, reassurance, a sense of hope for the future, and that they connect with the parents while providing assessment results. If steps are taken to provide these to parents then school psychologists can ensure adequate parent involvement with the evaluation process. Furthermore, as mentioned in the research reported by Faso, Neal-Beevers, & Carlson (2013), these guidelines can create the secondary benefit of promoting resiliency with parents who have children with disabilities.

Impact of the Findings

This study highlighted a variety of implications about the experiences parents of children with disabilities. First and foremost, this study easily demonstrated how closely aligned support is for parents of children with Learning Disabilities and Autism. The majority of the sample included parents whose children had these disabilities, and it was easy for the researcher to identify a variety of parent support groups for these disabilities when seeking parents for this study. What is concerning is that it was difficult to find parents whose children were identified as having an emotional disturbance, which is a disability category that represents a significant number of children with mental health needs who are in the schools. Knowing that these parents may not be as well connected leads one to wonder how closely aligned supports for these parents are. It is important to connect these parents to decreased feelings of confusion and isolation, given the evidence that highlighted these themes in this study.

Second, these findings provide a basis to train future and current school psychologists. Applying the practice guidelines from Figure 3 are small and simple places to start. An interesting facet that emerged in this study was that the parents seemed to be aware that many of the school staff were not free to discuss their opinions and many school staff, including the school psychologist, would have to risk their jobs to express ideas and recommendations freely to the parent. School psychologists can use these practical skills to give help to parents yet also allow school psychologists the opportunity to skirt around these more difficult situations where follow-up disciplinary actions from the district may occur, should they provide particular recommendations to parents

For currently practicing school psychologists and for test publishers, this study identifies a need to better use layman's terms to describe evaluation results. The best method would be to obtain detailed parent interviews, with examples and in contexts that can be related to real life examples. To help school psychologists who work in areas in which lack of time or barriers to parent involvement preclude this from happening, test publishers might develop better explanations of test results and indicate what these results mean. Test publishers could begin to develop samples in their manuals, explaining in layman's terms, how to express scores and skills in order to assist school psychologists when they write up results.

Last, this study could lead to advocacy efforts. The process clearly does not work for the parents and therefore, school psychologists could use this information as a method to advocate for a process that is more parent-friendly at the district level, and perhaps to alter the system at the state level. If aspects of the process, such as the format of the reports and the function that the reports serve could be better aligned with the needs of the parent, it would help the school psychologist with making sure the parents were better connected to the evaluation process.

Limitations

Several limitations were present in this study. First, the study did not reach saturation, because the number of participants in this study was relatively low to assess the entire experience of every parent whose child is being evaluated in the schools. The parents in this sample had five of the IDEA disability categories represented, and it is difficult to assume that the parents of children who have traumatic brain injury, orthopedic impairments, emotional disturbance, visual impairments, and multiple disabilities would be similar to the parents in this study, without asking parents who have children with those needs. As mentioned previously, the experience of a parent whose child has significant mental health needs (i.e. emotional disturbance) could potentially bring a very unique experience, given the lack of obvious support for parents whose children are emotionally disturbed.

Second, this study used a sample of convenience, which also limits the utility of the sample. It is possible that the experiences of the parents in this study are limited to parents who were connected to the researcher. Additionally, the methods of recruitment in a convenience sample were exhausted prior to the attainment of saturation, limiting the scope of this study.

Third, some of the themes that emerged may have been specific to a particular subtype of a parent who has a child with a disability. The fact that many of the parents participated in advocacy efforts and/or work with children in the schools suggests that this evidence may be relatively skewed to parents of children with disabilities who engage in these activities. Additionally, the number of parents who expressed interest in this study but did not continue due to lack of follow- up, suggests that there are more parents who have students with disabilities, but they may not have had time to complete an interview with the researcher. This supports the idea that there may have been some bias in the sample of parents who participated.

Fourth, there is a question regarding homogeneity of the sample. Although all of these parents met specified inclusion criteria, there were very unique aspects to each parent's experience. For example, some parents had a team of people present when they received results and some had an individual meeting with the school psychologist; some had received a medical diagnosis before the school evaluation, but some initially heard a diagnosis when they got the results; some of the parents worked in education, and some did not. Prior to conducting this research it appeared that the sample would be homogenous, but the input from the sample suggests that there maybe less homogeneity within the sample than originally anticipated. Despite the decreased homogeneity, there were enough commonalities within the sample to report findings.

Fifth, the participants in this study were asked to use retrospective recall to recount the initial assessment feedback conference. Therefore, the accuracy of what was recalled may be questionable. This study found that the evaluation process is highly emotional for parents and that many parents who participated in this study had a negative experience. Additionally, a significant amount of time had passed from the initial assessment feedback conference and these interviews. The details shared by the parents and the significance of the event indicate that the parents' recounts were likely accurate, but may not have been objective.

Finally, in qualitative research, the researcher needs to be able to set aside preconceived notions or ideas regarding the phenomenon of study. The demand for objectivity on behalf of the researcher is high both during the interviews and the coding process used in data analysis. This researcher has been practicing school psychology for over five years prior to the commencement of this study, and the experiences of the researcher during these years helped drive the study. Upon review of the journal entries kept during this research, it was a challenge to remain objective. On some occasions, it was difficult not to immediately "take a side" when a parent was saying particularly negative things about the school psychologist or when a school psychologist did something in an evaluation that was extremely contradictory to how this researcher chooses to practice. Caution had to be used when conducting this investigation in order to maintain objectivity. A validation team was utilized to help minimize the bias; although this team consisted of parents, including a parent of a child with a disability, all of the participants on this team were practicing school psychologists. Therefore, this researcher had to apply additional caution to ensure that there was no loss of objectivity on behalf of the input provided by the validation team as well.

Future Directions

This research provides a foundation for future research with parents who have children that have been evaluated in the schools. If this study was replicated on a larger scale, (perhaps the inclusion of parents from multiple geographic locations) then this would generate more ideas and recommendations that could be relayed to school psychologists and school personnel. These ideas can hopefully establish better parent connectedness with the process and decrease the feelings they experienced

As mentioned previously, this research could also be used to advocate for systems level change. Because some of the difficulties with the school based evaluation process are better defined, further research can confirm these results on a larger level. The data could be used to work with local education agencies and at the state level to change the process in schools. It would also be of interest to conduct a similar qualitative study with school psychologists, asking them about their experiences in giving results to parents. Similarities could be collated and reviewed in order to give more credit to the difficulties that parents experience with the school based evaluation process.

Replication of this study could include more questions specific to the parents' experiences. For example, probing the parents for more specific information about what their contact was like with the school psychologist prior to the initial assessment feedback conference would help describe what the contact looks like and discern how much time would be necessary to truly understand the parents' schema of their child. Along those lines, developing questions that could relate to the collaborative assessment approach could better describe how effective this approach would be used in schools.

Finally, this research could be replicated by asking specific questions about the parent's culture, including how that culture influenced his or her experience. The research stipulates the fact that many factors need to be considered when involving culturally and linguistically diverse parents in the schools. Detailed and in-depth accounts of this topic could be explored by incorporating questions related to culture into a similar qualitative study, thus allowing theories to emerge about the influence of a family's culture on the evaluation process.

Conclusion

The findings of this study conclude that there is a lack of connectedness between the parent and the evaluation process that occur in schools. The parents who participated in this study indicated that what they were seeking to learn from this evaluation were answers to questions regarding their child's difficulties. Specifically, parents are looking for recommendations, a name to call their child's disability, and information that will help them help their child. The desire for help drives many parents to request an evaluation; unfortunately, the gap between the parent and the evaluation process becomes more pronounced throughout the evaluation process, given the lack of context that parents have for the evaluation; the lack of explanation parents receive regarding the evaluation process; the daunting amount of paperwork used in the process, and the jargon used to explain the results.

The findings from this study highlight how important it is for the school psychologist to understand the schema the parent has for his or her child. By understanding the schema, the school psychologist can serve as the connection between the parent and the process. School psychologists can bridge the parents' needs with the evaluation process by using empathy to establish a therapeutic relationship with the parents. In turn, when the initial assessment feedback conference occurs, the school psychologist can be better prepared to help the parent cope with the multitude of emotions and thoughts that will arise as the parent learns new information regarding his or her child. Despite the challenges this may pose, there are several recommendations for school psychologists in order to help prevent some of this difficulties. Ultimately, remembering that each parent's experience is unique and by looking at this process through the eyes of someone who is not familiar with what is happening and who loves the person being discussed, a school psychologist can be better equipped for providing what the parents need: ideas for help, hope for the future, and, in the words of Marisa, assurance from the school psychologist:

> "Don't worry mom, he's ok"

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APPENDICES

Appendix A

PARENTS

Are you the parent of a child with a disability?

Do you live in Pennsylvania?

If so, let's talk!

Seeking participants who are willing to be interviewed regarding their experiences going through the evaluation process in their child's school. Interested participants should contact Katie Scipioni for additional information

katherinesc@pcom.edu

585-356-2505

APPENDIX B

Demographic Questionaire

What is your relationship to your child? ____ Biological Parent ____ Step Parent

____ Grand parent Other (please describe)___________________________

Please indicate the highest degree of education you completed:

___ High School Diploma or GED ___ Bachelor Degree

___ Master's Degree ___ Doctoral Degree

How many children do you have? ________

How many of your children received special education services?_________

How old is your child/children with a disability? _______

Approximately what age was your child when he/she were identified as having a disability by the school psychologist?

____ Birth to 3 ______ Age 3-5______ Elementary School

______ Middle School ______ High School

Did you have contact with the school psychologist before the initial assessment feedback conference?

How many years have passed since your child's initial evaluation?________

Does your child still receive special education services? ______________

How would you describe the school district your child was attending at the time it was determined they had a disability?

____ Urban _____ Suburban _____ Rural

Please indicate what disability the school identified in your child.

___ Learning Disability ____ Intellectual Disability ____ Autism

___ Emotional Disturbance ____ Visual Impairment____ Hearing Impairment

____ Other Health Impairment (such as epilepsy or ADHD)

____ Orthopedic Impairment _____ Traumatic Brain Injury

APPENDIX C

Screening Interview

Are you the parent of a child with a disability?

Do you live in Pennsylvania?

Is your child age 21 years or younger?

Did a school psychologist in a school in Pennsylvania initially evaluate your child?

Do you remember your child's initial evaluation?

"Parents & School Psychologists"-Interview Protocol

<u>Interview Script</u>

Thank you for taking time out of your schedule to participate in this study. This interview will be audiotaped. After the interview has been completed, it will be transcribed and reviewed in order to further my understanding of your responses.

Over the next 1-1 ½ hours I will be asking you a variety of questions about your child. These questions will focus on the time in your child's life when a school psychologist told you that your child had a disability. I will use the term "initial assessment feedback conference" to describe the time when you first received your child's evaluation results from the school psychologist. These questions will be personal in nature, so please tell me as much information as possible so I can best understand your responses. Each question will seek to obtain a clear understanding of your thoughts and reactions.

You may decline answering any questions that you are uncomfortable answering or that you do not want to answer. You may also stop the interview at any time if you do not wish to continue. The information obtained during this interview will be kept confidential. Any reports of the findings will not contain your name or any other identifying information.

At the end of the interview, if you have any additional comments or suggestions that you feel could contribute to this research or area of study please feel free to share your thoughts.

Do you have any questions for me before we begin? Ok, let's start with my first question.

Interview Protocol

1) Briefly describe your child.

2) Tell me about your experience when your child was being evaluated.

3) Tell me about your experience during the initial assessment feedback conference.

Follow up: What were you thinking during this event?

What were you feeling during this event?

4) Is there anything else you want to tell me about that day?

APPENDIX D

Resources for parents

For counseling services: Contact the phone number on the back of your insurance card for a list of approved providers in your area.

Additional resources include:

Bureau of Special Education's Consultline, a Parent Helpline

1-800-879-2301

The Pennsylvania Training and Technical Assistance Network (PaTTAN)

Harrisburg: 800-360-7282

King of Prussia: 800-441-3215

Pittsburgh: 800-446-5607

www.pattan.net

The ARC of Pennsylvania

800-692-7258

www.thearcpa.org

Parent Education Network (PEN)

800-522-5827 (Voice/TTY)

800-441-5028 (Spanish in PA)

www.parentednet.org

Disabilities Rights Network

800-692-7443

www.drnpa.org

Hispanics United for Exceptional Children (HUNE, INC)

215-425-6203; www.huneince.org

Parent Education and Advocacy Leadership Center

866-950-1040

www.peaicenter.org

The Mentor Parent Program, Inc.

888-447-1431

www.mentorparent.org

State Task Force on the Right to Education

1-800-446-5607 ext 6830