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## Parental Perceptions of the Diagnosis Process of Their Young Child with Special Needs

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LOYOLA UNIVERSITY CHICAGO

PARENTAL PERCEPTIONS OF THE DIAGNOSIS PROCESS OF  
THEIR YOUNG CHILD WITH SPECIAL NEEDS

A DISSERTATION SUBMITTED TO  
THE FACULTY OF THE GRADUATE SCHOOL  
IN CANDIDACY FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

PROGRAM IN CHILD DEVELOPMENT

BY

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CHICAGO, ILLINOIS

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## ABSTRACT

The diagnosis of a child with a special need can be an emotional and important time for parents. The existing research on the subject is decades old, limited in scope, and does not capture the current context. This is a qualitative interview study done with 24 families of children aged three to five who have been diagnosed as having a moderate to profound special need. The semi-structured interviews asked mothers, and some fathers, to tell the story of their child's diagnosis process. The data revealed that the process is very individual for each family. The results are shared in the form of five case studies, pattern models, and cross-sectional findings across interviews. The major findings were that professionals play an important role in the diagnosis process for families, that parents often believe the diagnosis process lasts a long time with three quarters of the families believing the process to still be ongoing for them, and that parental satisfaction with the process, as was studied in the previous literature, is an inaccurate measure of the process for parents.



## CHAPTER I

### INTRODUCTION

When a parent has a child diagnosed with a special need, it can be a devastating process. It can also be reassuring or validating, but it is almost never inconsequential. When parents find out for the first time that their child has a special need or disability it is a watershed moment, one that can change their thoughts and perceptions of their child and themselves. This emotional time can determine much of what parents are to experience over the next few years or several decades.

Most parents have some sort of ambivalence about the diagnosis process. No parents want to hear that their child is disabled. This revelation can bring about feelings of pain, anger, sadness, confusion, inadequacy, and blame. That being said, most parents have concerns about their child's development before the child is diagnosed and the knowledge that a diagnosis brings with it can be helpful, if not a relief. Most parents experience a mix of all these emotions, making the diagnosis process a particularly difficult transition for many parents.

As a service provider and member of a diagnostic team for preschool-aged children with special needs, I experienced parents' struggles with and through the diagnosis process. I know it is a pivotal time in their lives and the lives of their children. I have heard parents reflect on that time as a particularly dark point in their lives and heard others refer to it as a moment of great clarity and almost joy. The way parents

perceive this process can affect the way they accept their child's disability, their relationship with professionals, and their own understanding of themselves as parents.

The goal of this study is to gain some understanding into how parents perceive the diagnosis process of their young child with special needs. The overarching research question is: How do parents perceive the diagnosis process? Embedded within this question I also seek to find the answers to three, more specific, questions. What factors affect how parents perceive the process? What do parents want from the diagnosis process? How do parents perceive professionals during the process?

The diagnosis process is complex with many complicating factors. The role of professionals, specificity of disability, length of the diagnosis process, and parental expectations are all important facets that influence parental perceptions. It is also important to consider the current contexts of disability, special education, and society in general to understand the impact they might have on parental perceptions.

### **Definition of the Process**

The diagnosis process, itself, is not easily defined. It is influenced by many factors. The child's actual disability, the age of the child at diagnosis, and the agency or professional making the diagnosis can all influence the process. Therefore, it may be different for each family. For some families the diagnosis process may begin soon after the birth of the child, or even before, and end shortly thereafter with the disclosure of genetic test results. For other families the process may be much longer and never have a definitive ending point. Some families ultimately arrive at what they believe to be an

accurate diagnosis, some keep searching indefinitely, while others forgo the search before ever receiving a definitive diagnosis.

Many researchers and families seem to define the beginning of the process as the time when concerns about the child's health or development were first expressed. This initial concern may be expressed by professionals or by parents. Those concerns then often lead to an evaluation of some kind, whether medical, educational, therapeutic, or a combination of these disciplines. Different disciplines often have different names for the diagnosis process, as well. Evaluation, assessment, identification, and diagnosis can all mean the same thing for different professionals. These different terms give insight into the various purposes of the diagnosis process. Professionals may use diagnosis for eligibility for educational or therapeutic services, permission for pharmaceutical or surgical interventions, or any combination of these.

The various terms used by professionals also correspond to their chosen professional branch with the term "diagnosis" originating with the medical profession. Historically, disabilities were diagnosed by medical professionals. As will be discussed further in the context section, the medical profession has been joined by many other diagnosing agencies over the last 30 years and for the sake of consistency I have chosen to use the term "diagnosis" for all professional branches.

For some families the disclosure of the evaluation results and subsequent follow-up ends the diagnosis process and begins the treatment process. For other families it may be only the first of many evaluations and tests that may or may not eventually lead to a definitive diagnosis. Many families may only receive a diagnosis of a delay in

development without a clear reason for the delay. For these families the diagnosis process may only end when they choose to stop searching for a more definitive diagnosis. The diagnosis and treatment processes may overlap. An initial diagnosis of developmental delay may qualify a child for services but parents and/or professionals may continue to search for a more refined diagnosis.

For this study what is and is not part of the diagnosis process will mostly be determined by the participants. The participants will be asked to share their experience(s) with the diagnosis process. This open format allows for each participant to define his or her own experiences. I encouraged the participants to begin when their initial concerns for their children surfaced and to continue on until they believe the process ended for them or until the present if they do not believe they are finished with the diagnosis process.

### **Importance of Diagnosis to Parents**

Most children are diagnosed with special needs through parental pursuit of a diagnosis. While some children may be diagnosed through medical testing either shortly after birth or during routine care, the majority of disability diagnoses are made only after parental initiation of the process. Parents may pursue a diagnosis for their child for a number of reasons. Many parents pursue a diagnosis because it often holds the key to services to meet their child's deficit areas. If parents want help for their children it is very often granted only after it has been proven, or diagnosed, that their child has a special need. Most services are fiscally dependant on a diagnosis. Whether the source is state funding or private insurance, a diagnosis is frequently needed to pay for the

subsequent therapy services. The two are inextricably linked. Parents have refused services that they wanted for their child because the services came with a diagnosis or label that they did not want to accept. One must have a diagnosis to get services. The pursuit of services can be a driving force in the pursuit of a diagnosis.

Another reason parents pursue a diagnosis for their child is knowledge. Most parents of children with special needs accurately perceive their child's deficits and want an explanation for them. Other families have been referred to a diagnosing agency by concerned friends, family, or doctors and want more information that either dismisses or confirms these concerns. While most families wish for a person of authority to tell them that their child is fine and perfect, many families can be relieved to receive a diagnosis of a special need as well. A diagnosis can tell them that they are accurate assessors of their child's needs and that they are "not crazy" for thinking these things about their child. A diagnosis can give them a course of action, a likely prognosis, and a network of support. All parents want to know how their child will grow and develop, what they can do to help their child progress, and some sort of support in doing so. For parents of children with special needs who often don't follow typical growth and development patterns, this kind of information and support can be crucial.

Because the diagnosis process is the family's first knowledge of or confirmation of their child's special need, it can be an emotionally-laden experience. This is the time in which they begin to redefine themselves as parents of a child with special needs and when they begin to construct how their child's life will be affected by the disability. How parents cope with this adjustment can be linked to the diagnosis process. It can be

easier to adjust to a known diagnosis. Knowledge provided by the diagnosis process can help parents better prepare emotionally for what lies ahead. Parents of children with special needs start out the same as all parents. Like most people they have preconceived notions of what a disabled person or child is like, know little about what to do with that child, and want help making the transition to the parents and caregivers of a child with special needs. Professionals often have much of the information parents seek and how much and how that information is shared can matter tremendously in that family's life.

Diagnosis is when parents of children with special needs begin to "share" their child with professionals. During this uneasy time professionals play an important role in diagnosing the child with special needs, disclosing the information to parents, and then guiding families through to the next phase of treatment and intervention. This is often the first of many contacts parents have with the professionals that will play an important role in the life of their family. Often based on the interactions during the diagnosis process, parents learn whether they can count on professionals as allies in this new journey or as adversaries.

How parents perceive this process can influence their child's services. It can influence their interactions with professionals now and in the future. It can influence parents' acceptance of the disability and their child. It is also likely that it can influence many more aspects not yet discovered.

### **Context**

Much has changed in the way young children are diagnosed with special needs. Federal special education legislation drew attention to and gave more purpose to the

diagnosis of children with special needs. In 1975, PL 94-142, the Education of All Handicapped Children Act, gave parents and professionals a real, viable alternative to institutionalization. This made the diagnosis process not just the disclosure of unpleasant information, but a possible doorway to intervention and services. The diagnosis process now need not be a relegation to a life without choices or options. Up until this point diagnosis was used primarily to institutionalize children and left the families with little other options. This made the diagnosis process of a special need something to be feared not unlike the diagnosis of a fatal illness.

Enacting PL 94-142 was not a smooth road, however. Schools had to not only make room for students with special needs; they had to make services for them, too. Many of these changes came slowly and unevenly for students, parents, and schools. Many parents today remember the special education classrooms of their youth and the students within them and they do not have fond memories. When they have a child diagnosed with a special need they are afraid for their child's future based on their own limited knowledge of the special education system of years ago.

PL 99-457, Education of the Handicapped Act Amendments, passed in 1986, extended school-age special education services down to preschool nationwide and gave incentives for state-based birth to age three early intervention programs. It also mandated aspects of the special education eligibility process, such as parental involvement and interdisciplinary team assessments. This legislation entitled children with special needs to services even before typically-developing children entered public school. It reflected the changing beliefs of society that disabilities could be ameliorated through intervention

and that sooner was better. Society began to believe in the power of early intervention and education.

The Individuals with Disabilities Education Act or IDEA, passed in 1990, and its subsequent revisions, have only strengthened the parental role in assessment and education of their children. Because of these legislations, children with special needs are now entitled to receive services to help make them successful in school and later life.

These legislations not only revolutionized public education, but are changing societal attitudes, as well. By including children with special needs in public schools it shows that all children are special and valued. It has also allowed many more typically-developing children and adults to know, grow up with, and learn with individuals with disabilities. This has helped to remove some of the stigma of special needs, but the progress has been and is slow. Many parents who have young children diagnosed with a special need have to come to terms with the feelings they had or have about people who have mental or physical handicaps.

As demonstrated by the passage of PL 99-457, another dimension of change in the context of special needs diagnosis is the emergence of the early intervention systems. The concept of early intervention is widely accepted as what's best for children with special needs. Because of this strong belief in the power of early intervention, children are being diagnosed earlier and earlier. Diagnosing very young children can be challenging, as much of their development is still unknown. This has led to more evolutionary diagnoses. Children may receive an initial, general diagnosis, such as Developmental Delay to entitle them to services, but parents may still not know what is



“wrong” with their child. Children may be shuffled from professional to professional looking for a refined diagnosis. It is also entirely conceivable that a young child may receive several different diagnostic labels from several different professionals, leaving parents to wonder which one is the most accurate. Much of this is because a wider range of disabilities is being diagnosed in young children. Early intervention programs that were designed in the 1970s and 1980s to service children with Down Syndrome are now comprised of children with Developmental Delays, Autism, and Speech and Language Disorders. With the accepted power of early intervention, professionals often err on the side of identifying more children earlier than servicing too few children too late (McLean, Wolery, & Bailey, 2004, p. 111). When trying to get services to all children who may need it, professionals don’t rely on medical tests as the only qualifiers, as was once the case. Most disabilities in young children are diagnosed by clinical opinion with the aide of a diagnostic tool(s) such as standardized assessments, rating scales, checklists, or questionnaires.

With this emphasis on early intervention we see new service delivery models and therefore new diagnosis processes emerging. Most states have early intervention programs that identify and service children with special needs from birth to age three. All public schools now identify and service children with special needs from the age of three to 21. Many private insurance programs also pay for therapies for young children with special needs. In addition, many parents choose, or are forced by a lack of services in their area, to pay out of pocket for developmental therapies for their children. Early intervention services can be provided by any or a combination of these various agencies.

As stated earlier, no services are ever rendered without a diagnosis process. Children must be made eligible for services to receive the funding that pays for them. Therefore, more children are being diagnosed with special needs and at younger ages. Each of the providers of early intervention services has a diagnosis process and each provider follows its own guidelines and system. This is another reason why the diagnosis process is so complex and varied.

With the young age of children being diagnosed and services, not exclusion, often as the ultimate goal certain disability labels are used more widely. Developmental Delay is often a blanket term used by service providers to enable access to services. For our purposes the term “developmental delay” is comparable with “disability.” While in some instances these terms may have distinct differences, those differences are becoming less definable and the terms are often used interchangeably. In the interest of early intervention we are diagnosing children with special needs earlier than ever before. When children, especially young children, are first diagnosed with a special need it can be difficult to know with any certainty the child’s prognosis and how severe the need will manifest itself throughout the child’s life. What initially appeared to be a developmental delay may grow into more of a disability as the child progresses through life or vice versa. Additionally, the language of disability is changing. Words and labels can have profound effects on people and society is constantly redefining terms. The term “mental retardation” in its initial use and truest definition meant a delay or slowness of mental functioning and is now understood to mean a marked discrepancy in mental capacity that is unlikely to go away or lessen over time (Abrams & Goodman, 1998). Similarly,

developmental delay is becoming synonymous with disability. While an initial label of “developmental delay” may entitle a child to services it gives parents little information about the child’s specific needs and prognosis. For this reason parents may still pursue a more refined diagnostic label.

### **Need for Research**

Little research has been done on this topic and even less has been done in the United States. There have been only a handful of empirical research studies looking at this experience with none of them done in the United States. Additionally, much of the research done is over a decade, if not decades, old. Much has changed in this country with how and why we diagnosis children with special needs. It is a topic that so strongly affects the lives of families that it seems almost absurd that it has garnered such little research.

In an effort to find relevant research done in the United States, I contacted several professionals in the field. Ann Turnbull (personal communication, August 9, 2006), Penny Hauser-Cram (personal communication, August 24, 2006), and Barbara Keogh (personal communication, September 2, 2006) all concurred that little if any research had been done on this topic in this country. They all also expressed that they believe the topic to be an important one. Some pointed out that the topic has many facets and complications possibly leading to its lack of study. Carl Cooley (personal communication, August 17, 2006) pointed out the differences in looking at the diagnosis process as a whole versus just disclosure, as well as the differences between disabilities such as Down syndrome that can be proved with an “unequivocal laboratory test” and

disabilities such as Autism that may be considered a “matter of opinion.” Hauser-Cram discussed the difficulty of specificity of diagnosis and what might be considered a diagnosis to parents. In reference to the term “developmental delay” she states that in her experience “some parents considered this a diagnosis, others didn’t.” These are complicating aspects of the research, but they do not make it impossible to study. Any research done in this country should try to be as inclusive of these aspects as possible to try to get the broadest picture of the topic.

This lack of research leaves us guessing about how U.S. legislation, particularly, early intervention has affected the diagnosis process in this country. Many aspects of the process, as discussed earlier, are mandated by law and yet we have little knowledge about how the process is perceived by parents and whether those aspects dictated by legislation are helpful or hurtful. We also don’t know if the different diagnosing agencies and their various diagnosis procedures have any affect on parental perceptions of the process. The current state of the U.S. special education and intervention systems, as well as society, is something that cannot be duplicated by older studies or ones done outside the U.S. Therefore it is imperative that to understand the current diagnosis process in this country and how it is perceived by families, research must be done here and now.

The research that has been done focuses mostly on parental satisfaction with the diagnosis process (Cunningham, Morgan, & McGucken, 1984; Edelstein & Strydom, 1981; Krauss-Mars & Lachman, 1994; McKay & Hensey, 1990; Pearson, Simms, Ainsworth, & Hill, 1999; Piper & Howlin, 1992; Quine & Pahl, 1986; Quine & Rutter, 1994; Turner & Sloper, 1992). In all but two of these studies (Pearson et al., 1999; Piper

& Howlin, 1992) satisfaction with the process was measured with a single indicator, usually a single survey question. While parental satisfaction is certainly an important aspect to parental perceptions of the diagnosis process, given the complexity of the process and the emotional investment made by parents it is not the only aspect worthy of study. With the diagnosis process affecting parental coping, professional partnerships, service delivery and possibly other facets of a family's life, parental satisfaction may be an oversimplification of what needs to be studied. Research is needed that will study parental perceptions of the process as a whole so that important aspects are not missed.

Research has also focused mainly on the event of disclosure during the diagnosis process (Cunningham et al., 1984; Krauss-Mars & Lachman, 1994; Quine & Pahl, 1986; Quine & Pahl, 1987; Quine & Rutter, 1994; Turner & Sloper, 1992). As discussed when defining the diagnosis process, disclosure is a small, for some families, nonexistent part of the process. The diagnosis process can be long with stops, starts, and detours. Examining only the disclosure piece misses a majority of what many families go through. If we are to have a better understanding of how parents perceive the diagnosis process we need to try to understand what parents perceive of as the *whole* process. Only then can we begin to determine which aspects may or may not hold more weight with families.

Most of the current research also focuses strongly on parental and professional interactions (Cottrell & Summers, 1990; Cunningham et al., 1984; Edelstein & Strydom, 1981; Krauss-Mars & Lachman, 1994; McKay & Hensey, 1990; Pearson et al., 1999; Quine & Pahl, 1986; Quine & Pahl, 1987; Quine & Rutter, 1994; Turner & Sloper, 1992). While this initial interaction is one of the aspects that make the diagnosis process unique

and important, it surely is not the only important aspect. We know little about families' interactions between themselves, with their children, support groups, or with other families during the diagnosis process. Knowing that families often seek support during this time, these would likely be fruitful avenues for research.

Also, it is worth noting that work done on this topic within this country is largely anecdotal (Berube 1996; Choutka 1999; Featherstone 1980; Fling 2000; Frost 2002; Gonzalez-Abreu 2005; Kennedy 2001; Marsh 1994; Naseef 1997; Seligman-Darling 1997). Diagnosis stories have been told by parents and either published themselves or collected by professionals and published in books speaking to the role of parenting a child with special needs. Those who have investigated this process have wanted to share the information in its entirety, as a story. This suggests that the best way to study this phenomenon would be to study families' stories. Studying parental perceptions of the diagnosis process as complete stories told by parents gives the researcher the most complete picture of data on which to base a study. With so much left unresearched in this area using qualitative data gives the researcher the firmest, broadest base on which to base this and further research.

With a better understanding of parents' perceptions of the process we could help families make an easier transition and more fruitful relationship with service providers and possibly their own children.

## CHAPTER II

### REVIEW OF THE LITERATURE

The current literature available is limited, but does none-the-less shed light on a topic that is crucially important for families. As will be discussed in greater detail later, recent trends in legislation, special education, medicine, and early intervention emphasize the importance of the parental role in assessment and intervention. Professionals are acknowledging the expertise parents have about their children and are seeking input from them. This only underscores the importance of studying and understanding parental perceptions of the diagnosis process. If professionals are to treat parents as partners in practice then their opinions should be valued.

In this literature review I will review studies that examine parental perceptions of the diagnosis process of a child with special needs. In order to get the most complete picture of this topic, I will also review literature that examines the diagnosis process more generally, literature that examines specific aspects of the diagnosis process, as well as literature that examines factors closely related to parental perceptions of the diagnosis process.

The diagnosis process, with all its complexities, is somewhat cyclical and transactional. The factors that can influence the process are often part of the process itself. For example, professionals' role in the process can be an influencing factor, but is often seen by parents as a large part of the process itself. Likewise, parental perceptions

of the process can also influence the process itself. Parents do play a role in the diagnosis process and their perceptions influence their actions, thus influencing the process. For these reasons it can be difficult to create distinctions between the process, influencing factors, and parental perceptions. However, in the interest of organization, some categories have been created and distinctions have been made. These categories, while necessary to make meaning out of various kinds of literature with multiple findings, do not erase the connections between the process, influencing factors, and perceptions.

Another important aspect of the topic being studied is that it is usually filtered through a professional's lens. Most of what we know about the process comes from professional literature. Professionals may see and interpret parents' thoughts and actions as a professional, not a parent. There is, as will be discussed, some literature written by parents but there is less of it and it is more limited in scope. The majority of the literature is written by professionals about parents. This may not necessarily create a problem, but it does create a potential for bias. Professionals have traditionally held the power during the diagnosis process and the literature reflects that in its composition and may reflect that in its findings.

This may account for the fact that much of the literature is focused on professional role during the diagnosis process and parent and professional interactions during the process. The literature is so focused on parent and professional interactions that it often seems to refer to the interaction as the entire diagnosis process itself. Many studies focus solely on the disclosure aspect of the diagnosis process and even further on professional behavior during disclosure. These aspects of the diagnosis process often



represent the entire process in the literature. This concentration on professionals creates a skew in the literature and consequently this review of that literature. In this review, the variable definition of the diagnosis process, as well as a strong focus on professional role during the process are consequences of the construction and data provided by the existing literature. This supports the need for more research to be done and in a broader manner than it has been done.

Another potential limitation of the literature is that much of it is focused around parental satisfaction with the diagnosis process. Nearly all studies cite a parental satisfaction rate with most claiming that around 50% of parents describe themselves as being satisfied with the process. While this does tell us something important about the process and parents' perceptions of the process, it is likely that parents' perceptions of the process are more complicated than a simple yes or no statistic. Parental satisfaction rates are reported and discussed in this review with the understanding that this narrow focus is likely a limitation of the literature.

This focus on parental satisfaction leads the literature to identify certain important factors of the diagnosis process. While these factors do indeed seem influential, the narrow focus on parental satisfaction may cause other possible influential factors to be overlooked. While the literature focuses on aspects such as parent and professional communication and timeliness of diagnosis, parental perceptions may also be influenced by less obvious forces such as parental preconceptions, educational level, and temperament. There is little existent literature on these or other more subtle influences

on parental perceptions. They may arguably play a larger role than more obvious influential factors and would be a beneficial avenue for future research.

This review of the literature is done with the understanding that parental perceptions of the diagnosis process are subjective. They are, however, the subjective reality of families and are therefore powerful and important. I have made no effort to search for an objective viewpoint of the diagnosis process. These parental perceptions, however subjective, are the true understandings and feelings of parents. Therefore, they are important and worthy of study. To make the diagnosis process more satisfying for all parties involved parental perceptions must be valued and understood.

The literature is drawn from several disciplines of study: Special Education, Sociology, Medicine, Social Work, Early Intervention, and Child Development.

### **Parental Search for a Diagnosis and its Importance**

An important aspect of the diagnosis process is that it is often parent-led. While some parents have the news of their child's disability spontaneously shared with them, most parents must seek a diagnosis for their child. There are various reasons parents do this. Even when abnormality or delay is established, parents often seek a more definitive diagnosis. Rosenthal, Biesecker, and Biesecker (2001) studied parental attitudes towards a diagnosis of their children with unidentified multiple congenital anomaly syndromes. They found that parents pursue a diagnosis for several reasons. They characterize these reasons by six dimensions: labeling, causation or etiology, prognosis, treatment, acceptance, and social support. Without a concrete diagnosis or label parents can be fearful that people will think their child is "just stupid" (p. 109). It can also be harder to

procure services for a child without a definitive diagnosis. When a disability is present without a known etiology parents may feel guilty because without an identified cause they may feel that *they* are the cause of their child's disability. Parents of a child with special needs with no known diagnosis have no reference point for their child's prognosis. They also have no set treatment program that may be present with other known disabilities. They may also have delayed acceptance of their child's disability, instead seeking a way to "fix" their child (p. 110). Lastly, parents of a child with special needs, but no known disability, aren't able to partake in the kind of social support parents of children with known disabilities can. They cannot contact a certain support group or find families of other children with the same disability. Rosenthal et al. acknowledge that it is often not possible to diagnosis a child with a definitive label, but it is important to understand what parents want from the experience and the importance of the diagnosis to them.

The diagnosis process is important for many reasons. Parents, themselves, identify this time as a particularly salient time in their child's life. Parents often give detailed accounts of the diagnosis process, even years later, showing its perceived importance to parents (Marsh & Boggis, 1995; Todd & Jones, 2003). This is the time in which they begin to define themselves as parents of a child with special needs and when they begin to construct how their child's life will be affected by the disability. Many authors have noted that a lack of diagnosis, or delay or uncertainty in diagnosis, can affect how parents cope with and accept their child with special needs (Edelstein & Strydom, 1981; Quine & Pahl, 1986; Rosenthal et al., 2001). The diagnosis process is

also the first interaction between parents and professionals in the context of their child's disability and has a lasting effect on future interactions (Quine & Pahl, 1987; Turner & Sloper, 1992). For a young child with special needs and his/her parents these first interactions are also likely to be the first of many. The diagnosis process can shape much of a family's future life which makes it an important time in the lives of these families.

### **Context**

#### **Societal View of Disability**

The diagnosis process is largely influenced by societal forces. One of the most obvious societal influences on the diagnosis process is the societal construction and treatment of disability. Much of this social construction is linked to professionals' treatment of children with disabilities and their parents. Professionals diagnose and define disabilities specifically and disability in general. They also have a powerful status in society, thus much of what they believe and purport becomes ingrained in society. This affects parental perceptions of the diagnosis process by affecting the current societal atmosphere as well as professional treatment of families with children with disabilities.

Booth (1978), examining the idea of what he calls subnormality in families with children with mental handicaps, states "subnormality is not a quality within the person but a status allocated to them" (p. 218). That status can and has changed over time. In the years since PL 94-142, children with disabilities are being educated as opposed to institutionalized and intervention is ameliorating some previously believed permanent symptoms of disability. Likewise, parents of children with disabilities are being seen differently than they were before. Previously, professionals defined what parental

behavior seemed appropriate when coping with a child with special needs and those exhibiting different behaviors could be seen as unfit or pathological. Change occurs, but often slowly, and families with children with disabilities, like society in general, are often in flux. Families with children with disabilities enjoy a more elevated status than those of 20 years ago, however they often still struggle with a lower status than families with children who are typically-developing.

Family members often define children with disabilities more in terms of their individuality and relationships rather than in the more clinical terms of their skills and deficiencies. This can create a disconnect between how families feel about their children and how professionals and society feel about the same children. Booth (1978) states:

In more general terms the clinical perspective, which interprets social artlessness or incompetence as symptomatic of individual pathology, and which accounts for the realities of discrimination and prejudice they encounter in terms of the facts of their disability and their deficiency of skills, is inadequate for explaining the social roles which mentally handicapped people are allocated and the status ascribed to them in the private world of close personal relationships where they figure as individuals rather than cyphers. (p. 206)

With an emphasis on family-focused assessments and interventions, professionals are attempting to acknowledge and value the complex roles a child with a disability, and his/her parents, may play.

### **Professional and Parental Roles**

Another contributing factor to the diagnosis process is the societal construction of and varying appreciation of parental and professional roles. While many current trends in assessment and intervention portray parents as equal partners with professionals, it is often a tense relationship. “It is argued that the construction of parents as equal experts is

fraught with difficulties created at the interface between a liberal ideology and institutional structures, which are organized hierarchically around expertise” (Avdi, Griffin, & Brough, 2000, p. 328). Parents, while enjoying a societal role with more status than previously allocated to them, are still seen as in need of professional help and expertise making them less than equal partners. Professionals, too, struggle with this partnership. They want to be inclusive of parental input, but are often ultimately responsible for making a diagnosis. This ultimate responsibility coupled with a desire to be inclusive of and sensitive to parents can make diagnosis difficult for professionals.

With specific reference to diagnosis, professionals were represented as ambivalent, being generally reluctant to diagnose and at times inconsistent in their use of diagnostic labels. This reluctance was explained in terms of a mixture of factors including thoughtfulness, good intentions and fear of making mistakes. (Avdi et al., 2000, p. 332)

Professionals, particularly medical professionals, are given a powerful status in society (Avdi et al., 2000; Featherstone, 1980). Their expertise and knowledge is highly-valued and often unquestioned, even by other professionals. Featherstone discusses the resistance of doctors to working with other professionals, even advising families against seeking educational interventions (p. 185). She also discusses the resultant inadequacy sometimes felt by educational professionals. While Featherstone’s observations may be somewhat dated with the recent emphasis on interdisciplinary assessments, the underlying constructs and emotions may still be present. Little research has been done in this area.

With much of the diagnosis process dictated by law, professionals are having to give parents a bigger role in the diagnosis process. Pediatricians, the professionals who

see young children most consistently, are often considered to be responsible for initially identifying developmental delays (American Academy of Pediatrics [AAP], 2001; Blackman, Healy, & Ruppert, 1992; Haber, 1991; Oberklaid & Efron, 2005). In theory, parental input is seen as important to the diagnosis process (AAP, 2001; Beange, 1978; Blackman et al., 1992; Oberklaid & Efron, 2005), however, in practice, medical professionals still may rely on developmental assessments and clinical opinion with no consideration of parental knowledge (Haber, 1991). This reflects a traditional, and still present, view that parental report is an inaccurate assessment measure (AAP, 2001) and that only a doctor or instrument can accurately detect delays in a child's development. However, parental report has been found not only to be an accurate measure by which to screen for developmental delays, but has been found to be extremely cost-effective (AAP, 2001; Chen, Lee, Yeh, Lai, & Chen, 2004; Coonrod & Stone, 2004; Diamond, 1993; Heiser, Curcin, Luhr, Grimmer, Metze, & Obladen, 2000; Henderson & Meisels, 1994; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003). Researchers have also noted that parental reports are *more* accurate than professionals' assessments in that they reflect a more ecologically valid picture of the child (Diamond, 1993; Suen, Logan, & Neisworth, 1995). In attempting to understand parental perceptions of the diagnosis process it is important to note the role they may play in that process and the value placed on that role.

Spurred by legislation, parental involvement is an important part of special education services, as well. Children receiving birth through three early intervention services are required to have Individualized Family Service Plans (IFSPs). Children

receiving services aged three and above are also mandated to have parental involvement in the development of Individualized Education Programs (IEPs). Boone and Crais (1999) suggest that initial assessment is an important time to show parents that their involvement is respected and valued as it sets the tone for the rest of the professionals' and family's interactions. Although parental involvement is mandated, many professionals doubt parental abilities to be true partners (Brink, 2002; Minke & Scott, 1995). This shows the disconnect that often occurs between best practice touted by legislation and professional associations and actual practice by professionals in the field.

### **Parental Coping and Professionals**

Some of the distrust between professionals and parents may have its roots in how parents of children with special needs are understood by many professionals. Many researchers have studied the phenomenon of parenting a child with special needs however such a phenomenon cannot be easily understood by professionals. This is important to consider when seeking to understand parental perceptions of the diagnosis process. "All too often, professionals predict parental reactions from their own interpretation of the relative severity of the condition and their own set of attitudes, beliefs and value judgements" (Cunningham & Davis, 1985, p. 163). Professionals often pathologize parental reactions to diagnosis (Cunningham & Davis, 1985; Dale, 1996; Gallagher, Fialka, Rhodes, & Arceneaux, 2002; Roll-Pettersson, 2001) possibly seeing emotional reactions as indicative of poor coping. In actuality, most parents have very normal and even healthy reactions to the news (Cunningham & Davis, 1985; Dale, 1996; Gallagher et al., 2002; Naseef, 1997; Roll-Pettersson, 2001; Seideman & Klein, 1995). In my



experience, many professionals believe that parental perceptions of the diagnosis process are tied directly to parental coping. They believe that if a parent copes with the news well, they are happy with the process and if they don't cope with news well then they are unhappy with process. This view fails to account for the myriad other factors influencing the process as well as portrays a simplified view of parental coping.

Parental coping with the news of diagnosis has long been compared to that of bereavement. This stage theory, while valid in some respects, has been found to be an oversimplification of parental reactions. The literature discusses many proposed models of parental coping that may or may not better fit the feelings and adjustments felt by parents (Cunningham & Davis, 1985; Dale, 1996; Gallagher et al., 2002; Naseef, 1997; Roll-Pettersson, 2001; Seideman & Klein, 1995). The important aspect of all these proposed models is that they are all models of *coping*. Parents of children with special needs are not usually pathological in their grief and adjustment and they are not homogenous. They are individuals with individual circumstances and their reactions and adjustments to the news of diagnosis are just as individual. "There has been a tendency until recently for researchers and practitioners to focus on the negative and pathological reactions of parents at the cost of recognizing *the positive side* of being a parent of a child with special needs" (Dale, 1996, p. 67). Professionals, who traditionally struggle to understand parental coping adequately, should be wary of judging parental perceptions of the diagnosis process by how well they believe the parent is coping with the process.

Professionals themselves must be aware of their own feelings and coping mechanisms for dealing with the often uncomfortable experience of the diagnosis

process. They often feel emotions similar to that of the parents, albeit to a lesser extent, and must not let those emotions color their interpretations of parents and families (Cunningham & Davis, 1985; Dale, 1996).

### **Parental Accounts**

Insight into how the diagnosis process occurs and the roles of professionals and parents in that process leads to a more complete understanding of parental perceptions of the diagnosis process. An excellent source for the understanding of how parents perceive the process of diagnosis is the words of the parents themselves. Many parents have written, or transcribed, their stories of life as a parent of a child with special needs. Many parents share heartbreaking stories of first hearing the news of diagnosis, but there are heartening stories as well. Some parents refer to the diagnosis process throughout their discussion of parenting their child(ren) and living their lives. Others discuss it more specifically, with great detail. Their stories also reflect the varying length of time, from hours to years, in which they experience the diagnosis process. Very often these stories are told as part of a more general story about parenting their child with special needs. For these reasons, it can be difficult to tease out parental perceptions of the diagnosis process from parental perceptions of having and raising a child with special needs.

It is through these stories, however, that we are privy to the most intimate thoughts and discussions of parents not mentioned in the other literature. Some share the doubts they have in themselves as parents, “Could we meet even the simplest challenges this child might pose? Would we ever have normal lives again?” (Berube, 1996, p. 6). Others describe shock, guilt, and even relief (Featherstone, 1980; Fling, 2000; Kennedy,

2001). They also discuss how families deal with and cope with the diagnosis process within themselves. Parents describe leaning on each other for support, helping each other through the process, and even how it can strain relationships (Berube, 1996; Fling, 2000; Kennedy, 2001; Naseef, 1997). Many refer to the support of other parents and belief in a higher power as comforting and enabling them to manage day to day (Featherstone, 1980; Fling, 2000; Kennedy, 2001; Marsh 1994). They almost always discuss the intense love for their children and how this can be a driving force in the diagnosis process and their lives. It is these more personal accounts that allow us to get a glimpse into parents' minds and hearts in a way that the professional literature doesn't enable as easily.

These first-hand accounts do discuss professionals and the important role they have during this time and after. The stories often expose the insensitivity of professionals, but they also show the tremendous difference even one caring professional can make. These accounts show that diagnosis need not be an unduly traumatic experience for parent or professional. In fact, when professionals are perceived to have handled the process reasonably well, parents seem to only briefly mention the diagnosis process, moving on to the other important aspects of raising a child with special needs (Berube, 1996; Choutka, 1999; Kennedy, 2001). Even parents who write about more painful diagnosis periods can often look back and see that their pain was more from the sting of the actual diagnosis than from the professionals giving the news (Featherstone, 1980; Naseef, 1997). This combats the wide-spread notion that all parents will be unhappy with the diagnosing professional regardless of how the process is handled.

Although diagnosis is a difficult time for parents they are often sensitive to the

difficult job professionals have giving the news and they often have reasonable expectations for such interactions. However, many parents do describe more distressing interactions with professionals during the diagnosis process (Featherstone, 1980; Fling, 2000; Gonzalez-Abreu, 2005; Marsh, 1994, Seligman & Darling, 1997). Many parents had their concerns ignored and their parenting skills questioned by professionals while others had information purposefully withheld (Featherstone, 1980; Marsh, 1994, Seligman & Darling, 1997). Most parents, though, were hurt by general insensitivity from professionals (Choutka, 1999; Featherstone, 1980; Marsh, 1994; Seligman & Darling, 1997). Conversely, this can be seen by how incredibly touched parents are when professionals show caring and sensitivity to their children and to them. Even parents who undergo a long diagnosis process, or who still have no concrete diagnosis, can show a measure of contentment if they have been treated with care and respect (Fling, 2000; Frost, 2002). This only emphasizes the important role professionals play in parental perceptions of the diagnosis process. They can ease this difficult time for parents or further add to the pain and helplessness parents can feel. It appears that parental satisfaction with the diagnosis process does not hinge on the actual news received, but in how it is given.

### **Factors that Affect How Parents Perceive the Process**

Much of what influences the diagnosis process is closely linked. The timeliness of a child's diagnosis is often linked to how readily the disability can be identified and, often, the severity. The specificity of the diagnosis can also be influenced by these things. How parental knowledge influences the process all depends on how that

knowledge is shared and then used and perceived by professionals. Therefore, much of the distinction between the following categories is for the sake of organization as all of these categories are closely intertwined.

### **Timeliness of Diagnosis**

The literature shows that the concept of early intervention is widely accepted as best practice among professionals. It also shows that the earlier a child is diagnosed with a special need the more likely parents are to be satisfied with that process (Cottrell & Summers, 1990; Cunningham et al., 1984; Edelstein & Strydom, 1981; Palfrey, Singer, Walker, & Butler, 1987; Pearson et al., 1999; Quine & Pahl, 1986; Quine & Pahl, 1987). Quine and Pahl (1987) found that parents of children diagnosed younger and parents of children diagnosed with a known condition were more likely to be satisfied with the diagnosis process. These two factors often go hand in hand. Children with easier to diagnose conditions (e.g., Down Syndrome versus cerebral palsy) are typically diagnosed earlier and more succinctly than children with less definable symptoms or conditions.

One of the most influential factors of the diagnosis process is the timeliness of the diagnosis. Several studies cite this as one indicator of parental satisfaction with the process. Quine and Pahl (1986) surveyed 190 parents of a child with severe mental handicap in the Southeast of England. Thirty-five percent of the children had severe mental handicap with no known cause, 33% had Down Syndrome, 14% had Cerebral Palsy, and 18% had other known conditions (p. 54). Quine and Pahl present satisfaction rates by age of the child when parents were first told. Parents told earliest were most likely to be satisfied with parents told at birth showing a 51% satisfaction rate. Parents

told within the child's first year had a satisfaction rate of 33% and parents told during the child's second year or later had a rate of 27.5% (p. 55). This is typical of information presented in the literature. The sooner parents learn of a diagnosis, the more satisfied they are with process and the likelier they are to have an easier adjustment and acceptance of their child.

Edelstein and Strydom (1981) interviewed 22 families with a child recently diagnosed with Down syndrome in South Africa. They also administered mother-child relationship scales to assess the acceptance or rejection of the child by the mother. They found that half of the parents were told of the child's disability within 48 hours of the child's birth with an additional three parents told within one week. However, five parents were told over six weeks later. Edelstein and Strydom found that these five parents had the hardest time adjusting to their child's disability.

Cottrell and Summers (1990) examined the diagnosis process for parents of a child with an evolutionary diagnosis, one in which disability and/or the level of disability is not initially known. This has been a group found to have the lowest satisfaction rates for diagnosis. They gather their data primarily from a mothers' support group in London consisting of five families with a child with brain damage not present at birth. They found that parents want to be told as soon as possible, even if the disability is uncertain and the prognosis is unknown.

One of the more recent studies of the diagnosis process was done by Pearson et al. in 1999. They compared parental perceptions of newly diagnosed children with those of parents who had children who were diagnosed ten or more years earlier. Sixty-five

percent of the younger group felt that they were told about their child's special needs soon enough compared to 37% of the older group. This likely reflects the recent acknowledgement of the importance of early intervention.

An interesting addition to the findings linking timeliness of diagnosis to parental satisfaction and acceptance of their child comes from Quine and Pahl (1987) in an article published a year after their initial study. They examine the emotional response of parents to the news of diagnosis. This is noteworthy because professionals often cite poor emotional responses on the part of parents as reasons to delay a diagnosis (Edelstein & Strydom, 1981; Turner & Sloper, 1992). Quine and Pahl found that the majority of parents, 64%, spoke of their first reaction as one of shock (p. 233). Nineteen percent accepted the news rather easily because they had suspected something was wrong and 4% expressed that the news was a relief after a long diagnosis process (p. 234). Only 8% expressed feelings of anger, often because they believed mistakes had been made in their child's care by professionals or they had spent a great deal of time trying to convince professionals there was cause for concern (p. 234). Four percent said they felt feelings of rejection and most expressed that this was temporary (p. 233). This shows that parental reaction to the news of diagnosis is not something to be feared and certainly not a reason to delay diagnosis when a timely diagnosis has been shown to be so beneficial to families.

It is also worth noting that parents, although they want to be told as soon as possible, are tolerant of delays in the diagnosis when the reasons are justifiable (Cottrell & Summers, 1990; Cunningham et al., 1984). Parents also understand the difficulty in

making concrete diagnoses and want to be told as soon as possible that there is cause for concern (Cottrell & Summers, 1990; McKay & Hensey, 1990). In the current climate of early intervention it is especially important to make a diagnosis, even a non-specific one, to procure services (McKay & Hensey, 1990).

Palfrey et al. (1987) looked at some factors influencing the timeliness of diagnosis. They found that children with more complex, more severe disabilities were diagnosed earlier than children with higher-prevalence, less severe disabilities. Children with low-prevalence disabilities were more likely to be diagnosed by medical professionals earlier, whereas children with high-prevalence disabilities were more likely to be diagnosed by non-medical, often educational, professionals later. Not surprisingly then, early identification was strongly associated with physician identification. This brings up the question of the role that the diagnosing agency (e.g., physicians, state-run Early Intervention professionals, educators) plays in the process. It is possible that the diagnosing agency is also a factor that may influence parental perceptions of the process.

Another important finding from this study is that maternal education was found to be a predictor of early identification of disability. Being white and having a higher income level was also found to be linked with earlier identification of low-prevalence handicaps. This is quite possibly due the varying levels of access to resources and quality of resources experienced by families with different socio-economic status.



### **Specificity and Severity of Diagnosis**

Closely connected to the timeliness of the diagnosis is the specificity of the diagnosis. Children with more ambiguous disabilities are often diagnosed later than children with more readily identifiable ones. As mentioned earlier, many parents never get a specific diagnosis for their child only getting a diagnosis of delay or global disability (e.g., developmental delay, brain damage, cerebral palsy, mental and/or physical impairment).

Cottrell and Summers (1990) stressed that with an evolutionary diagnosis it is important to have regular appointments to keep parents informed of changes and developments in the diagnosis process. Cottrell and Summers state “it cannot be stressed enough that breaking the bad news is a process which may continue for years rather than a ‘one-off’ event,” (p. 214). McKay and Hensey (1990) interviewed the parents of 84 children with cerebral palsy in Ireland. They also discussed the difficulties associated with diagnosing a non-readily definable disability. However, parents still expressed that they would like to know as soon as possible if there are concerns. They also discussed how it is often difficult to procure assistance and interventions without a diagnosis.

Quine and Pahl (1986) found that parents of children with Down Syndrome and other conditions of known etiology were the most satisfied with rate of 45% and 41% respectively. Parents of children with cerebral palsy and those children where no cause was identified for their disability were less satisfied with satisfaction rates of 21% and 32% respectively. This is consistent with aforementioned findings that found that

children diagnosed earliest had parents who were the most satisfied since conditions with known etiology are often diagnosed earlier than other conditions.

It is unclear how disability severity is linked to parental perceptions of the diagnosis process. McKay and Hensey (1990) found that dissatisfaction was not proportional to severity of disability. Parents of non-severely disabled children were as likely to be dissatisfied as parents of children who were severely disabled. Piper and Howlin (1992) found that satisfaction with the process was found to be linked with the severity of the child's diagnosis with the parents of children with more severe disabilities being least satisfied. However, in their study parental perceptions of the value of the process was not linked to the diagnosis given. While not conclusive, what is shown in these studies is that having a child diagnosed with a severe disability does not inherently make parents unhappy and unsatisfied with the process. This is contrary to the long-held belief that parents are unhappy with the diagnosis process because it brings bad news and that the worse the news the more dissatisfied they will be.

### **Parental Knowledge**

Parents are the ones who know their children best and their assessments of their children have been found to be accurate. Pearson et al. (1999) who compared perceptions of the diagnosis process of parents who had newly diagnosed children and parents who had children diagnosed ten or more years earlier found that the majority of parents in both groups: 74% for the younger group and 69% for the older group, suspected something was wrong with their child before a professional's diagnosis. It can be frustrating for parents when their knowledge is not valued. McKay and Hensey (1990)

found that one of the main causes for parental dissatisfaction with the diagnosis process was having their concerns dismissed. Many parents felt as though something was wrong earlier than was recognized by doctors, but their concerns were not taken seriously. This not only frustrates parents, but wastes valuable time in which children can be receiving services.

Edelstein and Strydom (1981) found that one-third of the parents had suspicions about their child before they were told of their child's Down Syndrome. Some of these parents were concerned because of their child's development while others were suspicious of the behavior of hospital staff. This can be especially hard for parents when they feel like they are the last to be told about their child's disability. It makes it clear to them that they are not a valuable part of the process.

### **How Parents Perceive Professionals During the Process**

Much of the diagnosis process is directed by the professionals involved. Therefore, how parents perceive the process is largely dependent on the professionals: their knowledge, manner, and status. Professionals are an important influential factor on parental perceptions of the diagnosis process. Much of the literature is written with professionals as its audience and many guidelines have been written for professionals to follow.

### **Model Program**

In a landmark study by Cunningham et al. (1984), a 100% satisfaction rate was achieved by implementing a model program for disclosure of a diagnosis of Down's syndrome. This is important in that it is the most cited study on this topic in the literature.

The Cunningham et al. model has become, at least among researchers, the gold standard for disclosure practices. In the study, they interviewed 59 families of newly diagnosed children with Down's Syndrome in England. The findings from this research showed that 58% of the participants expressed some sort of dissatisfaction. Cunningham and colleagues then had an opportunity to take their results a step further. Pediatricians from one of the centers studied in the initial interview survey inquired about ways in which to improve their services. A model program for disclosure was then set-up. The program was based on these basic tenets: parents would be told (1) by a pediatrician and health visitor, if possible; (2) as soon as possible; (3) together; (4) in a private place; (5) with the child present; (6) directly and with time to ask questions; (7) a follow-up interview would be arranged (p. 36). Seven families received this model program of disclosure and 25 contemporary families from other similar centers comprised a control group. "The seven families who received the model provision made no critical comments at all, and when directly questioned all expressed complete satisfaction with the services" (p. 37). Only 20% of the control group expressed satisfaction with the process. This shows that, at least in some measure, higher levels of parental satisfaction are not only possible, but very doable. The Cunningham et al. model of disclosure has become the gold standard for the literature written about this topic if not for the diagnosing professionals.

Other researchers used the Cunningham et al. (1984) study as the basis for their own studies and professional evaluations. Turner and Sloper (1992) studied the diagnosis process of 24 pediatricians and compared it with Cunningham et al.'s model program. They also compared the results with parent interviews of the diagnosis process done in an

earlier phase of the study. Overall, “52 percent of the mothers said they were dissatisfied with the way their child’s diagnosis was given to them. None of the pediatricians interviewed used or were even aware of a standard, written policy for disclosure at their hospital. The pediatricians were found to not closely follow the Cunningham et al. model with no doctors mentioning all nine elements of the model program in their own disclosure methods and seven pediatricians mentioning fewer than half. Turner and Sloper also noted an inverse relationship between doctors’ years of experience and adherence to the model program showing that perhaps younger, more newly trained, doctors are better at following the elements of the model program.

Pearson et al. (1999) asked parents how their child’s disability was disclosed to them with questions structured around the Cunningham et al. (1984) model. Parents were asked if they were told together, what kind of environment they were told in, and was the child present. Fifty-six percent of the younger group and 43% of the older group were told together. Of those parents not told together, 47% said were given reasons for this, but that they did not find those reasons justifiable. Eighty-two percent of the younger group said they were told in an appropriate place with 43% of the older group feeling this was true. The main reason cited for the inappropriateness of the disclosure location was lack of privacy. Eighty-two percent of the younger group and 56% of the older group said their child was present during disclosure (p. 7). This appears to show some improvement in the disclosure practices of professionals over time based on the Cunningham et al. model.

## **Communication**

There are other factors, perhaps not given enough weight in the Cunningham et al. (1984) model, that affect how parents perceive their professional interactions during the diagnosis process. One of these factors is the communication between parent and professional. Abrams and Goodman (1998) examined the disclosure of diagnosis and how parents and professionals “negotiate” this process. Professionals are in the difficult position of sharing undesirable information so they must try to break the news gently, with sympathy and hope, but without being untruthful. Professionals do not enjoy sharing bad news with parents, because of this they often mitigate their assessment information and even change parts of it depending on parental reactions. Professionals use euphemisms, hedging, and negotiation while discussing diagnosis with parents (p. 88). Disability labels such as autism and mental retardation can be seen as especially hurtful and thus avoided. Abrams and Goodman found, though, that parents who were given less ambiguous diagnosis information, including a label of mental retardation asked less questions about the diagnosis and more questions about the prognosis “suggesting that the label facilitated some understanding of the diagnostic category” (p. 95). While certain diagnostic labels may be difficult to give and receive, Abrams and Goodman show that purposeful avoidance of such labels can lead to confusion during the diagnosis. They add that “parental confusion may inhibit acceptance of and accommodation to their child’s needs” (p. 96).

Bartolo (2002) saw similar behavior in both medical and educational professionals. In a study examining the diagnosis of preschool children with suspected

Autism Spectrum Disorders at both a medical and educational site, Bartolo finds that professionals from both sites have difficulty balancing “realism” with “hopefulness” (p. 66). Similar to Abrams and Goodman, he finds that professionals’ diagnosis can vary dependant on the interaction between parents and professionals during disclosure. He outlines three frameworks for negotiating diagnosis with parents: parent-friendly frame, hopeful-formulation frame, and defocusing frame. Professionals could defocus the disclosure off of a diagnostic label or hedge conclusions so much as to no longer be truthful. “A parent-friendly frame could be carried to the extreme of complete evasion of the bad news issue, with the professionals focusing instead on the child’s progress and special education provisions,” (p. 69). Professionals in the educational setting simply did not label the child’s disability diagnostically and professionals in the medical setting were seen to sympathetically agree with parental rejections of their own diagnostic label of autism. The diagnosis process is difficult for professionals and parents alike. It is important, however, for professionals to learn how to be both honest and kind when delivering a diagnosis to parents. The balance between realism and hopefulness in not easily achieved, but it is imperative for parental understanding and acceptance.

### **Information Sharing**

A more specific aspect of communication is the sharing of complete and timely information. In their study Turner and Sloper (1992) found that 53% of the mothers said they were not given enough information. Maternal satisfaction was also found to be less influenced by format of disclosure than manner of telling and whether they felt they were given enough information. However, it could be argued that more closely following the

Cunningham et al. (1984) model would more fully address the issues of manner of telling and making sure parents were given enough information. This is especially plausible considering the two most frequently missing elements of the model program from the pediatricians' own practices was presence of the child at disclosure, often seen as a sensitive gesture, and follow-up within 24 hours. A follow-up within 24 hours might have addressed maternal desire for more information given than many people believe this is the time for parents to process through and ask questions about what they may not have absorbed at the initial meeting.

McKay and Hensey (1990) also found that lack of explanation was one of the main causes for parental dissatisfaction. Parents complained of not having their child's condition explained to them, being scheduled for appointments and not knowing why, and the use of jargon that was not properly clarified. Krauss-Mars and Lachman (1994) examined the diagnosis process in Cape Town, South Africa and the cultural influences of the population on that process. A survey was taken of 90 parents of children, 40 of whom were coloured, 26 white, and 24 black. The children were all diagnosed as having mild, moderate, or severe physical and/or mental handicap present at birth or later. Krauss-Mars and Lachman note that the complicated diagnosis process is "even more complex in multi-lingual communities and in developing countries where the opportunity to break bad news arises only once" (p.102). This makes information sharing an even more crucial part of the process. Based on their findings, they suggest parents be informed in clear terms and that professionals be non-patronizing and open to questions. They also suggest that parents be given a written report and that follow-up appointments



for the whole family be made. Cottrell and Summers (1990) suggested a “key worker” approach to managing interactions between parents and professionals as parents complained about having advice, sometimes conflicting, come at them “from all sides” (p. 215).

Quine and Pahl (1986) suggest that another possibility is that professionals give adequate information, but patients don’t understand and/or remember all that was shared during such an emotionally-charged time. They suggest making follow-up visits because parents are often “too stressed” at the initial visit to absorb all that has been said (p. 60). Quine and Phal (1987) also suggest that parents be given a written report after the initial meeting. Interestingly, Piper and Howlin (1992) found that in terms of the feedback meeting after the assessment “nearly half felt that the amount of detail provided in the feedback was not very extensive but, nevertheless, 70% reported that, at the time, that amount was just enough to cope with” (p. 46). However, parents on average remembered 44% of the topics discussed at the feedback meeting, but remembered 67.5% when they had requested advice on such topics (p. 45). This is especially important in relation to Quine and Pahl’s (1987) suggestion that parental satisfaction with information sharing during the diagnosis process is really more of an issue of parents understanding and absorbing what it is said. It appears that parental retention is increased when they get answers to their own questions.

Written reports, as suggested by several researchers, would seem to aide in information sharing and retention. However, Pearson et al. (1999) found that of the two groups they studied 61% of the younger group and 87% of the older group reported not

receiving any kind of written information about their child's special needs. Interestingly, 77% of the younger group and 68% of the older group stated that they would not have found written information useful to refer to after the disclosure. This can possibly be explained by that fact that, of those that received written information, only 57% of the younger group and 71% of the older group found it useful. While written reports have been cited in other studies as important to parental satisfaction perhaps their content, not their mere presence, is just as important. Especially in this information age, where there is ready research on nearly anything, it is important to include specific, individualized information in written reports or information given to parents.

### **Professional Sensitivity**

Perhaps the most important factor in parental satisfaction, and arguably the hardest to define, is professional sensitivity. Often described in the literature as the "manner" of being told, professional sensitivity, or lack thereof, is incredibly important to parents. One of the main factors influencing parental satisfaction/dissatisfaction is the sensitivity of the professionals involved in the diagnosis process (McKay & Hensey, 1990; Turner & Sloper, 1992). Krauss-Mars and Lachman (1994) suggest that professionals need to be emotionally supportive and Cottrell and Summers (1990) suggest that professionals need to give parents hope. The parents in the study said that doctors seemed much more focused on them understanding the permanency of their child's condition than on giving them information about therapies.

On the other hand, parents who are satisfied report sensitive professionals. Piper and Howlin (1992) report 86.7% of parents found the experience to be "very" or "fairly"

valuable with the same number being “very” or “fairly” satisfied (p. 48). They also report 77.8% of parents viewed the teams’ assessment as “very” or “fairly” accurate in terms of their child’s abilities and 66.7% viewed the assessments as “very” or “fairly” accurate in terms of their child’s difficulties (p. 44). The parents generally felt that feedback was given sensitively and that even parents who received more troubling diagnoses didn’t feel the professionals were insensitive.

As another aspect of the study completed earlier by Quine and Pahl (1986, 1987), Quine and Rutter (1994) examine the effects of affective and cognitive models on parental satisfaction. Korsch’s affective model and Ley’s cognitive model (1968, 1977 respectively as referenced in Quine & Rutter, 1994) were tested in reference to parental satisfaction. They found that 58% of parents were dissatisfied or very dissatisfied with only 33% expressing satisfaction and the remaining 9% unsure (p. 1280). Using multiple regression analysis they found that “Korsch’s affect scale was a much stronger predictor of parental satisfaction than was Ley’s cognition scale. The variance added by other predictors was relatively small” (p. 1283). This shows that professional affect, or emotion, during the diagnosis process was found to be much more important to families than their cognitive understanding of the diagnosis. Korsch’s affective scale was found to account for 35.7% of the variance in satisfaction with Ley’s cognitive scale accounting for 1.4% of the variance. This quantifies what many other studies have noted, that a kind and sympathetic approach by professionals is needed. It is also consistent with the findings by Turner and Sloper (1992) that the manner of telling and information sharing are most important.

This is perhaps an oversight of the Cunningham et al. (1984) model. Sensitivity can be hard to quantify or even describe. Although they cite that parents wish to be told in an “honest and sympathetic way” (p. 33), the resulting model fails to capture that. It is also worth noting that very few professionals studied seem to follow the Cunningham et al. model. This may hint at some of the institutional structures and hierarchies that may interfere with a best practice approach.

### **Professional Politics and Structures**

All professions have structures and politics within them. It is worth noting some of the ones noted in the literature that may obstruct parents from having a positive diagnosis experience.

Turner and Sloper (1992) noted that none of the pediatricians interviewed used or were even aware of a standard, written policy for disclosure at their hospital. When “asked for their view of the value of such guidelines, ten were negative, seven were positive and seven were unsure or made qualified comments” (p. 355). Quine and Pahl (1986) and Featherstone (1980) discuss the complexities of professional autonomy. Professionals sometimes feel that their roles are questioned and undervalued, thus professionals, especially doctors, may be very protective of their right to use clinical judgment. This may prevent professionals from breaking from with long-standing protocols even if something better exists.

Krauss-Mars and Lachman (1994) found quite high satisfaction rates in their South African study. They reported satisfaction rates of 80% for white parents, 78% for coloured parents (used in this context to describe parents of mixed-race), and 75% for

black parents (p. 105). They give two possible options for such a high satisfaction rate. The first option is that the news was broken to them by experienced professionals at a developmental clinic. However, they acknowledge that this is not concurrent with Turner and Sloper's (1992) findings. The second option is that "given the political history of the country, many disempowered members of the population have a subservient respect for the medical profession and for authority as represented by white doctors, and are less inclined to criticize" (p. 108). This view is supported by the fact that although satisfaction rates were quite high, a quarter of the parents, comprised of 50% of the white parents, 18% of the coloured parents, and one black parent, made suggestions for improvement. Professionals enjoy a more elevated status than parents in most countries and the repercussions of this are likely felt by parents during the diagnosis process.

Quine and Pahl (1986) also examined possible barriers to implementation of best practice suggestions for disclosure of a diagnosis. First, in expressing concerns to parents as soon as possible, there are hierarchical structures within professions as to who is allowed to share this information with parents. In their study, it was almost always a doctor who had to disclose the news to parents sometimes leading to delays in telling when several other medical staff knew of the condition. This is a practice that may be changing when various kinds of professionals can make an initial diagnosis in the interest of early intervention. Secondly, professionals may appear unsympathetic to parents when traditionally 'clinical detachment' has been a staple of good professionalism in the medical field (p. 58). This stoicism has been valued in the medical tradition as a method of seeing and solving problems rationally and as a defense mechanism protecting doctors

from the ever-present stress and anxiety that comes with treating and sometimes losing patients with difficult conditions. Lastly, there are several possible barriers to full disclosure and information sharing between professionals and parents. One possible explanation lies within the traditional power structure between doctor and patient with the doctor having all the information and the patient following orders submissively.

### **What Parents Want From the Process**

When Cunningham et al. (1984) conducted their landmark study they reviewed the existent literature at the time and found consistencies in how parents wanted to be told about their child's disability.

All have concluded that parents wish to be told as soon as possible, together, in a private, direct, honest and sympathetic way, and to have immediate and easy access to services which provide accurate, comprehensive and practical support and guidance. (p. 33)

Other researchers found similar requests from the parents in their research. One of the most frequently requested actions from the diagnosing professionals was that they be sensitive and supportive (Edelstein & Strydom, 1981; Krauss-Mars & Lachman, 1994; Quine & Pahl, 1986; Quine & Pahl, 1987; McKay & Hensey, 1990). Clear, full, and useful information is also something that parents want from the diagnosing professional (Edelstein & Strydom, 1981; Krauss-Mars & Lachman, 1994; McKay & Hensey, 1990; Quine & Pahl, 1986; Quine & Pahl, 1987). Some researchers and their participants gave greater detail of what kind of information is the most beneficial. Some specified a written report would be helpful (Krauss-Mars & Lachman, 1994; Quine & Pahl, 1987) while others wanted practical advice on the care of their child (Edelstein & Strydom, 1981; McKay & Hensey, 1990). Other important aspects identified were being told as

soon as possible (Cottrell & Summers, 1990; McKay & Hensey, 1990; Quine & Pahl, 1986; Quine & Pahl, 1987), in an honest way (Cottrell & Summers, 1990; Edelstein & Strydom, 1981; McKay & Hensey, 1990), and with a follow-up appointment (Cottrell & Summers, 1990; Krauss-Mars & Lachman, 1994; Quine & Pahl, 1986; Quine & Pahl, 1987). Others mentioned being told together and in a private place (Cottrell & Summers, 1990; Quine & Pahl, 1986; Quine & Pahl, 1987).

### **Discussion**

There is agreement in most of the studies on what a diagnosis process should look like to be the most satisfying for parents. It has been established that parents of children with both readily identifiable diagnoses and those with evolutionary diagnoses would like to be told as soon as possible of professional concerns. It has also been established that parents are often the first to suspect abnormalities in their child's development and that these suspicions are credible and should be respected. Findings also show that *how* parents are told about their child's disability strongly affects their satisfaction with the process and even their acceptance of their child.

Cunningham et al.'s (1984) model program has become the gold standard for disclosure practices. Recent studies show that perhaps the program could be amended to give greater priority to the professional's affective behavior during the disclosure and to outline communication and information sharing practices more explicitly. With recent emphasis on parent/professional partnership and the research findings that show initial parental concerns rebuffed by professionals, the program could also be expanded to cover the entire diagnosis process and not just disclosure. Suggestions for best practice earlier

in the diagnosis process might be to treat all parental concerns as justified until clinically proven otherwise.

Another important aspect of the research is its breadth over time. Much of the research, most notably the study by Pearson et al. (1999), claims that the diagnosis process has gotten better over time and recent parents are more satisfied. However, with most overall satisfaction rates hovering around 50% regardless of when the research was done that claim seems difficult to justify across the board. What does seem to have changed dramatically over time is the overall make-up of the process and what parents expect from it. Parents have always wanted a sympathetic professional to guide them through the diagnosis process, but that profile has undergone some qualitative changes. Parents of children diagnosed most recently share stories of insensitivity such as “They were fairly sensitive but I couldn’t get over the fact that they used the word ‘retarded’” (Piper & Howlin, 1991, p. 51). Whereas parents of children who were diagnosed years or decades before share stories like the mother who was sedated by hospital staff and coerced to try to sign a release for her daughter with the pediatrician telling her that “she has something that was too much to talk about, that I shouldn’t worry myself” (Darling, 1979 in Seligman & Darling, 1997, p. 42). Clearly much has changed over the years that have affected the diagnosis process and professional communities and society have come a long way in their acceptance of children with special needs. However, the literature is unclear on whether the changes undergone by society are enough to affect parental satisfaction with the diagnosis process.



### **Implications for Future Research**

None of the empirical studies reviewed here were done in the United States. While studies done in the United Kingdom, Ireland, and South Africa have something to add to our understanding of the diagnosis process they cannot substitute for studies done within the United States and all the institutional, political, and cultural nuances it brings. There needs to be research done in the United States on this topic. Some of the potential complications of this research are that the parameters of the diagnosis process are hard to define, there are several patterns to diagnosis in this country, and that any research done on this topic is forging new conceptual frameworks. Therefore, new research will need to define the diagnosis process carefully to be inclusive of as many families' experiences as possible. The research should examine the various systems and agencies families experience through the diagnosis process and their possible effect on parental perceptions. Most notably the medical community, birth to three early intervention programs, and school-based early intervention programs are all professionals likely to be encountered by families seeking a diagnosis. Lastly, research done in this country could build on the existing anecdotal reports by finding conceptual frameworks and research designs that capture parental experiences during this important time.

The diagnosis process of children with special needs is complex. However, parental perceptions of the diagnosis process need not be as complex. While all parents, children, and families are unique, they are all still families. The research shows that most parents share the same set of core wants and needs. This is a good starting point for future research.

However, the scope of the literature is somewhat narrow both in how it defined the diagnosis process for parents and what influencing factors it studied. Future research would benefit from a broader definition of the diagnosis process, an increased scope of influencing factors, and less focus on parental satisfaction as the single measure of the process. Although professional role and interaction are important parts of the diagnosis process, future research would also benefit from a broader base of study. With such little known about parental perceptions of this process creating too narrow of a focus leaves the possibility of missing important aspects of the research.

## CHAPTER III

### METHODOLOGY

This research studied parental perceptions of the diagnosis process of their young child with special needs. The overarching research question was: How do parents perceive the diagnosis process? Embedded within this question I also sought to find the answers to three more specific questions. What factors affect how parents' perceive the process? What do parents want from the diagnosis process? How do parents perceive professionals during the process? I interviewed families about the diagnosis process as they experienced it. I interviewed 24 families chosen by criteria outlined later to create a purposeful sample of families with a variety of experiences with the diagnosis process.

The research that has been done on the topic in this country is largely anecdotal. This influenced my research in two ways. First, it led me to a qualitative methodology. With so little research done, there is much to be learned about the diagnosis process. Qualitative methodology allows for the depth of research important for a topic so overlooked. It enables theory generation, preservation of a rich and personal context, and the breadth sufficient to study a complex and varied phenomenon. Second, qualitative methods are more akin to the anecdotal research that has been done in this country. What anecdotal stories lack is the empirical authenticity of an organized research study? Qualitative methods enable that authenticity while preserving the heart and context of the anecdotal stories.

### **Theoretical Framework**

This research was a qualitative interview study. While all research designs have their limitations, a qualitative methodology enables one to build a broader base from the existent anecdotal work. A qualitative methodology can enhance the anecdotal data by giving it authenticity through a semi-structured protocol, designed sample, and analysis of data. The anecdotal stories in the literature have a richness of detail and emotion that can be captured in a qualitative interview study. However, a qualitative interview study can make that data more useful by giving the interviews some uniformity and a structured sample design developed to account for relevant factors. The resultant data can then be analyzed within and across interviews allowing important concepts to emerge and be studied further. A qualitative interview study can take the “stories” of families and make them useful and relevant to the research community.

A qualitative study allows for the complexity of this process and the context in which it occurs to be captured. Even with the existing literature, there is still little known about this topic. At this point, one cannot choose which factor(s) to study while overlooking all other potentially important factors. The literature can inform a direction in which to look, but broader data must be collected and analyzed since so little is known about a process with many influential factors in a context not yet studied. A qualitative interview study allows for inquiry into certain potentially fruitful avenues while keeping the study’s focus broad enough to accommodate unforeseen findings.

Qualitative interviews provide rich data that can have numerous applications. However, narrative inquiry, especially the kind proposed here, can be idiosyncratic and

emotional. A good interviewer with a good protocol has to work to maintain the valuable aspects of such a methodology without letting the interview go off-course or the data become muddled with inconsistencies or personal agendas. A sympathetic, but objective interviewer can make participants feel comfortable enough to share their experiences while maintaining the research's goal.

This research was a mix of phenomenological research, grounded-theory, and case study methodologies. It is phenomenological because, in essence, I studied the phenomenon of diagnosis from the parental point of view. I also understand that the phenomenon I studied is completely subjective as seen through the eyes of the parents. This is the exact phenomenon I was interested in; the one experienced by the parents, not an objective reality unseen or unfelt by the participating parties (Berg, 2001; Creswell, 2007; Moustakas, 1994).

While I believe my study to be essentially phenomenological in nature, it is not adequate to only describe the process as such. I studied factors that shape parents' experience of the diagnosis process, as well. My study used a purposeful sample created using some of the factors suspected to influence the diagnosis process. I created a sample that included several participants under different categories including disability label, diagnosing agency, and age at diagnosis.

My research could also partially be considered grounded-theory driven. I went into this research with only a skeleton of what the important theoretical constructs could be. As is a hallmark of grounded theory research, I modified my methods and protocol questions to pursue aspects of the research that cropped up or proved especially salient

(Berg, 2001; Creswell, 2007; Strauss, 1990). For example, when it became obvious that many parents believed the diagnosis process to be ongoing for them and their family, I turned what was designed to be a more summative question into a more probing aspect of the research. However, each family's experience is unique and I treated each interview freshly while still pursuing important avenues that emerged throughout the study. It was important to maintain the totality of each family's story while finding new ways to characterize the process as a whole. I did not create new theories but looked for useful ways of conceptualizing the diagnosis process.

One of the ways I sought to build theory or conceptualize the diagnosis experience was through the use of the interviews as mini-case studies. Given the complexity of the topic, it was beneficial to be able to look at factors in-depth within one family's story (Berg, 2001; Creswell, 2007). With that being said, I looked for overarching themes, similarities and/or contrasts between the experiences. However, those themes and characteristics are best understood in their unique context and I did not want to lose that reference point. Each interview was summarized and five families' stories were chosen as illustrative case studies and analyzed as such. Therefore, I analyzed the interview data two different ways: once examining the individual factors that affect the diagnosis process and once examining how those factors come together to make each individual family's story.

First, I analyzed individual aspects of the process as they applied to the interviews in the study. This analysis allowed individual factors and themes to be discovered and compared across interviews. This way, these factors could be analyzed for their effect on

the diagnosis process as a whole. Then I examined how these factors came together to create each family's unique story. Examining and illustrating how these factors came together to create a single experience for family's can help to show the complexity of each family's experience.

### **Description of Protocol**

I did qualitative interviews with the sample families. The interviews were semi-structured with questions and sub-questions that I asked only if the participant did not cover the topics on his/her own. I interviewed the participants for about an hour, though times varied from about a half hour to over an hour and a half, and asked them to tell me about the diagnosis process as they experienced it. I changed the protocol slightly from interview to interview, but essentially asked the participants about the same topics. The protocol was as follows [the items with asterisks may have been repeated if the parent(s) sought multiple diagnoses]:

Tell me a little bit about (your child).

How would you describe his/her needs? Strengths?

Describe the diagnosis process as you experienced it with (child).

How did this all unfold?

What were your initial concerns, if any?

How old was your child when these concerns surfaced?

How did you feel about it?

What did you do with the concerns you had?

How did you make the decision(s) to seek a diagnosis?

What action did you take next?\* Why?\*

How old was your child at this time?\*

Where did you go?\* Why?\*

How did they diagnose your child?\*

What was your role?\*

How did you feel about the experience?\*

How did you feel about the disability/label?\* Why?\*

Do you feel like the diagnosis phase is over for you? Why?

Is your child receiving services?

What made/makes this process difficult?

What made/makes it easier?

How did/do you feel about the professionals you encountered?

Were they sensitive?

Did you feel supported?

How did/do you feel about the information you were given?

Was it helpful?

Was it enough?

How have these things affected your present life?

Your relationship with (your child)?

Your spouse (each other)?

Your family/friends?

What did/do you want from the diagnosis process?



Do you feel like you got it?

If I were a parent just beginning the diagnosis process with my child, what would you want to tell me?

How satisfied were you with the diagnosis process as you experienced it?

I designed this protocol with several criteria in mind. First, I understood that talking about their child's diagnosis experience could be an emotional experience for parents and I wanted to begin by having them tell me generally about their child. This, I believe, made them feel more at ease and give me a general picture of their child as a context for the information they shared.

Second, I designed the protocol to begin with general questions and progress to more specific questions. When interviewing I asked the more general questions and only asked the specific ones if the topic was not covered in the participant's answers to the more general questions. Occasionally, I clarified questions if parents were unsure of how to answer them. The most common example of this was when I asked parents to "Describe the diagnosis process as you experienced it with (child's name)." Many parents expressed that they were unsure where to begin and I told them to begin when they or someone else first had concerns about their child's development.

Third, the protocol was designed to answer the research questions. The overarching research question "How do parents perceive the diagnosis process" was answered generally by the participant's entire story. More pointed questions such as "Do you feel like the diagnosis phase is over for you?" helped answer this research question in more nuanced ways. The first research sub-question "What factors affect how parents'

perceive the process?” was answered by the participant's description of the process and their discussion of what factors seemed to be important to them. The second and third sub-questions are addressed specifically in the protocol by the probes “What did/do you want from the diagnosis process?” and “How did/do you feel about the professionals you encountered?” as well as through the general discussion of the process.

Fourth, the last two questions “If I were a parent just beginning the diagnosis process with my child, what would you want to tell me?” and “How satisfied were you with the diagnosis process as you experienced it?” forced the participant to think about their experience in ways they might not have before and make some concrete conclusions of their own.

### **Sample Construction and Rationale**

I constructed a sample of 24 families with children with various diagnostic labels. In order to look at this issue with the widest lens, I wanted a spectrum of diagnostic labels and, indeed, was able to achieve that. I also tried to group the labels as much as possible in order to investigate some possible similarities or differences between groups. I looked for disability labels that might logically correspond to different patterns of experiences within the diagnosis process. I created a sample with diagnostic labels that covered four specific factors. I recruited families with children that had different methods of diagnosis, different diagnostic agencies, different time frames, and labels that varied in their specificity.

First, I looked for disability labels that represent different likely methods of diagnosis. Down Syndrome, or similar chromosomal or genetic disabilities, is often

diagnosed at birth or before with medical tests whereas a disability such as Autism is typically diagnosed around age two or later with clinical opinion, possibly coupled with ratings scales or checklists, being the usual diagnostic tool. Evolutionary diagnoses, those disabilities diagnosed over time as opposed to diagnosed with a single test or procedure, create a unique experience for families. Children diagnosed later often have more evolutionary diagnoses compared to children diagnosed younger. The literature tells us that these two populations are likely to have markedly different diagnosis experiences (Cottrell & Summers, 1990; Cunningham et al., 1984; Edelstein & Strydom, 1981; Palfrey et al., 1987; Pearson et al., 1999; Quine & Pahl, 1986; Quine & Pahl, 1987).

Second, different ages at diagnosis for the child likely means they were diagnosed by different agencies, as well. Children diagnosed at birth or shortly thereafter were likely diagnosed by the medical community. Very young children in general, before age three, are likely to be diagnosed by medical professionals or therapeutic professionals either through a state-run Early Intervention program or private practices. Children age three and above may be diagnosed by their local school district. The special needs diagnostic community consists of these three diagnosing agencies; medical, therapeutic (including the state EI program), and educational. This mosaic of diagnosing agencies is unique to this country and therefore important to capture in this study.

Third, differing ages at diagnosis also creates a sample in which varying amounts of time have elapsed between diagnosis and interview. Although this aspect has not been studied specifically, it is possible that the passage of time may make a difference in how

parents remember the process, both in recollection and emotion (Pearson et al., 1999).

For example, families may remember the diagnosis as less traumatic with the passage of time or they may grow increasingly dissatisfied with the process if they encounter new obstacles in their child's life that they feel should have been addressed at diagnosis.

Fourth, I looked for labels that varied in their specificity, which may affect how families perceive the diagnosis process. A global Developmental Delay label is likely to engender different feelings from parents than a more specific one such as Autism or Down Syndrome. This is an area that is not well-examined in the literature. The use of the term Developmental Delay may be utilized much more in this country than in others. Penny Hauser-Cram shared this aspect as a complicating factor about studying the diagnosis process in this country (personal communication, August 24, 2006). The specificity of the label may also be tied to how evolutionary a diagnosis may be.

### **Setting**

I recruited families enrolled in early childhood programs run by a special education school district cooperative. The cooperative consists of eighteen school districts located in the suburbs of a large Midwestern city. The cooperative encompasses elementary and high school districts and provides various services to them.

I recruited from the early childhood programs in the cooperative. There are approximately 12 classes with about 150 students total of various disabilities. Children in the Early Childhood Programs are typically aged three to five.

## Recruitment

The cooperative sent recruitment packets (see Appendices A-C) home to families of children with Individualized Education Programs enrolled in the early childhood programs for children with special needs. Children in these programs are classified as having moderate to profound special needs. In the recruitment packet there was a cooperative introduction letter, a research introduction letter, a consent form, and a brief questionnaire.

I sorted the families for the sample based mostly on their child's disability label. On the questionnaire, the parent(s) chose which disability label *they* felt best fits their child's needs. Families often encounter many disability terms when searching for an appropriate diagnosis for their child. For example, one child may receive the disability labels of Developmental Delay, Speech Language Impairment, and Autism from three different professionals. Having the parents choose the label gives them the power to express which label they believe to be the truest assessment of their child.

I recruited families for the research study with a single mailing and additional independent searching for families to fit the Down syndrome disability label, which will be discussed later. I received responses from families that represented a broad spectrum of disability labels. The interview and recruitment phases were overlapping and lasted about three months.

### **Interview Procedures**

I piloted the interview protocol with three families who had a child diagnosed with a special need, but who were not part of the recruitment pool. The results of those three interviews were used to refine the protocol and interview techniques, especially in light of the sensitive nature of the topic being discussed. One of those interviews was included, in a limited scope, in the research study. That mother's contributions can be found in the analysis section discussing Down syndrome as a disability type.

Of the chosen research families, I interviewed all the mothers and four fathers also contributed to the interviews. I interviewed whoever consented to the study. My goal was to get the family's diagnosis story and I understood that the parents may have different viewpoints on the subject. However, for a qualitative study such as this, that does not diminish the integrity of the sample but adds interesting dimension.

I let the participant choose a location for the interview in which he/she felt comfortable. I interviewed families in coffee shops, libraries, cafes, workplaces, and their homes. The interviews were semi-structured with talking points I wanted addressed, but with flexibility for the participant to tell his or her own story. I asked the broader, more open-ended questions and let the participant tell his or her story. If the participant did not cover aspects of the protocol within his or her story then I asked about the topics more pointedly. Typically, much of the protocol was answered through the natural course of the participant's story. Interviews were digitally recorded and later transcribed in their entirety by a transcription service.

### General Analysis Procedures

The analysis process took place on various levels to capture the influence of individual factors and the experience as a whole. First, all interviews were treated as a single data set and individual factors and themes were studied. This cross-examination of the data was done first with a completely open analysis and then analyzed based on the study factors and interview questions. A content analysis was done and all interview data were coded to sort the data and therefore facilitate analysis of grouped topics. Codes (see Table 1) were devised to sort the data into comments about relevant topics.

Table 1: Interview Response Codes

Professionals in general	Parental knowledge of their children's needs
Pediatricians	How information was shared
Other medical professionals	If and when the process was over
Medical-based practices	What made/makes the process easier
EI professionals	What made/makes the process more difficult
EI-based practices	What parents want from the process
School professionals	How the process fulfilled their expectations
School-based practices	How satisfied they were with the process
Private therapists	Parental advice
How parents learned about service providers	

This conceptual coding encompassed topics of parental discussion rather than single words or phrases. Sections of interviews discussing the relevant topics were coded and reports were then generated by code using TAMS Analyzer software. Some of these codes became analysis sections of their own, such as pediatricians, EI professionals, and school professionals, while other codes, such as how information was shared and parental

knowledge of their children's needs, were absorbed into and discussed within other sections.

Once codes were devised and data were sorted, analysis within those codes took place. Within codes, data were further grouped by similarities of comments and comment topics. For example, comments within the pediatrician code could be further sorted into comments about deferred parental concerns, pediatricians' limited knowledge of developmental issues, how pediatric practice groups impact the process, and the power differential between pediatricians and parents. Then each of these subgroups was further examined for its impact on the larger diagnosis process. For example, parental concerns deferred by pediatricians can lead to parental frustration and delay in diagnosis and thus a delay in receiving services.

Each interview was also read and analyzed on its own. This analysis shows how all the individual influential factors combine to make a unique, multifaceted experience for families. This is a strength of this type of qualitative data. The literature, as well as my personal communications with researchers in the field, expressed the challenge of studying the diagnosis process because each family has such an individual experience. This retrospective analysis of each interview as an individual story did show similarities of themes and issues between stories. Many of the themes noted in the individual interviews became the foci of the case studies such as difficulty finding a diagnosis, emotionality surrounding the process, and familial cultural factors. Representative case studies were then chosen and analyzed to highlight the specific issues experienced by these families and others within the sample.



In addition to case studies, summaries were created of all family stories. These summaries were created using an outline that highlighted aspects that were present in all stories, such as age of child, diagnostic label, birth order, whether parents believed the process to be over, and parental satisfaction with the process. Using a similar formula for all summaries shows how the individual mix of each family's factors creates a unique experience. These summaries can be used as a contextual reference for the reader when discussing the results and analysis of any family experience.

The concept of diagnosis patterns was also examined in the retrospective analysis of familial experiences. Through this analysis three different patterns emerged. Within these pattern models families shared similar aspects of the experience. Specificity and severity of diagnostic label, diagnosing agency, and subsequent treatment all seemed to be associated with the pattern of diagnosis. This pattern classification became another way to characterize the diagnosis process for families.

Examining the data in these ways enabled the data to be used to characterize the process in several ways. The cross-sectional analysis of the data allowed the data to show the impact of various factors on the diagnosis process across the sample families' experiences. Case studies, summaries, and diagnosis pattern models all characterized the data in different ways but all characterized the process within the entirety of each family's story. As a whole, the various methods of analysis uncovered influential factors to the diagnosis process and how those factors come together to make a family's experience.

## CHAPTER IV

### RESULTS

I conducted qualitative interviews with 24 families about their experiences with the diagnosis process. The results answer the four basic research questions: How do parents perceive the diagnosis process? What factors affect how parents perceive the process? How do parents perceive professionals during the process? and What do parents want from the diagnosis process? These questions provide an overarching structure to the results, but the results can and will be described in many different ways.

Some of the results were what might be expected, while other aspects of the interviews were quite surprising. As the literature had predicted, professionals play an important role in the diagnosis process. While the number of professionals and the importance of their roles varied from interview to interview, most parents spoke often of professionals without being prompted to do so. The role of the child's pediatrician was especially important as it was discussed in nearly all the interviews. In the sample interviewed, most considered their pediatrician the person they would contact first with concerns about their children. The experiences with their pediatricians varied from invaluable support to demeaning and confrontational.

Another predictable aspect of the interviews, based on the literature, is that the satisfaction rate was about 50%. Of the 24 families interviewed, 12 described themselves as generally satisfied with the diagnosis experience. Six described themselves as not

really satisfied and six were either unsure of their satisfaction or were satisfied with certain aspects of the process, but not with others.

The surprising aspect of this was the reasons they gave for their satisfaction and the relatedness of their satisfaction to the story of the diagnosis itself. There were, of course, fairly smooth diagnosis stories in which the mother described herself as satisfied with the process and, likewise, there were more difficult stories of the process in which the mother described herself as not very satisfied. However, there were stories such as the mother whose pediatrician berated her for going over his head and contacting EI against his recommendation. When EI qualified her daughter for services, the pediatrician accused the mother of lying to EI and would not sign the paperwork to begin services. This mother described herself as “100% satisfied” with the diagnosis process. This was presumably because she eventually had very positive experiences with EI and the school district and was pleased with the progress her daughter has made. There were also stories such as the one in which the mother described a fairly benign diagnosis process with a daughter with rather mild needs. She described a smooth process in which developmental concerns were brought to her attention by her daughter’s private preschool, the school district qualified her for services and she accepted them. When asked if she was satisfied with the process, however, she expressed that she wasn’t sure because she sometimes questions whether the school district qualified her daughter for services just to get more funding. Indeed, the satisfaction aspect of the study was not just found to be an oversimplification of the process, as the researcher predicted it might be, but a particularly subjective question.

Perhaps the most surprising aspect of the study was the question “Do you consider the diagnosis process to be over for you?” Only six families answered that they did consider the process to be over. Eighteen did not consider the process to be over or were unsure. Again, however, it was the reasons for their answers that were most compelling. As might have been predicted, there were families still actively searching for a more refined diagnostic label for their child, but there were also families who didn’t believe the process to be over because they saw their child’s diagnostic label as possibly changing over time. Some of the families hoped their child would “lose” the diagnostic label or be cured in a sense, but others just saw their children’s needs as changing, especially later in their schooling when the demands placed on them would be different. Still others didn’t believe the process to be over because there are other issues associated with their child’s disability that their child currently does not exhibit, but they do not know if that will change. Lastly, some families just felt like the process was not over because they still deal with the disability every day. It is an everlasting part of their lives and therefore they do not see the process as over.

### **Introduction to Sample**

I interviewed 24 families for my study. Of these families, I spoke with all of the mothers and four of the fathers. Their children’s disabilities ranged from mild/moderate to profound and they had been diagnosed by various agencies. Every story they told was unique and all of the data are complex. These are real families affected by all the intricacies of real life as well as a child with a disability. Their stories are rich and not easily quantified. Interviews ranged from less than 30 minutes to over an hour and 40

minutes with an average of about 57 minutes. Each family's path was unlike another, yet there were similarities. The challenge with these data is to make connections but not lose the individuality of each story.

The sample was well-balanced in terms of gender, birth order, child age and disability label, but was less balanced in terms of income and ethnicity. Twelve families interviewed had a female child with special needs and 12 families had a male child with special needs. Of these children, nine were the first-born in their families with two of those nine having a twin. Eleven were the second-born, two children were the third-born, and one child each was the fourth and fifth child in the family. This can be relevant in that parents' knowledge of both child development and available services seemed to be affected by whether the interview subject was the first or subsequent child born into the family. Seventeen families identified themselves as Caucasian, two were Caucasian/Hispanic, two were Asian, one was Caucasian/biracial, one was Caucasian/African-American, and one was African-American. Twenty-one families identified themselves as making over \$60,000 a year; two identified themselves as making between \$40,000 to \$60,000 a year; and one family left the question blank. The unbalance of ethnicity and income level certainly influences the stories the families told and the possible implications will be discussed further. However, many aspects of these families' stories are universal and can be felt and understood by anyone, especially other families who have children with disabilities. Many parents discussed how they connected with other families that had children with special needs and commented how they have found support and great friendship in these families. Some were candid enough to say that they

probably never would have been friends with these people before their child was diagnosed with a disability. Several families commented how their child's disability influenced who they, as parents, are friends with in remarkable ways. There is a connection between families that have children with special needs and it is likely these families will feel an association to the research families.

Child age (see Table 2) was an especially important variable in that it was related to two other variables: age at diagnosis and time lapsed since diagnosis.

Table 2: Child Age at Time of Interview

Child age-range in years and months	Number of children	Percentage of the sample
3-6 to 3-11	6	25%
4-0 to 4-5	5	21%
4-6 to 4-11	4	17%
5-0 to 5-5	6	25%
5-6 to 5-11	3	12%

The distribution of these numbers would be expected recruiting from an early childhood preschool program. With the exception of a child who had just entered the program on his or her third birthday, all age groups are well-represented. Typically-developing children often enter kindergarten when they are five years old, but it is not unusual for children with special needs to be given an extra year of early childhood services before kindergarten.

Child age (see Table 3) at diagnosis was a factor mentioned frequently in the literature and a spectrum of ages was sought in the sample.

Table 3: Child Age at Diagnosis

Child age-range in years and months	Number of children*	Percentage of the sample
0-0 to 0-5	8	33%
0-6 to 0-11	3	13%
1-0 to 1-5	0	0%
1-6 to 1-11	0	0%
2-0 to 2-5	3	13%
2-6 to 2-11	4	17%
3-0 to 3-5	5	21%

\*one family wasn't sure when to call the feedback they got from professionals a "diagnosis"

This age span of over three years allows for several families to have had access to the three possible diagnostic agencies: medical, therapeutic, and educational. It also allows for different families to have had their initial diagnosis with each of the diagnostic agencies. The gap in children diagnosed between one and two years of age is notable. There could be several reasons for this. A possibility is that pediatricians, the professionals seeing these children the most at this age, often tell parents to wait for their child to develop more before they act on any concerns they may have. Another possible and related reason is that developmental age-ranges for most skills that are acquired around age one, such as walking and talking, encompass large time frames of months to years and thus any developmental lags that may appear at this age could just be attributed to a child being a "late bloomer." A third possible reason is that a "gap of severity" may appear around this age in that children who are diagnosed before age one often have more severe disabilities and those diagnosed after age two have more moderate disabilities. This possibility will be explored further.

Table 4: Time Lapsed Between Initial Diagnosis and Interview

Time lapsed in years and months	Number of children*	Percentage of the sample
1-8 to 2-5	6	25%
2-6 to 3-5	7	29%
3-6 to 4-5	7	29%
4-6 to 5-6	3	13%

\*one family wasn't sure when to call the feedback they got from professionals a "diagnosis" therefore no time lapse could be calculated.

Several families gave the indication that their thoughts and perspectives on certain aspects of the diagnosis process have changed over time therefore it is beneficial to have a broad spectrum of time lapses since diagnosis (see Table 4). Similar to the lack of children who had just turned three years old, there were no families who had a length of time lapse less than one year and eight months. However, an almost four-year span of time lapses does give a nice range in which to see how time may affect a parent's feelings about the diagnosis process.

### **Sorting Families into Disability Categories**

Categorizing the families by children's disability label was especially complicated as diagnostic labels at this age are often vague (such as Developmental Delay), have the possibility to change over time (such as Apraxia), and/or encompass large spectrums of functionality (such as Autism Spectrum Disorder; ASD). To create a more meaningful categorization system, I developed five-point scales for specificity and severity.

The specificity scale (see Table 5) was developed using my knowledge as a professional as well as using the data from the families' stories to see how children of this age are typically diagnosed as having special needs.



The severity scale (see Table 6) consists of examples of disabilities that may be present at each severity level instead of a criteria used to qualify a disability for each level. With the vast range of disabilities seen in children and the different ways that they may affect a child and his or her family, a criterion list would have been too exclusionary or too vague. Instead, I used my knowledge as a professional and a mother to categorize each child's specific disability and its particular manifestation on a case-by-case basis. I based these decisions on how much the disability impacts the child's and the family's life, how well the disability typically responds to therapy, and the child's progress and possible or likely prognosis. I also categorized each child at the level he or she was with the disability at its most severe level. A child may appear to have relatively small delays that grow over time or a child may have apparently deep deficits that respond well to treatment and he or she makes great progress ameliorating those deficits. Therefore, I categorized each child at his or her most severe to try to capture the full spectrum of these children's disabilities.

Every child was given two numbers, a number that corresponded to each scale. The sample was well balanced in that a few to several children were in each category on each scale. Each scale and the sample distribution follow.

Specificity scale:

- 1-general delay(s) diagnosed with nothing more concrete known and/or given
- 2-diagnosed with clinical opinion that has some concrete aspects, but does not meet one specific profile
- 3-diagnosed with clinical opinion based on a specific profile
- 4-diagnosed by MRI or similar medical test
- 5-diagnosed by unequivocal genetic test

Table 5: Distribution of Children on the Specificity Scale

Specificity scale number	Number of children	Percentage of the sample
1	8	33%
2	5	21%
3	3	13%
4	3	13%
5	5	21%

Severity scale:\*

- 1- mild/moderate delays in area(s)
  - 2- Apraxia, moderate delays in multiple areas
  - 3- Asperger's syndrome, severe physical disability
  - 4- Down syndrome, severe Autism
  - 5- profoundly disabled, with severe physical, cognitive, and communicative delays
- \*at the most severe

Table 6: Distribution of Children on the Severity Scale

Severity scale number	Number of children	Percentage of the sample
1	3	13%
2	10	42%
3	3	13%
4	5	21%
5	3	13%

There are obvious clusters in the specificity scale category 1 and the severity scale category 2. I believe these to be indicative of what is typically seen in an early childhood classroom program. Many children have the diagnostic label of Developmental Delay (DD), which would be a 1 on the specificity scale and many children have delays that would be classified as in the moderate range, a 2 on the severity scale.

Caution should be taken when reading these tables, however, in that it is each child's mix of specificity and severity that creates his or her experience. For instance, if two children both have a specificity category of 4, but have severity categories of 2 and 5, as is the case with two interview families, they are likely to have extremely different circumstances and experiences. Likewise, there are several children with a specificity category of 1 yet with severity categories ranging from 1, 2, 3, and 5. The way a child's disability specificity and severity combine is greater than the sum of its parts.

### **Analysis of Factors Affecting the Process**

I will answer the research questions with a part to whole approach. The larger, over-arching research question of "How do parents perceive the diagnosis process?" will be set aside for now while possible influencing factors are examined. This section will answer the research questions: What factors affect how parents perceive the process? How do parents perceive professionals during the process? and What do parents want from the diagnosis process? After these factors have been examined in a cross-sectional manner, treating all the interviews as one data set, I will examine how these factors come together to create individual family stories.

First, the factors of age of the child at diagnosis, time lapsed between initial diagnosis and interview, influence of specific disability type, and these factors effects on the diagnosis process will be examined.

Then, parental experiences with and perceptions of professionals during the process will be analyzed. Parental experiences with pediatricians, medical professionals besides pediatricians, state-run Early Intervention professionals, school system

professionals and privately-funded therapeutic professionals will be examined. The perceptions of interactions with individual professionals as well as the various diagnostic agency systems will be investigated.

Lastly, what parents want from the diagnosis process will be looked at from several angles. How parents perceived the end of the diagnosis process, their satisfaction with the process, what they wanted from the process and how those wants were or weren't fulfilled, what made the process easier for them, and advice they might have for other parents going through the process will all be examined.

### **Age of the Child at Diagnosis**

There are many reasons to examine the child's age at diagnosis as a potential influential factor on the diagnosis process. One of these reasons is that child age correlates to timeliness of diagnosis, which was discussed in the literature as being one of, if not the most, influential factor on the diagnosis process. In this research there was a strong link between the age of a child and the severity and specificity of the disability with the youngest children diagnosed also having the most severe, most specific disabilities. This shows that age can, in effect, act as a proxy for specificity and severity.

Looking for trends among the sets of families grouped by age at diagnosis, severity, and specificity is not a straight-forward task. Many of the factors being studied are interrelated. Just as age at diagnosis is connected to severity and specificity, it is also connected to the diagnosing agency, which therefore affects the possible classification pattern. The similarities between the sets of families grouped here are mostly along these lines. All eight children with a 4 or 5 on the specificity scale, the most specific

disabilities, were diagnosed by medical professionals and are classified as a “Medical Diagnosis to Therapeutic Treatment” pattern. Likewise seven out of eight children with a 4 or 5 on the severity scale, the most severe disabilities, were diagnosed by medical professionals and are classified as a “Medical Diagnosis to Therapeutic Treatment” pattern. Also, all eight children in the youngest age at diagnosis bracket were diagnosed by medical professionals and are classified as a “Medical Diagnosis to Therapeutic Treatment” pattern. These results are not surprising. There are nine children classified with a “Medical Diagnosis to Therapeutic Treatment” pattern and they are largely clustered in the groups mentioned. Children classified with a “Progress over Time” or “Searching with Some Successes” pattern model are interspersed throughout the other age categories.

### **Influence of Disability Type on Diagnosis Experience**

It had been suggested in the literature that a child’s specific disability affects how parents perceive the diagnosis process. Certain aspects of this idea held true in the research. When looking at families with children with Down syndrome, the similarities in their stories is striking, however, other disability labels are not as concrete and their stories are not as finite. Disability types will be defined, grouped, and examined for instructive similarities and differences.

**Experiences with a diagnosis of Down syndrome.** Families that have a child with the diagnostic label of Down syndrome had a collectively unique perspective and one that warrants an extensive discussion of its own. This diagnostic label grouping was the most straightforward in that all the children had the label of Down syndrome and the

disability is an extremely specific one. The families all had similar experiences and their collective experiences seemed the most different from the rest of the research sample. Their experiences and what makes this diagnostic label unusual will be discussed here.

In total, I interviewed four families that had a child diagnosed with Down syndrome. A summary of each family's story can be found in Appendix D. The stories of Amy, Will, Hailey, and Colin will be referenced here. One mother interviewed, Amy's mother, was part of the pilot study for this research, but due to her particular circumstances I have chosen to use her data in this section, as well. The three other families, although part of my research study, did not come from the same pool of participants from which the other families came. When recruitment packets were returned to me, there were no families who had a child with Down syndrome that volunteered for the research. There could be various reasons for this. One reason could simply mean that my pool of participants combined with the response rate was not big enough to include a disability that occurs in one out of every 800 live births ([http://www.nads.org/pages\\_new/facts.html](http://www.nads.org/pages_new/facts.html), retrieved on September 26, 2009). This seems unlikely given that the school district co-operative covers a general population of hundreds of thousands of people. Another possibility is that the incidence of Down syndrome is decreasing, though this concept is disputed by some. A third possibility, proposed by a research participant, is that parents of children with Down syndrome often like to work on causes more specifically related to Down syndrome, rather than disabilities in general. These possible reasons may or may not account for the lack of families that had a child with Down syndrome in my initial recruitment sample.

Regardless of the cause of the lack of responses, I felt it was important to find families to interview who had children with Down syndrome within the specified age range. The pilot interview I did gave indications that because of prenatal and unequivocal genetic testing at birth, the experience of families with a child with Down syndrome was likely to be distinctive and important. Due to that specific perspective and the focus on the Cunningham et al. (1984) model based on the disclosure of Down syndrome in the literature, I decided to recruit families with a child with Down syndrome through other avenues. I contacted a friend, colleague, and Down syndrome support center whom I knew all had access to a family or multiple families with a child with Down syndrome within the specified age range. Each contact ultimately brought me one family each for my study.

Having a child diagnosed with Down syndrome is a distinctive experience for several reasons; the first being that Down syndrome, itself, is a fairly well-known disability. Other mothers interviewed shared how little they knew about developmental disabilities before their child was diagnosed and that they had really only heard of Down syndrome as a developmental disability. Indeed, all of the mothers who had a child with Down syndrome had heard of the disability before their child was diagnosed, which was not always the case with other parents who had children with less distinguishable disabilities. This does not mean that the mothers of children with Down syndrome knew a lot about the disability before their child was diagnosed, but they certainly knew what it was in a general sense. For better or worse, literally and metaphorically, Down syndrome is often the “face” of disability. This means that parents who have a child diagnosed with

Down syndrome may have to overcome more than the average number of preconceived notions, both in their own hearts and minds and in that of society in general, that come with having a child with a diagnosed disability.

While Down syndrome, like all disabilities, encompasses a spectrum of functionalities and limitations, it does fit a specific profile. For example, all of the children with Down syndrome had a 4 on the severity scale, a 5 on the specificity scale, and were categorized as a “Medical Diagnosis to Therapeutic Treatment” pattern. It is also diagnosed with a genetic test either before or shortly after birth, making the need to search for a diagnosis nonexistent for these parents. These parents did not experience the frustration of sensing something was wrong with their child’s development, needing to find someone to help, and then needing to find the correct diagnosis and treatment for their child. These parents’ experiences with the disclosure of their child’s disability did vary somewhat, but for the most part their diagnosis stories were similar and relatively finite. However, none of these families felt as if the diagnosis phase was really over for them. Similar to the other families interviewed their reasons for this varied. One mother said that because of the medical nature of Down syndrome she does not know if her daughter will have other medical complications related to Down syndrome later in life. The other three families expressed that the diagnosis is something that they either cope with every day or periodically in their child’s life and therefore do not feel like it is over. This is especially pertinent as many professionals would believe the diagnosis of Down syndrome to be a short experience. Indeed Cunningham et al. (1984) appear to assume that in their model that covers only disclosure. Although these families do not experience



an evolutionary diagnosis in the traditional sense, they clearly live with the diagnosis process much longer than had been assumed.

Perhaps the most exceptional aspect of having a child diagnosed with Down syndrome is the potential for prenatal testing. While only Amy's mother found out in-utero that her child had Down syndrome, the aspect of prenatal testing played a significant role in the other families' stories, as well. The three other families did not have prenatal testing that would have detected Down syndrome however it is something they all spoke about. Prior to 2007, it was common practice to recommend the screening measure that detects Down syndrome and other developmental disabilities only to women over the age of 35 (Hanson & Mueller, 2009). Colin's mother and father expressed that the prenatal testing would not have mattered to them as their strong Christian faith would have guided them not to terminate any pregnancy. Colin's mother did have the prenatal screening with Colin's younger brother because, she stated, they wanted to be prepared if the child had Down syndrome, but she would not have terminated her pregnancy. Interestingly, Both Amy and Will's mothers spontaneously shared that they are pro-choice but that they do not see Down syndrome as a reason to terminate a pregnancy, at least not for them. Hailey's mother shared a story about her babysitter who has an infant with Down syndrome. Her babysitter found out that her son had Down syndrome in-utero and felt very pressured to terminate including verbally being given a list of states that could give her an abortion. Hailey's mother also expressed that the hospital the babysitter's obstetrician is affiliated with is a local hospital with a Down syndrome clinic. She found this sad and hypocritical.

While a research participant's story of her babysitter cannot be considered data per se in this research, it helps to express the mindset shared by these parents. These parents felt as though their children and families were under attack. They were all active within the Down syndrome community and relayed stories like this as a personal affront even if it did not happen to them directly. These families love their children and it is difficult for them to conceive of mothers and fathers terminating a pregnancy because the child has Down syndrome. As Amy's mother expressed, it dehumanizes their children. The availability of prenatal testing for Down syndrome appears to single out that disability as something that can be too horrible to live with so it should be tested for before birth. In actuality of course, it is the medical, genetic make-up of the disability that actually enables the testing prenatally. While other disabilities may be more difficult or more debilitating, Down syndrome is testable in-utero and therefore bears the burden of possible termination.

Other families interviewed discussed having prenatal testing done with one mother openly sharing that she had it done because she did not want a child with a disability. Obviously, all families interviewed did have a child with a disability and many brought up the topic of prenatal testing to illustrate that they thought everything was fine with their child. While the burden of prenatal testing is most acutely felt by the families of a child with Down syndrome, the false sense of control and security that it gives to all families is not to be overlooked. One must question what it means when we seem to give parents a choice about having a child with a disability when in reality no one has that choice. The majority of developmental disabilities are not medically testable

in any way, let alone in-utero. Parents cannot control if their child has a disability any more than they can control any other aspect of parenthood. The false sense of security that prenatal testing provides coupled with the unspoken message about the lesser status of people with disabilities can add to parental guilt. If we seem to imply that parents have control over having a child with a disability then parents question why they do have a child with disability.

**Examination of other disability types.** While Down syndrome has the most distinctive collective experience of any disability label, there are important trends that become evident when examining other disability labels. There are interesting findings specifically in the possible ongoing nature of speech and language needs, the difficulty in labeling a child with ASD, and the especially challenging task of getting a diagnosis and effective services for children with behavior disorders.

Parents who had children with speech and language needs were generally quite pleased with the progress their children have made with interventions. This can make the process more gratifying for these parents. However, they also have concerns about their children's functioning later in life and particularly in school. This makes it hard for these parents to see the diagnosis process as over. This was evident in the stories of Ty, Christina, Vimal, Sydney, Nicole, Sasha, and even Jessica, whose needs were quite mild. This is interesting because these children have made great progress, by their own parents' descriptions, but the nature of their disabilities makes it difficult to know if the process is over. It is not unusual for children who have moderate speech and language needs to

have persistent or other disability symptoms later in life, especially in the educational realm. This can result in a long diagnosis process for parents and child.

It is interesting to examine the actual label of Autism and ASD and how nebulous they seem to be in application. In fact, only one child has an unequivocal diagnosis of Autism and that was Rachel who has a rare genetic form of the disorder. Joel received a “provisional” diagnosis of Autism from one diagnostic team and received a diagnosis of Autism from a developmental pediatrician, whom the mother strongly disliked. Nevertheless, the mother identifies his disability label as Autism. Kevin and Jack, both higher functioning than Rachel or Joel, had various labels somewhere on the Autism spectrum suggested to them as possible diagnoses. However, none seemed an exact fit and Jack’s mother was told that he has certain characteristics (e.g., a shared perspective and shared sense of self) that preclude him from having ASD. While ASD has a somewhat specific profile of symptoms, it can be difficult both diagnostically and emotionally to fit a young child into the profile unquestioningly. This can be seen in the very different experiences of all these families. The difficulty and/or reluctance of professionals to label a child with ASD can be an especially frustrating aspect of the process for parents. While some parents can be reluctant to have their children labeled, the proper diagnosis can bring proper treatment, which often drives parents to seek concrete diagnostic labels.

The overlap between children with possible ASD and behavioral issues is also interesting. If ASD can be hard to diagnose with a specific clinical profile, general behavioral problems can be even more challenging. It can be hard to distinguish between

the two as well as difficult to diagnose behavioral problems in general. This was the case with Kevin and Jack. Behavioral problems are often intermittent and occur most often in the home, especially given the young age of the children and the lack of time they spend in other settings. This can be challenging for parents and professionals. Parents are struggling with their children's behavior and struggling to get that very behavior diagnosed. The parents of Kevin and Justin both encountered difficulties in getting their children diagnosed and therefore getting them services. During the diagnosis process, Jack's mother had to work extensively with his community preschool so that they would not expel him before the school district could observe his behaviors there. Even after diagnosis, effective treatment can still be elusive with Kevin's and Justin's parents still searching for help. However, the relative success story of Jack's diagnosis process and treatment can be seen as encouraging.

Enough evidence exists to show that links between diagnosis experiences are evident within disability types. This sample was small and, by design, covered a wide breadth of disability types. This could prove to be a fruitful avenue for further research. A study that specifically examined a defined disability type could better illuminate the nuanced issues of the diagnosis experience for that disability label.

### **Effects of Professionals and Professional Practices on the Diagnosis Process**

Overall, the largest amount of interview time was spent discussing professionals and professional practices and their roles in the diagnosis process. These interactions with professionals have been divided into five different sections as follows: Pediatricians, Medical Professionals (i.e., interactions with medical professionals other than

pediatricians), Early Intervention or EI, Private Therapists, and School System. Each section contains general discussions of the professionals, discussions of the processes and systems that surround that group of professionals, as well as interactions with and feelings toward individual professionals.

Since parents defined the diagnosis process so broadly, with three-quarters of the families feeling like the process was still ongoing for them, all professional interactions will be examined even though some seemingly occurred during treatment and after what some might call the initial diagnosis.

### **Interactions with Pediatricians and Pediatric Practice Groups**

Pediatricians were the professionals seen by the majority of research participants' children and seen as the central figure in children's health and development. While socio-economic status and culture likely play a role in how parents view their pediatrician, in this sample, parents saw the pediatrician as their main and initial source for help and information on their child and child development, in general. Sometimes parents felt fulfilled and gratified within this relationship, but more often they were disappointed in their dealings with their pediatricians. As with many aspects of the study, the interactions between parents and pediatricians are complex and cannot merely be categorized as positive or negative. In fact, for most families their interactions with their pediatricians span long periods of time with positive, negative, and neutral aspects.

Only two mothers did not discuss their interactions with their pediatricians in their interviews. This was likely because both children were preschool-age when concerns surfaced and both mothers knew, from different sources, to go to the school district for

assistance. It is also quite possible that the children did not have any regularly scheduled check-ups during the time they were undergoing the diagnosis process as pediatric check-ups often occur only once a year at these ages.

Some families spoke about their pediatric interactions more generally, as their pediatrician did not really serve an integral role in their child's diagnosis, such as those diagnosed at birth or those diagnosed with complex medical issues. Many families, though, began their diagnosis process with their pediatrician.

**Parental concerns deferred by pediatricians.** The most common complaint among parents was having their concerns about their child ignored or deferred. Eight families spoke about bringing up concerns to their pediatrician and either having those concerns ignored or told to wait. Families were told to wait either until the next appointment or a certain age presumably to see if their child's development would progress by that time. Many families were told to wait multiple times. In general, this was frustrating for parents.

But the doctor said it's ok, it's ok, it's ok all kids are different, you know, some start early, some later. And my mom came and said "Give us something, some information or refer us somewhere." (1)

I did raise some questions with our general, uh, pediatrician, and he said, "You know, you really don't have to worry about it 'til 2." And then, when he became 2, he said, "Well, let's wait 'til he's 2½ because, um, a lot of kids don't start talking 'til they're 2½," but we thought it was strange because he had lost his words. (6)

Soon it was time for his 18 month check. So he went and I talked to the pediatrician who said "Well, yes, his vocabulary is low, but uh, no problems. You keep an eye on things," which you come in at two years. I called them three months later that nothing has changed. There have been no words. I was very concerned, uh, what should be the way? (8)

Two mothers did explicitly say that they liked that their pediatricians were not “alarmists” and that they made sure you didn’t “overreact.” However, both of these pediatricians listened to the mother’s concerns when they were first brought up and either sent them for an evaluation or were supportive of them going for one when the mother already knew about the service. Therefore, it could be assumed that the doctors’ reassuring manner yet action on the mothers’ concerns was desirable and that simply ignoring or deferring parental concerns is not desirable.

Having their concerns rebuffed was frustrating for families at the time and after the fact when their child’s disability had finally been diagnosed.

I think it's important that children – and I don't know enough about all the special needs brackets, but in our case, it was imperative he got diagnosed early and that the therapy started early. I think that made a huge difference in his protocol or whatever. So when a mom comes in and might have, you know, a 12 month old, 13 month old, 14 month old and expresses a concern to her pediatrician, I think the process could be so much more encompassing if that pediatrician listened and said, “Okay, it's still early, but let's do this for the next three months and see if we see a change.” Or, “If we do this for the next three months, and in two months you still don't see a change, then come back.” Because I think – I don't think it's too early to start with some of these kids, and I think again, the earlier you start, the more intensive you are, the less you need in the long run, so I would like the medical community, the pediatricians because that's who you go to. I mean, you're not in pre-school, you're not – so I think that that's where that diagnosis kind of failed for me. I would have liked the pediatricians to have said, “Okay, you're concerned, that's all I need to hear.” And that's what Dr. Andersen eventually said, “You're concerned, you're the parent, it's a concern.” Yeah, that would be huge. (8)

Nine families expressed that, ultimately, their pediatrician did refer them to EI or the school district for an evaluation. Two families were sent to private therapy centers by their pediatricians and not told about EI or school-based services. Most families expressed that they believed their pediatrician would be the person to facilitate assistance



with concerns about their children's development. With this in mind, both the referral rate and the timeliness, or lack thereof, in which parents were sent to agencies that could help them seems inadequate. This is a likely reason for the parental frustration expressed around interactions with their pediatricians.

**Parental interactions with pediatric practice groups.** Many families belonged to a pediatric practice, as is common in health care now, and often dealt with many different pediatricians giving them varied experiences from visit to visit. This was both incredibly frustrating for families; the most combative episodes came from this model, but also helpful in that parents had another recourse if they had a bad experience with a particular pediatrician. However, this depended upon parents advocating on behalf of their child and themselves and actively seeking the opinion of another pediatrician in the office. This could be difficult for some parents.

In the first situational example of this, the mother was presented with a solution to her problem simply by chance. After a particularly confrontational episode with her pediatrician, the mother found herself at a standstill with no services for her daughter. An acquaintance then joined the practice and enabled the mother to get the services her daughter needed.

The pediatrician's the one I had the biggest issues with because he – he at one point reprimanded me and said that, you know, that I need to stop doing this and stop over – God, what was the word he used? Like, basically overriding his – his opinion by, you know, seeking out therapists. And so at one point, he started yelling at me in his office and he's like, you know, he's like, "I don't know what's wrong with you." He's like, you know, "I told you that there's nothing wrong with her and you're just looking for things," and – I mean, just – it was horrible. Like, I went in there – we went in there for a checkup and he was looking at the therapist notes that they sent him and he – he accused me of lying. He's like, you

know, “What did you tell them to make them think that she has these disabilities?” And I told him, I said, “Read the report. Whatever I told you is the exact same thing I told them.” I said, “I didn’t embellish, I didn’t make things up. It’s in – you can read in the report. [...] The pediatrician refused to sign all the consents to get therapy started for Nicole. He led me on for about one, two months, wouldn’t sign them. (14)

Then eventually, an acquaintance of mine joined the practice, so we started seeing her, and it was a whole different world. She was a lot more open to, you know, her – to Nicole’s issues and she saw the reports and, you know, as a friend, I asked her, I said, “You know, be honest with me, am I going over the line here? I mean, look at the reports.” And she said – she said, “No.” She said, “You have very valid concerns.” She said, and I – she said, “If Nicole had started with me, I would have sent her to EI, it wouldn’t have been an issue.” (14)

Another mother brought up concerns about her daughter’s development and had her parenting questioned. Feeling hurt and lost, she called up one of the pediatricians with whom she had a better rapport and felt validated.

And I went in for the 3-year-old checkup, and got one of the other doctors, who I didn’t know so well, and, um, I was mentioning my concerns about her development, and she’s active, and he all but came out, and said, “You know what, you’re just a bad mom.” And I was just like, wow, you know, okay, and I thought, you know, here this is, Kid No. 5, I have some level of education in education. I’m – I’m probably an average mom, but I don’t think I’m a bad mom, you know, and so I left there just going, oh wow, I’m alone in the world with this child that’s got some issues, and where do I go from here? (20)

When asked about how the doctor implied she was a bad mom, she said he said she had a lot of kids and probably had “a lot on her platter” (20) and was clearly “not setting any limits” (20) with her daughter. After coming home and reflecting on the experience she called the pediatrician in the practice whom she “adored” (20) and told her she had gotten a flyer from the school district about evaluations and that she wanted to take her daughter. This doctor told her “If you have concerns that’s enough, you know, you

should go, and have her evaluated,” (20). This was validating for the mother.

The following mother had had her concerns about her son’s speech development rebuffed by different pediatricians in the practice. She felt like her concerns were not heard or respected. She called the office, described the situation, and demanded someone more knowledgeable about the relevant issues.

So I go in for an ear re-check, which, you know, you go to [inaudible] call-in and, you know, it's just a pool of doctors; you don't necessarily see who you're going to see. The doctor said to me, "Well, this isn't really the time to talk about a speech delay; I'm just checking his ears for an ear re-check." I said, "Well, I understand, but I need to know what my next step can be." So he gave me, like, Private Therapy Group down here on Evergreen Park or whatever, did not tell me about EI, did not say, well, why don't you schedule him an appointment and come back in, you know, really, just brushed it off. (8)

And then, I remember going at 24 months – that would have been September and I saw one of the pediatricians. Not the one – I remember I had another breakdown in the pediatrician's office because she kind of, well, “That's good, you've got EI,” and sort of poo-poo’d it again, wasn't really willing to help me kind of digest what was going on because we didn't have a diagnosis at that time. (8)

So I called back and I said again, I need to have a doctor in the practice – there's like 16 doctors in this practice, one of them has to have this as their passion. I'm sure that if I had a child with diabetes, you'd link me with Dr. X. If I had a child with leukemia, you would link me to – this is just the general practice. I need someone who will sit and listen to me because this is important. So they gave me two names; I ended up calling Dr. Andersen, who's just a general practitioner. Fabulous man. Absolutely validated within two minutes everything that I needed; I came in, I told him what was going on, he's like, you're absolutely right, you have a concern, let's find a specialist. Huge difference. Huge difference. (8)

**Pediatricians’ limited knowledge of developmental issues.** There was a sense, expressed by at least five families, that pediatricians, as medical doctors, do not have the knowledge or the training to properly help families with children with developmental

disabilities. For some families, this insight was borne only from several frustrating interactions with their pediatrician. Other mothers' own careers—two were physicians themselves and one was a speech and language pathologist—coupled with their experiences gave them a bit more insight into the limits of pediatricians. Despite these limitations, it was discussed how pediatricians are often the first to see families who have concerns about their children's development and how this is an unfortunate situation.

The pediatrician knows nothing [laugh], you know. If you have a cold, fine. If any of this stuff, no. He really has no clue. (15)

Pediatricians are so trained – I can't – I mean, I've been to enough of them with my kids to know that it's – they're so trained to look for physical issues, so if she doesn't have a cold or broken bone or something that's physically apparent, then she's fine. (14)

I think that the pediatricians are great for ear infections and you know, stuff like that, but like as far as development, and just from my background in speech pathology, like I don't think. (7)

They have so little training and background and support for anything beyond a medical, pure medical situation. They continue to be a source of frustration for me. (24)

Maybe [if] a pediatrician was more knowledgeable about the kids' deficits that are there, [rather than] just relying on okay, this is what I can do with medicine. Let me just concentrate on that. Everything else is therapy. They're not going into the things, and that's part of – that part is probably the hard part. (19)

**Power differential between parents and pediatricians.** Examples of a power differential tension between parents and pediatricians could be found in many of the families' stories, but it was openly expressed by at least three mothers. It should be noted that the parents interviewed were, on the whole, very well-educated, confident, and savvy. As evidenced in the interactions with pediatric practices, the parents interviewed

advocated skillfully for their children, but all parents are subject to the pressures of society and the medical community. The entire experience is so overwhelming that parents are looking for guidance, but they often find that they need to be the leader. So much of the responsibility for a child's diagnosis is shouldered by the parents that parents can feel like they are pushy when advocating for their child or feel regret later about not being pushy enough.

*Interviewer:* And this, when you said the pediatrician said she was developmentally delayed and low tone, and he had or she –

*Mom:* She.

*Interviewer:* – she had never shared this with you before?

*Mom:* No, no.

*Interviewer:* Okay.

*Mom:* And you know, and I'm not one to be like, "Why didn't you tell?", like I, you know, it takes a lot for me to really like, like get angry and confront her. But I was sort of, I was just so overwhelmed. It was so overwhelming. (7)

It's been difficult working with our pediatrician who I really respect, and I know a lot of people do, but I don't – I feel like we could have been a little more active earlier if he had listened to me a little bit more or maybe I – I should have been more assertive. So, you know, he was saying, "Let's wait 'til he's 2." Then, "Let's wait 'til he's 2½," but that was frustrating. (6)

You know, and like I said, you know, just in talking with friends who have kids with similar issues, I mean, I found, you know, they've had similar experiences where the doctor just kind of brushes them off, like, your kid's fine and – for some of them, it's been a little too late, in terms of their kid gets diagnosed once they're in grade school, and the parents are really angry. So I'm glad – part of me is glad that I persisted and I was pushy and, you know, got Nicole what she needed. (14)

Parental reports of interactions with their pediatricians express frustration, more

than anything. However, there were families that were more satisfied than others. One mother expressed great satisfaction with her pediatrician calling him a “blessing” and “brilliant” (21). Overall, parents want to have their concerns heard, they want guidance, and they want help for their children. Pediatricians are uniquely positioned to help parents enter the diagnosis process and guide them through it, however, for most families, this did not happen. Pediatricians should respect parental concerns and consider them a starting point for discussion and/or referral.

### **Interactions with Other Medical Professionals and Medical Systems**

While pediatricians were, by far, the medical professional discussed by the greatest number of participants, many families saw other medical professionals during the diagnosis process, as well. Most of these professionals were developmental pediatricians, neurologists, geneticists, and other similar specialists. Any interactions within the medical community, outside a general family pediatrician, are discussed in this section.

These experiences within the medical community seemed different than those within the EI and school system communities. Many of these children were the children with the most severe disabilities and the experiences revolved around not just development, but health issues, sometimes life-threatening ones. Familial interactions with medical professionals were also more finite than their interactions with EI or school professionals. Families typically see EI and school staff several times a week for years, while even the most integral medical professional in a child’s life is usually seen either frequently for a short period of time, usually days, weeks, or months, or several times a year for many years. Many are seen only once. This means the data here are composed

more of isolated situations and individual anecdotes than of reflections on an ongoing series of experiences.

While there is often a power differential between parents and professionals, in general, this is often more evident within the medical community than in the therapeutic and educational communities. Doctors, at least in the United States, are generally afforded more societal status than teachers and therapists (Featherstone, 1980). This was evident in some of the interactions between families and medical professionals. Several parents did seek medical help and guidance for that reason, because they believed it to be the best. Within the medical community, parents would often refer to specific doctors as “well-known,” “head of the department,” or “the best” indicating that that status meant something to them in this context. In this sample, many parents were able to afford what they considered to be top-ranked doctors and sought them out for their children.

**Medical professional information sharing.** Parents recalled how information was shared with them and the disposition of those who shared it with them within the medical community. For some families, the initial diagnosis or disclosure was a single, brief interaction and for others it was a more lengthy process in which little bits were revealed from various medical professionals over time. The children diagnosed by medical professionals often had very specific disability labels or at least very specific symptoms that the medical professionals shared with parents. This created a different experience than those within the school or EI systems who often were focused on a child qualifying or not qualifying for services rather than on specific labels. For some families,

this was gratifying. They wanted answers and these professionals gave specific answers when they had them.

*Dad:* Yeah, I mean to me, when we talked to the doctors, I mean people who had MD's and stuff, they would give us pretty concrete information.

*Mom:* Like the developmental pediatrician.

*Dad:* Yes. Exactly.

*Mom:* That – she was helpful.

*Dad:* She was very helpful.

*Mom:* Yeah. She actually took – after we got the OT, psych and social work evals, you know, privately, we brought them all of those too, and they're the ones that kind of seconded [Dad]'s idea about Asperger's and referred us to First Midwest Neurobehavioral. And, you know, finally we kind of could at least say he's got these kinds of symptoms like Asperger's or high functioning Autism or whatever. (2)

For other families this act of labeling was hard and the straight-forward manner in which the information was given could also be difficult. While all parents wanted truthful diagnosis information, they often wanted it tempered with “hope.”

The following mother is a good example of wanting a truthful diagnosis, but not a harsh one. She sought the advice of a developmental pediatrician to bring some clarity to a “provisional diagnosis of Autism” that her son had been given previously. She said she wanted “closure” on the diagnosis.

She met with us while Joel was kind of being observed in the background, and she said, “Yes, Joel has Autism, and basically, he'll always have it.” We were asking her, “Do you think we're doing the right thing?” being we signed him up for school at this point. We were doing this OT. “Yeah, you're doing great things, but it's probably not good enough.” Basically, she gave us – she made us feel hopeless. Like I even said to her. You know, I just – I want Joel to be independent, have a happy adulthood, and, um, want him to have friends, and, you know, I'm worried. We're older



parents [...] we're worried about the future, and she even said, "Well, there's really a wonderful home that could take him," and she basically – she made me so angry. And I don't know if it was because I got that diagnosis, and it was hitting me at that point or it's just because she seemed to say – she seemed to say that what we were doing wouldn't really matter. (6)

It did not appear to be the actual diagnosis that bothered this mother, but the sense of hopelessness that she was given. It also illustrates, again, a possible disconnect between the medical and therapeutic communities, which is further elaborated on in the next example.

One parent, Becca's mother, shared how the initial diagnosis process went for her family and her daughter. She was sent to a neurologist who told her and her husband that her daughter was "significantly globally delayed" (7). This was the first the parents had heard of this and the mother did not like the way he rattled off everything that was wrong with her daughter or that he had several medical students present behind him during the meeting. The mother conceded that "There's no easy way to say, 'Okay, I'm about to shatter your world,' but I think there's better ways," (7). During the diagnosis process, she also saw therapists and geneticists. She shared one "noteworthy bad" (7) experience with a geneticist. The mother, trying to get a sense of her daughter's prognosis, asked the doctor a series of questions.

Is she going to be able to dress herself? Is she going to live independently? Is she going to have a job? Is she going to walk? Is she going to talk?" She said, "Is she going to walk? Maybe. Is she going to dress herself? Maybe. Is she going to have a job? No, I don't think so. Will she live – will she have a job like you or me?" and I'm thinking like, you're a geneticist. I don't think that my daughter's going to be a geneticist. "No. Will she live independently? No," and I was upset, and she said, "Well, you asked," which I thought was really shitty, and then she was walking out [...] but she could tell I was upset, [...] She goes, "Well," she said, "She's

beautiful.” She goes, “That will get her far in life.” And I was like, I said to [my husband], “Of course she thinks she’s beautiful. She’s a geneticist. She sees like all the kids with like 18 heads, you know. (7)

Her story also illustrates the tension between the medical and therapeutic communities in that the doctors seemed to downplay the role and potential of therapy and therapists are sometimes overly optimistic in the skill level they see in her daughter. Doctors would also downplay the advice of therapists and vice versa. She felt, in general, that the medical community gave grave news with no hope whereas the therapeutic community and one therapist in particular, gave her hope.

Families that had a child diagnosed with Down syndrome also wanted professionals to convey a sense of hope with the disclosure of the diagnosis. The following mother experienced a change in hospital staff attitude once a diagnosis was suspected. She arrived at the hospital around midnight, during what is normally a shift change. The mother was going to be delivering the baby breech and naturally so several of the nurses stayed to see the delivery since this was something many of them had not seen before. Once a diagnosis of Down syndrome was suspected, however, things changed.

Once there was the possibility of a diagnosis, everyone at that point, they don’t, you know, really look at you anymore. It’s like, “Oh, you know, we’re so sorry.” At that point, it became everyone in the hospital just telling us, you know, “Oh, we’re so sorry. Of course, she doesn’t have it. She just doesn’t have it.” I remember the lactation nurse saying, “Oh, I’ve seen hundreds of babies, she doesn’t have Downs. You don’t have anything to worry about.” And I’m thinking, “Well, if she does, it doesn’t really matter,” and in my heart, I knew that she did. (22)

While parents often don’t want a harsh delivery of a diagnosis, denial of a diagnosis, especially by medical staff can make the diagnosis process worse. Denial of a diagnosis,

or even of a warranted developmental concern, can make the issue seem so terrible that it cannot be considered, which can be not only unhelpful, but hurtful.

Another couple that had a child diagnosed with Down syndrome shared that they did not believe their disclosure of the diagnosis to be especially happy or sad. It was “sort of indifferent,” (17) which they acknowledged might not be a bad way to have the news delivered. “There was sort of like a medical, ‘Yeah, I think the arm is broken.’ You know ‘We’ll see you later.’ [Laughs] Okay.” (17). For these parents, and other parents with a child with Down syndrome, this was preferable to a disclosure that expressed just sadness and sympathy. One mother felt like the doctors explained her son’s Down syndrome diagnosis in a way that was helpful to her.

And Dr. Fitz, and Will’s other specialist, at that point, had explained too, “Now, you know, just think of Will as a regular baby. He’s – he’s a regular baby,” and, um, definitely when a child has Down syndrome, and they’re an infant, they’re pretty much like any other infant, and that’s what they said, and it turned out to be true. (23)

Her hospital did also send for a representative from a nearby hospital with a Down syndrome clinic to meet with her. The mother said “she was the one that really, explained it, a) from a genetic perspective, and then b) talked about it from a life perspective” (23).

These examples show that parents want truthful diagnosis information, but that they would like medical professionals to also convey hope during the disclosure of the information. There is also a tension between the medical and therapeutic communities and it is possible that therapists share more positive aspects of child’s disability with parents than medical professionals do and that this adds to the tension between

disciplines.

Parents did share positive aspects about working with medical professionals. This shows that parents will not inherently be displeased with diagnosing professionals and that medical professionals with more positive dispositions can be well-received. In fact, it shows the impact even one professional can have in the day-to-day life of a family with a child with special needs. Most parents shared general comments about professionals being “good” but some shared specific attributes that they found desirable. In the following examples parents appreciated the professional’s empathy, patience, and apparent common sense.

My epileptologist, who I love to death, can tell you the worst news in the best and the most calming way that you think he’s kind of a freak. I mean, you know, “Let’s talk about the fact that your son may die of a seizure in the middle of the night and there’s really nothing you can do about it. But it happens to other people, too.” You know. “Should you get a monitor? No, ‘cause then you’re just gonna’ be up all night listening to the monitor, you know. Like, let things happen the way that they need to happen, you know.” So, you know, he has this kind of way – he’s like the absent-minded professor, but he can talk about, like, the most horrible things in just a really calm and relaxed way. And I’m sure he’s had practice at it, but it takes a certain depth and skill to be able – and emotional empathy to be able to handle that kind of conveyance. (18)

The neurologist we’ve only seen once so far, but, you know, he made sense. When I talked to him about processing problems, he goes, of course he has processing problems [laugh], you know. And he says, you know, you don’t need to – and it was kinda’ refreshing because he said, you don’t have to do all that testing. Of course he has problems. You don’t need tests to tell you that. [...] It’s not going to necessarily tell you how to treat him, anyway. And it’s like thank God, somebody who says I don’t have to go do another test [laugh]. So I liked him and he was very patient. I mean, Justin was climbing all over his furniture, so he was a good guy. (15)

**Medical practice logistics.** All systems can be complicated to navigate at times,

but parents reported having several difficulties trying to work within the medical community. Parents with children undergoing the diagnosis process within the medical community shared these logistical issues: difficulties in appointment scheduling, lack of information sharing between medical professionals, and inept disclosure methods.

Scheduling and appointments, while difficult for all parents of children with special needs, had a particularly frustrating aspect to it for families working within the medical community. Frequently, needed tests or appointments with specialists were either impossible to schedule or scheduled months out. Parents learned to use every tactic they had to get an appointment but also had to settle for long wait times or seek help elsewhere.

One mother used her familial connections within the medical community to get an appointment with a difficult to see doctor. Two other mothers got appointments for medical tests or with medical specialists when their pediatricians intervened. Even using every means and connection they had, parents still described long wait times for and during appointments and having to settle for other doctors when the highly touted doctor in the practice was impossible to see.

Once families were able to see the specialists they needed to or get the appropriate tests, they often found they had to coordinate any sharing of information between professionals. A mother described the burden of needing to be the keeper of all her son's information because of a lack of communication between medical professionals.

And remember, every doctor has his or her specialty, which is the most frustrating part about this. So the vision person isn't going to talk to the, you know, ENT. And the ENT isn't going to talk to the brain specialist. And because of that, what I started doing was getting everything. So

anytime a report was written, I got a copy. Every time something was done, I got a copy. I just started hoarding copies. (21)

The lack of communication between professionals was not only difficult logistically, but medically it made her son's diagnosis and initial treatment fragmented. The mother and father described how all these doctors are "experts in their field" (21) and how they each look at issues with your child within their field of medical expertise but never "take the time to connect the dots" (21) or communicate with each other. She also described the difficulty, as a parent, in trying to get all her son's information. She described hounding hospital staff and calling doctors repeatedly to get information, meetings, and reports. She shared how she kept a book of who to call and when to check up on pending reports or certain aspects of her son's diagnostic care. She also shared the relief that she has now that all of her son's care is coordinated by his pediatrician.

So luckily, our doctor, who is just so good, is at the hub of everything. Reports are all sent to him, and I get all information from him. I don't try now anymore to get it from any other place. I just make sure he gets it. And then I go to him. Whereas, before I tried so hard, which now I wish I hadn't. (21)

It is worth noting that no other parent seemed to experience this kind of care coordination from a pediatrician.

Another mother also talked about the difficulty in needing to be the intermediary between the medical professionals who care for her son and the special challenges it presents.

I had to be that conduit of trying to pass along a lot of very specific medical jargon that I don't even necessarily know what I'm saying, but I'm trying to be accurate, to tell one person what the other person said. (4)

This particular aspect was frustrating for parents for several reasons. Not only was it difficult logistically, but intellectually parents had to understand and pass along key information to other medical professionals. This put a lot of pressure on parents to remember, understand, and even anticipate all their children's complex medical issues. This was further complicated when the parents would go to medical practices or clinics and see different doctors each time.

When the doctor comes in there, "Okay, so tell me about Franklin," and I need to start from the beginning. It's like, you've got to read his chart. I can't tell you everything. You know, it's like, it's hard enough that you're not the same doctor that we saw last time, or the time before, or the time before, but it's like, I can't tell you everything in these 20 minutes.

(4)

Forcing the parent into this intermediary role was confusing and frustrating for parents, especially during the time of diagnosis when parents felt like any little detail could be crucial to helping professionals uncover what might be wrong with their child.

In what appear to be examples of a poor information sharing system, two parents learned of their children's diagnoses in particularly upsetting ways. One mother had an emergency Cesarean section and was told of her child's suspected Down syndrome before she was fully coherent. This obviously created confusion and the mother was disappointed in how that transpired. Another mother described how after her family had had genetic testing done she got a phone call from the geneticist's office. The woman on the other line, presumably a receptionist, asked the mother when they could set-up an appointment with the genetics team to talk about the fact that her daughter had this specific, genetic disorder referring to it by name and, in effect, giving the diagnosis over the phone. The mother was shocked and disappointed to receive the news that way.

While working within any system could be frustrating for families, the medical community, made up of independent medical professionals, was especially difficult for parents to work within. Getting recommended tests or medical opinions from specialists and sharing information between professionals were barriers to getting a cohesive diagnostic picture and coordinating early care.

**Lack of answers.** One of the reasons parents sought help from the medical community was because they thought it would give them the best level of expertise and care. They were sometimes disappointed to find out that this wasn't always the case. Parents with children with more developmental issues were, in general, more disappointed in their interactions with medical professionals. However, even families with children with more medically-based disabilities were sometimes disappointed in the lack of information they received from medical professionals.

One mother shared how she formed a relationship with the medical professionals who worked with her son, but that she was disappointed that she had to bring her son's medical issues to their attention more than once. Her son, being born premature, spent months in the NICU and when she brought him home her mother noticed that one of his hands was smaller than the other and wouldn't open. Neither the hospital staff nor his pediatrician had noticed this. While the mother was disappointed that none of the therapists noticed it at the hospital she said it really didn't change the outcome. If it had been a case where things could have been different if it were caught sooner, the mother said she would have been more upset. She also said it was hard to be upset because she had formed a relationship with the staff in the NICU. The mother also had to point out



that her son's pupils were different sizes to the pediatric ophthalmologist. This mother sometimes felt frustrated because it seemed like she had to be the one to bring all these issues to the attention of the medical professionals. She, in effect, became her son's diagnosing professional.

The mother who had her daughter's genetic diagnosis told to her over the phone was then disappointed in her subsequent meeting with the genetics team. She researched the disorder herself in preparation for the appointment.

So there's one website. It's called – it's a parent support group called [name of group], and I had all the stuff. And I go there [to meet with the geneticist] to where I thought I was gonna' get some more answers, and they basically, like, printed off, the same stuff I already had. So, I was like, are you kidding me? I thought that, you were gonna' be able to give me more information than this. I just printed that same stuff off. They couldn't answer any questions. They're like, join this group and, you know, get involved, and basically, like, that was the end of it. (11)

Her daughter has a diagnosis that is considered by some to be a genetic cause of Autism so her diagnosis and treatment are partially medical and partially developmental. While her initial diagnosis and disclosure are through the medical community, the traditional medical community has little to offer her regarding treatment, similar to the families with children with more developmental, less medically-definable diagnostic labels. This may be why the genetics team had little information to offer her.

However, even though the medical community may not offer much help to families of children with strictly developmental disabilities, it can shed light on possible underlying medical conditions which can sometimes be overlooked in light of the larger developmental issues and it can rule out other medical causes of delays or disabilities.

One mother sought medical advice from several sources for her son who has

behavioral issues and has more recently been diagnosed with a learning disability, as well. The mother says she was alarmed by some doctors' willingness to medicate her son without seeing his symptoms and without a clear diagnosis. The mother never got a clear diagnosis, but was given some more nebulous terms such as executive functioning disorder and processing problems, which she did not really find helpful. Doctors were able to rule out Autism and seizures, however, which the mother was grateful for.

Another illustration of this is one mother, whose child was adopted, did have an evaluation for her daughter from a pediatric neurologist that was recommended by her pediatrician. She wanted to rule out Fetal Alcohol Syndrome as the source of her daughter's developmental issues. The doctor believed it was not the source of her daughter's difficulties, however, the mother called the evaluation a "dead-end" (20) and said it "wasn't really as helpful as I thought" (20).

Lastly, one mother shared that a team of medical professionals wanted to do a "whole gamut of medical tests" (6) on her son, but her pediatrician said "usually they don't find things from that and your course of action is going to be the same anyway," (6) so they held off. When they did have the tests done they determined that her son had sleep apnea so she wished she had done it sooner.

Parents seeking answers within the medical community often found that the information they received was concrete, but limited. For some children, the concrete information was needed and helpful, for other children the information was a start but parents wanted to know more, for still others there was no concrete information to be shared. Perhaps this is the information to be expected from a field that does not generally

treat children with developmental delays. The information they have comes from tests and diagnostic training, but they do not have much experience *working* with children with special needs so parents who seek to know more, such as developmental trajectories or suggested treatments, are often left disappointed.

Working within the medical community provides can provide a different experience for families than working within the EI or school communities. This experience can afford a specific, concrete diagnosis for some families, but can offer little in the way of diagnosis or explanation to others.

Working with medical professionals, not unlike working with other professionals, can be highly dependent on the individual disposition of the professional. In general, parents found medical professionals more abrupt and straight-forward in their information-sharing than other professionals. Their interactions with medical professionals were also more finite, which is a possible explanation for the curt manner described by some parents. Parental interactions with medical professionals, in general, were not ones of hand-holding and guidance. However, when parents did experience positive dispositional traits in medical professionals they were appreciative.

The relationship between the medical and therapeutic communities can be tenuous. This is possibly because medical professionals traditionally work on curing ailments and therapists work on ameliorating them. It is also possible because, in general, they work with different diseases or disorders and different populations. People serviced through the developmental therapeutic community sometimes do not get answers in the medical community. Likewise, a child with strep throat is not going to be

cured by speech therapy. However, children with special needs often require the expertise of both. It does a disservice to families to have such a disconnect between the medical and therapeutic communities.

Some parents were frustrated by the fragmented diagnostic service they experienced within the medical community and had to be their own children's case-managers, in a sense. When diagnosing professionals are so disconnected from one another it not only frustrates families, but it can lead to inept disclosures and eventually disjointed service delivery.

### **Interactions with Early Intervention Professionals and Systems**

The role that the state-run Early Intervention (EI) program plays in the diagnosis process for families is especially crucial to understand because it is a contextual factor completely unstudied in the literature. The relative recent establishment of the EI system, born from legislation passed in 1986, coupled with the fact that it is a national incentive program run state by state means that it was not a factor in any of the previous studies on the diagnosis process. In the location studied, EI services are available to all who qualify and fees are on a sliding scale.

This section highlights parental experiences with the EI system such as their first experience with an evaluation or diagnosis and disclosure process, how parents perceived the procedural aspects or inner-workings of the system during the diagnosis process, and lastly how they felt about the EI professionals they encountered, especially the therapists. Looking at these factors it is obvious that the EI system is complex and often

inconsistent. However, many parents were grateful for the system and had positive things to say about their experiences.

The parents in this study typically were serviced through two different EI offices. The EI location that services families is dependent on location of residence with one EI office servicing the families in Cooper County and the other EI office servicing the families in Lee County. Two of the families that had a child with Down syndrome also were serviced through two other EI offices. Some parents spoke of a service differential between the two main EI offices studied.

I talked to people in Cooper County and they would ask for play group therapy, which nobody ever does, and they were like, "Sure, go," you know. Cooper County is just night and day from Lee County and I didn't understand that, I didn't get that. (8)

It did appear that parents living in Lee County described longer wait times for services, often several months, and parents living in Cooper County remarked how EI appeared "almost immediately" (1) when called. Parents living in Cooper County did seem generally more pleased with the overall EI experience, as well. However, there were significant variations between experiences in general and not all parents shared which EI office provided their services, though many did. There is enough evidence to at least infer that EI services are likely, at least somewhat, dependent on individual office branches and that this likely influences parental perceptions of their experiences with the program.

For many parents their experiences with EI were their first ventures into the diagnostic process, the world of families with children with special needs, and government-run programs. While some entered the EI system with a medical diagnosis,

most did not. The combination of these things could be overwhelming, relieving, confusing, and helpful—sometimes all at the same time. Many of these feelings were expressed when parents discussed the initial evaluation process with EI.

**Experiences with the initial evaluation process.** When EI does an initial evaluation it is typically done in the child’s home and in an arena format where there are several therapists/professionals present at once. They interact with the child and try to get him or her to do certain tasks that may indicate levels of development based on an assessment measure. Some parents found that process strange and frightening.

And I remember them asking me all these questions, like does she do this, this, and – and, you know, they ask you a gazillion things. And you have to try and think, well, I think so. And how many minutes does she look at you and does she respond to her name and does she do this and this and this. And I was like, oh, my God. Like, then I really started freaking out. (11)

I filled out questionnaires. Um, they gave me the handbook, which about that thick and explained the process of EI. It was really overwhelming in, in the fact that, you know, you’re walking into a new system and you don’t know anything about it, and it’s your baby. And – so it was a bit overwhelming in terms of that, and then you have people coming in and out of your house. You’ve got people coming in and, and doing stuff with your kid, and they’re measuring and they’re kind of--the thing is they’re kind of talking to each other, and you’re just sitting there like an idiot. (13)

Other parents found the initial evaluation process enlightening and relieving. One parent commented that after the evaluation “I thought he did pretty good. Much better than I had expected. I was like, oh, these ladies can get things done out of him. It’s amazing” (19). Another parent was grateful for the understanding shown by the evaluators and their seeming desire to qualify her son.

They were testing him and, you know, he was doing some strange things there. [...] He just was doing things that were not normal. I don’t

remember exactly what he was doing, but he just – I said to them, I go, “This can’t be normal.” And they said, “No, it’s not,” the behaviors that he was showing. And I think that they were really trying to find a diagnosis for me so that he would qualify for services, so at least he could get plugged in, you know. Even though maybe he didn’t quite fail every test that they did, you know, stacking blocks and what not, they could definitely see that there wasn’t something quite right, even if it wasn’t, like, maybe as obvious as maybe some other children. (15)

After the initial evaluation process, the EI team of professionals shares their findings. For many families this happened, at least in some manner, right at the end of the evaluation appointment, while a more traditional disclosure usually takes place at another meeting. This is presumably done to give anxious parents immediate feedback about the assessment. EI assessments often culminate in an expression of a percentage of delay, an age-equivalent of the child’s developmental skills, and/or a general diagnosis of “Developmental Delay.” Some parents candidly shared what those first few moments were like when they got the disclosure.

The following mother conveyed her confusion and shock when they shared the extent of her son’s developmental delays.

And they said, yes, um, I don't know whether we even want the second meeting to see. He would clearly qualify. [...] And I said so, what are his deficits? And they said [...] we are calculating him out at nine months receptive and 12 months expressive. And I said, [...] I’m sorry. I don’t understand. The coordinator had understood that I had not. And he is now 26 months. She said he is calculating at – as though he is understanding as a nine-month-old baby. I don’t think I heard anything after that. And it came as a total shock. I don’t think the other two people realized that I never expected that at all. Um, and my question was at that time, in my mind, what does this mean? Is he going to get better? Is it going to be this pace? Or is it, is it going to be a growth curve like this, a mental curve like this? We – can he ever catch up? Can we just make the gap this or – I didn’t even think that he could cross – could we make sure that the gap doesn't increase. Or what can we do? I mean, what therapies – what would help?

*Interviewer:* Were you just thinking this or did you voice that?

*Mom:* No, no, I was still stunned. (19)

The next mother did share that although the process can be scary and overwhelming, aspects of it can be reassuring.

And it was overwhelming and a little scary and a little – you know here they are talking about your child and he’s not where he should be and he has this 40 percent delay and yes he qualifies for all these things, you know? So it was, it’s a little upsetting, but they didn’t seem too concerned that he was severely delayed, so that was reassuring to me. (9)

One mother shared the frustration of getting services, but not getting what she considered to be a diagnosis. Early on in the process, the mother had asked an EI administrator who had come to her house to “meet and greet” (6) the family if she thought her son had Autism. The woman assured her that she didn’t think her son had Autism, when, in fact, he would be diagnosed later by other professionals with that disorder. The mother says she doesn’t “blame her or anyone” (6) because “It’s such a strange disorder and he was so young” (6). The mother says she is still getting conflicting advice all the time on the course of treatment for her son. This does highlight the sometimes difficult line professionals walk in trying to give parents information and services, but not label children prematurely. Sometimes parents seek a concrete label and sometimes parents seek to avoid it. Professionals also function at both ends of the spectrum.

Even beyond the initial evaluation, one mother expressed how hard it was to sit through the regular IFSP meetings, and later, in school, the IEP meetings. She talked about her feelings during these meetings not unlike parents who talked about their initial



feelings at disclosure. This mother did express that she felt like the diagnosis process was over for her daughter, but the feelings she expressed were like those parents who expressed that the process was not over for them because they continually deal with the diagnosis and its affect on their family. Experiences like this could be one of the reasons parents feel like the diagnosis process is ongoing.

You're sitting in a room. It's usually your house with, you know, eight people around you. You know, you have PTs and OTs and, and coordinators and speech and developmental. And everyone is around you, and you're, you know, making cookies for them. And you're sitting there and each person goes boom, boom, boom, boom, boom, and tells you all the deficits of your child. It is draining, heart-wrenching, awful experience. It's awful. And you feel powerless and sad, and you know, my husband was never here for those, so it was just me. (13)

**Experiences with the procedures and processes of EI.** The most frustration expressed by parents was around the procedural, inner-workings of the EI process. They expressed frustration with poor case-workers/coordinators, long wait times, and not getting services they qualified for. Many parents expressed going to great lengths, such as finding their own therapists and writing letters to government offices, to get the services their children needed.

Just getting evaluated and initial services started was an obstacle for many parents. EI services children birth through age three; on their third birthday they are no longer in the EI system. This made parents not only feel the urgency of getting their children services as soon as possible, but also the time constraints of trying to work within the EI system and its allotted age range. Getting services going and then keeping them going sometimes took an immense amount of effort and patience.

I was told that there is, of course, an initial evaluation, and then you know,

determination of needs. And there is a process that you have to go through. I said start that immediately. And they said, “Okay, there’s a wait, and you would have to wait three months,” uh, before I would be assigned a person. So that would take us to two years. He’ll be over two years, and he’s not talking, and he’s got a 12-word vocabulary right now. Um, and they said “We hear you, but our hands are tied. You can try individual [private therapy] or this and that.” (19)

For some parents this initial lag time and spotty service implementation was complicated by a missing or difficult case-worker. One of these parents described leaving multiple unreturned phone messages and writing to the head of Health and Human Services to get a new case-worker so her daughter could get the services she qualified for.

Parents described difficulty working within the system to not only get the amount of services they felt their children needed, but to actually secure therapists to provide the services for which their child was already qualified. Two parents described having to find their own therapists because although their child qualified for services, EI was either unable to find a certain type of therapist or unable to find one to work with within the parent’s schedule. These two parents used their own connections and the internet to find EI therapists for their children.

For all the frustrating experiences that were shared, there were some stories of the system working well for families. One mother, who had a son with Down syndrome, had his initial assessment the week he got home from the hospital. “We didn’t miss a beat,” (23), she shared. She said her experience with EI was “great” (23) and that it “spoiled” (23) her for working with the school system, which, she said, through “no fault of the teachers or therapists” (23) cannot provide the same level of attention as in EI.

**Experiences working with therapists in EI.** The most positive experiences shared were those around the therapists. Some parents who shared very frustrating stories of working within the EI system had kind words for the therapists they encountered. Again, although most parents encountered these therapists after their initial evaluation or diagnosis through EI, the seeming ongoing nature of the diagnosis process for families makes these experiences relevant and important. These therapists are often working with families showing them, implicitly or explicitly, how their child's disability manifests itself and possible courses of action. The therapy, itself, is often changing their child's needs and how the parents perceive these needs linking the therapy to the diagnosis. This ongoing information sharing can be part of the diagnosis process as it helps parents better understand their children and their needs.

Five parents specifically mentioned the EI therapists as a positive aspect of EI. One parent shared how they were great at helping her to understand her daughter and her needs and how they never tried to label her daughter or otherwise “put fear in me” (16). Two parents mentioned the special relationship they formed with the EI therapists. One talked about how she knew they loved her child and cared about his development while another talked about how she was skeptical at first, but eventually “built wonderful relationships” (98) with her son's therapists and how “the information I gained from all of them was phenomenal” (98). One mother compared the EI therapists to private therapists and felt as though the EI therapists were better and “spend more time” (12) working with her child.

One mother described a very special therapist who not only helped her son make

great developmental gains, but who mentored her through the EI process and beyond. In fact, this therapist was the one who returned the mother's initial call expressing concerns about her son. She recalled this moment with sadness but expressed relief when she felt as though she was finally heard.

And uh, she said, "I got your message. Tell me your concerns." I started telling my concerns, and I heard a dead silence on the other end.

*Interviewer:* How did you feel about that?

*Mom:* And um, for the first time it seemed that somebody was actually getting what I'm saying. And her response was, uh, "This little boy needs help." And I said "How can I do that?" (crying). I'm sorry.

*Interviewer:* No. Take your time.

*Mom:* It's sad to think about those moments. (19)

The mother shared her amazement at watching this therapist, Cindy, work with her child. "Whatever best possible could be coming out of that little child; she would be able to do that" (19). She discussed their shared joy at watching her son make developmental gains. When her son first learned how to say "mom" she said "that was another good moment for us – for both of us. I mean, Cindy and I" (19). The mother began to trust Cindy tremendously and Cindy mentored her through the EI program and beyond, helping the mother navigate systems and giving her advice on the best course of action for her son. Many parents cited the lack of guidance through the diagnosis process regardless of the diagnosing agency. This therapist seemed to fill that role for the mother and she was appreciative of it.

People like Cindy, you know, who – in her eyes, she might not have done anything above and beyond. You know? I can see that from her. Um, but in whatever way she did, it changed our life. People like Cindy, do make a

huge difference in the lives of people, like mine and Vimal's. I'm glad that, uh, that destiny brought us together, but if it wasn't for her, again, I would have not known what is the direction to be taken. (19)

**Hospital evaluations through EI.** The EI program offers the option of a hospital evaluation to either some or all of the families within their system. It was unclear from the research if all families were offered this and some didn't feel the need or desire to pursue it or if only certain families were offered the opportunity. Two families spoke about going through the evaluation with the hospital as offered by EI. Both families did express a level of satisfaction with the process and the professionals they encountered there. However, each family did have some issues with the evaluation. The first mother had some confusion over the final diagnosis and its level of ambiguity, while the second mother was frustrated that EI offered the hospital evaluation but would not give the services recommended by it.

One mother shared how after the evaluation they gave her son a "provisional diagnosis of Autism" (6). The mother was unsure what this meant and they explained that since her son was still so young he could still makes gains and they recommended a "whole course of action" (6). The mother said she was pleased with the evaluation but would "just like to be told, "Yes, your son has Autism," because then we can move on and do something about it" (6).

A second mother seemed impressed with the evaluation provided and the scope of it but was disappointed in EI's lack of willingness to follow up on the recommendations.

Even though that medical team suggested OT, getting OT from EI was like pulling teeth. She would argue with me, like, that's a medical model and we're not – you know, you guys paid for this, you sent me there, how can you not give me this? (8)

The diagnosis process within the EI system is complex and seemingly inconsistent. Parents were grateful for the services it afforded them, but the services were far from perfect. The system itself, with the possibility of long wait times, leaves much room for improvement. However, parents often described their EI experiences as largely positive. This was sometimes because of individual staff members who made a difference in their families' lives. It could also be assumed that since EI was the first therapeutic experience for most of these families, that the therapy itself was gratifying to families. Having a positive early therapeutic experience can affect how parents perceive the diagnosis. If their children can be seen to make developmental gains, it can change how they view their children's identified needs. After struggling, as many parents did, with their children's needs and trying to get them identified, it was likely reassuring to see that not only were their concerns eventually heard, but that their children's needs could be met, at least somewhat.

### **Interactions with School Professionals and Systems**

The school system was the one diagnosing agency that all interview families had experienced, since the majority of families were recruited through school district co-op early childhood programs. Even the families with children diagnosed with Down syndrome that were recruited through other means were of the same age and were also enrolled in early childhood programs in other school districts. Therefore, the data here are extensive.

In the recruitment sample, most families resided in an area where the local school districts contract through a special education co-operative that provides their district with

early childhood services. Any services that the children qualify for are supplied free of charge to the families. The actual roles of the school district and the co-op can vary somewhat from district to district, but the majority of actual services (i.e., diagnostic evaluations, classroom programs, etc.) are provided by the co-op. However, many parents were unsure of each institution's individual role and therefore the "school system" experience for this study is a combination of the school district and the co-op, with the terms often used interchangeably.

One of the interesting things about the families' experiences with the school system is that families could be at very different points on their journey when they enrolled their children in the school system. For some families the school district provided the initial diagnosis for their child. For other families the school district was one of many diagnostic experiences during a larger diagnosis process, providing what we will call here a "re-diagnosis" experience.

**Experiences with the initial evaluation process.** Of the families that spoke of the initial evaluation process with the school system, most spoke of it positively. One parent commented that "It's well planned, well done and well acted on, with highly professional people. I felt like I could trust them right through the process" (3) while another felt pleased that they used so much of her judgment and with that she was able to push for her child to get into a classroom program. However, there is still the emotional component of getting an initial diagnosis and two parents spoke of how it affected them, each in different ways.

One mother described the various emotions a parent can go through when their

child is first diagnosed. She shared how her first thoughts were: “Is my child going to be okay?” (10) and then how she criticized herself and felt emotional about sharing the news with family. She said they accepted the diagnosis and wanted to know the professionals’ opinion, but that you can come through the process a “bit jaded” (10) and wonder about “if she has an IEP and they’re gonna’ get more funding from the state” (10). She says that is “just a very cynical view” (10) though.

Another mother, who is a physical therapist, shared how different the experience is on the other side of the IEP table. “It’s really opened my eyes to see, you know, the decisions that the team makes really affect the whole family” (5). She talked about how the services suggested can really disrupt a family’s life, but that you have to just trust the professionals and believe they have your child’s best interests in mind.

**Experiences with re-diagnosis in the school system.** Professionals may be tempted to think that parents who enter the school system with a child who already has identified needs are over the initial shock, sorrow, or confusion of the diagnosis, but many parents spoke of the “re-diagnosis” process as an emotional one, as well. It is a process in which the parents do have some prior knowledge of their child and his or her needs however that can sometimes complicate the process and the emotions for parents. Most parents by this time value the therapy services that their child receives, but they also understand that their child only gets those services because of a deficit of some kind. Many parents don’t know what to wish for from this new step in the process.

Three parents spoke about the complicated emotions that go with wanting your child to qualify for services, but also wanting them to have progressed past needing them.



One mother shared “So when they called to tell me that he qualified, I was like ‘Yah!’ Oh wait a minute, that means he needs, that means there’s something not quite right” (9).

Another shared that when she learned her daughter qualified for services “part of me was a little disappointed because I thought she had really progressed” (14). A third mother shared how her EI therapist had guided her understanding of the level of services and what would be best for her son even though she “wanted him as normal as possible” (19). She was thankful for this guidance that ultimately led her to seeking and accepting a more intense level of service than she would have initially.

Two parents shared how they were surprised and little saddened by how much actual school time their children qualified for. One parent shared that she wondered “Gosh, he's just three. Every day?” (8) after hearing the school team’s recommendation. Another parent shared that initially she felt “like the system has kind of taken my child away” (17). She did share that he is “thriving” (17) at school and that has made it easier.

One mother shared how she was surprised at how they did the assessment with her child. They took her daughter away to a separate room to do the assessment only to eventually bring her back crying to try and finish the assessment in the presence of the mother. The mother describes the mixed feelings this gave her.

I remember getting in the car, and thinking you are going to underestimate my child. And for no reason, just because you needed to see her by herself, but then if you think about it, okay, bite my tongue. They’re gonna’ underestimate her – which I mean – they’ll give her more services, so it’s a good thing. So, so in the end, it all works out, but it’s hard for the parent. (22)

Another parent shared how one professional’s comment made her particularly upset. This is a good example of how an IEP meeting, or any parent/professional

encounter, can be just another day at work for professionals, but for parents it can be an anxious time in which they scrutinize professional's words and demeanor looking for meaning and information.

But even at that meeting, this [...] district early childhood program person, she was going through the papers. She was the one who took us like on these tours [of potential placements] and both my husband and I were like, we just didn't care for her, and she was going through the papers. I remember that, at that meeting, "This is for this and this for that and for this," and she goes, "And this is this," you know. She's like, "Whatever floats your boat." and I wanted to look at her and say, "You know what? None of this floats my boat." Like it floats my boat to send her to the preschool that my son went to and just drop her off and pick her up at the end of the day. Like none of this floats my boat. So that, you know, that definitely rubbed me the wrong way. (7)

Lastly, one mother shared what a positive experience it was transitioning to the school system. She felt like the evaluation was thorough and that the professionals had her son's best interests in mind.

These therapists from the 3-year-old program, they all came to my house to meet Andrew before we had the meeting. I was like, are you – really? I mean, they had such a nice sense of what he could do and what he couldn't do and what he would appreciate, you know. It was great. (18)

She also shared that her mother, who came to the IEP meeting with her, was moved because of the number of therapists there and presumably their demeanor. She shared that her mother was in tears and said "All these people are so concerned about Andrew, oh, my God" (18).

In addition to the emotional piece, it is yet another system for parents to navigate in the diagnosis process. Many parents had learned how to push for more services or otherwise advocate on behalf of their child, but they didn't know this new system and that can be scary and difficult.

One mother shared how even though the co-op was very good about giving her the paperwork ahead of time and/or telling her that if they use any terms she doesn't understand to let them know, "it's very hard not to get defensive and protective in those meetings" (8). She pointed out how the school staff does so many of these meetings but it is a parent's first one and it can feel very "odd" (8). Even though her transition went well, it's still an anxious and potentially confusing time for parents.

Another mother shared that she had to push to get her daughter into the placement that she wanted. Although she was successful, it can be difficult for parents to navigate a new system and advocate for their child within this new system simultaneously. She shared that "it was a little bit more pushing that I needed to" (7).

One parent shared how she had planned for the transition into the school system in a particularly savvy way, but that that didn't turn out as she planned. She purposely employed a therapist from the co-op when her son was young to "facilitate a smooth transition into the educational system" (21). However things did not turn out that way when the therapist told her that the co-op had told her she could not attend any of his IEP meetings because of a potential conflict of interest.

She had asked the co-op, and they felt that because she had worked with our family for so long, that basically, which is a terrible thing, I think, and typically I never heard it work this way. Um, that she would be – how do I say this in a nice way? She would have difficulty if she – if it came to choosing sides. So if the co-op said one thing, and felt that this was your objective, and the family and therapists said the other thing, she would somewhat be compromised in her ability to be objective. And so that backfired. [...] My reasoning didn't quite turn out the way I had thought, I had thought it was logical. But time told me that it wasn't. (21)

This shows how parents who are used to advocating for their child and navigating service systems can have difficulty when it comes to transitioning into another system.

Parents undergo this “re-diagnosis” not only when the child turns three and enters the school system, but each year when it is determined if their child is still eligible for services and which ones. This is hard for parents and some spoke of the frustration of not knowing from year to year what will happen with their child.

Two mothers shared how hard it is not to know from one year to the next if their child is going to qualify for services. They both described spending large amounts of time and emotional energy getting “ready to fight” (20) for services for their child. Both of their children qualified again for services, but they didn’t know until the actual IEP meeting, which created stress for both families.

One mother felt that “the teachers have an incredible amount of pressure put on them to not find things wrong with these kids” (15). She feels like the schools are “tapped out and they don’t have the money to find anything else wrong with your kid so that they have to provide more services” (15). This underlying suspicion likely affects parental anxiety levels as they await each IEP meeting to find out if and what services their child is going to get.

**Individual family struggles within the school system.** Most parental struggles with the school system were similar to their struggles with other institutions. Getting services initially, getting more services, and the power differential between parents and professionals were issues parents had with both the medical community and EI and some parents expressed these problems with the school system, as well. However, these

struggles seemed to be more isolated with school professionals. There did not seem to be common complaints across several participants. Instead, there were some parents who seemed to have difficult experiences with the school system and those experiences seemed to be very dependent on their individual circumstances. There are possible reasons for this. It could be that most parents are pleased with the school system, in general, but that the school system does not do as good of a job working with individual family concerns as they do providing services. Another possible and related reason could be that the school system has a good spectrum of services to meet the needs of the majority students, but that they have a harder time providing services to students who may require more individualized service plans. The best example of this is two families who each have a child with behavioral needs.

The next two parents both had children with behavior issues, which may present a bigger issue to service providers, especially school systems. School systems work on an educational model in that a child's disability needs to affect his or her education in order to be serviced through the schools. This can be difficult to prove with children with behavior issues. It can also be difficult for service providers to find effective treatments for behavioral problems thus providing a need to consistently work on refining the diagnosis.

One mother described her difficulty in trying to get her son services through the school district. Now that he is receiving services through the school system, they want to put him in a more restrictive setting. The mother expressed her frustration with the apparent irony of the two issues. Her son was found not eligible for school services when

he turned three and transitioned from the EI system. At the time, the mother “wasn’t sure that there was anything really wrong with him. I mean I knew he had issues, but I didn’t know how atypical” (2). The mother kept in touch with the school district over the next 18 months and updated them periodically on the problems he was having in his community preschool, though, the mother admits that he did do fairly well at his preschool. However, she says “To me, I think that if he head butts a teacher and has to be removed a half dozen times, the school district should have evaluated him then” (2). The mother eventually “cried and went up the chain-of-command and insisted on the evaluation” (2). He was found eligible for services and was placed in the co-op preschool program where, the mother says, “they weren’t really prepared for his level of violence” (2) and he has struggled. At this point the school district is looking for more restrictive placements for kindergarten, which is frustrating for the mother.

The next mother also has a son with behavioral issues. She described her frustrations with the school system. Her son received services from the school system from the time he turned three, but the mother has had difficulty getting him the services he needs. She thinks the school district has had a hard time seeing that he has other issues, besides the behavior, that need services. She thinks that the school district works very slowly and that many of their decisions are based on funding. She also shares that, although she is an educated person, she finds the school district special education system very confusing.

You don’t really understand all these pieces of paper. And I still don’t, you know. It’s like I read over them every time we got to an IEP and I’m like, I didn’t really understand the implications of this behavior plan, but I guess it does have an implication of some sort. (15)

The mother says she has been pushing to get her son services based on learning and fine motor needs, but that the school district, up until recently, has been reluctant to acknowledge any needs other than behavior. This has been frustrating for the mother and she, like many parents, feels like she has to walk a fine line between advocacy and congeniality.

A lot of parents say that, you know, like the squeaky wheel is the one and I never feel like I'm squeaky enough, but I'm too nice 'cause I don't want them to be mad and then think I'm this difficult parent and then they'll take it out on Justin and not give him the services that he needs. (15)

**Positive experiences within the school system.** Like with EI, parents were most complimentary to the people working with their children and their complaints were more with the system, at large. Most parents were very pleased with the school system and the services they provided. Parents were appreciative of individual programs that helped their children progress and professionals who were respectful of them and loving towards their children. Most parents seemed like they found this within the school system.

Fourteen families specifically mentioned how pleased they were with the school system and the professionals within that system. Most mentioned how knowledgeable and supportive the teachers and staff were. They also mentioned how the information they got from them was helpful to them and how they respected their opinions. One mother shared how "her teacher even came to our house one time and was like, all right, you know, this is what you can do here and here and here to make things easier" (11). Some really appreciated the school professionals' special skill knowledge, citing their teacher's years of experience or knowledge in their field. One parent shared the peace of

mind it gave her to know her son was with such knowledgeable professionals who would know if his development was lacking in some area. Another mother shared that she was happy to have someone who could diagnose and treat her daughter accurately.

Because the pediatrician can [only] help you so much. There are things with some of the people, they know a little bit better and there are kids being evaluated in a different way, so we don't notice right away, but they know because they know their work. They know what they're doing. (3)

Two parents mentioned specifically how their children's teachers "love" them. That seemed to be especially gratifying to these parents, who both had children with profound disabilities.

The group of women that work there, and men, there's some men there, they are just remarkable. And the co-op, um, you know, my son can't be someplace without a nurse. And they made it possible. [...] The nurses are great. The teachers, the aides are fantastic. They love my son. My son loves them. You can hear it in his voice. When I walk in and he's happy, I can hear him in the other room. I mean, it just fills me with joy. Such a great place. (18)

When Becca goes to school, she is so well loved. [...] I really feel like when Becca's at school, when she's in that world, she's a superstar. Everything she does is amazing to them. You know, you need to be able to go to a place where your kid is just great, like everything they do is great, and you know, a place where you feel like they really appreciate her as a person. Because everywhere else like pretty much, she's overlooked. Our experience there has been 100 percent positive. (7)

In the school system, as with EI, the professionals who diagnose and reevaluate the children at regular intervals are also the professionals who work with them every day. Having professionals that you have formed a bond with and ones that you feel care about your child diagnose and "re-diagnose" your child could help parents feel more at ease about the process. Many of these parents felt like the school professionals really had their child's best interests at heart.



Parents, in general, described generally positive experiences with the school system. However, they sometimes qualified those statements with individual issues they had with the system. It is important to note that parents' overall contentment with the school system could be highly dependent on their location, which is determined in large part by their socio-economic status. The co-op in which the sample was recruited from enjoys a positive reputation within the larger community area. These families had access to good schools with a broad spectrum of services for their children. Results could, and would likely be, different in other communities with less-funded services and amenities.

### **Interactions with Private Therapists and Therapy Groups**

When discussing the three diagnostic agencies, the medical community, EI, and the school system, it is important to acknowledge that a fourth option exists for some families. Private therapists and therapy groups can sometimes play a role in the diagnosis and treatment of children with special needs. Families who either can afford to pay for such services themselves or have medical insurance that covers all or part of the costs can choose to pursue a diagnosis in this way.

At least 13 of the 24 families interviewed used private therapy services in some way. However, only one child's initial diagnosis was from a private therapy service. This mother pursued a private therapy evaluation while her son was still going through the steps of an evaluation through the school system. She felt it gave her son a quick start to a diagnosis and services.

We started immediately, and her suggestion was, "Let's not try and diagnose, you know, how do you feel about instead of finishing a formal evaluation process, and then starting, let's jump in. Let's get started and we can evaluate and treat at the same time," and we said, "Great." (24)

While private therapy may meet the unmet needs of some families, it can also serve as a source of frustration. One mother tried to contact private therapists while waiting for her son to be evaluated by EI. She found it difficult to get an evaluation for her son in the private therapy sector. The mother needed direction in what to do to help identify and treat her son's needs, but, she says, the private therapists asked her what evaluations had been done and told her "Well, you know you need to really work on finding out what's wrong with him" (19). This was frustrating for the mother who said "I was like that's what I'm trying to do" (19).

The possibility of quick action and freedom from potential public service bureaucracy is an appealing aspect of private therapy. However, parents found more success in treatment services from private therapists than they did with an initial evaluation. It may be that private therapists are more accustomed to treatment than diagnosis.

### **Summary Themes in the Research Questions**

#### **What Parents Want from the Diagnosis Process**

What parents want from the diagnosis process will be examined by looking at several aspects of the research. First, I will examine when parents believe(d) the diagnosis process to be over for their child. This gives definition to the process and subtle insight into what parents might want from the process before they consider it to be over. Then, I will examine parental satisfaction with the process. This was a consistent indicator used within the literature. What that indicator tells us will be analyzed here. Next, what parents said they actually wanted from the process and how well those wants

were fulfilled will be looked at. After that, parental responses to a question that asked what made the diagnosis process easier for parents will be examined. Responses to this question gave an informal list of parental supports during the process. Lastly, parents were asked to give their advice to other parents just beginning the diagnosis process. The advice they gave often shed light on the process, how it was experienced by those families, and how they wanted it to be experienced.

### **When Parents Believe the Diagnosis Process to be Over**

One of the most basic features of this study would be to define the diagnosis process in terms of a timeframe. However, this is not an easy task. One of the most surprising findings of this study can be found in the parental responses to the interview question “Do you feel like the diagnosis phase is over for you?” This question was asked, because as a professional who worked closely with families, I felt that many parents felt that the diagnosis process lasted longer than their initial disclosure meeting, which was what was largely studied in the literature. I knew that within this country many children get a general label of deficit or delay that qualifies them for services, but that many parents continue to search for a more refined diagnosis. However, I was surprised by the fact that only six of the 24 families believed the diagnosis process to be over for them. Even more compelling, were the reasons families gave for their answers. While searching for a more refined diagnosis was an issue for some families, there were many other reasons parents did not believe the diagnosis process to be over. Also, the families that did believe the process to be over shared their reasons for their answer giving possible insight to what might bring closure on the process to some families.

Six families shared that they believed the diagnosis process to be over for them and their child. The most cited reason for this was that they knew their child's issues. Some parents also shared that their child's issues were unlikely to change and/or they were not going to get any new information about their child's issues. One parent did expressly share that although she believes the diagnosis process to be over, their ongoing life is hard. While having concrete information seemed to be important in parents' feeling of closure to the process, these were not necessarily the families with the most specific disability labels. Of the six families one has a child with Cerebral Palsy (a specificity label of 4), one had a child with a genetic disorder (specificity label of 5), one had a child with a brain malformation syndrome (specificity label of 4), one had a child with a physical injury at birth (specificity label of 4), but two families had children with general delays (specificity labels of 1). This means there was an equal number of families with the most specific specificity labels, 4 and 5 that did not believe the diagnosis process was over for them.

Eighteen families either did not think the diagnosis process was over for them or were unsure if the diagnosis process was over for them. The most common reasons given for this answer were that their child still had disability issues and that the parents didn't know if these issues would continue and/or if they would change into other disability issues, particularly as the demands of school changed. Some parents expressed that their child was doing well, but still had delays in some areas and they worried about him or her going to kindergarten, and subsequent grades, where he or she might struggle more. Parents also worried that their child's current delays (e.g., developmental or speech and

language delay) could manifest differently (e.g., learning disability or Attention Deficit Hyperactivity Disorder) later on in school. The second most common reason given for this answer was that they were looking for a more refined diagnosis. This often meant that they were still looking for ways to help their child so they were not only looking for a more refined diagnosis, but more refined treatment, as well. The third most common reasons given were that there are associated issues with the child's diagnosed disability that the child currently does not exhibit, but they don't know if they will develop later on and that they live with the disability every day and it is a constant part of their lives. Some parents with children with more specific disabilities worried about common associated issues that may develop over time. Some parents simply shared that they think about their child's diagnosis all the time so they can't consider the process over. Parents also mentioned that they didn't think the process was over because they don't know why their child has these delays, the mourning process is ongoing, and that they hope their child might "lose" the diagnosis or be cured, in essence. While these more emotional reasons were mentioned the least, they are relevant and at the heart of the issue for some parents.

Parental reasons for believing the diagnosis process to be ongoing are varied. They are logistical, emotional, and valid. Parents search not just for the diagnosis, but for what it means to them, their children, and their lives. It is obvious from these responses that the previous literature and likely professionals in general, underestimate what the diagnosis process means to families and how long the process is for them. This highlights an important issue for any future research into the diagnosis process. The

definition and time frame of the process itself is individual to families and any future research into this topic should address that.

### **How Satisfied Parents were with the Diagnosis Process**

Parents were asked “How satisfied were you with the diagnosis process as you experienced it?” This question was asked specifically because much of the literature seemed to base its research on some sort of satisfaction index. This question was left completely open-ended to give parents the opportunity to characterize their satisfaction level in their own way and to talk more in-depth about their satisfaction or dissatisfaction with the process. This provided valuable insight into parents’ thoughts about the diagnosis process in general and what they considered to be their satisfaction level, more specifically. This question showed that thinking about the diagnosis process in terms of satisfaction levels is not only an over-simplification, as was suspected previously, but also extremely subjective. Parents each interpreted the question differently and how they answered it in relation to their diagnosis experience was also subjective. Parents commented on the awkwardness of having to answer such a question. One said “It’s such a weird way to look at it, as if it’s like a customer service thing” (24) while another shared that “Nobody can walk away and go, “It was satisfying,” because it sucks” (7). These same parents shared how difficult it can be to “rate” such an emotional process. “What was this? You know, for sure, the most emotional thing that’s ever happened to me” (24). “I mean if you find yourself in this position, I don’t care if like the first set of tests, they find it, and everybody’s on the ball. I mean no, nothing like, I mean nothing’s

like really good about it” (7). While these mothers surely don’t speak for all the participants, they illustrate the complexity and subjectivity of such a question.

The open-ended nature of the question does pose a challenge when characterizing the parental responses. Twelve parents seemed to express a positive level of satisfaction with the process they experienced or were experiencing. Some parents shared explicitly that they were “satisfied” or “very,” “pretty,” or “100%” satisfied. Several of these parents did also discuss difficulties they had with the process or things they would like to see improved, however. Other parents responded that the process was “fine” or they were “happy with it.” Some parents also categorized as having some level satisfaction with the process didn’t respond with a concrete answer but, in response to the question, described aspects of the process that were positive to them or described how they got what they needed from the process. It is important to remember that several families characterized as showing a measure of satisfaction with the process also discussed aspects of the process that were more negative for them.

Six families responded in ways that could not easily be characterized as satisfied or dissatisfied. Some of the families discussed specific aspects or professional interactions that were satisfying to them and specific ones that were not satisfying to them. One couple discussed between the two of them, how one’s own outlook on life factors into the diagnosis process, but they both also acknowledged that a very poor disclosure experience would make the process more difficult. They did not believe their process to be that bad. One mother, as quoted earlier, did not think you could ever say you were satisfied with such a difficult process but did say she was satisfied with the

level of care that her daughter has received. Lastly, one mother said she didn't know if she was satisfied because, although she accepted the diagnosis, she questioned if the school district qualified her daughter for services to "get more funding from the state" (10). However, she says that view is cynical.

Six families were characterized as being more dissatisfied with the diagnosis process than satisfied. Three families expressed that they were "not very satisfied" or "not satisfied whatsoever." Two families did not give a concrete satisfaction answer but, in response to the question, described aspects of the process that were frustrating to them or made suggestions for how to improve the process. One mother described that she was "sad" about her daughter's delays and that she wonders why it happened to her. This response is a good illustration of how difficult it can be to respond to such a seemingly unemotional question about such an emotional process.

Parents, throughout the course of the interview, would share positive and negative aspects of the diagnosis process. When asked about their satisfaction with the process, however, they would often mention specific aspects to support and describe their level of satisfaction or dissatisfaction. The most-mentioned satisfying aspects of the process for parents was finding good help and getting a concrete diagnosis. Parents also talked about having a good disclosure experience with professionals and receiving a diagnosis that was not as severe as perhaps they were fearing. Working with a proactive pediatrician and having their own concerns confirmed were also cited as reasons that helped to make the experience more satisfying.



When discussing reasons why the experience was not very satisfying for them, parents most talked about the emotional difficulty of the process and wanting more information shared with them by professionals. They also expressed frustration around trying to get services for their child, needing more guidance in how to go about the process, and difficulties in making the actual diagnosis. A poor disposition on the part of individual professionals was also dissatisfying for parents.

An interesting aspect of parental responses to the satisfaction question was the match or mismatch to their overall diagnosis story. While it is not my intention to judge a parent's story as one of satisfaction or not, it is important to see what an expressed level of satisfaction really means. As was noted earlier, some parents who expressed a positive level of satisfaction with the process described many hurdles and frustrations with the process when telling their diagnosis stories. Likewise, parents who seemed to describe rather uncomplicated and benign diagnosis processes expressed that they were not very satisfied with the process. Other parents, of course, answered the question in a way that seemed to perfectly mirror their described experiences. A satisfaction level index or percentage tells a reader little to nothing about a parent's actual diagnosis experience.

Parental answers to this question can be formed by a number of factors. Some of these factors may remain unchanged over time and some many change from moment to moment. For instance, this was one of the last questions asked in the interview. That may have influenced parental responses. If discussion of the process was cathartic for the parent or if discussion of the process was painful it would have influenced their answer. While all the interview questions are subjective to a point and could be influenced by

many factors, the responses to the satisfaction question are so complex that it can be difficult to know what they really tell us. Asking a parent to synthesize such a multifaceted, emotional process into a concrete statement of satisfaction or dissatisfaction is perhaps too artificial a process to really tell us anything definitive. What it can tell us, if we look beyond the one-phrase answers and calculated satisfaction rates, is how parents think about the question and the process as a whole. Looking beyond the actual 50% satisfaction rate we get insight into how parents feel about the process, how they think about those feelings, and perhaps what they might find satisfying about a complex, emotional process.

### **What Parents Wanted from the Process and Whether They Received It**

Parents were asked two questions toward the end of the interview, “What did/do you want from the diagnosis process?” and “Do you feel like you got it?” These questions were asked as a possible way to get at a more genuine indication of fulfillment than the satisfaction question seemed to illustrate. While the responses do tell us what parents were looking for from the process and how well the process met their needs thus far, they also show us, like the satisfaction question, the complexity of the process and its interpretation by parents. Fourteen families were able to share what they wanted when they embarked on the diagnosis process with their child and how well those wants were fulfilled. Five families shared that what they wanted from the process changed over time and how well those wants have been fulfilled. Lastly, four families, three of whom had a child with Down syndrome and one who had a child that was born prematurely and spent months in the NICU, never made a conscious choice to seek a diagnosis so didn’t

necessarily want anything specific from the process. The three families with a child with Down syndrome did answer with what they wanted from the process as more of a reflection on what they might have wanted.

In the most general sense nearly all parents expressed that they wanted to know what was wrong with their child and how to help him or her. While parents had different ways of expressing this and some wanted more specifics than others, this was at the heart of nearly all parental desires from the process. They wanted to know what was wrong and they wanted help for their child. At least six parents expressed these desires with words such as we “just wanted” or “all we ever wanted” showing that they believe their expectations were simple ones. One parent shared that “All we ever wanted was help. All we ever wanted was someone to tell us what was going on, and how we could work on it” (24). Most, but not all, of the parents who expressed these more basic expectations were fulfilled in their desires from the process.

About five parents expressed a more specific version of wanting to know what was wrong with their child and wanting help. One example of this is the following parent who wanted a concrete label and a concrete action plan.

Well, I think like a lot of parents, I wanted a name for what was wrong and then, you know, how to fix it, like a manual on how to fix it. Okay, what’s this called and now give me the manual on how I can fix it [laugh].  
(14)

Some of these parents also expressed that they wanted to know why their child had these delays. These parents, in general, were less fulfilled in their desires, though some did get what they felt they wanted from the process. For parents who expressed the desire to know “why,” this was often the most unfulfilling part for them. One parent said “I

wanted to know why does he have a deficit. Not necessarily a name of a diagnosis, more what is this process that's not letting him be normal. I wanted to know that" (19).

One parent expressed a desire to be heard. This mother had had a hard time getting her concerns heard by her pediatric practice as well as other mothers. She described telling anyone who would listen how concerned she was about her son's lack of speech and language skills and how she felt like no one responded.

One parent shared the end product that she wanted from the diagnosis process. She seemed to be referencing the child's next evaluation through the school system.

Of course, I expect that they will tell me that she's normal. I know that maybe they won't because I understand that she has to improve a lot of things, but I'm really hoping that at least she is in the average so I can feel comfortable. (3)

Five parents shared that what they wanted from the diagnosis process changed over time. Two parents expressed what they wanted from the process in the beginning but then ultimately shared that they felt fulfilled by just knowing their child's diagnosis. The first of these two parents shared that she initially wanted a "solution" (11) or cure for her child, but now feels "fortunate that we got a diagnosis 'cause there's a lot of people who never get a diagnosis" (11). The second mother, who has a child with profound needs and a limited projected life span, shared that she initially wanted "specifics" (18) such as "How long is he gonna' live? [...] What should we start doing? How should we prepare our older son?" (18). While those answers were not forthcoming, she did share that she, too, feels fortunate to know her son's diagnosis because "the worst possible situation to be in is not to have a diagnosis" (18).

Three other parents shared how their perspectives changed over time and how what they wanted from the process changed. One mother shared that her initial desire was to get her daughter “caught up” but her outlook has changed a bit and now she thinks maybe her daughter doesn’t need to conform to all the standards that she thought she did. The second set of parents initially wanted help from professionals or as the mother said “someone else to kind of take care of the problem” (2). When her child was not progressing, she and her husband began to actively search for a diagnosis themselves. The third mother said initially she thought “I want answers. I want you to tell me what is wrong, and then I want you to tell me how I can fix it” (20). She continues “then when you realize okay, this is a bigger problem than that, let’s at least tell me what’s wrong, and tell me what I can do to make it better” (20). Of these three families, the first parent expressed that she felt fulfilled in her new desires, the second set of parents shared that they were about “halfway there” (2), while the third parent expressed that the process is still ongoing.

Some parents did share an emotional component of the process where they initially wished their child did not have a disability or could be cured of the disability. They all shared, though, that they knew, in some way that was not realistic.

My heart wanted to hear everything was fine and it would be just fine. And I’m just worrying about nothing. That’s what my heart wanted to hear, but truly, I wanted to know why does he have a deficit. (19)

We’d like somebody to say, just make sure he eats a carrot every day, and he’ll be a perfect angel. (2)

I think everybody wants, uh, the process to fix your child and make them whole and make them perfect. And then you sit back and get realistic, and you think, okay, now, I know that isn’t real. (20)

Parents of children with Down syndrome had a difficult time answering these questions as the questions didn't really represent the process as they experienced it. These parents felt like they never really started the diagnosis process and therefore had no preconceived desires. Their children were born and they were told of the suspected disability almost immediately. They did have thoughts on how they would have liked the information disclosed to them, however. Two of the families shared that they wanted someone to express the positives of the disability to them, in essence that their child and their lives would still be "normal" in many ways. One mother added that she would have liked a sense that she was not alone, as the hospital stay felt very isolating for her with all the other new mothers and their babies without special needs. The other mother added that she would have liked information as she was given none by the hospital where she delivered. The third mother said she would have liked to have been more coherent when the news was first shared because her son's birth had been an emergency C-section and she was still heavily sedated and essentially asleep when they told her. She added that a personal, verbal approach with something comprehensive in writing would be best.

While these questions may or may not be a truer indication of fulfillment than the satisfaction question, they do illustrate parental desires around the diagnosis process. The responses illustrate parental thoughts at different points in the process as well as different kinds of thought processes, both cognitive and emotional. It is the interplay between these thought processes and how it manifests itself over time throughout the process that lends to the complexity of studying this issue. Any understanding we can gather from these responses illuminates the process and therefore the study of the process.

### **What Makes the Diagnosis Process Easier for Parents**

Parents were asked what made the process difficult for them and what made it easier. Much of what parents expressed as making the process difficult for them has been characterized in other sections. Most parents expressed frustration with not knowing how to find services for their children, the uncertainty of the diagnosis and treatment processes, and having to do so much of the coordinating of the process themselves. Other parents commented on how just having a child with special needs makes life more difficult.

When discussing what made or makes the diagnosis process easier for them some parents choose the one thing that seemed to make the process easier for them and some parents discussed a few aspects that made process easier. The result of this inquiry is a list of parental supports during the diagnosis process. The most frequent response from parents was that the professionals they worked with made the process easier. Nine parents mentioned this. This shows the tremendous effect professionals can have on parental perceptions of the diagnosis process. Parents appreciated professionals who gave them hope and showed they “really value” (7) their child. They also appreciated skilled professionals who knew how to help their children and shared their knowledge and information with them. Lastly, one parent acknowledged that “there is a certain amount of hand-holding that needs to go along with something like this” (16) and parents appreciated professionals who did that, both emotionally and logistically.

Four parents discussed how connecting with other parents with children with special needs has made the process easier. Whether in the form of a formal support

group or an informal group of friends, parents found value in connecting with people who understood their special parenting challenges. This topic was mentioned throughout the interviews by more families than the four who singled it out here. Several parents found a special kind of support from other parents in similar situations. The support they got was in various forms. One mother found having others further along the parenting spectrum was helpful, another found having people to pool knowledge and resources with was important, while still another seemed to enjoy the emotional support of other parents. One parent did mention that she found talking with other parents helpful, but that she has a hard time working it out.

I mean there has been a lot of opportunities for me to do that, and I probably could be more proactive in getting together with others mothers that but its hard because I don't have a sitter, and then, like I said, we have two younger kids. So I can't really do that, even though I know it would be good for me. (6)

This brings into question if the parents who could most benefit from this type of support are the ones who have the hardest time accessing it.

Three parents discussed how the services they got made the process easier for them. While some parents probably believe service delivery to be outside of the diagnosis process for them, with parents defining the process so individually it seemed to be an important part of the process for some. Importantly, parents did not need to see the services as perfect to believe they made the process easier for them. A fourth parent cited the positive response her son had to therapy as something that made the process easier. This could be seen as related to service provision in that the child got the services he needed to progress.



Two families each said family support, getting good information, and having their knowledge validated made the process easier for them. One parent each said that the support from her pediatrician, and being a stay-at-home mother with time to devote to the process helped make the process easier.

In trying to understand parental perceptions of the diagnosis process, it is helpful to understand both where parents find support during the process and what aspects of the process can be gratifying to them. Professionals should be interested in creating an easier process for families and this shows that they are well-situated to do so.

### **Parental Advice for Other Parents Going Through the Process**

The last question asked of all families was “If I were a parent just starting the diagnosis process, what would you want to tell me?” This appeared to be one of the most thought-provoking questions for parents. Some parents answered almost immediately, seemingly having their answers and advice at the ready. Other parents had a difficult time trying to put such a complicated, emotional process into useful advice for another parent. However, all parents contributed thoughtful comments that were individual and unique to their circumstances, yet had universal wisdom and appeal for other parents. There are themes that are repeated throughout different parents’ comments such as start early, reach out to other parents, trust your instincts, and everything is going to be ok. There is also seemingly conflicting advice such as “trust what they said” (3) and “trust no one” (2). This adds to the rich compilation of advice as a whole and shows the individuality of each family’s experience.

The question was changed slightly for some parents to fit their individual circumstances. Most notably, parents who had a child diagnosed with Down syndrome often didn't understand the concept of "starting the diagnosis process" and how it related to them as they never saw themselves as "starting" the process, it just happened. In turn, I asked something similar to "If I just found out that I was going to have a child with Down syndrome or just had a child with Down syndrome, what would you want to tell me?" These answers, understandably, have a different tone, but have experiential wisdom that goes beyond the diagnosis of Down syndrome, as well.

Some parents gave emotional advice on coping with the process and having a child with special needs. Other parents gave more logistical advice of how to get through the diagnosis process and how to get the best services for your child, though much of this advice had an emotional component, as well.

The most mentioned aspect of parental advice, shared by at least eight parents, was some version of "go with your gut" (9). This likely reflects the difficulty many parents had in getting their initial concerns heard. It also may reflect the less powerful role parents have in society compared to that of professionals. Parents advised other parents to trust their gut and have confidence in their knowledge. Somewhat ironically, the second most mentioned piece of advice, mentioned by at least six parents, was to trust professionals. While these two pieces of advice may seem contradictory, some parents mentioned them both. Parents seem to have a keen understanding of taking the useful information given to them by professionals, but trusting their own knowledge, as well. Some parents did qualify this piece of advice somewhat by telling other parents to find

“good” professionals and trust what they say. The third most mentioned, and related, piece of advice was to research and find out as much as you can. At least five parents shared this piece of advice. As one mother says “[You] probably need to ask every question you can possibly think of, research every single test that they order and gather questions based on research” (11). Parents seem to say that the best course of action for new parents embarking on the diagnosis process is to trust their instincts and the knowledge of professionals, but learn everything you can to make the best most informed decisions for the care of your child.

The next pieces of advice were all mentioned by at least four parents each. The first is don’t entirely trust what professionals tell you. Some parents elaborated that the professionals may have certain motives while others just shared that they might not really know what they are talking about. Some parental advice on this topic was more tempered such as “take it with a grain of salt” (13) in reference to professional advice on what your child will or will not be able to do. The second piece of advice was to “Start it as early as you can” (1). This sentiment was likely held by many of the parents, but parents of children with certain disabilities felt the acute nature of the urgency of time more than others. The third piece of advice was to connect with other parents of children with disabilities. This is not surprising given parental responses to other questions that showed this as a sense of support for many families.

The next group of responses was each mentioned by at least three parents each. The first piece of advice was to be involved in the process and your children’s care and advocate on their behalf. This can be seen as an extension of the earlier responses of trust

your instincts and research everything you can. The next three pieces of advice are different, but related. The first of those is to be patient. Parents mentioned this in different ways. Some emphasized being patient with the process such as “Everything has a waiting period. Everything has to be done step-wise. There are several steps. Don’t give it up,” (19) while others focused on being patient with your child and the progress you want him or her to make. The second piece of advice related to that is to take the process and your life one day at a time. As one mother put it “This isn’t a sprint. It’s a marathon” (7). That same mother emphasized to remember that “at the end of the day, you’re just a mom” (7). Lastly, other parents offered reassurance that it’s going to be ok or as one parent put it “I would say it may suck but it’s not the end of the world” (18)

At least two parents suggested to lean on your support system of family and/or friends and one parent advised to find happiness in your life and in your child. While this mother emphasized that she loved her son very much, she shared that having a child with special needs is like going on a trip where you think you are going somewhere wonderful, like the “Taj Mahal” (21) but instead you wind up in the “slums” (21).

You have to take a moment to realize that, you know, while you’re talking to all these professionals that you are going through an experience. And it is definitely – you’re traveling somewhere. Usually we all know where we’re going. At some point, we have a sense, you know. I bought tickets. I’m going to England. I’m going to here. I’m going to there. But in this case, you don’t. You’ve got to get yourself a break sometimes and realize that you’re doing the best you can, and that there are roses blooming in the slum somewhere. [...] It might be under something, but you just have to find it. And when the doctor says to you, “This is what it is,” you have to say to yourself, “Okay, this is what it is. Now that I know that this is what it is, where is the garden?” There’s got to be a garden. There’s got to be a garden. There’s a garden at the Taj, somewhere, some person is enjoying something about that place, and that is what I find with Peter. I enjoy him. I have found a way to enjoy him even though I feel like in the end, I think,

he's killing me, which is I guess the last note to end on. Um, in the end I think he's taking years off my life. I will die much younger. I have a feeling that I would have had it not been for him, I mean, this is to me probably a slow death what I put myself through, [...] Well, then I better find something from him that I can just enjoy, just in its purest sense. (21)

It is important to realize how open and candid parents were in sharing this advice with me and other parents. Their advice is borne from experience and emotion and they were happy to share their knowledge to potentially help other parents in their situation.

### **Analysis of Process as a Whole**

In order to get the most complete picture of parental perceptions of this experience, I will look at how the previously analyzed factors come together to create a family's individual story. Each of the factors affects the process in different ways and families experience these factors in combination and in context. In reference to the overarching research question that this section seeks to answer, "How do parents perceive the diagnosis process?," the short answer is that they perceive the process individually and uniquely. However, uniting themes and patterns can be found and will be explored here. In this section, I will analyze the stories in their entirety holding true to each parent's story and context while highlighting both the unifying and defining factors. First, I will categorize the stories by specific patterns. I will explore and explain three different diagnostic patterns that the families experienced. Next, each story will be summarized and then I will highlight five individual stories as case studies. Each case study will be summarized for how it represents the spectrum of experiences of the larger research sample.

### **Family Patterns Through the Diagnosis Experience**

When trying to understand the longitudinal nature of the diagnosis process for families it can be helpful to characterize their experiences as patterns; three distinct patterns were evident. Nine families had experiences that can be categorized as a “Medical Diagnosis to Therapeutic Treatment” pattern, four families had experiences that can be categorized as a “Searching with Some Successes” pattern, and 11 families can be categorized as experiencing a “Progress over Time” pattern. These families did still have experiences that were unique, but they have similarities to the other families’ experiences that shared their pattern, as well.

Children of families experiencing a “Medical Diagnosis to Therapeutic Treatment” pattern were all diagnosed by a medical professional and, in general, had the most severe and most specific disabilities. While these families’ children may still have ongoing medical issues that are treated within the medical community they were and are all also receiving therapeutic treatments through the state run EI system, the school district, private therapists, or a combination of these. Moving from the medical community to the therapeutic community, and often still navigating both, coupled with the severity and specificity of their children’s diagnostic label gives these families a particular set of experiences.

Families experiencing a “Searching with Some Successes” pattern generally have children with a medium severity, less specific diagnostic label. All of these families expressed that they did not think the diagnosis process was over for them and they were still searching for effective therapies for some issues. While these parents have seen

some improvement in their children, these families experience a lot of frustration as they are still struggling through the diagnosis process while receiving treatment and therapies that they feel do not fully address the spectrum of their children's needs.

Families experiencing a "Progress over Time" pattern generally had children with the least severe and least specific disability labels. The children were also all diagnosed by either the state run EI system or the school district. These parents all expressed marked improvement in their children's development. While these families can be seen as the relative success stories of early intervention, and many characterize their experiences that way, the path was not always an easy one.

Following are graphic representations of the pattern models using one family's experience as an example for each pattern (see Figures 1, 2 and 3).

### **Introduction to Family Summaries**

Summaries of all the interview stories can be found in Appendix D. Each summary contains the child's age at the time of interview, the age at diagnosis, and the approximate time lapse between the two. It also contains a general sibling and/or family description and a general description of the child's needs. A summary of the diagnosis process experience including the family's interactions with their pediatrician, how they learned about various services, if they believe the process to be over, and their satisfaction with the process is also included. At the end of each summary, the child's specificity and severity labels can be found, as well as their pattern categorization.

Day care worker expresses concerns to the mother when Rachel is five months old.	Sees pediatrician who orders MRI and gives the mother dev. pediatrician , private therapist, and EI numbers.	Rachel qualifies for DT, OT, PT, and Speech from EI.	Sees dev. pediatrician who orders hearing test, EEG, and genetic testing.	Receptionist calls to set-up appt, with geneticist and gives diagnosis over the phone.	Parents research diagnosis on the internet.	Meet with geneticist who gives them the same information they just found on their own.	Parents join syndrome support group and go to conference.	Rachel continues to get services through EI and then transitions to a school program.
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**Medical Diagnosis to Therapeutic Treatment, 9 out of 24 (37.5%)**

Medical diagnosis, in all cases but one with a specificity of 4 or 5

Mostly therapeutic treatments with possible occasional medical procedures

Families with children with the most severe, most specific disabilities

*Figure 1. Illustrative Model of Medical Diagnosis to Therapeutic Treatment Pattern*



The mother has concerns about Justin's behavior at two and half years old.	Sees pediatrician who gives the mother EI number.	Justin qualifies for EI with a fine motor delay.	Behavior escalates in therapy. Justin turns three.	School qualifies Justin for program because of behavioral needs.	The mother begins to have learning concerns about Justin, school says it is just behavior.	Sees neuropsychologist and rules out ASD.	Sees neurologist and rules out seizures.	School district adds LD label and OT services to Justin's IEP.
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**Searching with Some Successes, 4 out of 24 (16.5%)**

- Diagnosis process not over
- Still looking for effective therapies for some issues
- Families with children with medium severity, less specific disabilities

*Figure 2. Illustrative Model of Searching with Some Successes Pattern*

The mother has concerns about Nicole's speech and motor development at ten months	Sees pediatrician who says she's fine and will catch up.	The mother knows about EI and calls on her own.	Nicole qualifies for OT, PT, and Speech in EI.	The mother gets reprimanded by pediatrician for going to EI. Pediatrician will not sign paperwork.	New pediatrician in practice signs paperwork.	Nicole gets EI services until she turns three.	School qualifies Nicole for program because of speech and social needs.
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**Progress over Time, 11 out of 24 (46%)**

- EI or school district diagnosis
- Parents see marked improvement in children's development
- Families with children with the least severe, least specific disabilities

*Figure 3. Illustrative Model of Progress Over Time Pattern*

These summaries were created to show the individuality of each family's story and to unite them with similar components in each. The first three components (i.e., age, age at diagnosis, and time lapsed since diagnosis) are significant because the literature identified these as possible influential factors. The sibling or family description was pertinent in that many parents' knowledge of child development and/or of services available was influenced by whether or not the child had siblings, particularly older ones. The child's need description and specificity and severity labels are also included because the child's specific disability can be a factor in how parents' perceived the diagnosis experience. Lastly, and most importantly, a summary of each family's diagnosis experience can show how each family's set of unique factors contributes to their overall experience. I created these summaries using four sub-components that proved to be especially prominent summary themes. They are as follows: experience with pediatricians, service knowledge, whether or not they believe the process to be over, and overall satisfaction with the process.

### **Illustrative Case Studies**

I created five case studies, chosen specifically, to highlight the overall spectrum of experiences of the study sample as a whole. Each child's story is followed by an analysis of what the particular case study demonstrates in reference to the study as a whole. Each family's story shows the individuality of their experience and what ties their experience to others' experiences in the sample.

**Kevin.** Kevin is a five-year-old boy with a twin sister. He loves cars and trucks and enjoys riding his bike and playing at the park. He is also a rigid thinker and has social and fine motor needs.

When Kevin was about two and a half years old his mother called the day care provider to say that Kevin was having a particularly hard day and had he given his sister a bad bite. The day care provider then began to discuss with the mother that she didn't think Kevin was a typical two and a half year old. Before this moment, the mother had always thought that the difference between her children's behavior was because Kevin was a boy. The day care provider was cautious in sharing her concerns with the mother because when she brought up similar concerns with other families they immediately left her care. This mother trusted the day care provider's concerns and contacted EI for an evaluation. The mother knew about EI because Kevin's sister had been a late walker and she used EI's services then. The mother thinks the pediatrician is the one who told her about EI initially, but she is not sure. Their day care provider also mentioned EI services to the mother.

Kevin qualified for occupational therapy (OT), because they believed him to have sensory processing issues, and social work through EI. The social worker they were assigned was a new graduate and the mother "was not impressed" by her. The mother soon cancelled social work services. Because of Kevin's age, he was only in EI for a couple of months. When he turned three, the school district said that he did not qualify for services. At this point the mother was not sure if his needs were such that he really did need any special programming.

They continued occupational therapy (OT) privately though the mother and father did not know whether or not it was helping. Some of her suggestions would work and some would not. That particular occupational therapist went on a maternity leave and they got a new OT who was very qualified, but whom the mother and father felt put an overemphasis on OT. They felt as though she believed all of Kevin's behavioral and rigidity issues could be solved with OT, but they were not really seeing any improvements. The mother did not know what to do because Kevin did not really have a diagnosis and she did not know how else to get him help so they continued with the OT. When the OT suggested more OT services for Kevin and the mother and father refused, she suggested adding social work to Kevin's therapies. The mother and father thought this might be a good idea and agreed. They liked the social worker and she gave them good ideas to try, but they did not really work. Kevin just did not seem to be a typical case. The social worker tried to show the mother and father how to hold Kevin to restrain him and he attacked the social worker "making her bloody." Although the OT and social worker both did evaluations, neither gave Kevin any kind of diagnostic label. The OT also pressured the mother into getting Kevin's eyes checked because she believed his peripheral vision was bad because he kept bumping into things. The mother felt his vision was fine and that he was "excitable." The OT talked to Kevin's other therapists and the day care where she gave Kevin services, though, and they all began questioning Kevin's peripheral vision. The mother then took him to the eye doctor and his vision is fine.

Kevin's first year of preschool, although he needed to be removed from the room several times, went "mostly ok". Whenever incidents would occur, such as when Kevin threw furniture or head-butted his teacher, the mother would call the school district and say that she thought he needed help. The woman she spoke with said that his behavior was not affecting his education, partly because he was performing adequately at his current school. Someone from the school district also observed Kevin at this preschool, but he was fine during the observations. The mother says she did not know enough to pursue it then.

Meanwhile, the mother and father pursued other private evaluations. A psychologist who evaluated Kevin did not give him any kind of diagnostic label. At the same time, the father began searching on the internet and suspected that Kevin might have Asperger's syndrome. The father found traits in himself and his family while searching for Kevin's diagnosis and feels like he is more empathetic to Kevin's issues now. The mother and father brought all of Kevin's evaluations to a developmental pediatrician and a psychologist who worked for a well-known, area university. After the mother and father brought up the possibility, the professionals seconded the idea that maybe Kevin has something similar to Asperger's syndrome though he would not fit the traditional diagnosis. They referred them to a neurobehavioral center at a nearby hospital that specializes in high-functioning ASD. They recommended behavioral analysis and a social skills group. Kevin then began to work with a behavioral analyst who did not give him a specific diagnostic label either. The mother says they did not necessarily feel like

they needed a label for Kevin, but that they wanted the right services, especially since she felt like OT was the “wrong service for him” and they “wasted so much time on it.”

The professionals in Kevin’s life would reiterate to the mother that they thought Kevin needed to be in a special school placement. The social worker kept “pushing” a particular private school, which was frustrating for the mother because he was doing adequately in his current school and the social worker would bring it up repeatedly at meetings. Some of the professionals helped the mother negotiate the school system and at the end of Kevin’s first year of preschool, the mother called the school district again and “cried and went up the chain of command.” The mother insisted on an evaluation over the summer. Kevin was evaluated over the summer by a psychologist and speech and language pathologist from the school district. After observing him at camp, they agreed that he needed to be put in a classroom program. They gave him a general label of Developmental Delay.

When Kevin began the program in the fall, he had a very hard time transitioning. He enjoyed his old preschool and wanted to go back there. He had a difficult time with the demands that the new program put on him. The mother also believed that the program was not prepared for his level of violence. After he had several disruptive incidents, the school district discussed alternative placements for Kevin. The mother says that he is doing better now and that at least the school district is more prepared for him now. The school district does not want to send Kevin to a general education kindergarten class. The mother is bothered by this since they “insisted for so long his issues wouldn’t

affect his education” and now they want to send him to an alternative placement even though his behavior has improved.

The mother and father do not believe Kevin’s diagnosis process is over. They continue to see specialists because, although Kevin has made progress with the behavioral therapy, they “still have a serious problem with violence.” The mother and father say the most difficult parts of the process are professionals, like the OT, who are “so focused on their specialty and being right” that they do not really help the child. They also say that, in contrast, the behavioral therapist gives them ideas of how to help Kevin and if some suggestions do not work, he changes his approach and comes up with other suggestions, which has been helpful. They also say getting the school district to give Kevin an evaluation was very frustrating and, although the school placement has had mixed results, if they evaluated him sooner they might have been better prepared for him sooner.

The father says that with the exception of the Applied Behavior Analysis (ABA) therapist, he feels like most of the professionals they saw knew very little about how to help Kevin and would not admit it. He says at his most cynical, he feels like they were “all a bunch of scam artists out for more billable hours.” The mother partly shares this view, but thinks some of the professionals were nice, just unhelpful. The mother and father feel like they did not get a lot of information along the way and what they did get was not helpful. The mother did find other parents of children with Asperger’s syndrome and ASD and found some good resources through them, including the ABA therapist who is “the only one who has helped Kevin so far.” The mother and father say what they



want from the diagnosis process is “just to get the right services” for Kevin to make their lives easier and Kevin’s life more enjoyable. The mother and father say they feel like they are “on the right track” to getting what they want from the diagnosis process. They are “about halfway there.” Their advice to other parents would be to question what professionals tell you. If it does not seem right for your child, it might not be right. The mother says they were pretty unsatisfied with the diagnosis process because they were getting the wrong services for so long and it was so hard to get the school district to listen to them.

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Kevin’s family’s story is instructive in many ways. His story shows some of the frustration parents can encounter when trying to find a diagnosis for their child. Families, even with a substantial degree of means and education, can have a difficult time finding the appropriate resources for their child. Kevin’s parents pursued help for him through various channels, often resulting in less than helpful services from professionals with whom they had little confidence.

Many children do not fit neatly into diagnostic categories, which can be difficult for professionals who are looking for ways to help and even more difficult for parents who are desperate for assistance and answers. Families who have children who exhibit behavioral issues can have an especially difficult time finding help and services. As was the case with Kevin, behavioral issues can be hard for a professional to readily and/or consistently see. Therefore, it can be problematic to secure services. If services are recommended, finding effective ones can be a lengthy process requiring close teamwork

from parents and professionals. Kevin's parents found that certain professionals were well versed in their particular brand of therapy but knew little of other options to try if that did not work. This left Kevin's parents feeling not only lost, but as though the professionals did not value them or their opinions.

This also shows two different roles parents can play when actively engaged in their child's diagnosis process. The mother handled many of the day-to-day dealings with professionals while the father pursued options, and ultimately a possible diagnosis, on his own. They both worked together and they both worked with Kevin and his sister daily giving each of them a keen understanding of Kevin's challenges.

**Christina.** Christina is over four and a half years old. She has an older sister and is happy and outgoing. She used to be very shy, especially with other children, and had a hard time communicating. Christina's family speaks English and Spanish.

When Christina was about two and a half years old, her mother noticed that she was not developing like her other daughter did at that age. The mother says that she knows children all "develop at different paces," but that Christina was having difficulty with her speech and her mother knew she needed some help. Christina knew some words in English, some in Spanish, and some "were her own language." The mother had worked for a non-profit group in another state and was familiar with EI in that state. She knew that they helped children developmentally. She brought up her concerns to her pediatrician and asked him for the number for EI. He said that Christina would "probably need some help later on, but that it's still kind of early." He gave the mother the number for EI.

EI came and evaluated Christina. She had a limited vocabulary and could not put sentences together, but her speech and language skills were not delayed enough for her to qualify for services at that time. The mother “waited a while” and then called EI again. This time Christina was over three years old and the mother knew EI only gave services up to age three. The mother asked EI whom she should contact and EI got her in touch with her school district.

The school district screened Christina and the mother filled out paperwork specifying her concerns about Christina. The mother was concerned about Christina because she was code mixing and “she would disconnect inside.” After the screening, the school district set-up an evaluation for Christina with a bilingual speech and language pathologist and other diagnostic team members. They told the mother at the evaluation that they thought Christina needed help. They diagnosed Christina with Apraxia and said that her difficulties with communication were affecting her socially. Christina qualified for a classroom program.

The mother felt guilty initially, because she thought she had done this to Christina by speaking Spanish to her. After the mother read about Apraxia on the internet, though, she realized that “it is something that just happens” and that while teaching Christina two languages might have been more confusing for her, she did not cause her daughter’s disability. She also knew Christina could be helped. The mother says she tries to follow all the suggestions from the school district, such as “cutting back on speaking Spanish” to Christina until she “puts herself together,” and she knows that Christina is getting better. The father says he isn’t that concerned about Christina. He is pleased that the school

district can help her and that she is going to be ok. The mother says that she and the father expect different things and that she wanted to be sure that Christina would be understood at school and that she had friends. She thinks she has that now.

The mother and father do not think the diagnosis process is over for Christina. They think kindergarten will be a significant transition for her and only then will they know if the progress she has made is enough and if her services may need to change. The mother says the most difficult part of the process was that Christina did not want to go to the school program at first. She would resist going to school and felt anxious about it. Now, Christina loves school and is doing well. The mother and father felt all the professionals they encountered acted quickly, were very knowledgeable, and were sensitive and encouraging. The mother says they gave her all the information and always let her make the choice. The mother says they gave her all the information she needed to help her daughter and that she “can’t think of anything bad to say because everything was good.” She says she refers people to the school district all the time and that it was the best thing to happen to them. The mother is hoping that eventually they will say Christina is fine, within the average for her age, and that she will not need services anymore. The mother says the school district has told her Christina is “fine” and now they have to wait for the next evaluation to see if she has “caught up.” The mother says they are satisfied with diagnosis process because the school district diagnosed her accurately and she has been making progress with them. The advice the mother and father would give to other parents is to not delay and “just start” the process. They say to trust the professionals and help them. Also, they say to look up information for yourself

so you have two sources of information and have a more complete understanding of the issues. The mother recommends for other families with concerns about their children to go through the process because a pediatrician “can only help so much and these people know different ways to evaluate and help children.” She wishes more people knew about the program because “it is free and it can help your child.”

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Christina’s story is informative in that her severity is not extreme and that she has made great progress. However, it’s important to note that her developmental issues were hard for her family, especially her mom, and that they believe she is doing so well because of the interventions she received.

Christina’s story also illustrates some of the complexities in diagnosing young children. Although both the pediatrician and Christina’s mother had concerns about her development and knew she needed intervention, she could not get it until she turned a certain age and her skills were then discrepant enough from her peers to qualify for services. This is not uncommon for children with less severe disabilities.

Christina’s bilingual household can also be a complicating factor in the diagnosis process. A professional must have the skills to distinguish between a true developmental delay or just a cultural or linguistic difference. Christina’s school district did provide her with a speech and language pathologist who was bilingual in English and Spanish, meaning that she can not only speak both languages, but perform her professional duties in both languages, as well. Common therapy practice for children with speech and language delays is to eliminate or lessen, at least for a time, any confusing language or

communication models such as a family's home language. This can cause stress within families and can seem to devalue a family's home language and/or their wishes for their child to be bilingual. Christina's mother and father seemed to be fine with this recommendation and had proficient enough English skills to only speak to Christina in English. This can be a bigger obstacle for some families than for Christina's family.

Christina's family's story also gives another look at possible parental interactions and roles within the diagnosis process. The mother clearly was the driving force and the coordinator of Christina's diagnosis and subsequent services. The father was supportive, but as the mother stated, they had different expectations for Christina. Although both parents were very pleased, the mother had stronger opinions about the diagnosis process and was more passionate about it.

**Becca.** Becca is almost six years old. She has an older brother and her mother is expecting another baby. Becca loves school, music activities, and watching videos. She is interested in people who will interact with her in a way she can understand and enjoy. She enjoys looking at people's faces and having them sing or talk to her. Her need areas are extensive and she is profoundly, globally delayed.

When Becca was born she didn't come home from the hospital immediately because there was a blood incompatibility issue for which she needed to be treated. She was also a very poor eater, a very fussy baby, and she had bad reflux. So when Becca missed her first developmental milestones, she wasn't smiling or making eye contact, her mother and doctors were concerned about her other, seemingly bigger issues. When the mother would bring up concerns to the pediatrician, she expressed that her developmental

lags were due to her other medical issues and that she had had a rough start in life. When Becca was four months old, the pediatrician referred her to a pediatric ophthalmologist because one of her eyes was turning in and she thought she might have a lazy eye. The pediatric ophthalmologist intimated to the mother that Becca had more than a lazy eye and that perhaps she was blind. Although Becca's eyes were structurally sound, the ophthalmologist said Becca's developmental issues were indicative of a very low level of vision and that possibly her brain was impairing her vision.

Becca's pediatrician told the mother to get an MRI. She told her when she scheduled the MRI to tell the technician that Becca was developmentally delayed and had low tone. The pediatrician had never mentioned this to the mother before. When the mother called for the MRI they tried to schedule her one five months out. The mother expressed to them that was completely unacceptable and, although the mother is not quite sure how, she got Becca an MRI that same week. The MRI results came back normal, which was a big relief for the mother and father. The mother then took Becca to a therapeutic team at a local university hospital. The mother has a background in speech pathology and went to therapists recommended by a colleague who also has a child with special needs. The mother felt they were much more positive about Becca than the doctors had been. They discussed treatment for Becca and set-up a follow-up appointment. The mother then took Becca to a developmental ophthalmologist and the mother felt like Becca "did horribly" on the assessment there but no one could really tell her why.

The next day they had two appointments, one with an OT and one with a neurologist at the local children's hospital. The mother felt like the OT was very positive and she gave the mother hope. Becca also looked at the OT while the OT was working with her and that was the first time she had looked at anyone, which was encouraging. The mother and father took Becca to the neurologist. The neurologist began by asking the mother if she was sick at all during her pregnancy with Becca. The mother told him she only had the stomach flu once, but she knew the question meant something was wrong with Becca. The neurologist shared that he did not think they really needed to be concerned about Becca's vision because she was significantly and globally delayed. There were also medical students and a nurse present and when the mother asked for them to leave, they seemed taken aback. The father pressed the neurologist about his diagnosis and the neurologist gave them all the ways in which Becca was delayed and all the reflex tests she had failed. When the mother asked him about Becca's prognosis, i.e., would she walk, talk, be potty-trained, the neurologist said he did not know and he suggested they get genetic testing. He also said they could do therapies but made it sound unimportant and that it would not change things. The mother says that was the worst day of her life.

Becca has since been to many geneticists, none of which have been able to give them a diagnosis. The mother asked many of them about what Becca's life might be like, similarly to how she questioned the neurologist, and none were really willing and/or able to give her answer. One geneticist answered most of the questions the mother asked by telling her that maybe Becca would walk, talk, and dress herself but that she would not



have a job or live independently. When the mother got upset, the geneticist told her “Well, you asked.” Then she told the mother that Becca was beautiful and that that would “get her far in life.” The mother believed that interaction to be an especially bad one.

Becca continued to see the OT for the first year of her life. The mother really trusts her and they still work with her today. She was Becca’s sole therapist for the first year because the mother felt like she was working on everything with Becca and the OT said you only want to have a limited number of people working with an infant. When Becca turned one, she got involved with EI. The mother heard about EI from the same colleague who recommended therapists to her. Becca qualified for several therapies and she received developmental therapy (DT), physical therapy (PT), vision, and speech therapies through EI. This colleague also helped the mother to balance therapies. Becca was getting twelve a week when she turned one, with living a somewhat normal life as a family. The mother said the EI process was slow to get services started and then there were paperwork glitches that would come up and cause delays in therapy. In general, she was pleased with most of her therapists and even hand-picked some with her colleague’s help. There was one physical therapist (PT) who made several ignorant and offensive remarks about people with disabilities in general and who made other insensitive remarks to Becca’s brother and to the mother about her own child’s development. Although these remarks bothered the mother, and she told the PT she was offended by some of them, she kept on working with the PT because she was a good PT and she did not want her to treat Becca poorly.

Becca transitioned into a co-op preschool program when she became three. The mother had to push the school district because they wanted to put her in a different placement than the mother did. In the end, she is at the placement the mother wanted and they have been extremely pleased with the school. Becca loves school and the mother loves the school and school staff, as well. The mother says she believes they make Becca feel like a star when she's there.

The mother does not think the diagnosis process is over for Becca. She thinks it will be "soft and in the background." She says they may never know what Becca has and that with any diagnosis the prognosis is not going to be good, but that she worries about possible medical implications. Becca got sick last year and was hospitalized. The mother and doctors were concerned and thought it might have farther-reaching complications but tests were inconclusive. The mother says she also wants to know what Becca's diagnosis is because she is a mother and mothers want to know everything about their kids.

The mother says the most difficult part of the diagnosis process is the lack of guidance and amount of work that you have to put into the process. The mother says you enter into the situation with an "impossible set of emotions" and you have to figure out what to do. You have to navigate and find everything out yourself, which is difficult. The mother says finding professionals who give you hope and are sincere makes the process easier. She says therapists are generally more positive than doctors, but they can be overly optimistic. Finding professionals who love your child and you can trust is

great. She says Becca is pretty much overlooked everywhere in her life, but she is a “superstar” at school and that really helps.

The mother says their experience with professionals has been mixed. She does think there is a certain amount of nurturing that needs to be done in the beginning that is not there. She says what she needs now is different from what she needed then and she has much thicker skin now, but that when people first come to you in such a fragile state there should be more empathy. She does feel that teachers and therapists, in general, are more empathetic than doctors. She also feels as though she could have used more information and guidance in the beginning. She never went online and searched Becca’s symptoms because she does not believe that would have been helpful to anybody. She talked to many people and used any connections she had to obtain information.

What the mother wants from the diagnosis process is, especially before becoming pregnant again, to “know the gene.” She would like to know recurrence risks and any possible medical implications. She also says she just wants to know. It is “such a big mystery” in her child’s life and she wants to know everything about her children. She says all her friends who have children with a diagnosis say they cannot imagine not knowing. The mother does not feel like she has gotten what she wanted from the diagnosis process because she still does not have a diagnosis.

The mother says it is hard to say the process is satisfying because it is such a terrible process, but that she feels confident everything has been done by her and her husband and the doctors to try to determine Becca’s diagnosis. She says she is satisfied with the level of care Becca has received but that it is a lot of work on the part of the

parents. The mother says she would have such a hard time giving advice to parents just starting the diagnosis process because she would feel so bad for them. She says, though, to remember that at the end of the day you're "just a mom." Nobody comes equipped to deal with this and that it is a marathon, not a sprint, so try to pace yourself because it feels so never-ending. She says utilize your resources and rely on your support system. Focus on yourself and your family so that you can take care of your children and try to find someone who has done this before and who can help you.

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Becca's diagnosis came from the medical community, but her ongoing care and therapy is more in the therapeutic and educational realm. This is typical for children with severe disabilities. Sometimes a disconnect exists between these disciplines, as Becca's mother encountered, which can make it difficult for parents. Although these children are often serviced in the therapeutic and educational fields after diagnosis, medical professionals may have little knowledge of and/or faith in those disciplines. Therefore, parents have to find their way to and navigate through two rather separate processes. Parents who begin their child's journey in the therapeutic field are automatically, by law, connected to the educational field when the child turns three. The possible disconnect between the medical community and other diagnostic fields require parents to discover these other fields themselves. As Becca's mother expressed, she would not have know about EI if her friend had not told her. No medical professionals gave her that information. Obviously, some medical professionals are more diligent about sharing this kind of information than the ones Becca's mother encountered, but without a mandated

transition or information sharing system, as exists between EI and the school system, Becca's story is not unusual.

Becca's story is also interesting in that she is the only child whose journey can be characterized in the "medical to therapeutic" pattern who has a very non-specific label. Becca has been diagnosed with a global developmental delay, which the mother says at this point is a "funny" label because she is not really "delayed" as she is profoundly impaired in all areas of development. The combination of Becca's severity, a 5 on the scale, and her ambiguous diagnosis, a 1 on the specificity scale, could prove an especially difficult experience for families. While Becca's mother is very forthcoming about the difficulties with the diagnosis process and raising Becca in general, she also states that she is satisfied with the diagnosis process despite the lack of diagnosis for Becca, because she is confident that all the professionals she has encountered have done their best to try and find a diagnosis. The literature would have suggested that the combination of severity and ambiguity in Becca's case would have made for an especially frustrating experience for Becca's parents, but that does not seem to be the case. The mother describes the difficulties, mostly emotional, in the process but does not express frustration to any large degree. While the mother says she will continue to pursue a diagnosis for Becca, she accepts Becca's disabilities as they are and says she knows that at this point any diagnosis that is made is not going to have a good prognosis.

**Shannon.** Shannon is almost four and a half years old. She has an older brother and a younger sister. She loves school and likes to do gymnastics and horseback riding.

She also likes playing with her siblings and friends. Her needs areas are physical and mostly ambulatory.

When Shannon was three weeks old, her mother and she developed a bad cough. Shannon would cough and gasp for air. The mother brought her in to the pediatrician's office and the nurse practitioner that she saw said babies just cough sometimes. She said she was probably just choking on milk. The mother also went to the doctor for her cough, but her doctor said she was probably just tired and overwhelmed with Shannon and her brother. The doctor gave the mother the number of her babysitter. By the time Shannon was five weeks old, she was still coughing, gasping for air, and turning blue when she could not get enough air. Shannon was also still at birth weight. The mother brought her to the pediatrician's office again and the pediatrician thought Shannon might have whooping cough. There had been cases in the area.

Shannon was sent to the local hospital for overnight observation and to check her weight. The hospital did not have equipment small enough for Shannon and her blood oxygen levels kept dropping until they were unable to wake her. They rushed her to the local children's hospital in an ambulance. At the children's hospital, she was put into the ICU and diagnosed with whooping cough. The mother was terrified and overwhelmed. She says she kept looking at her own mother "to jump in" because she couldn't believe she was the mother and this was her responsibility. They also thought she might have meningitis and did three spinal taps on her. The attending physician came in the next day and said she clearly did not have meningitis. Her blood oxygen levels were still desaturating, though, and she remained in the ICU for another two weeks. She had a

bedside nurse who would restart her breathing whenever she coughed. She stayed in the hospital for another week in the infectious disease unit and was then sent home. She continued to cough, needing to have her breathing restarted, for another three months. Shannon slept in her parents' bedroom and her mother carried her in a baby carrier during the day, even at work, and helped her restart her breathing whenever she had a coughing spasm. The mother says she had told herself that if Shannon made it to six months old, she was going to be ok. Shannon was doing well by then.

The mother had noticed when Shannon was four or five months old, that her legs were stiff and tight, "like a mermaid." Since she only had a boy she was not sure if this was just a difference in gender. The mother has a friend who is a PT and she said Shannon had high tone. When the mother took Shannon to her six month check-up she told the doctor that she thought something was wrong. The doctor gave her the number for EI and told her to see if she could get an evaluation. Two months later, EI came and diagnosed Shannon with a three-month physical delay. They also said she should get a neurological evaluation. The mother shared what a strange experience it is to have your child evaluated. She said it is hard because they are measuring and interacting with her and you do not know what they are doing. She said it is also strange because you want her to do her best, but you know that if she does poorly she will get more services.

The mother took Shannon to the local children's hospital where she had an MRI and met with a neurologist. The neurologist explained that Shannon had minimal bilateral scarring on her white matter, which affects motor development. The mother says the neurologist was very kind and very nice, but that he started talking about his

brother who has Cerebral Palsy (CP) and how he has a normal life with a job and a family. This was upsetting to the mother and father because they “didn’t want her labeled.” They did not really want a diagnosis. The neurologist told them they should go to a local rehabilitation institute to discuss various treatments that can be used with CP.

The doctor at the rehabilitation institute told the mother that the CP was probably caused by an amniocentesis that she had had with Shannon that had gone badly. This was devastating for the mother. The mother said she had the amnio because she wanted to make sure everything was fine with the baby because she already had a son at home and she “couldn’t have a child with special needs.” She said the ultrasound had shown that everything was fine and her husband said she did not need to have the amnio, but that she wanted to anyway. When she had the amnio, the needle pulled out blood and Shannon’s heart rate dropped and they needed to intervene to bring it back up again. When the doctor said that this likely caused Shannon’s CP, the mother blamed herself. She said this put her into a deep depression in which she could barely work and she was crying all the time.

When the mother took Shannon to the pediatrician, she said that her CP was not caused by the amnio, but by her oxygen loss from the whopping cough. The pediatrician said Shannon was fine at birth and they would have seen these signs then if it was caused by the amnio. Another doctor at the rehabilitation institute confirmed this and the mother said that revelation saved her life and brought her out of her depression.

The mother said the neurologist wanted them to keep coming in periodically, but they did not see a reason to since Shannon has a static brain injury and it is unlikely to



change. They do see a physiatrist at the rehabilitation institute who coordinates Shannon's care and treatments.

Shannon continued with EI and her physical delays became more pronounced with the passage of time. What started as a three-month delay turned into a six-month delay, then a delay of a year and more. Shannon rolled over at nine months, but was still army crawling at a year and a half. Shannon's EI case manager had a family illness and did not return the mother's calls. Shannon was getting PT once a week, but was eligible for more services that she was not getting. The mother called many times, pleading and crying in messages, but never heard from the coordinator. Meanwhile, the mother found her own therapists. She also talked to the coordinator's supervisor and eventually wrote a six-page letter to the head of the Department of Human Services. After months of trying, she was given a new service coordinator. Shannon then had to be reevaluated.

Shannon transitioned to school services when she turned three. She says the school system is great, but that she still has to fight for certain things that she thinks Shannon needs, which is hard. The mother also still finds it hard to go through the evaluation processes and, now, the Individualized Education Program (IEP) process. She says it is "very, very hard" to hear that type of information about your child. She says the process is "draining" and "heart-wrenching" and "you feel powerless."

The mother says she believes the diagnosis process is over for Shannon because her condition is not going to change. She says the ongoing life, though, is "very, very hard." It is hard financially and it is hard on her marriage. She says she still has hope that something will be discovered to help Shannon, though. The mother says what makes

the process more difficult is sitting with all the professionals at Individualized Family Service Plan (IFSP) and IEP meetings and listening to all of your child's deficits and you feel powerless. The mother says what makes it easier is having a support system of friends who have children with special needs that you can share resources with. She also says bringing in your own therapists or other support people, to meetings is helpful.

The mother says she felt overall "pretty good" about the professionals she encountered. She says she will "hate the nurse practitioner" who first sent her away "until the day I die," but that the pediatrician who put Shannon in the hospital saved her life and she is thankful for that. She has mixed feelings about Shannon's therapists and says she "didn't love them all." She "hated" the neurologist, but is very happy with the physiatrist that they see. She says the information she got was medically good and that she has never let herself look up Shannon's diagnosis on the internet. She says the best information she obtains is from other people. She feels that the information from EI and the school district has been good. Shannon also qualifies for aide from the Department of Specialized Care for Children and the mother says the information from them is limited.

The mother says what she wanted from the diagnosis process was an answer and a plan. She says she realizes now that it is "more gray" than that and not so quantifiable. She says now that she knows what Shannon's issues are, what she wants is "something to fix it." She says she is very satisfied with the diagnosis process because they know what it is. She has friends who still do not know their child's diagnosis. She says the advice she would give to other parents just starting the diagnosis process is that whatever professionals tell you about your child, "take it with a grain of salt because they don't

know your child.’ She says you don’t even know your child or what they are capable of when they are so young. She says “the things they will do will astound you” and that “they are little and they will make their own way.” She also says it does not help to know that someone is worse off than you. She says she tells herself that, but when other people say that to her it just makes her angry because they do not know what she goes through on a day-to-day basis.

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Shannon’s story begins with a medical or health issue that leads to a disability or discovery of a disability. This is not an unusual path, though the circumstances are unique. Medical diagnoses often come about because of an initial medical concern. Shannon’s story is more unusual, though certainly not rare, in that the medical condition caused the disability. Of note in Shannon’s story, is the swiftness with which the initial doctor at the rehabilitation institute attributes Shannon’s CP to the amnio that Shannon’s mother had with her in-utero. This doctor’s, somewhat superficial if not careless, assessment sent the mother into a deep depression. When the cause of Shannon’s CP is found to be her bout with whooping cough not the amnio, the mother said this news “saves her life.” This is one illustration of the profound effect professionals and their words can have on families during this delicate time. While this example is more extreme, it is not unlike many of the parents who share exact quotes of things they have had professionals tell them. For better or worse, what is a day at the office for professionals is a life-changing event for many of these families.

Shannon's mother was also very open about her day-to-day struggles raising a child with special needs and this gives a glimpse into the complicated lives of these families. Shannon's delays, though she makes improvements, get more pronounced over time. Shannon's delays are solely physical and almost completely ambulatory in nature, however the delays that she has become more discrepant as she gets older. This may complicate the diagnosis and coping process for the mother. Though Shannon's disability severity is a 3 on the scale, her lack of progress can be seen by the mother or others as more akin to more severe disabilities. The stark contrast between Shannon's abilities, age-appropriate in all other areas, and her disabilities may also make the situation difficult. Shannon is and/or will be fully cognizant of her disabilities and the mother constantly sees a daughter so close to perfect. All parents despite severity and specificity struggle or have struggled with their child's disabilities. Shannon's mother's pain is not more or less, but an illustration of the distinctive circumstances that each family faces.

**Vimal.** Vimal is five and a half years old. He has one older brother. He has a great memory and enjoys being read to and playing videogames. He has made great progress but he previously had a very limited vocabulary and struggled with communication in general.

The mother began to have concerns about Vimal's development when he was about a year old. The mother remembered that Vimal's brother was saying monosyllable words and waving bye-bye when he was that age and Vimal was doing none of this. She knew that children develop differently and she thought maybe Vimal was just a late

talker. When Vimal was 15 months old, the mother went away on a trip and talked to the children over a webcam. She remembers being concerned because Vimal had no reaction to her on the webcam and she thought that was a real problem. When she took him in for his 18 month check-up she mentioned her concerns to her pediatrician. He said Vimal's vocabulary was limited but that there was no cause for concern and to just bring him back when he was two. The mother called the pediatrician three months later when there had been no change in Vimal's development. The pediatrician told her about EI and said to get a speech evaluation done because all his other areas of development were fine. She called EI, but there would be a three-month wait to get Vimal evaluated.

She tried to find help for Vimal in the meantime but had difficulty doing so. EI had given her the numbers of some private speech therapists, but when she called them they all wanted to know Vimal's diagnosis, though he did not have one. The mother expressed how lost she felt because she didn't know how to find help for her son, even though she is a physician. The mother said it was so hard because she was calling these therapists she did not know and she did not know what she needed. She just wanted to help her son. At the local swimming pool, the mother saw a flyer "for if you have concerns about your child's development before kindergarten." Even though Vimal was much too young for kindergarten, the mother thought they might be able to help her. She called the school district co-op who generated the flyer and they referred her to the co-op birth to three program. The mother left a message for someone there. When the woman called her back and the mother described her concerns to her, she heard "silence on the other end of the line." The woman told her that Vimal needed help and the mother felt

like she was finally heard. The mother spoke with the woman about what she had done so far and where she was in the process. The woman gave her the number of a private speech therapist, as well, but she had no openings.

When EI evaluated Vimal, he was 26 months old and the mother was impressed with how the evaluators were able to get Vimal to perform some skills. They found him to be functioning at the nine-month level for receptive language and the 12-month level for expressive language. The mother says at first she did not understand what this meant, but when they explained that he was understanding communication at the level that a nine month old baby would, she was devastated. Shortly after the evaluation, the father called to see how it went and the mother shared the news with him. They were both stunned and unsure about what this meant for Vimal's future—would he catch-up? Could he be helped? Was he retarded in some way? The mother says she wanted someone to tell her he would be ok.

EI found that he qualified for developmental therapy (DT) and speech therapy. The mother spoke with the woman at the co-op who helped her understand the therapeutic process better. She said the co-op would provide DT and EI would provide speech therapy. The woman became Vimal's DT and they had a great connection. She also became a source of information and support for the mother. Vimal first had to wait six weeks before they found a speech therapist; then he had three different speech therapists during his months in EI with varying successes. His DT was able to make great progress with him, though.

At the DT's suggestion, the mother took Vimal to a neurologist who diagnosed him with an auditory processing disorder. He ruled out other disabilities, such as Autism, and said to monitor Vimal's needs over time because he is too young to diagnose some disabilities like attention issues, but that they may present over time. He also said not to rely on the pediatrician to monitor him.

When Vimal transitioned into school services his DT told the mother that he should be in a co-op classroom program. The mother trusted her very much by this point and that became Vimal's placement. Because of his how birthday falls on the school calendar, Vimal is in his third year in the co-op preschool programs and he has really "bloomed" there. Vimal's teacher is going to be retiring this year and she told the mother that if she were to count the 10 children she has taught who have responded the best to intervention, Vimal would be one of them. The mother says she has become a "big believer" in early intervention and that with the right supports at the right time, children can make great progress.

The mother says she and her husband are disappointed in the lack of guidance they got from their pediatrician. She says pediatricians are the ones most likely to be asked about developmental issues and she feels like the information they got from him was very limited.

The mother says she does not think the diagnosis process is over for Vimal because although he got what he needed and he has made great progress, she is not sure if he will need different services as he goes to kindergarten and beyond. The mother says the most difficult part of the diagnosis process was not knowing where to go or how the

process worked. She says it was also difficult having to wait for everything when time is precious at that point. She says the easiest part of the process was how well Vimal responded to the interventions. It validated her concerns and instincts and let her know he was on the right path. Vimal's DT, who became like a mentor to the mother, also made the process easier. She says how good professionals are is very dependant on their individual personalities. She talked about how some people make you feel like their "heart and soul" is working for the best interests of your child and how other people just seem like it is a job. She did say how Vimal's DT probably thinks she is just doing her job, but what she did for their family "changed their lives." She says once the information started coming it was a lot and it was needed. The mother says she relied heavily on the professionals who guided her.

The mother says when she started the diagnosis process "her heart wanted to hear that everything was fine" and Vimal would be just fine. However, she says that she really wanted to know why he had these deficits, though she didn't necessarily need a name, just what was wrong. She also wanted to know how to help his need areas and his prognosis. She says although Vimal has made great progress and she is so pleased with that, she wonders about his needs later in life since he does not have a diagnosis, she does not know what to expect. The mother wishes there was better information out there about EI and resources to access if you have concerns about your child's development. She also wishes the guidance to and through those resources was better. The mother says she would tell a parent just beginning the process to know that there is a process and things have steps and take time, but do not give up. She says to trust the professionals even if it



does not initially make sense to you. However, be involved and educate yourself about the process, as well.

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Vimal's story details a savvy, educated mother trying desperately to navigate various systems to find help for her son. The mother is a physician, though despite her profession is no more equipped to find help for her son than any other parent. She is disappointed in her interactions with Vimal's pediatrician, she must endure long waits for services with little instruction on what to do in the meantime, and all the while she feels her son desperately needs some help. She, like many other parents, thinks not enough information is out there for families in need of help. She finds her way to services through various, sometimes chance encounters, including a flyer posted at her local swimming pool. This is typical for parents. They learn about EI or school district services from pediatricians, friends, or flyers. There is no one way parents learn about programs and the ways they learn about these services are based on luck, happenstance, and often, other helpful parents. Many parents wished information about how to find services was more available.

Vimal's story also illustrates the profound, beneficial effect professionals can have on a family's experience. The woman who became Vimal's DT changed his family's life for the better. She was the first one who the mother felt really heard her concerns, she helped the mother navigate the EI and school systems, and she helped Vimal make great developmental strides with therapy. For all the difficult encounters parents shared about professionals there were several parents who had similar stories,

often of one special professional who helped and guided them through this process.

These professionals were understanding, empathetic, knowledgeable, and good at their jobs. They often went above and beyond their traditional professional roles to give parents needed advice and guidance. These professionals did not solve all the families' problems or cure their children's needs, but they provided information and compassion, which was what many parents needed during this trying time.

## CHAPTER V

### CONCLUSION

Looking at the factors affecting the diagnosis process, as well as the process as a whole, gives a well-rounded view of the diagnosis process from the parental perspective. It also helps to answer the four research questions: How do parents perceive the diagnosis process? What factors affect how parents perceive the process? How do parents perceive professionals during the process? What do parents want from the diagnosis process?

#### **How Do Parents Perceive the Diagnosis Process?**

Looking at each interview as a longitudinal story shows us that each family has a unique experience however there are commonalities among the stories. In general, parents experience the diagnosis process much longer than was previously believed and the diagnosis and treatment processes do not just overlap, but are interwoven. Families' reasons for the ongoing process give insight into what the diagnosis process means to them. Families seemed to believe the process to be over when they knew their children's issues and they seemed unlikely to change. However, only one quarter of the families studied felt this was true for them. Any future research into the diagnosis process at large must take care to accommodate parental definitions of the diagnosis process.

The diagnosis stories also show us that families experience the process on many levels, emotionally and cognitively. It is a process that is not easily characterized as it is complex and emotional for families. A single satisfaction indicator, or possibly even any

satisfaction indicator, does not represent the process for families. This study found half of the families interviewed to be satisfied with the diagnosis process. However, it found the concept of “satisfaction” with the process to be a dubious one. Parents themselves commented on how odd the concept seemed to them and their answers showed that the question was extremely subjective. Declaration of satisfaction or dissatisfaction with process seemed to give little, if any, insight into how parents perceived the process. However, the individual reasons they gave for their answers were telling.

Parents experience the process as a unique combination of factors, yet their stories can have similarities to other families with similar factors. For example, a family that has a child diagnosed with speech and language issues in the school system can have similar experiences to other families that have children with speech and language issues as well as other families that have children diagnosed through the school system.

### **What Factors Affect How Parents Perceive the Process?**

When looking at factors that affect the diagnosis process, age at diagnosis, severity and specificity of diagnosis, and thus type of disability, were found to be related. While age at diagnosis did not seem to influence parental perceptions of the diagnosis experiences strongly, type of disability did seem to influence the process for families. Examining the data in this way shows us that the families with children with Down syndrome have a collectively unique experience. Their experience can be instructive in relation to other families with children with disabilities, especially in the area of prenatal testing. However, their collectively unique experience can also show the error of basing diagnosis process research on a Down syndrome model, as was done in much of the

literature. The way most families currently experience the diagnosis process is different than those families' experiences that have a child diagnosed with Down syndrome.

Aside from the experience of having a child diagnosed with Down syndrome there are other findings based on disability type analysis that proved interesting. These findings include the possible ongoing nature of speech and language needs, the difficulty in labeling a child with ASD, and the challenging task of getting a diagnosis and effective services for children with behavior disorders.

### **How Do Parents Perceive Professionals During the Process?**

Professionals were found to have a large impact on parental perceptions of the diagnosis process both in the literature and this research. Examining the various professionals and professional agencies shows that each can influence the diagnosis process differently. In general however, professionals are found to have more perceived power during the diagnosis process than parents which affects both how parents interact with professionals and parental perceptions of those interactions. Also, the diagnosis process was found to be a longer process for families than the literature, and likely most professionals, assumed. Therefore, professionals who may view themselves as service providers and not diagnosticians, such as therapists and teachers, are often still part of the perceived diagnosis process for families.

Pediatricians, specifically, were largely influential especially in that they often served as a gate-keeper for parents who had developmental concerns about their children. Many parents brought up their initial concerns to their pediatrician and what the pediatrician did with those concerns affected how the diagnosis process went for families,

especially as perceived by the parents. Parents were often frustrated by pediatricians who did not seem to “hear” or act on parental concerns. They were also frustrated by pediatricians’ perceived lack of knowledge of developmental issues.

The larger medical community provided some families with concrete diagnostic answers, while being a source of frustration for families whose children were not easily medically-testable. Parents also expressed that they had to serve as their child’s “case manager” and coordinate care between the various medical professionals. Parents expressed that this task was daunting and frustrating. In the medical community, more families seemed to find a straight-forward, sometimes perceived as harsh, demeanor from professionals. There is also a perceived tension between the medical and therapeutic communities which could make it difficult for families to work with and between the various service providers.

EI, the state-run early intervention program, was seen by parents as both helpful and frustrating. In general, parents spoke more positively about individual therapists and professionals within the system than of the system itself. Parents appreciated the perceived kindness and guidance from some of the EI professionals. However, long initial wait times made the system more frustrating for parents. There was also evidence to show that individual EI offices can give varying levels of care and service thus affecting parents’ experiences with the system.

The school system was found to be a satisfying, but not perfect, experience for many parents. However, evidence seems to show that although the school district and the co-op do a good job of meeting most families’ needs, families that may require a less-

traditional evaluation approach, such as families that have children with behavioral needs, are the most frustrated. It is important to note that parents often go through a re-diagnosis experience within the school system. During this re-diagnosis, parents can mentally struggle with the concept of wanting their child to progress past the need for services and wanting them to get the most and best services they can. It is also acknowledged that the school system studied is considered by many in the surrounding area to be of good quality with better than average services.

The last group of professionals examined was that of private therapists. For families that were able to pay for a private therapy evaluation or diagnosis, they could sometimes find freedom from system restraints and lengthy wait-times. However, private therapy centers seemed to be more focused on treatment than diagnosis sometimes creating more frustration for families.

### **What Do Parents Want From the Diagnosis Process?**

Another aspect of the study meant to shed light on the satisfaction index previously used in the literature was to look at what parents wanted from the diagnosis process and how well those desires were fulfilled. Most parents wanted to know what was wrong with their child and how to help them. Parents who had more general ideas of this felt more fulfilled, while parents who had specific notions of what they wanted generally felt less fulfilled. Several parents did acknowledge how their expectations and desires of the diagnosis process changed over time. A more in-depth study of this aspect of the diagnosis process could lead to better understanding of parental desires

surrounding the diagnosis process and could give more insight into parental fulfillment from the process than a satisfaction indicator.

Parents were asked about what made the process easier for them and their responses show what parents found supportive during the process. The response parents gave the most is that good professionals made the process easier for them. They also discussed how the support they got from parents of other children with special needs could be invaluable during this time and beyond. Parents also cited good services and good information as helpful aspects to the process, lending even more support to the idea that professionals and the services they provide influence the diagnosis process tremendously for parents. Professionals and researchers can use this information and further study on this aspect of the process to ensure that parents get the support they need to help them through the process.

Lastly, parents were asked to give advice to other parents just beginning the diagnosis process with their child. Parents answered this question with a mixture of logistical advice and emotional wisdom. Parents stressed important concepts such as starting the process early and being as informed as possible. They also discussed the emotional part of the process, however, and that it's important to remember to love your child, that you are a good parent, and that, in the end, it is going to be ok and that life will go on.



## **Implications**

This research has several implications for professionals and professional practices. Professionals working with families during the diagnosis process should understand that the process is long and many parents believe themselves to be working through the process for years. As was shown in the literature, parental concerns are reliable and should be trusted. When professionals do not act on parental concerns it creates frustration for families and delays services for children. Professionals should understand that many parents perceive a power differential between professionals and themselves. Because of this, parents often interact with professionals carefully. Parents can be hesitant to advocate on behalf of their child if they believe the professionals to have a higher status than them or if they believe their child's care may be compromised. Also, professionals' words carry weight with parents and stay with them for many years. Professionals should take care to be empathetic when sharing information with parents during this emotional time.

Professionals, especially pediatricians, should make a greater effort to share information with parents about where they can receive diagnoses and services for their children. Ideally, parents would benefit from a defined process that would lead them to EI and the school system when they had concerns about their children. Several families found out about the school system's services from flyers generated by the school system showing that an outreach of information on behalf of EI and the school system could also benefit families seeking diagnosis and services. The various professional agencies should also strive to work together more cohesively with less tension between branches. Parents

often work with more than one professional agency during the diagnosis process and if these agencies worked together it could create better services for children and families.

All professional branches could prove to be good paths for further research. Any future research done in these areas should be sure to account for the context of the population and geographic area being studied as well as how the service agency works or does not work with other service agencies. Also, it should be noted that the sample population was highly educated, had access to good resources, and still found the process confusing and difficult.

### **Limitations**

The limitations of this study are the high socio-economic status and resources of the area and families. The families studied likely were more equipped and had more options to pursue for diagnosis than other families. This study also utilized a retrospective methodology in which parents reflected on the diagnosis process as they remembered it. This can be problematic in that parental perceptions may change over time and they may remember certain aspects of the process more or less than they did originally. Lastly, this study is also largely a study of maternal perceptions of the diagnosis process. While some fathers participated in the research, and their participation did show that they may perceive the process differently than mothers, the majority of research participants were mothers.

The scope of this research is broad in that it covers many aspects of the diagnosis process, all of which could be studied further individually or in conjunction with other facets of the process. This research does, though, give significant insight into a process

that was previously inadequately researched. The openness of the individual families and the rich context that the study captures proves not only the importance of the topic to families but to professionals, as well. It also provides a rich and stable base on which to build further research.

APPENDIX A  
DIAGNOSIS RESEARCH LETTER

January 21, 2009

Dear Parents,

The XXXXXXXX Early Childhood Programs have a long-standing tradition of partnering with universities to support the professional growth and development of early childhood educators and related service providers (e.g., speech/language pathologists, OTs, PTs, school psychologists) as well as facilitating Best Practices in research and applied practice for young children. We are pleased to announce an exciting opportunity for families to share their experience and insights about the initial evaluation and diagnostic process. Ms. Sue Stolzer, doctoral student at Erikson Institute and Loyola University, is conducting a research study designed to understand the parental experience of going through the process of having a child diagnosed with a special need.

Please find enclosed additional information regarding this important research project. If you would like to participate, please complete the family questionnaire and return it in the self-addressed, stamped envelope. Participation in the project is completely voluntary and all information will be kept confidential. All mailings are processed through our XXXXXXXX Early Childhood Program office. Family questionnaires will be directly returned to Ms. Stolzer. XXXXXXXX Early Childhood Programs will have no information regarding which families chose to participate in the project. We will receive a final summary of the research outcomes which will be beneficial in helping our program understand how to better facilitate the initial evaluation process for young children and families. No educational information will be shared by the XXXXXXXX Early Childhood Programs for this research project. If you have any questions or need additional information, please feel free to contact me at (XXX) XXX-XXXX.

Sincerely,

XXXXXXXX, Administrator  
Early Childhood Program

enclosures

APPENDIX B  
INTRODUCTION LETTER

Dear parent(s),

My name is Sue Stolzer and I am a student at Erikson Institute and Loyola University. I am pursuing a doctoral degree in Child Development with a minor in Special Education. For my dissertation, I am doing a research project about the diagnosis process of young children with special needs. My research has been reviewed and approved by XXXXXXXX.

I will be interviewing parents and asking them to share the story of how their child was diagnosed as having special needs. It does not matter when or by whom your child was diagnosed, the information you have to share is important to me. It would take about an hour of your time at a location of your choosing. If you think you might be interested in sharing your story with me please read the attached information. If you want to be a part of the research study mail the completed family questionnaire back to me in the attached envelope by February 6, 2009. Review the consent form, but you won't need to sign it until we meet for your interview. Upon completion of the interview, you will be given a \$10 gift card to Target stores to thank you for your time. At the end of my research study I would be happy to provide you with a summary of my findings, as well.

Please understand that all information, including your and your child's name, will be kept confidential. Your participation in the study is completely voluntary and there is absolutely no penalty if you do not choose to participate.

Thank you so much for your time and consideration,

Sue Stolzer  
(XXX) XXX-XXXX  
suestolzer@gmail.com

APPENDIX C  
FAMILY QUESTIONNAIRE



## FAMILY QUESTIONNAIRE

Thank you so much for agreeing to speak with me about your child's diagnosis process. I truly appreciate your willingness to share your experience. In order to create the most meaningful research sample I would like to have a little information about your child and your family. Please also provide your contact information so that I may call you to set up a good time to talk with you about your experiences.

Contact information:

Your name \_\_\_\_\_

Phone number \_\_\_\_\_

Best time to reach you at this number \_\_\_\_\_

Secondary phone number \_\_\_\_\_

Best time to reach you at this number \_\_\_\_\_

Background information:

Child's birth date \_\_\_\_\_

Please check the *one* box that *best* describes your child's needs:

- |                                                        |                                                                               |                                                 |
|--------------------------------------------------------|-------------------------------------------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> Down Syndrome                 | <input type="checkbox"/> Cerebral Palsy                                       | <input type="checkbox"/> Traumatic Brain Injury |
| <input type="checkbox"/> Autism                        | <input type="checkbox"/> Attention Deficit Hyper Activity Disorder (ADD/ADHD) |                                                 |
| <input type="checkbox"/> Learning Disability           | <input type="checkbox"/> Behavioral/Emotional difficulties                    |                                                 |
| <input type="checkbox"/> Speech Language Disorder      | <input type="checkbox"/> Developmental Delay                                  |                                                 |
| <input type="checkbox"/> Other (please describe) _____ |                                                                               |                                                 |

How old was your child when he/she was diagnosed as having special needs \_\_\_\_\_

How would you describe your family's ethnicity:

- |                                                        |                                                 |                                          |
|--------------------------------------------------------|-------------------------------------------------|------------------------------------------|
| <input type="checkbox"/> White/Caucasian               | <input type="checkbox"/> Black/African American | <input type="checkbox"/> Hispanic/Latino |
| <input type="checkbox"/> Asian                         | <input type="checkbox"/> Native American        |                                          |
| <input type="checkbox"/> Other (please describe) _____ |                                                 |                                          |

How would you describe your family's annual household income:

- |                                                  |                                                  |
|--------------------------------------------------|--------------------------------------------------|
| <input type="checkbox"/> Less than \$25,000      | <input type="checkbox"/> Between \$25,000-40,000 |
| <input type="checkbox"/> Between \$40,000-60,000 | <input type="checkbox"/> More than \$60,000      |

Thank you so much for your help. I look forward to talking with you soon.

Sincerely,

Sue Stolzer  
 Doctoral student  
 Erikson Institute/Loyola University

APPENDIX D  
SUMMARIES

1- Sasha was born in this country to Russian immigrant parents. She is a four-year-old girl and was diagnosed as having special needs at about six months old. Approximately three years and six months had elapsed between the time of initial diagnosis and the interview. Sasha is the younger of two daughters in the family. The mother hopes Sasha will be bilingual in Russian and English, like their older daughter. The mother had initial concerns that were supported by the maternal grandmother. As an infant, Sasha appeared to be curled up to one side with one side weaker than the other and did not have any speech sounds by 9 or 12 months. The family pediatrician initially rebuffed concerns citing normal developmental ranges. After prompting, she referred Sasha to an orthopedic surgeon, who found nothing of note, and then to EI. EI found her to have delays of more than 33% in different areas. At one point Sasha was receiving PT, OT, and Speech therapies. She no longer receives OT or PT and is in a co-op classroom program. Speech is her mother's biggest concern currently. The mother is not sure if the diagnosis process is over for Sasha. She says she does not understand why Sasha has these delays so she is not sure if the process is over. The mother says she was satisfied with process and didn't seek second opinions because she didn't think she needed them. The mother wishes everyone had to go through the process so more families could get services and it would be less stigmatizing.

Spec: 1          Sev: 2          Pathway: PT

2- Kevin is a five-year-old boy who has a twin sister. Parents are unsure of when to call his need validation a diagnosis. Concerns were first brought up at two and half years old

and he began receiving services from EI just before he turned three years old. A little over two years have elapsed since Kevin first began receiving services and the interview. The family's childcare provider brought up initial concerns about Kevin's behavior at two and half years old. The mother and Father had believed the difference in their children's behavior was gender-linked before this. They were receptive to the caregiver's concerns and contacted EI. They knew about EI because they had used their services for Kevin's sister, who was a late-walker. The mother is unsure where they got the information initially, but thinks it may have been their pediatrician. The mother never brought up Kevin's issues specifically to the pediatrician until recently, though his behavior was an issue at appointments. The pediatrician sent them to a developmental pediatrician with whom they consult. Kevin qualified for OT and social work through EI, but only remained in EI for two months due to his age. Parents met with the school district, which said he did not qualify for services. Parents continued to seek private help and therapies through various medical and mental health professionals. The mother also kept calling the school district repeatedly asking for an evaluation. Using the internet, the father researched and thought Kevin might have Asperger's syndrome. Various professionals agreed that this might be right or close to Kevin's issues (i.e. high functioning ASD such as PDD or Non-verbal learning disability). After eighteen months of trying, the school agreed to an evaluation for Kevin and he qualified for services. He goes to a co-op preschool program with related services. The family and the school are debating kindergarten placement for Kevin. The mother and father don't believe the diagnosis process to be over because, although he's better, they still have a serious

problem with Kevin's violence. Parents expressed general dissatisfaction with the process because they believe they had the wrong services for a long time and they had to try so hard to get services.

Spec: 2      Sev: 3      Pathway: SS

3- Christina is over four and a half years old. She is the younger of two girls born to a native English-speaking father and a mother whose native language is Spanish, but speaks English fluently, as well. Christina was diagnosed as having special needs at about three years old. Approximately one year and nine months had elapsed between the time of initial diagnosis and the interview. The mother had concerns about Christina's development at about two and a half. She worked for a non-profit children's organization while living in another state so she knew services like EI existed. She asked her pediatrician for the contact information for EI. The pediatrician did not have concerns about Christina citing her dual language learning and that it may take longer. The mother called EI and Christina was not eligible because she was not delayed enough for her age. The mother waited and called EI after Christina turned three and asked them who to contact. They sent her to the school district, who identified Christina as having apraxia and said that it was affecting her socially, as well. She qualified for services through the school district. The mother and father don't feel like the process is over yet because they know she will be reevaluated before kindergarten and they don't know how she is going to do in kindergarten. The co-op classroom she is in delivers more intensive services with low student to staff ratios and they worry about what will happen to Christina in

kindergarten. Parents are satisfied with the diagnosis experience because they feel she was accurately diagnosed and they are seeing improvements in Christina.

Spec: 3      Sev: 2      Pathway: PT

4- Franklin is a four-year-old boy. He was diagnosed as having special needs close to birth and approximately four years and two months had elapsed between the time of initial diagnosis and the interview. Franklin is the older of two siblings. He has a younger sister and the mother is expecting another baby. Franklin was born at 27 weeks and six days and spent 87 days in the NICU. After he was home for a few days his maternal grandmother was concerned that one of his hands never opened and was smaller than the other. The mother contacted the pediatrician who sent her to the local children's hospital to make sure there was no constriction. There wasn't. The mother took Franklin to a couple of different specialists and had tests done. About two months later, Franklin was diagnosed as having a brachial plexus injury. Simultaneously, she had EI come and evaluate Franklin who qualified for PT and OT. The mother knew about EI from a nurse in the NICU with whom she became friendly and kept in contact. Franklin also later received speech services and surgery on his eyes. He currently attends a co-op preschool program with related services and private therapies. The mother thinks her pediatrician is phenomenal but at such a general level that he never really coordinated Franklin's care and missed some diagnostic opportunities. The mother thinks and hopes the diagnosis process is over for Franklin. She thinks it is over because all of Franklin's issues seem semi-related to each other and he has had an MRI that shows that there is no brain injury.

The mother says she is not very satisfied with diagnosis process because it was so disjointed. She says no professionals noticed the little stuff and the family always had to point it out to them.

Spec: 4          Sev: 2          Pathway: MT

5- Sydney is over four and a half years old. She was diagnosed as having special needs at age three. Approximately one year and eight months had elapsed between the time of initial diagnosis and the interview. She is the younger of two sisters. The mother began to have concerns when they transitioned from mom and tot classes to independent classes and Sydney would seem to get lost, especially with verbal directions. She had similar problems when she began preschool. The mother had her screened by the school district who said she was just young. The mother kept pressing that she believed more was going on so the district sent someone to watch her in her preschool and they gave her an aide in preschool and began speech services shortly after that. The next school year Sydney qualified for a co-op preschool program with related services, which is her current placement. The mother has been told Sydney has an expressive language delay. The mother did not discuss any interactions with her pediatrician during the interview. She knew about the school screening process because they sent flyers to her house and she had done it with her older child. The mother does not think the diagnosis process is over for Sydney because she doesn't know how her needs will manifest themselves later on and what other challenges may arise in school or what tools Sydney will learn to cope with her needs. The mother says she is satisfied with the diagnosis process because she

feels the professionals use it as one of the tools to help Sydney and she doesn't feel like they see her as a label.

Spec: 2      Sev: 1      Pathway: PT

6- Joel is over four and a half years old. He was first diagnosed as having special needs at two and half years old. Approximately two years and two months had elapsed between the time of initial diagnosis and the interview. He is the oldest brother of three siblings. Joel has a younger brother and sister. The mother began to have concerns before Joel was two because he seemed to be developing typically but then seemed to lose speech over time. The mother brought up her concerns to the pediatrician who told her to wait until her was two and then at two told her to wait until two and half because he said a lot of kids don't talk until two and half. The mother persisted and the pediatrician gave her the number for EI. EI qualified Joel for OT, DT, and Speech therapies, but gave no concrete diagnosis. EI offered for the family to get a hospital evaluation that resulted in a provisional diagnosis of Autism. The hospital team cited Joel's young age as the reason for the "provisional" piece of the diagnosis. The diagnosis of Autism was later confirmed by a developmental pediatrician recommended by Joel's pediatrician. The mother felt the developmental pediatrician was very pessimistic and awful. Joel attends a co-op preschool program with related services and private therapies. The mother does not think the diagnosis process is over because she is still hoping he will lose the diagnosis of Autism. The mother says she was satisfied with the hospital's diagnosis because she felt they were sensitive and optimistic but was unsatisfied with the



developmental pediatrician's diagnosis because she was not well-versed in treatment and portrayed hopelessness.

Spec: 3      Sev: 4      Pathway: SS

7- Becca is almost six years old. She was diagnosed as having special needs at four months old. Approximately five years and six months had elapsed between the time of initial diagnosis and the interview. She is the younger of two siblings. Becca has an older brother and her mother is currently pregnant. When Becca was born, she was a fussy baby with some minor medical problems. When the mother expressed concerns to her pediatrician about Becca's behavior and missed milestones, he said it was just because she'd had a rough start in life. At four months old, the pediatrician referred her to a pediatric ophthalmologist because she had one eye that was turning in. The ophthalmologist intimated that more was going on than a lazy eye and that Becca might be blind. Becca's pediatrician suggested she get an MRI and told her mother to tell the technician that Becca was developmentally delayed and had low tone. This had never been expressed to the mother before. After the MRI came back normal, they went to see a pediatric neurologist. The Neurologist expressed to them that Becca was significantly globally delayed. The mother described this neurologist and the experience as dismal. They have been to many geneticists who have been unable to find a concrete diagnosis for Becca. The mother heard about EI from a friend of hers and also enrolled Becca in EI. Becca is now in a co-op preschool with related services. The mother does not think the diagnosis process is over for Becca. She is not sure if she will ever know what

Becca's true diagnosis is but she wonders about health implications associated with certain syndromes and would like to know Becca's diagnosis, if possible. The mother doesn't think anyone can walk away from a process like this and say they are satisfied because it is such a terrible thing, but she feels confident that everyone has done their part to try and discover the source of Becca's delays. She says a lot rests on the parents, though, and that is hard.

Spec: 1      Sev: 5      Pathway: MT

8- Ty is almost four and half. He was diagnosed as having special needs when he was two years and nine months old. Approximately three years and eight months had elapsed between the time of initial diagnosis and the interview. Ty is the youngest of four children. He has two older sisters and an older brother. The mother began to have concerns at fifteen months because Ty was not talking and wouldn't engage in a peek-a-boo game. The mother voiced her concerns to the pediatrician practice a couple of times and was told that boys often talk later. The mother expressed her concerns again and this doctor gave her the number of a private therapy group, but did not nothing else. The mother could not afford to pay out of pocket and called the nurse practitioners at the pediatrician's office and they told her about EI. At nineteen months old, Ty tested at the nine month old level. The mother looked for guidance from the pediatrician at the next appointment, but again felt rebuffed. She called the pediatrician practice and told them she needed someone in the practice who had knowledge of the issues Ty was dealing with. She has been happy with that pediatrician. They also work with a

neurodevelopmental pediatrician. Ty has been diagnosed with oral motor apraxia. Ty attends a co-op preschool program and private therapies. The mother doesn't think the diagnosis process is over for Ty. She thinks they are on more a break. She is not sure how his needs will manifest themselves later on and she worries about issues like ADD. The mother expresses general satisfaction with the process once the ball got rolling. She thinks it went pretty smoothly and she was able to rule out ASD which she was previously worried about.

Spec: 3          Sev: 2          Pathway: PT

9- Brian is over three and a half years old. He was almost three when he was first diagnosed as having special needs. Approximately one year and ten months had elapsed between the time of initial diagnosis and the interview. Brian has one older brother. The mother first brought up concerns to the pediatrician around eighteen months because Brian had only a few words. She said it was probably nothing and they could readdress the issue in a couple of months. The mother was also concerned about Brian's lack of responsiveness. The mother heard about EI from a friend and had him tested just before he was two years old. His expressive language was mildly delayed, but he had a 40% delay in his receptive language. He qualified for DT and Speech therapies. At three he transitioned into a co-op preschool program because they had some additional concerns about a mild social delay. The mother seems to think the diagnosis process is over for Brian because he seems like he is where he needs to be skill-wise. The mother was very satisfied with the process because it was not a very scary diagnosis and Brian got help to

move him along. The mother also expressed that maybe Brian's development would have caught up and he wouldn't have needed the interventions, but she felt better doing them.

Spec: 1      Sev: 1      Pathway: PT

10- Jessica is five and a half years old. She was first diagnosed as having special needs when she was three. Approximately two years and six months had elapsed between the time of initial diagnosis and the interview. Jessica has one younger sister. The mother did not discuss any interactions with her pediatrician during the interview. When the mother enrolled Jessica in the neighborhood preschool they brought up some social concerns they had about Jessica. The preschool called the school district and arranged for an evaluation. Jessica qualified for the co-op preschool program with related speech services. The mother is not sure if the diagnosis process is over for Jessica. She says even though she's made good progress you never know if something might crop up later. The mother is not sure if she is satisfied with the diagnosis process. She says sometimes she questions the school district's motives about possibly qualifying her daughter to get more funding. However, she says she knows that cynical and she would want to give her daughter help if she needed it.

Spec: 1      Sev: 1      Pathway: PT

11- Rachel is almost four and half years old. She was diagnosed as having special needs at five months old. Approximately four years and eleven months had elapsed between

the time of initial diagnosis and the interview. Rachel is an only child. Rachel's home day care provider brought up concerns about her developmental milestones to her mother at five months old. She strongly urged her to see her pediatrician and not to wait. The mother brought Rachel into the pediatrician who also was concerned. The pediatrician told the mother to see a developmental pediatrician, get an MRI, and gave her the number for EI. Until this point neither the mother nor the pediatrician had ever expressed any developmental concerns about Rachel. The MRI came back normal. Rachel started in private PT while waiting for the EI process to get started. She eventually qualified for OT, PT, DT, and Speech therapies through EI. They went to the developmental pediatrician who ordered various tests, including genetic tests. When the genetic test results came back the receptionist from the genetic office called the mother to make an appointment to talk to the geneticist and told the mother Rachel's genetic diagnosis over the phone. The mother researches the syndrome on the internet and when they see the geneticist he simply gives them the same photocopied pages from the internet. This genetic syndrome presents similarly to Autism and is considered a possible genetic cause of Autism. Rachel is currently enrolled in a co-op preschool program with related services, which is an out-of-district placement for her. During Rachel's second year in the home district preschool the mother pushed for another placement when a series of incidents made her believe the placement was no longer appropriate or safe for Rachel. The mother is very happy with the current co-op placement. The mother is not sure if the diagnosis process is really over for them. Rachel's syndrome has medical implications for later in life that concern the mother and she shares that the mourning process is long

and she still thinks about how things could have been and that makes it hard for the process to seem over. The mother was satisfied with the pediatrician's role in the diagnosis process and was thankful for how quickly they acted and pushed her to pursue tests and appointments. She was dissatisfied with the communication of Rachel's ultimate diagnosis over the phone by the receptionist.

Spec: 5      Sev: 4      Pathway: MT

12- Jyoti is over three and half years old. She was diagnosed as having special needs at age two. Approximately one year and nine months had elapsed between the time of initial diagnosis and the interview. Jyoti is the only child born to Pakistani immigrant parents. When Jyoti was two, her mother became concerned that she wasn't talking yet. She expressed her concerns to her pediatrician who told her it was ok, but if she wanted she could take Jyoti to a speech therapist and she gave her the number of a private speech therapist. At the therapist's office, another mother told Jyoti's mother about EI. Jyoti qualified for OT, DT, and Speech therapies through EI. Jyoti transitioned into the co-op preschool program from EI. The mother believes the diagnosis process to be over because Jyoti has only minor speech and language needs now. The mother was not very satisfied with the diagnosis process because it's still sad for her and she wonders "why me?"

Spec: 1      Sev: 2      Pathway: PT

13- Shannon is almost four and half years old. She was diagnosed as having special needs at six months old. Approximately three years and eleven months had elapsed between the time of initial diagnosis and the interview. Shannon has an older brother and a younger sister. Shortly after Shannon's birth, both the mother and Shannon developed a bad cough. The nurse practitioner at the pediatrician's office said Shannon was fine and that babies just cough. The mother's doctor told her she was fine, just overwhelmed and run down. A couple of weeks later, the mother brought Shannon back to the pediatrician because Shannon was still coughing and now gasping for air. The pediatrician sent her to the hospital because she might have whooping cough. The hospital was not equipped to deal with such a tiny baby and Shannon became unconscious. They rushed her to the local children's hospital via ambulance. They eventually stabilized Shannon, diagnosed her with whooping cough, and she remained in the hospital for about three more weeks. At about four or five months, the mother noticed that Shannon's legs were very stiff and stuck together. The mother brought her in to the pediatrician for a check-up and mentioned her concerns. The pediatrician gave her the number for EI. Shannon qualified for DT and PT through EI. EI encouraged them to see a neurologist. The neurologist, through an MRI, diagnosed Shannon as having a static brain injury, CP. He also said that it probably occurred during a complication from an amniocentesis that the mother had when she was pregnant with Shannon. This was devastating for the mother. However, Shannon's pediatrician said the CP resulted from the loss of oxygen during the time Shannon had whooping cough. This was confirmed by another doctor. The mother said that saved her life from the guilt she was feeling.

Shannon is currently enrolled in a co-op preschool with related services and private therapies. The mother believes the diagnosis process is over for Shannon because it is a static brain injury that is not going to change. The mother says she is satisfied with the diagnosis process because they know what it is and what to expect to some extent.

Spec: 4      Sev: 3      Pathway: MT

14- Nicole is a four-year-old girl. She was diagnosed as having special needs at nine months old. Approximately three years and three months had elapsed between the time of initial diagnosis and the interview. Nicole has an older brother and a younger sister. Nicole's older brother has some developmental delays, as well, so the mother had some prior experience both with the process and what to look for in development. The mother had concerns when Nicole was ten months old and couldn't roll over or sit up on her own. She also was not babbling or making other speech sounds. When the mother brought up her concerns to the pediatrician he said Nicole was fine and that kids catch up. The mother called EI on her own and Nicole qualified for PT, OT, and Speech therapies. Nicole's pediatrician reprimanded her mother for going over his head to EI and accused her of lying to them to make her qualify for services. He refused to sign the EI paperwork. Coincidentally, a friend of the mother's signed on the pediatric practice and she signed the forms for the mother. When Nicole transitioned to school services she qualified for the co-op preschool program because of her speech and social emotional needs. The mother feels like the diagnosis process is mostly over for Nicole, but she knows she still has speech and emotional needs and she worries about her in



kindergarten. The mother says she was 100% satisfied with diagnosis process. She felt comfortable with the professionals having been through the process before and she felt like Nicole got what she needed and didn't get any unnecessary services.

Spec: 1          Sev: 2          Pathway: PT

15- Justin is almost five and a half years old. He was first diagnosed as having special needs at two and a half. Approximately two years and ten months had elapsed between the time of initial diagnosis and the interview. Justin is the younger of two brothers. The mother began to have concerns about Justin's behavior at two and a half. He was head-banging, mouthing objects, and covering his ears for loud noises. A therapist, whom Justin's older brother had been seeing due to some familial issues, suggested that Justin may have sensory disintegration. When the mother brought this up to the pediatrician he didn't think that was the issue and referred the mother to EI. At the evaluation, the EI professionals shared the mother's concerns about Justin's behavior and the mother felt like they were looking for a diagnosis to qualify him for services. EI qualified him for OT under a fine motor delay label and it was during these OT sessions that Justin's behavior escalated. When he turned three, the school district observed him in his day care setting and qualified him for the co-op preschool program because of his behavioral issues. Soon after he began the program, his mother felt like his academic skills were lagging, but the school district believed his needs to be solely behavioral. The mother pursued a neuropsychologist on her own who ruled out ASD for Justin. He also saw a neurologist who ruled out seizures. At Justin's most recent IEP, the school district did

qualify him as learning disabled. The mother does not think the diagnosis process is over for Justin because he doesn't have a diagnosis and the mother thinks the closer they get to better identifying his needs the better off Justin will be. The mother says it's hard to describe if she's satisfied with the diagnosis process because parts of it have been so hard and she has had to push for so much, but she feels like he is getting more of what he needs now.

Spec: 1          Sev: 3          Pathway: SS

16- Morgan is a little over five years old. She was diagnosed as having special needs at age two. Approximately three years and two months had elapsed between the time of initial diagnosis and the interview. Morgan has a younger brother. The mother became concerned when Morgan was two years old and not communicating. She didn't speak or even point or grunt. She would also get very upset by loud noises. The mother shared her concern with a friend whose daughter was speech-delayed and with her pediatrician. They both sent her to EI. She qualified for OT, DT, and Speech therapies through EI. EI shared that she was speech delayed with sensory component and some developmental issue intertwined. When Morgan transitioned to school services she qualified for the co-op preschool program with related services. Morgan has made great strides and will likely be dismissed from services. The mother does not believe the diagnosis process is over for Morgan, though. She hopes it is, but she still sees that Morgan struggles with some sensory issues and she worries how that will manifest itself in kindergarten. The mother says she was very satisfied with the diagnosis process.

Spec: 2      Sev: 2      Pathway: PT

17- Colin is over three and half years old. He was diagnosed as having special needs at birth. Approximately three years and eight months had elapsed between the time of initial diagnosis and the interview. Colin is the third of four boys in his family. His mother had a normal labor and delivery. Shortly after Colin was born, The mother's OB told them that they saw some signs that baby might have Down syndrome and that they should have him tested. The hospital offered to have their pediatrician come in and talk with the mother and father. He answered their questions about the signs they were looking for and when asked how sure was he that Colin had Down syndrome, the pediatrician said he would be shocked if he didn't have it. The mother and father said they knew then that he had Down syndrome and didn't need to wait for the blood test. The social worker at the hospital gave them lots of information about Down syndrome and support groups in the area. Colin also had some bowel issues and went to the local children's hospital for diagnosis and surgery. The mother and father said they think the diagnosis phase is over for them, but there are still hard days and days they wish he didn't have Down syndrome so then they don't feel like it's totally over for them. The father thinks their Christian foundation helps them be satisfied with the diagnosis, because, he believes, no matter how it's delivered it helps to have that perspective. The mother thinks that, from talking to others, it is really hard for families who don't get the news shared in a positive way regardless of Faith or perspective. She thinks in comparison their diagnosis was not that bad of an experience.

Spec: 5      Sev: 4      Pathway: MT

18- Andrew is over three and a half years old. He was three months old when he was diagnosed with special needs. Approximately three years and five months had elapsed between the time of initial diagnosis and the interview. Andrew is the younger of two boys. When Andrew was three months old he had a seizure. The mother called the pediatrician who told her to take him to the hospital. Their local hospital was not really equipped for such young babies and the mother felt there was a lot of guesswork going on as to what was wrong with Andrew. The pediatrician told the ER to send him to the local children's hospital and to keep him overnight. Various doctors ordered several tests, including a neurologist who ordered an EEG. He shared the EEG results were not normal and that it appeared that Andrew was having infantile spasms. Andrew stayed in the hospital for twelve days and parents got set up with an epileptologist. At that first appointment they were told that a test came back that Andrews tested positive for a disorder, but that it was really rare so they didn't think it was right. They retested Andrew twice and tested the rest of the family, as well. All tests came back positive. They had a meeting with the neurologist and geneticist who shared that Andrew had a very rare, genetic, metabolic disorder. It is newly discovered and the children with the disorder haven't lived past three years of age. Andrew now has many doctors that he sees regularly. He was in EI services and is in a co-op preschool program now. Andrew is globally and profoundly delayed. The mother says she tries to balance therapy with his quality of life. The mother says she thinks the diagnosis process is over for Andrew.

Unless someone discovers a new drug or something that could enhance Andrew's quality of life, she doesn't think much is going to change. The mother is fairly satisfied with Andrew's diagnosis process. His disorder is fairly concrete and she thinks that is good and helpful.

Spec: 5          Sev: 5          Pathway: MT

19- Vimal is almost five and a half years old. He was first diagnosed as having special needs when he was two years old. Approximately three years and five months had elapsed between the time of initial diagnosis and the interview. Vimal is the younger of two boys. The mother started to become concerned when Vimal was a year old and he didn't do some of the things his older brother did at that age or things she expected a one-year-old to do. He didn't have any sounds, wasn't waving bye-bye, and didn't know any body parts. When Vimal was sixteen months old, the mother went on a trip and talked to her sons via webcam. Vimal didn't react to her at all and she was struck and concerned by this. The mother brought up her concerns to her pediatrician at Vimal's eighteen month check-up who said to just keep an eye on things and come back for his two year check-up. The mother called back in three months and the pediatrician gave her the number for EI. The mother called EI and there was a three-month waiting list. The mother tried to call private therapists, but they wanted to know what Vimal's diagnosis was and the mother didn't know. The mother saw a flyer at the pool for screening for kindergarten readiness and she thought they might know who could help her. The school district sent her to the co-op's birth to three program. The mother talked to someone

there and finally felt like her concerns were heard. Vimal qualified for DT and Speech therapies through EI and got his services through EI and the co-op. At twenty-six months, Vimal's language skills tested at nine months receptive and twelve months expressive. Vimal made great progress in EI and transitioned into a co-op preschool program where he has continued to make nice progress. The mother also took Vimal to a neurologist before he turned three and he said Vimal had an auditory processing disorder. The mother thinks the diagnosis process is not over for Vimal. Although he has made good progress, the mother wonders where his skill level is at and if they need to look at some other things before kindergarten. In terms of satisfaction, the mother wishes that the information of where to go if you have concerns about your child's development were more readily available.

Spec: 2      Sev: 2      Pathway: PT

20- Grace is almost five and half years old. She was three years old when she was diagnosed as having special needs. Approximately two years and four months had elapsed between the time of initial diagnosis and the interview. She is the youngest of five sisters and she was adopted. The mother began to have concerns about Grace at six months old. Grace seemed very slow to develop, but then would have a burst of development and then lag behind again and then have another burst. The mother brought up her concerns to the pediatric practice who said they weren't concerned since she was still developing. At Grace's three year check-up, the mother mentioned her concerns to that pediatrician who told her that she was just overwhelmed and not parenting Grace

properly. The mother later called a pediatrician with whom she was better acquainted at the practice and voiced her concerns. She had also just gotten a flyer from her school district about developmental screenings and she and the pediatrician thought she should take Grace. Grace qualified for the co-op preschool program with related services. The mother feels like she pushed them to qualify her for the program and for them to keep her in the program. She also supplements with private therapies. The mother also had Grace evaluated by a pediatric neurologist which the mother didn't find very useful, other than it ruled out fatal alcohol syndrome, which was one of the mother's concerns. The mother does not think the diagnosis process will be over for Grace until they have managed all her issues and she knows she will be ok in long run. The mother says she is pretty satisfied with the process but that she wishes she could know before an IEP meeting what they were going to recommend in terms of services. She says she doesn't feel like a partner in the process if that is a big secret.

Spec: 1      Sev: 2      Pathway: SS

21- Peter is almost five years old. He was diagnosed as having special needs shortly after birth. Approximately four years and eleven months had elapsed between the time of initial diagnosis and the interview. Peter has a twin sister. Peter failed his hearing test in the hospital. He also developed many medical issues, which had him in and out of hospitals for the first couple of months of his life. He had trouble eating and was not gaining weight, he had trouble regulating his temperature, and he had poor circulation. His parents checked him into the hospital for a week of testing. He saw many specialists,

including a geneticist, a doctor that specializes in epilepsy, and a brain specialist. They all did various tests. After some misdiagnosis, Peter was diagnosed as having a rare brain malformation syndrome. The diagnosis, though not certain, seems to be the best match for Peter's issues. Children with this diagnosis are profoundly disabled often don't live past the age of one. Throughout this process and now throughout his treatment, Peter's pediatrician helped the mother get into difficult to see doctors and helped coordinate his care. The mother describes the pediatrician as their blessing. The pediatrician told her early on about EI and Peter got services almost from the beginning. He is in a co-op preschool with related services, but the mother only sends him part of the time because she and the school district do not agree on the best course of action for Peter and she doesn't feel like they see her a partner in his education. Peter gets many additional private therapies. The mother thinks the diagnosis process is over for Peter. In the past they looked for a more refined or alternate diagnosis, but now the mother says they know his issues and she is more focused on fixing what is wrong with him. The mother is not very satisfied with the diagnosis process because she felt like they were putting out a lot of fires and she was always running around with him. She wishes someone had taught her the system and that things could have been more condensed.

Spec: 4      Sev: 5      Pathway: MT

22- Hailey is over three and a half years old. She was diagnosed as having special needs at birth. Approximately three years and nine months had elapsed between the time of initial diagnosis and the interview. Hailey has an older brother and sister. When the



mother was pregnant with Hailey her doctor told her that Hailey would have club feet. A few minutes after Hailey was born, the hospital staff told the mother that they believed Hailey had Down syndrome. The hospital staff all expressed condolences and some even assured them that Hailey probably didn't have Down syndrome. When the test results came back seven days later, the nurses shared the results with the mother. The mother didn't receive any other information from the hospital. When she brought Hailey in to pediatrician, the pediatrician said she had other patients with Down syndrome and gave the mother some growth charts and other information. The mother heard about a Down syndrome support group from some friends and she contacted the National Association for Down Syndrome (NADS) on her own. She heard about EI from a family in NADS. Hailey received EI services until she transferred to her school district. Hailey attends a school district preschool program with related services. The mother doesn't think the diagnosis is over for Hailey because she might develop issues later on that are because of her diagnosis of Down syndrome. The mother was not satisfied with Hailey's diagnosis process because she didn't get any kind of information from anyone at the hospital. She had to find everything on her own.

Spec: 5      Sev: 4      Pathway: MT

23- Will is over three and half years old. He was diagnosed as having special needs at birth. Approximately three years and nine months had elapsed between the time of initial diagnosis and the interview. Will has an older sister. When the mother was in labor with Will, they couldn't find his heartbeat and she was given an emergency C-section. When

the mother was waking up after the procedure she was very groggy and they apparently told her then that something was wrong with Will, but she doesn't remember it. When the mother wakes up later she is confused and angry and asks to see someone who can tell her what is going. Someone then comes in and tells her that they think Will has Down syndrome. At the mother's urging they wheeled her surgical bed past the NICU so she could see Will, but she couldn't really see him. Will was in the NICU because he had heart problems but his mother didn't know this yet. They later sent in a doctor from the NICU who explained Will's issues. The next day they had a geneticist from a nearby Down syndrome clinic come in to talk to the mother. A social worker also came in and gave the mother many pamphlets for organizations, support groups, and EI. Will's pediatrician does not know much about Down syndrome, but the mother likes the practice and she just tells them what they need to know. She gave them the Down syndrome growth charts and other information. The mother enrolled Will in EI right away and he qualified for services and then transitioned to school district services. Will is in a school district preschool program with related services. The mother does not feel like the diagnosis process is over for Will because it's something that they deal with every day. The mother said she is pretty satisfied with the diagnosis process because she feels like the process at her hospital was probably better than the process at a lot of other hospitals, though she wishes they made sure she was coherent before first sharing the news.

Spec: 5      Sev: 4      Pathway: MT

24- Jack is over five and a half years old. He was three years old when he was first diagnosed as having special needs. Approximately two years and nine months had elapsed between the time of initial diagnosis and the interview. Jack has one younger brother. Jack's preschool began to have concerns about his development and they mentioned them to his mother and gave her the name of some professionals and told her she could call her school district for an evaluation. Around the same time, they went on a family vacation and Jack seemed to just come unglued and had tantrums the entire time. When they got back, the mother took Jack to a child psychologist who thought he was having sensory problems and that he needed an OT. While the mother was trying to find places to help Jack, his behavior was deteriorating. His preschool threatened to kick him out, but the mother arranged for a babysitter to join Jack at school until the school district could do their evaluation and observe him in the preschool. The mother also took him for an evaluation with a private therapy group. The mother had checked off some concerns she was having about Jack on a questionnaire when he went in for his three year check-up, but the pediatrician group never contacted her. She contacted them and met with a social worker through the practice, but the social worker didn't really see anything wrong with Jack. Jack currently goes to a co-op preschool program with related services and receives private therapies. Some professionals have classified Jack as PDD while others have said he has traits and skills that preclude him from being on the ASD spectrum. Jack had made some nice developmental progress. The mother says she sort of believes the diagnosis process to be over for Jack because, although they are still honing in on his challenges, she believes his issues are so clear that she doesn't really think about the

diagnosis aspect any more. The mother thinks she is fairly satisfied with the diagnosis process because they found good people and got good information even though it was a very emotional process.

Spec: 2      Sev: 3      Pathway: PT

Pilot Study- Amy is ten years old. She was diagnosed as having special needs before birth. Approximately ten years had elapsed between the time of initial diagnosis and the interview. Amy has three older siblings. She has an older brother, an older step-sister, and an older step-brother. When Amy's mother was pregnant with her, a prenatal screening test came back positive for Down syndrome. Assured by the doctor that many of those are false positives, the mother had a level two ultrasound. Looking at the ultrasound, the doctor said with 90% certainty that the baby had Down syndrome. He told the mother and father to talk about it because not all families choose to raise a child with Down syndrome. The mother was 22 weeks pregnant and shocked at the idea of termination because she could already feel the baby kicking. With the mother and father visibly upset, the doctor put them back in the hallway to wait with the other pregnant couples waiting for their ultrasounds. The mother had an amniocentesis the next day. They met with a geneticist who explained Trisomy 21 and told them all the increased medical risks children with Down syndrome have. The mother says she felt very pressured to terminate her pregnancy. When they called with the results of the amniocentesis that confirmed Down syndrome, the mother was asked over the phone what they wanted to do about it. A doctor also told the mother that she could choose to

have the baby then put her in a home. The mother thought that thinking was strange and outdated. The mother then had a level 3 ultrasound with a pediatric cardiologist who told her that the baby had no heart defects. The mother says that was like whole other diagnosis experience. Now she knew she had a healthy baby who happened to have Down syndrome. The mother says she was more affected by the dehumanizing of her daughter and her bond with her daughter than she was with the diagnosis. The mother doesn't feel like the diagnosis process is over because she says life stages and events come up that dehumanize her daughter and it is like getting the diagnosis all over again.

APPENDIX E  
CONSENT TO PARTICIPATE IN RESEARCH

### CONSENT TO PARTICIPATE IN RESEARCH

**Project Title:** Parental Perceptions of the Diagnosis Process of their Young Child with Special Needs

**Researcher(s):** Sue Stolzer

**Faculty Sponsor:** Dr. Robert Halpern

**Introduction:**

You are being asked to take part in a research study being conducted by Sue Stolzer for a doctoral dissertation under the supervision of Dr. Robert Halpern of Erikson Institute and Loyola University of Chicago.

You are being asked to participate because you have a young child with an Individualized Education Plan.

Please read this form carefully and ask any questions you may have before deciding whether to participate in the study.

**Purpose:**

The purpose of this study is to better understand the parental experience of going through the process of having a young child diagnosed with a special need.

**Procedures:**

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

- Participate in an interview about your child's diagnosis process. You will be asked about your thoughts, feelings, and experiences in reference to the diagnosis process. The interview will last about an hour and will be held at a location of your choosing where you feel comfortable (e.g. your home, local library, coffee shop, etc.). The interview will be digitally recorded and later transcribed.

**Risks/Benefits:**

There are no foreseeable risks involved in participating in this research beyond those experienced in everyday life. The researcher understands that the subject matter is personal and possibly emotional. Every effort will be made to make you feel comfortable during the interview process.

Participation in this research provides no direct benefit to you. The research may have greater implications to influence how the diagnosis process is carried out which could be of benefit to other families and professionals.

**Compensation:**

Upon completion of the interview you will be given a \$10 gift card to Target stores as a token of appreciation for your time and experience.

**Confidentiality:**

Loyola University Chicago: Lakeside Campuses  
Institutional Review Board for  
The Protection of Human Subjects

Date of Approval: 12/16/08

Approval Expires: 12/16/09

- Every effort will be made to keep your and your child's identity confidential. No real names or locations will be used in the writing of the research. However, certain indicators such as a child's age and disability label will be used. If this provides a foreseeable breach of confidentiality you will be made aware of the potential risk.
- The digital audio files of the interview will be kept on a password-protected computer and back-up audio discs of the interview will be kept in a locked desk inside the researcher's home. The audio files will only be shared with the transcription assistants and faculty overseeing the research.
- All identity indicators will be removed from the transcribed text that will be used in the writing of the research.

**Voluntary Participation:**

Participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free not to answer any question or to withdraw from participation at any time without penalty. A decision not to participate will not affect your access to resources or services in any way.

**Contacts and Questions:**

If you have questions about this research study, please feel free to contact Sue Stolzer at [suestolzer@gmail.com](mailto:suestolzer@gmail.com) or the faculty sponsor Dr. Robert Halpern at [rhalpern@erikson.edu](mailto:rhalpern@erikson.edu).

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

**Statement of Consent:**

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

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's Signature

\_\_\_\_\_  
Date



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## VITA

Susan Stolzer received a BA in English from Truman State University. She received her MAT in Early Childhood Education from National-Louis University. She taught in the public school system for several years. She spent most of her teaching career co-teaching in an Early Childhood Special Education inclusion program. During this time, she served on the district diagnostic team working with families undergoing the diagnosis process. This, coupled with her familial experiences, ignited her research interest into the diagnosis process. She continues to work with professionals and pre-service teachers to meet the needs of families that have children with special needs.