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# “We Can Do Better”: Parents’ Experiences of the Diagnostic Process of Their Child’s Intellectual and Developmental Disability

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**“We Can Do Better”:  
Parents’ Experiences of the Diagnostic Process of Their Child’s Intellectual and  
Developmental Disability**

by

Victoria Hickenbotham

A Thesis

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St. Cloud State University

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### **Abstract**

The main purpose of this study was to examine parents' experiences of the diagnostic process of their child's intellectual and developmental disability. Research over the past thirty years has demonstrated that most parents are not satisfied with the diagnostic process, and has suggested best practices for professionals. The hope for this study was that parents' experiences have improved since the last research was done and that best practices are being followed. Parents in the Twin Cities metro area of Minnesota were interviewed regarding their experience of the diagnostic process. The results indicated that parents are still dissatisfied with the process and raised a number of concerns, some of which were unique to this research. Suggestions and implications for practice based on these results are presented.

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## Chapter 1: INTRODUCTION

Many parents experience dissatisfaction with how they receive the diagnosis of an intellectual or developmental disability for their child, and often recall it negatively. When my own brother was diagnosed in the 1970's, doctors told my parents to put him in an institution, and that he would never be more than a vegetable. Forty odd years later, he's completing his Ph.D. in Control Science. Research over the past thirty years has demonstrated my parents weren't alone in their experience, and that it continues to be an experience in which parents are not satisfied. The research also gives recommendations for best practice. As early as 1984, Cunningham, Morgan, and McGucken set out to prove that dissatisfaction was not inevitable, and that best practices could be implemented that changed the experiences of parents. In 1986, Quine and Pahl examined how the experiences of parents could shape best practice for health professionals. Over the next thirty years, continual research has been done to determine whether or not best practices have been put in place. Overwhelmingly, this research has found that despite some minor gains, most parents are still dissatisfied with the process.

These early studies remain the seminal research on this topic, and more recent studies simply reinforce their findings. A plethora of studies were done in the late 1980's-early 1990's, and then not again until the early 2000's. There has been a smaller resurgence lately that focused on autism, however, this research simply echoes those earlier studies. Whether seminal or more research, much of this past research has taken place in countries other than the United States, and to my knowledge, not in Minnesota. Minnesota is often considered to be one of the "best places to live" in a variety of surveys. Despite this, however, my experience has been that at least anecdotally, parents in Minnesota have been dissatisfied with the diagnostic process of their

child with disabilities. They recall it as being negative and feeling as though they were completely alone. If this is indeed the case, that Minnesota mirrors research findings that parents are dissatisfied with the diagnostic process and are not experiencing best practices when it comes to disclosure, this has implications for practice, for health professionals and practitioners who support parents of young children.

### **Definitions**

The following definitions are included to ease understanding of the research. Definitions are listed by order of relevance to this research.

***Diagnostic process***- Because receiving a diagnosis is not always a single event, “diagnostic process” is used to describe the period of time from which a parent or professional has a suspicion of disability to the time that a parent receives follow-up support or information. As defined in Graungaard and Skov (2006): “[M]ost often disclosure consisted of a series of tests, and then more tests, where the diagnosis or presumed diagnosis of the child was discussed with the parents several times (p. 303).” There is no set length of time, as the diagnostic process can take hours or years.

***Intellectual and developmental disability***- According to the Developmental Disabilities Act (P.L. 106-402) (2000), the term developmental disability is defined as “a severe, chronic disability that:

1. is attributable to a mental or physical impairment or a combination of those impairments;
2. occurs before the individual reaches age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more of the following areas of major life activity: (i) self care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and



5. reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated (as cited in The Arc United States, 2016).

**Satisfaction-** Parents may vary in how they interpret satisfaction. For that reason, “satisfaction” will be defined in one of the following three ways:

- “1. a happy or pleased feeling because of something that you did or something that happened to you
2. the act of providing what is needed or desired: the act of satisfying a need or desire
3. a result that deals with a problem or complaint in an acceptable way (Encyclopaedia Britannica, 2016)”

**Healthcare professional-** For the purposes of this research, “healthcare professional” will be used to indicate anyone who may be the individual relaying the news of diagnosis to a parent, unless otherwise specified. This could be a healthcare professional, such as a physician, pediatrician, nurse, or therapist, or it could be an educational professional, such as an early interventionist, or a teacher.

**Stress-** Several studies mention or measure parental stress. This is sometimes measured by tests or by parental admission. What causes stress for one person may not cause stress for another person. For the purposes of this research, stress will be defined broadly as a physical or emotional response to an event in one's life.

**Autism Spectrum Disorder (ASD)-** As defined by the Minnesota Department of Education:

Autism Spectrum Disorders (ASD) are a set of neurodevelopmental disorders that affect how an individual processes information and interprets the world. Core features of autism are persistent deficits in social interaction and communication and restricted, repetitive or stereotyped patterns of behavior, interests or activities. Each individual with ASD displays a unique combination of characteristics, ranging from mild to severe, requiring individually determined educational and treatment programming (Minnesota Department of Education, 2006).

***Fetal Alcohol Syndrome or Fetal Alcohol Spectrum Disorder (FASD)***- MOFAS (Minnesota Organization for Fetal Alcohol Syndrome) defines FASD as:

FASD is not a diagnosis, but is an umbrella term describing the range of effects that can occur when a developing baby is prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. There are many terms under the FASD umbrella, including these medical diagnoses: Fetal Alcohol Syndrome (FAS), Alcohol Related Neuro-developmental Disorders (ARND), Alcohol Related Birth Defects (ARBD), [and] Partial Fetal Alcohol Syndrome (pFAS). FASD is a lifetime disability that affects each child differently. Some children with an FASD have specific facial features and tend to be smaller in height and weight. They often have a brain injury that never goes away.

***Sensory Processing Disorder (SPD)***- “Sensory processing disorder is a condition in which the brain has trouble receiving and responding to information that comes in through the senses. Formerly referred to as sensory integration dysfunction, it is not currently recognized as a distinct medical diagnosis (WebMD, 2016).”

***ADHD***- Considered a learning disability, rather than an intellectual or developmental disability. “Attention deficit hyperactivity disorder (ADHD) is a problem of not being able to focus, being overactive, not being able control behavior, or a combination of these. For these problems to be diagnosed as ADHD, they must be out of the normal range for a person's age and development (National Library of Medicine, 2016).”

***Anxiety***- A mental health diagnosis, rather than an intellectual or developmental disability.

Anxiety is characterized by excessive worry over a period of more than 6 months accompanied by other physical symptoms, and not related to another mental health diagnosis (American Psychiatric Association, 2013).

**Statement of Purpose**

The main purpose of this study was to examine parents' experiences of the diagnostic process of their child's intellectual and developmental disability. The hope was that parents' experiences have improved since the last research was done.

## Chapter 2: REVIEW OF LITERATURE

### Dissatisfaction

Previous research has demonstrated that, on average, parents are dissatisfied with the diagnostic process experience of their child with a disability (Cunningham & Sloper, 1977; Lucas & Lucas, 1980; Cunningham, Morgan, and McGucken, 1984; Quine & Pahl, 1986; Sloper & Turner, 1993; Quine & Rutter, 1994; Pearson, Simms, Ainsworth, & Hill, 1999). This trend has been well documented in the research since the 1970s. More recently, Goodwin et al. (2015) found in their online survey of 559 parents from around the world, most parents found the diagnostic process to be stressful, worrisome, and that both the amount and quality of information from professionals was not satisfactory, nor did it give them an adequate understanding of their child's diagnosis.

Other research has shown that this dissatisfaction with the diagnostic process can have long-term effects for the family and the child. Keenan, Dillenburger, Doherty, Byrne, and Gallagher (2010), in their review of the literature, note there has been significant research into the impact the diagnostic process has, and subsequently, to the parents' initial reaction to the child. Parents may have a difficult time dealing with their emotions. In the Taanila, Järvelin, and Kokkonen (1998) study of 58 parents of older (ages 12-17) children and 27 parents of younger (ages 7-9) children, it was found that those with older children showed more feelings of insecurity, helplessness, worry, and guilt. The results of the Baird, McConachie, and Scrutton, (2000) study of 107 parents of children with cerebral palsy in the United Kingdom show that dissatisfaction with the diagnostic process is correlated with higher degrees of self-reported parental depression. Several studies have shown that the difficulty in dealing with emotions and

depression can have an effect on the attachment to the child (Marvin & Pianta, 1996) (as cited in Boström, Broberg, & Hwang, 2009). Button, Pianta, and Marvin (2001) found that if a mother showed negative emotions (such as worry, pain, or sense of burden), this often correlated with the mother being insensitive or unsupportive of her child (as cited in Boström et al., 2009, p. 94). A negative experience with diagnosis or unresolved emotions may prevent a parent from utilizing supports and knowing how to deal with the day to day issues of raising a child with special needs (Hatton, Akram, Robertson, Shah, & Emerson, 2003). Most researchers conclude that if the parents were to have a positive diagnostic process, some of these issues may be avoided.

While much of the research has identified the need to increase parents' satisfaction with the diagnostic process, some researchers have questioned whether dissatisfaction is inevitable given the large amount of stress that families are under and given previous research about it evoking a grieving response (Maxwell & Barr, 2003) (as cited in Howie-Davis & McKenzie, 2007, p. 28) (Abery, 2006; Bailey, Scarborough, & Hebbeler, 2003; Rogers, 2007) (as cited in Bingham, Correa, & Huber, 2012, p. 381) (Spain & Wigley, 1975; Chinn, Winn, & Walter, 1978) (as cited in Cunningham et al., 1984, p. 33). Sloper and Turner (1993) warn against assuming that all parents will have the same response to the diagnosis. In addition, Cunningham et al. (1984) found that given best practices, parents can, in fact, report feelings of satisfaction with the diagnostic process. Their study included interviews with 59 parents of children with Down Syndrome who gave birth in a general hospital in the United Kingdom. Parents were split into two groups, with one control group and the other being those who received the "model process" for disclosure. Their study determined that 100% of families who received the diagnosis

using the model process were satisfied with the disclosure, versus 20% of the control group. They hypothesize, given their research (and previous research), using best practices can facilitate healthy reactions from parents, strengthen the attachment process, and encourage a stronger relationship between professionals and parents. Best practices become important to ensure the best outcomes for the family, the parents, the child, and the professional as well.

It is important to note that while much research has been focused on the negative responses to disability diagnosis and disability in general (Hastings & Taunt, 2002; Green, 2007) (as cited in Boström et al., 2009, p. 94), it is possible for parents' levels of stress to increase because of the diagnosis or disability, while still maintaining positive emotions toward their child. Parents often vary in their feelings about their children (this is not disability specific). Sloper and Turner (1993) found that "satisfaction with disclosure was not a major determinant of long term satisfaction with life and adaptation to the child (as cited in Baird et al., 2000, p. 478)." Therefore, while best practices are important to a parents' satisfaction with the diagnostic process, a negative experience does not necessarily equate to a negative experience with the child, nor does stress mean that a parent has a negative relationship with the child. That is not to suggest that a positive diagnostic process is not important, in fact, it may help ensure more positive feelings and less stress on the parent.

Other research suggests there are variables that can influence a parents' satisfaction with the disclosure that cannot be controlled or enhanced. The first of these is the severity of the child's diagnosis. Hodopp, Fidler, and Smith (1998) suggest that different diagnoses can lead to higher levels of parental stress, given outcomes associated with that diagnosis and the predisposition certain diagnoses have for different behaviors, needs, or skill levels (as cited in

Howie-Davies & McKenzie, 2007, p. 29). Because of this, other researchers have suggested that diagnoses such as autism might lead to more stress than a diagnosis of Down Syndrome (Sanders & Morgan, 1997; Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004) (as cited in Howie-Davis & McKenzie, 2007, p. 29). This has been controversial, however, as other studies have shown that when certain factors such as maternal age, marital status, socio-economic status, and the child's level of functioning are held constant, there is no difference in stress levels or dissatisfaction with a diagnosis (Cahill & Glidden, 1996; Abbeduto et al., 2004) (as cited in Howie-Davis & McKenzie, 2007, p. 29). None of the studies, however, took into consideration the parents' prejudices or preconceived notions about the diagnosis.

A parents' previous experience with or prior knowledge of people with disabilities can have an impact on how they handle the diagnosis, although this has not been widely studied. Most parents have little to no prior knowledge or experience, although this may have changed in recent years. Murdock (1983) in a study of parents with children with Down Syndrome found that 90% of parents had little to no knowledge of the disability at the time of their child's diagnosis (as cited in Pearson et al., 1999, p. 4). To see if this had changed, Pearson et al. (1999) conducted a study of two different groups of parents in the United Kingdom, one who had children aged birth to five at the time of the interviews, and one with children aged 15-20 years. This distinction was to determine if there was a difference in satisfaction and disclosure practices in the approximately ten years' time, including knowledge of disabilities. Their study showed that 90% of the younger group and 87% of the older parents had little to no knowledge. Knowledge about disabilities had actually decreased, contrary to what was expected.

While the Pearson et al. (1999) study looked at the differences in age of the parents and whether time had changed experiences, age can also be a variable that can affect a parents' reaction or satisfaction. Baird et al. (2002), in their interviews with 107 parents, found that the younger the parents, the more likely they were to be dissatisfied with the diagnosis. There are also other variables in demographics that can impact reactions. Gender often plays a significant role. Mothers tend to have a more difficult time than fathers adjusting to disability (Taanila et al., 1998; Graungaard & Skov, 2006). It also affects the type of information the parent wants during the diagnostic process. Men tended to want more intellectual and action-oriented approaches with written literature, whereas women preferred to not have that information right away (Graungaard & Skov, 2006). Race is another demographic variable that researchers have examined. Baird et al. (2002) found that parents whose ethnicity was not Caucasian were more likely to be dissatisfied. In their study specific to South Asian families in the United Kingdom, Hatton et al. (2003) noted that South Asian families were less likely to experience best practices than their Caucasian counterparts. This may also be true for backgrounds that differ from the majority of the country in which the diagnosis is given.

Some of the discrepancies in satisfaction with the diagnostic process related to the demographic variables could have less to do with that particular variable and more to do with how physicians relate to that variable. MacDonald, Carson, Palmer and Slay (1982) found that physicians varied information given according to perceived social class, perceived emotional stability, and severity of child's condition (as cited in Turner & Sloper, 1992, p. 356). Turner and Sloper's (1992) research echoed these findings. They interviewed 24 physicians in the United Kingdom who varied in terms of experience. All of the physicians interviewed mentioned at least



one of five factors from the MacDonald et al. (1982) study as influencing how they disclose information to a family. Physicians mentioned changing tone, shortening the amount of information, presenting the information in a different way, or even changing the language they use. The variables physicians mentioned were: 88% - socio-economic status, 79% - emotional stability, 54% - ethnic background, and 25% - maternal age. In addition to those mentioned by McDonald et al. (1982), 21% believed that single parents needed different information than married couples. It is unclear from the study whether it might be best practice to alter information and manner based on group, however, it was indicated the physicians were making these decisions based on perceived difference, rather than factual difference. The study demonstrates how influential the health professionals' personal opinions or prejudices can be on a patient/parent experience.

### **Best Practices**

Despite the existence of variables that may or may not be unchangeable and influence the experience of the diagnostic process, there has been an abundance of research suggesting best practices. Much of the research over the past thirty years suggests similar models of practice, however, studies continue to show that parents are dissatisfied or that best practices are not being followed. Quine and Pahl (1986) make an important point in noting that “the existence of model procedures does not necessarily mean that all will be well: the best of intentions may still produce imperfect results (p. 61).” It’s also important to note families will have different needs and different things that are important to them. Therefore, all of the best practices are listed here, with the assumption that attempting to address all or most of them will produce best results for

the majority of families. Best practices include timeliness of diagnosis, setting, manner, content, and follow-up.

**Timeliness of diagnosis.** The first best practice is timeliness. For some families, the diagnostic process can be a moment, for others, years. It can occur before birth, as in the case of prenatal diagnosis (usually as a result of prenatal testing), hours or days after birth (e.g. most children with Down Syndrome who were not diagnosed prenatally (Hedov, Wikblad, & Annerén, 2002) ), or can even take years (e.g. autism (Keenan et al., 2010) ). While for some parents, the diagnosis may come as a shock, for many parents, they had suspicions well before a health professional gave the “official” diagnosis.

Research has validated that a large majority of parents have suspicions about their child, although they may not be able to identify an exact diagnosis. In a 1989 Census Survey in the UK, approximately two-thirds of parents were first to have concerns about their child (Pearson et al., 1999). Pearson et al.’s (1999) study found very similar results. Of the older parents, 69% said they had suspected something was wrong/different about their child before diagnosis (whose children would have been diagnosed around the time of the Census Survey). Of the younger parents, 74% had suspicions, although they felt their suspicions were acted on (59% versus 23% of older parents). More recently, Baird et al. (2000) found that 86% of parents had suspicions before anything was said by a healthcare professional. Both studies demonstrate the rate of parental suspicions has increased over the years. It’s possible this is due to increased efforts by organizations as a result of IDEA and Childfind, or due to increased use of the internet.

With the increase in parental suspicions, parents’ experiences of health professionals’ reaction to this suspicion seems to have also become increasingly negative. As early as 1986,

Quine and Pahl described parents' long battles with physicians to acknowledge their concerns about the child. Many parents were told their child "will grow out of it (p. 57)." Turner and Sloper (1992) found that 31% of parents who had suspicions believed they were not taken seriously by professionals. Similarly, Baird et al. (2002) found that 47% of parents who had suspicions about their child did not have confidence they were believed by professionals or that their concerns were acted on. Bingham et al. (2012), in a study of six mothers in an Early Intervention program in Nevada, found that while all of the mothers had suspicions, many did not, in fact, believe that their suspicions were taken seriously and/or had prompted action by health professionals. One parent described her experience with having to convince doctors that something was wrong. Doctors consistently told her to "wait and see." It wasn't until her son had a seizure that doctors began to take her concerns seriously (p.378). A recommendation from that study for best practice was that health professionals acknowledge parents' suspicions and realize they have validity. This was not the first study to make that recommendation; as Sloper and Turner (1993) also concluded parents were more satisfied with the disclosure process when they believed their suspicions had been taken seriously and the health professionals had acted on them in a timely fashion.

Given that parents are more satisfied when their suspicions are acted on in a timely manner, best practice would seem to be that a physician takes a parent seriously and begins moving the process forward. However, Starke, Wikland, and Möller (2002), in their study of 44 parents of girls with Turner Syndrome in Sweden, found that if a physician initiated the diagnostic process, the process went more quickly, with 56% being diagnosed within the first year. If a parent initiated the process, only 24% were diagnosed within the first year. Overall in

the United States, the National Early Intervention Longitudinal Study (NEILS) found it took on average up to 1 year for parents to receive a diagnosis after communicating their initial concern (Bingham et al., 2012). For those with autism, average time for the diagnostic process is longer, at 14-16 months (Keenan et al., 2010). In their study of 95 parents of children with autism in Ireland, 57% were diagnosed within 12 months, and 30% took more than 24 months. Down Syndrome is generally diagnosed more quickly, and in the Hedov et al. (2002) study, 75% were diagnosed within the first 24 hours after birth. Half of the parents in the study, however, still were dissatisfied with the timing, with most having the opinion that it was still too late (although there were several who had believed it came too early). It is possible, given these results, there is no “right moment” for parents, or that it will ultimately depend on the parent.

These studies identify the difference a certain diagnosis can make on the timeliness of the diagnostic process, and ultimately, the parents’ satisfaction with the process. There is debate in the research about whether delays are more common if the diagnosis is not specific (e.g., instead of “Down Syndrome,” the child is given a label of “Developmental Delay”). Quine and Rutter (1994) suggest that there is a relationship between the time it takes for diagnosis and the specificity of the diagnosis (as cited in Howie-Davis & McKenzie, 2007, p. 29). However, Howie-Davie and McKenzie (2007), in their study of 47 parents (children aged 5-17 years), found there was no significant difference in age at diagnosis between those who had a specific diagnosis and those who had a non-specific diagnosis. They suggest this difference could be because there were specific community assessment teams where the study took place. Another suggestion for the discrepancy could be that age at diagnosis and timeliness of diagnosis are two distinct variables, and that timeliness could be affected by specificity whereas age is not. If, in

accordance with Quine and Rutter (1994), specificity of diagnosis played a significant role in the timeliness of the diagnosis, this could be related to the rates of satisfaction with the process. Several studies have shown that more than 30-50% of children do not ever receive a specific diagnosis (Schaefer & Bodensteiner, 1992; Curry et al., 1997; Hodgson, 1998; Daily et al., 2000) (as cited in Graungaard & Skov, 2006, p. 297).

There is also some disagreement in the literature about whether timeliness of the diagnosis correlates with parental satisfaction of the entire process. Timeliness here refers to the amount of time it takes from a parent having suspicions of a developmental or intellectual disability and telling a professional, or a professional having a suspicion and acting on it, to the time the parent actually hears the diagnosis. Quine and Pahl (1986) noted that over half of the parents in their study thought the diagnosis could have been made earlier, and that the delay led parents to believe there was a “conspiracy of silence” (p. 58), wherein health professionals were deliberately keeping things from them. Half of the parents in the Keenan et al. study (2010) did not think the diagnosis was completed in a timely manner. For parents of children with autism, this may even be more likely to cause dissatisfaction, because they are also simultaneously told the need for early treatment and intervention (Keenan et al., 2010). All of the researchers suggest that a diagnosis should be made as early as possible, with as little delay. However, Cottrell and Summers (1990) found that parents will accept reasons for not having a firm diagnosis or delay, as long as they are kept informed of the reasons for the delay, if not, families feel as though “everyone knew before [they] did” (as cited in Baird et al., 2000, p. 478). Unlike the other studies, Sloper and Turner (1993), in their study of 107 families in the UK, found that the timing of the diagnosis was not significantly related to satisfaction. This, however, was the minority, as

it seemed most parents were more satisfied overall with the diagnostic process if it was handled in a timely manner.

A child's age at diagnosis and the timeliness of diagnosis are two closely related variables that, as mentioned, may be difficult to separate. Sometimes, if a child is diagnosed at a later age, it could mean that the diagnostic process took longer, at other times, it could be a short diagnostic process that occurred later in life. For instance, while the average length of time of diagnosis for autism is 14-16 months (Keenan et al., 2010), the average age at diagnosis is 5-6 years of age (Howlin & Moore, 1997) (as cited in Keenan et al., 2010, p. 391). Therefore, it is, at times, difficult to ascertain if dissatisfaction is with the delay or with the age, specifically. Baird et al. (2000) found that dissatisfaction with diagnosis was related to child's age, with those told later being less satisfied, whereas 41% were dissatisfied with the delay. In their quantitative study, Quine and Pahl (1986) found that parents whose child was diagnosed at birth had a rate of 51% being satisfied with the diagnostic process, whereas those who were diagnosed in the first year only had a rate of 33% being satisfied. If the child was diagnosed later than one year old, only 28% reported being satisfied. This has also been shown to relate to stress. The older the child at diagnosis, the more stress a parent was under (Most, Fidler, Laforce-Booth, & Kelly, 2006) (as cited in Bingham et al., 2012, p. 372). Those parents who found out the diagnosis before the birth of the child were able to cope more effectively (Glidden, Billings, & Job, 2006) (as cited in Bingham et al., 2012, p. 372). This could be related to a parent being able to access information and get supports sooner. It has been suggested that like a negative diagnostic process, not having a diagnosis can lead to "uncertainty, confusion, hostility, and avoidance of the child (Wiggins, Diaio, & Rice, 2006)" (as cited in Keenan et al., 2010, p. 391), so stress could

build as a result of these feelings. While much of the research has found that the older a child is, the more likely the existence of stress and dissatisfaction, mothers of children with Turner Syndrome in the Starke et al. (2002) study who had just given birth reported they may not have known testing was being done, or did not understand why. Many also felt there was too much happening too quickly. These findings suggest there may be a “critical period” in which it is best to deliver the diagnosis, although this could vary by family.

**Setting.** Where the diagnosis takes place is as varied as when families receive the diagnosis. The process can take place in multiple settings or one. It can be in a hospital, a clinic, an educational setting, or other health setting. Setting, however, is not just the physical location, but also includes the logistics of the room, who gives the news, and who is there to receive the news. Most parents in the research do not have a preference as to where the news is given, as long as the room is private (Cunningham et al., 1984; Turner & Sloper, 1992; Pearson et al., 1999). If a parent was dissatisfied with the location, the main reason was that it was not a private setting (which could include other people hearing the news, or parents feeling they did not have a space of their own to reflect in afterward) (Pearson et al., 1999). Baird et al. (2000) suggest that not only is it best practice to have a private space in which to tell parents, but that parents should be able to use the space privately afterward to “debrief.” Research also indicates it is important for both parents to attend. In cases where only one parent attends, the parent should have the opportunity to have a close family member, friend, or other support person present (Goodwin et al., 2015). Pianta, Marvin, Britner, and Borowitz (1996) advocate using a family systems approach where the whole family is involved (as cited in Bingham et al., 2012, p. 383), and Bingham et al. (2012) furthers this by arguing that “family” is defined by the parents and they

choose with whom they are comfortable. Turner and Sloper (1992) found that while most physicians believed they had offered the opportunity for both parents to be there, only 38% of mothers in their study said they were given that option. In the Pearson et al. (1999) study, approximately half of the mothers in both age groups were told without the father there. Both groups agreed that this was unacceptable unless it was completely unavoidable. Baird et al. (2000) suggests that if the situation is avoidable, it is critical that the health professional note that there are some problems and that it is important for both parents to be there (and/or other family members). Partners being told together is important best practice for multiple reasons according to the research. As Hatton et al. (2003) notes, “Without a shared acceptance and understanding, benefits were less likely to be mobilized, and parents were less likely to emotionally support each other (p. 183).” Starke et al. (2002) also noted the importance of this shared experience. It helps define the situation for both parents and allows them to move forward together. This can have a “protective” effect on not only the marriage, but the functioning of the whole family (Taanila et al. 1998). Taanila et al.’s (1998) research went on to show that only 42 percent of the younger families and 24% of the older families felt their marriage was stronger because of their child’s diagnosis. 17% of older parents and 4% of younger parents said that their disagreements had increased. It was not clear, however, from their research if both parents’ attendance at the diagnosis had an effect on these results.

The research is divided as to whether it is best practice to have the child present at the time of diagnosis. Cunningham et al. (1984) and Baird et al. (2000) argue that having the child there is best practice, unless the child is too ill. In the Pearson et al. (1999) study, however, only 58% of the parents agreed that it was useful or important to have their child present. Ten percent



said it made no difference, and 30% believed it was not helpful at all. There were no reasons given as to why parents felt this way, nor were the percentages delineated by the age groups. Regardless of their feelings of the importance of the child being there, 56% of the older parents said the child was present, as compared to 82% of the younger parents. Turner and Sloper (1992), in their interviews with physicians, determined that doctors with less experience were more likely to include the child than those who had been practicing longer. This could mean that the attitude toward this is changing in the medical field, although it is unknown if parental attitudes are changing regarding this being a best practice. It is also unclear if diagnosis or age of the child makes a difference in parents wanting the child there.

The next question of who, according to best practice, should be there in addition to the partner and the child is whether other staff should also be there and who should be the one giving the news. The recommendations for this vary across the research. Parents report that the news can be given by a variety of individuals, including but not limited to: psychologist, doctor, obgyn, pediatrician, or school professional. For individuals with ASD (autism spectrum disorder), 70% of children get an educational diagnosis rather than a medical diagnosis (Keenan et al., 2010). For most families, it wasn't as important WHO gave the news, but that the families knew and trusted the person. When this did not happen, families were dissatisfied. According to Hedov et al. (2002), 47% of the parents of children with Down Syndrome were told by the pediatrician on duty (not necessarily their doctor) and 20% saw three or more doctors for subsequent meetings. This did not allow the parents to establish a trusting relationship with the person. Baird et al. (2000) suggested the diagnosis should be done by the child's pediatrician, but that a health visitor or someone who would be responsible for ongoing care should be at the

initial diagnosis. This is in agreement with Pearson et al. (1999) which found most parents were told by their pediatrician, and almost all (97%) of the parents believed they were told by the person who should be telling them. More of the older parents had other staff in the room, and those who did not have someone else there actually believed someone else might have been helpful. Cunningham et al. (1984) suggested this other person be someone who was not a doctor, but rather a social worker or other support staff, who could help the family with the emotional aspects if the physician was not able to provide that support. It is important, though, that this additional person not be junior medical staff, and that it is not used as a training opportunity (Baird et al., 2000). For families who do not speak the same language as the individual delivering the message, an interpreter should be used, rather than someone in the family. This allows the family to concentrate on what is said, rather than on how to interpret it to other family members. In Hatton et al.'s (2003) study of parents in England who were South Asian, it was found that a chief complaint was the diagnosis was not given in the parent's preferred language. This can lead to parents not understanding the diagnosis and information or feeling as though they were not respected as a family.

**Manner.** The next best practice is the manner in which the health professional or whoever is a part of the diagnostic process delivers information. It addresses the approach this individual takes, rather than the content of the information. Parents are looking for a professional who gives emotional support and shows empathy (Quine & Rutter, 1994; Davies, Davis, & Sibert, 2003; Graungaard & Skov, 2006). Parents want their feelings validated and the opportunity to talk through those feelings with someone who is knowledgeable. The professional should show sympathy, be honest, and open. Those in the Davies et al. study (2003) study of 30

families in Wales reported they were more satisfied when the professional “listened to parents, took their concerns seriously, and were able to respond with human sympathy and understanding (p.79).” Unfortunately, the literature has not supported that this best practice is being experienced by families. In the Pearson et al. (1999) study of two groups of parents, only 69% of the younger parents believed the news was delivered with empathy, and only 25% of the older group. While this shows improvement, it also demonstrates only about two-thirds of parents are satisfied with the manner of delivery. Quine and Pahl (1986) suggest some of this could be a result of the training physicians, in particular, receive. Many have been taught to deny their emotions at the risk of burnout, and to show affective neutrality so as not to influence a patient’s decision. This is a practice referred to as “clinical detachment.” Unfortunately, parents of children with disabilities interpret this detachment as cold and unsympathetic. Davies et al. (2003) coined this a “technocratic approach” and noted parents did not want this approach (p. 81), but rather wanted professionals to try and understand things from their perspective, and to balance their needs for emotional support with the physician’s own knowledge and technical skills.

In much the same way that clinician training can have an influence on the physician’s emotional affect and manner of delivery, parents have also found that the same training may influence the way the professional views the relationship with the parent and the manner in which they communicate based on this view. Many professionals may view themselves as “experts” having gone through years of medical school. However, parents want to be acknowledged as co-experts (Graungaard & Skov, 2006). While they may not know as much medical information, parents know their child. In the Davies et al. study (2003), they tell a story

of a family who appreciated a doctor acknowledging the at-home changes they had made to better accommodate their child. Parents want to be able to make decisions, and to participate in planning both their child's current and future care (Taanila et al., 1998).

Families wanted to be treated as co-experts and wanted an emotionally based approach; however, they also appreciated when professionals gave information in a direct and confident way. Pearson et al. (1999) found that 81% of parents in their study wanted a direct style, whereas only 19% of the older parents felt the professional had been direct, as compared to 65% of the younger parents. Harnett and Tierney (2009) found in their study of parents in Ireland that most parents defined the professional as direct. The difficulty with assessing this data is that there is no clear definition of what "direct" means to a parent. It could mean honest and straightforward, but it could also mean blunt and candid. It is not clear in the Harnett and Tierney study if parents associated a positive or negative connotation to this word. Given the "honest" definition- Quine and Pahl (1986) found that parents wanted to feel as though the professional was not being evasive and was being transparent. For instance, in their study of 44 parents in Sweden, Starke et al. (2002) found that some parents in their study reported they did not even know an investigative process (genetic testing or assessment) had started. These parents were more worried and nervous. While Turner and Sloper (1992) reported that physicians in their study said their general policy was to tell a parent when they are suspicious there might be something wrong or they may have a diagnosis, however; they also said the disclosure of this suspicion depended on the strength of the suspicion, the severity of condition, and how they thought the parents would take the news. In other words, the physician may, in fact, be withholding information (for a variety of reasons) and begin assessments without the parent knowing what

they are for. Starke et al. (2002) suggests as soon as an investigation/assessment starts, the doctor should tell the parents what the suspicion is, what they are assessing for and why so as to avoid worry and speculation by the parents. This honesty is crucial for creating a positive parent-professional relationship.

In line with being honest, parents want professionals to be realistic. While some of this is related to content, parents also reflected on this when talking about the manner in which the diagnosis is delivered. Sixty-five percent of the older parents in the Pearson et al. study (1999) and sixty-eight percent of the younger parents held the opinion that the health professionals had been realistic in their manner. This was surprising to the researchers as they had believed this is one area where change should have been expected. This discrepancy could be that, again, it is difficult to define exactly what “realistic” means as this can vary by parent or for each child.

Other research has stressed the need for the approach to be a balance between realistic and hopeful and positive. In 1999, Leonard stressed the need for physicians to give positive messages to parents at the time of diagnosis (as cited in Harnett & Tierney, 2009, p. 260). However, Harnett and Tierney (2009) found in their study of 1558 professionals and 584 families in Ireland that although both professionals and families agreed messages should be hopeful, positive, and realistic, less than half of the families in their study described their experiences as matching this expectation. Hedov et al. (2002) also found this to be true, as 25% of the families in their study reported the news had been delivered in too negative of a manner. Bingham et al. (2012) stressed that physicians should provide messages with hope and optimism to help facilitate the parents’ reframing process. Reframing, according to Bingham et al. (2012), is a powerful coping strategy, defined as emphasizing a situation’s positive aspects over its

negative ones (p. 380). While Bingham et al. (2012) argued physicians should err more on the side of hope and optimism, Boström et al. (2009) stressed the need for a balance. They suggested if professionals were too positive and not realistic enough, mothers might also not be realistic. It was their opinion that based on previous research (Steinberg & Pianta, 2006), while this may promote a more positive experience and affect toward the child, it may also lead to the parents not accurately sensing and responding to the child's needs (as cited in Boström et al., 2009, p. 98). However, there seems to be a difference between giving positive and realistic messages and the negative experience that most parents had.

Delivering messages of hope and optimism while remaining realistic means seeing the inherent worth and dignity of a child. Parents in Graungaard and Skov's (2006) study of 16 parents in Denmark whose child had been recently diagnosed (ages 1-27 months) indicated a huge discrepancy in how professionals seemed to perceive their child versus how they, as parents, did. Health professionals focused on the disability, and the symptoms, and treated their child as a "case" rather than an integral part of the family. Parents wanted their child to be seen as "whole," not just as symptoms or lack of abilities. Parents in Harnett and Tierney's (2009) study also reported that often their child was seen only in the context of their disability or diagnosis. One parent in their study commented that not a single person congratulated her on the birth of her daughter. Harnett and Tierney (2009) recommend using the child's name as often as possible, and to focus on aspects of the child and not just the disability. Parents want to hear about the diagnosis and the outcomes, however, they want it done in the context of their individual, unique child and family.

**Content.** Content and manner are often inseparable, in that the most horrible story can be told in a positive tone, or the most wonderful story can be told in a negative tone. Both the content and manner have an impact on how a parent perceives the diagnostic process. Baird et al. (2000) found that while 75% of parents were satisfied with the manner in which the diagnosis was given, only 54% were satisfied with the information content. Whereas manner is how something is said, content is what is actually said.

The healthcare/medical field can be a brand new world for families. This new world has its own language, its own rules, and its own values (Starke et al., 2002; Bingham et al., 2012). Quine and Pahl (1986) noted there are separate worlds of experience and reference and this can also cause a distance between a health professional and the patient, particularly in status. This can increase the likelihood parents may not understand what is being said to them throughout the diagnostic process, as well as their hesitation to ask questions or admit to not understanding. However, it is important to families that the information is understandable and/or that medical information and jargon is translated in a way they can understand. In Keenan et al.'s (2010) study, 49% of parents did not think that the information was presented clearly. Forty-six percent of parents in Hedov et al.'s (2002) study stated the information was not understandable. Parents in Davies et al. (2003) study commented that, at times, what the health professional said was incomprehensible. One parent mentioned the diagnosis was "like an alien word" (Davies et al., 2003, p. 78).

Language can become even more of a barrier when parents are not given an accurate diagnosis, or are given more than one name for the diagnosis. Often, parents will be given more than one term to describe their child (Howie-Davies & McKenzie, 2007), which can include

symptoms that may sound like a diagnosis (e.g. “spasticity”), or have multiple terms that mean the same thing (e.g. one physician using “intellectual disability,” another using an outdated term such as “mental retardation,” and a third calling it “developmental delay”). This can lead to parents not understanding the diagnosis or even being unsure of what the diagnosis is.

Uncertainty of the diagnosis (whether from misinformation or from a lack of a clear diagnosis) can also influence the amount of information given or the parents’ satisfaction with the diagnostic process. Graungaard and Skov (2006) found that parents’ reactions to their children’s diagnosis were connected to the certainty of the diagnosis. York, von Frauenhofer, Turk, and Sedgwick (1999) found that, in addition, more information is given to parents when there is a certain diagnosis, unless it is a rare diagnosis (as cited in Howie-Davis & McKenzie, 2007, p. 29). In Bingham et al.’s (2012) study, one parent said the diagnosis of “global developmental delays” did not give her enough information about what to expect. Those in the Starke et al. (2002) study indicated health professionals either did not give the diagnosis a name, or did not adequately explain the implications of that diagnosis. Further, several families received information about the diagnosis that was incorrect. Boström et al. (2009) noted parents are more likely to become preoccupied with the child’s disability and its outcomes if the diagnosis was uncertain, or if the parents believed the diagnosis was inaccurate or did not correspond to their view of the child.

Parents quickly become experts on information relating to their child, so it is important to them the health professional be knowledgeable about the diagnosis as well as prognosis and outcomes (Bingham et al., 2012). This type of information gives families a sense of control (Cunningham et al., 1984). Davies et al. (2003) noted parents wanted health professionals to



balance emotional support with being knowledgeable (what they called “technically competent”). Bingham et al. (2012) and Rogers (2007) also echoed this need for balance (as cited in Bingham et al., 2012, p. 373). Families in the Taanila et al. (1998) study specifically wanted the professional to be well-informed both about the child’s treatment (technical knowledge) and about ways of coping (emotional knowledge). When a professional does not know something, parents felt they should make referrals and expedite the process as much as possible for families. If a physician does not have the information, parents feel let down. In Hedov et al.’s (2002) study, 25% of the parents said the doctor lacked basic knowledge about Down Syndrome. This led to a negative diagnostic process experience for these families.

Along with knowledge about the diagnosis, families want the health professional to also be knowledgeable about possible outcomes, and they want both the positive and the negative. Most parents in the research felt as though when doctors gave information about outcomes, it was negative. Parents wanted professionals to present them with a spectrum of outcomes for their child, not merely the negatives. If a parent is given only the negative outcomes for the child, these messages can become a self-fulfilling prophecy (Harnett & Tierney, 2009). As Harnett and Tierney (2009) mention, while professionals may be well-meaning in “preparing” families for the worst the future might bring, “perhaps we should question whether the same statements would be made about a child without disabilities (p. 262).” One parent in their study remarked:

...look, if you had an ordinary child, they don’t give you a book saying... he’s going to rob a car and he’s going to get a girl pregnant or he’s going to fail his exams. So you have to live life as it goes by. They don’t tell you that [a catalogue of negative outcomes] with the ordinary child (Harnett & Tierney, 2009, p. 260).

While parents want information about the diagnosis, parents also have the emotional need to reconcile what a future might look like for their child. Many parents had a sense of uncertainty,

and tended to either create an overly optimistic future or a “worst case scenario.” Other research has indicated the need for physicians (or others delivering the diagnosis) to present a spectrum of possible futures, both positive and realistic (Harnett & Tierney, 2009). This helps parents reconcile this need for a future outlook. Perceiving the child (and not the disability), both in terms of future and present, was often mentioned in the Harnett and Tierney (2009) interviews as a point of contention with health care professionals, leading to both dissatisfaction with the diagnostic process and with future interactions. Whereas physicians would often communicate about the child in a way that was solely focused on the diagnosis and limitations, parents had the need to see possibilities and the uniqueness of their child. This could indicate the need for either training of physicians or a full team approach, with a physician to deliver diagnosis and limitations, and another professional to indicate future possibilities.

In seeing the possibilities in their child, parents want health professionals to give them an action plan, a way to help their child. If parents are able to find a way to do something for their child, stress is reduced (this is also related to sense of control) (Graungaard & Skov, 2006). As Bingham et al. (2012) say, “Families may actually feel they are coping more effectively if they can have the sense of doing something while still waiting to get a clearer sense of what is wrong with their child. Support providers who can offer an action plan during the diagnostic process might facilitate coping (p. 383).” This is also tied in to the expectations that parents have of the healthcare system- parents want to be able to take action to help their child, and assume that if there is a diagnosis, professionals will know the cause and a corresponding treatment. This can be particularly difficult if the diagnosis is uncertain, rare, or there is no clear action plan. Further distrust is created when families feel that they are not receiving enough information from the

professionals, or that the professional is not giving all the information they know (Graungaard & Skov, 2006). This creates more dissatisfaction in the parents about the process.

**Follow-up.** Another important component for families is follow-up. Although sometimes occurring after the actual diagnosis, for many families it is a critical piece to the diagnostic process. Follow-up includes information, referrals to supports and resources, the ability to ask follow-up questions, and second appointments.

Information is critical to parents throughout the entire process. Research has looked at parents' satisfaction levels with the amount of information, as well as the types of information families would prefer. The difficulty, however, with analyzing the research that has been done is it often does not distinguish between information given by the professional initially (verbal or written) versus the information that is given as follow-up (verbal or written). Many researchers combine the two. As Taanila et al. (1998) note, "Parents need early and continuous information about the diagnosis and prognosis, and want to talk to their child's doctor not only at the time of the diagnosis but also in the following months and years, as the child grows older and their needs for information, advice, and support change (p. 510)." Information needs are an ongoing process that should be addressed at different stages in a family's journey. The amount and type will change depending on the families' needs, and the professional providing the information should take that into consideration. Most researchers have found parents are not satisfied with the amount of information they receive at any stage in the process. Quine and Pahl (1986) found 74% of parents mentioned it was difficult to get any information about the diagnosis, and 74% said they wanted more information. Of the older parents in the Pearson et al. study (1999), only 25% were satisfied with the information they received, and only 69% of the younger parents

were. Of those same parents, most reported not receiving any written information (87% of older parents and 61% of younger parents), although those who had received written information found it useful. Parents found it helpful to have written information that included what was said at the time of the diagnosis in easily understood language (Baird et al., 2000). The amount of written information parents desire may have decreased since a majority of the research was completed before the easy access of internet information. This may place a greater emphasis on verbal information from the health professional. In the Howie-Davis and McKenzie (2007) research, the amount of information parents received was low, as was their satisfaction with that information. However, they found there was no significant relationship between the parents' level of stress and the information they received. Again, this could be due to the ease at which parents are now able to gather information from the internet. Graungaard and Skov (2006), argue however, that information gathering was a form of problem-solving, which is a coping strategy, in the parents they surveyed. Mitchell and Sloper (2001) agree, arguing that information is power and can give parents feelings of control and self-efficacy.

Mitchell and Sloper (2001) developed a set of guidelines for information at all stages of the process. They identified four key points for information to follow. The first is that it should be easy to read. This includes the language that is used and the look of written materials. Parents in their study preferred a tone that was conversational mixed with information about everyday life and strategies. The second criterion was that it was based on evidence. Families wanted to be able to rely on the fact that the information was truthful and accurate, and up to date. Thirdly, it should be developed (or reviewed) by someone who is in the intended audience demographic (so for instance, a pamphlet for parents with young children with ASD should be developed in

partnership with a parent of a young child with ASD). Lastly, the parents in Mitchell and Slopers' (2001) focus groups stressed the need for a balance between written materials and a key informant who acted as a resource for families. Along with these four key points, they identified best practices. They argued parents should receive the right information at the right time (most parents stated they received either too little or too much information). This means information should be available in different formats, in different levels of depth. Information should include diagnostic information, treatment, management, and support services available. Bingham et al. (2012) added to this suggesting parents receive information on ChildFind, Part C services, benefits, support groups, and applicable books, magazines, and internet sites. They also suggest that before birth parents should be told of possible adverse outcomes of prematurity, and guidelines on how to care for small, vulnerable infants. Most importantly, they suggest that parents are offered choices in the information available to them. Professionals needed to work together to share more information so parents and families have choices and options (Mitchell & Sloper, 2001; Keenan et al., 2010).

Parents reporting on the amount of information they receive may not be completely accurate, however. Some researchers have suggested that if parents are going through a shock reaction, they may fail to comprehend the information provided by the doctor, regardless of how easy to understand or informative it actually was (Davis, 1963; Frude, 1991) (as cited in Starke et al., 2002, p.353). Quine and Pahl (1986) quote a study by Ley (1982) in which it was discovered patients forget approximately half of what a physician has told them within the first five minutes of leaving the office (p. 60). These findings stress the importance of a mixture of both written and verbal information as Mitchell and Sloper (2001) recommended.

Whether written or verbal, parents wanted health professionals to give them information about services and supports, particularly during the follow-up period. Sometimes, the professional who gives the diagnosis is not the person who will be providing ongoing support, so parents want to know who this might be as soon as possible (Baird et al., 2000; Davies et al., 2003). Many times this requires a referral (Cunningham et al., 1984). Parents also want sources for support that are not related specifically to medical treatment, including community services, parent associations, and advocacy organizations. Howie-Davis and McKenzie (2007) found families are more likely to use these types of services when there is a specific diagnosis, or they are certain the organization supports their child. Less than half of the parents in their study had accessed a support organization. This might have been because they did not receive this information from the health professional who gave the diagnosis. These professionals may not be familiar with support organizations, or may not know what is appropriate. Lennox, Diggins, and Ugoni (1997) found most general practitioners had poor knowledge of what services and resources are available to families (as cited in Howie-Davis & McKenzie, 2007, p. 32). Another resource parents appreciated as a follow-up was access to other families, although this is often limited because of data privacy regulations. Bingham et al. (2012) suggested the health professional not only refer to other health practitioners, but also have networks of families they could refer families to. If this was not a possibility, Goodwin et al. (2015) suggested health professionals be able to suggest local and/or online support groups to families. None of the research around best practice evaluated parents' access to other families, although it was suggested by multiple researchers as a best practice.

Whether a support organization, another family, or the health professional who gave the diagnosis, best practices suggest parents want the ability to ask questions, both during the diagnosis and as part of the follow up. Of the older parents in the Pearson et al. study (1999), 75% said professionals were able to answer questions, and 83% of the younger parents felt that way. While these percentages seem positive, Pearson et al. (1999) also discovered that of those percentages, only 56% of the older parents believed their questions were answered fully, and 83% of the younger parents. Many parents stated they did not have enough time to ask all of their questions or to have them fully answered (Pulman, 1980; Tarran, 1981; Cunningham et al., 1984; Sloper & Turner, 1993; Quine & Rutter, 1994) (as cited in Taanila et al., 1998, p. 506), yet Sloper and Turner (1993) found parents were much happier if they did have enough time. Baird et al. (2000) suggested health professionals give parents as much time to ask questions as possible, and Sloper and Turner (1993) suggest parents should have the opportunity to contact the person again. Unfortunately, parents are often given “subtle, contextual clues” by the health professionals (such as walking away, limiting the appointment time, or physically sitting further away or standing) that let them know they should not ask too many questions (Quint, 1976; Cicourel, 1981) (as cited in Quine & Pahl, 1986, p. 59). It could be argued that many health professionals, especially those in a hospital setting, do not have enough time. It is in these instances that multiple researchers suggest the use of a key worker (like a social worker in the United States) or a “personal information advisor” the family could contact for future information needs or questions (Turner & Sloper, 1992; Baldwin & Carlisle, 1994; Beresford, 1994, 1995; Chamba et al., 1999; Mukherjee et al., 1999; Sloper et al., 1999) (as cited in Mitchell & Sloper, 2001, p. 79). This takes some of the pressure off a health professional who

may not have all the information, may not know of support resources, and simply might not have the time.

Many parents also mentioned the need/desire for a second appointment, to ask additional questions, get more information, and receive more emotional support. This second appointment could be with the health professional, a key worker, or with a specialist. Cunningham et al. (1984) suggested that best practice was the health professional offering a second appointment within twenty-four hours. Most of the studies found that parents were not offered an opportunity for a second appointment as much as they would have liked. Turner and Sloper (1992) found although many physicians said that they consistently offered follow-up, 43% of mothers in their study did not feel as though the health professional they were working with gave them the opportunity to contact them again for a follow-up appointment. Pearson et al. (1999) found 83% of the older parents and 94% of the younger parents were offered follow-ups, but of those who were not offered follow-ups 33% of older parents, and 52% of younger parents were disappointed that they did not have the opportunity for a follow-up. Most of the follow-up was offered by an early childhood or family professional (35% of older, 38% of younger). The exact percentage of parents in the Starke et al. (2002) research was not mentioned, however, it was noted that those who were offered it, appreciated it. Those who were not offered follow-up mentioned they felt alone (Starke et al., 2002). Parents in the Hatton et al. (2003) study also wanted a follow-up appointment so that health professionals could help tell the rest of the family about the diagnosis. Five percent of the families were offered this, although an additional 35% said that they would have appreciated the offer. While the Hatton et al. (2003) study focused on South Asian parents, and it could be argued this might have been a cultural preference, this was



also mentioned in one other study as something families from other backgrounds might also appreciate (Baird et al., 2000). Follow-up appointments seem to be important to families for a variety of reasons, and it should also be considered best practice for the health professional to not only offer follow-up, but to assess the reasons behind a particular family wanting/needing follow-up support, as their needs may be informational, emotional, or both.

### **Barriers to Best Practice**

If we lived in a perfect world, health professionals would be able to meet all of the best practices that have been suggested in the research. However, it's critical to understand that health professionals may feel that although they have the best intentions, there are barriers that stand in their way from providing the best possible experiences for families. It is essential to acknowledge these barriers, whether real or perceived, in order to be able to move past them.

**Training.** One of the most frequently cited barriers to delivering best practices in disclosure to families was lack of training. In fact, according to Harnett and Tierney (2009), 93% of the professionals surveyed thought that training in communication would be relevant to their practice, and 81% wanted training specific to giving a family the news of a diagnosis. The UN Convention, in particular, suggests a disability awareness training for all professionals. Baird et al. (2000) suggest a list of possible trainings:

reasons why it is important to break news well; society's attitudes toward disability and the likely influence of these attitudes on parents and staff; understanding parents' reactions; principles of counseling; the importance of having available written information; reviewing one's own difficulties in breaking bad news; roles of different staff members; cultural and religious implications; introduction to services and resources available; and procedures for maintaining and monitoring implementation of guidelines (p.480).

Turner and Sloper (1992) found 83% of physicians wanted training, although 42% did not want written guidelines for best practices. This may have something to do with accountability. Hedov et al. (2002) suggested one of the difficulties with implementing best practices is that there is no one person who is assigned to the parents. Often, the person giving the news specializes in children/pediatrics and may not have any expertise in adult learning or emotional support. It also means that health professionals may think that someone else is attending to the parents when no one is. Quine and Pahl (1986) also pointed to confusion amongst health professionals around who is “authorized” to give information to parents. Nurses may feel that it is the physician’s job to this, and likewise, a physician may think it is the social worker’s role. More training should also be done to clarify roles and responsibilities. This also points to the importance of a team approach, where each team member has a specific role.

**False hope and litigation.** Even when a health professional takes on the role of informer, they may be hesitant to deliver the news in a way that creates “false hope.” Professionals may believe if they are too positive, a family could later be let down by their words or feel misguided (Harnett & Tierney, 2009). This is often linked to a fear on the part of the professional of retaliation or litigation (Fallowfield & Jenkins, 2004) (as cited in Harnett & Tierney, 2009, p. 262). This may be why communication is “prestructured, goal directed, dominated by the professional, and related to legal and organizational restrictions and routines (Starke et al., 2002, p. 347).” Professionals may also not be willing to admit they are uncertain about something (as in the case of a certain diagnosis) or that there are limits to their knowledge, both for fear of litigation, but also in fear of appearing to not be competent in their profession.

**Prejudices.** Lastly, perhaps the most difficult barrier to address, is prejudice professionals might have in regard to disability. “Many professionals who provide diagnosis of a child’s disabilities work in mainstream health services and may not have direct or regular contact with people with disabilities (Harnett, Dolan, Guerin, Tierney, & Walls, 2007) (as cited in Harnett & Tierney, 2009, p. 263). In fact, in a study by McKenzie, Paxton, Murray, Matheson, and McCaskie (1999), it was found that in the United Kingdom, 21% of health professionals had misconceptions about the term “learning disability” (intellectual disability in the US) (as cited in Howie-Davis & McKenzie, 2007, p. 32). This can lead to health professionals giving overly negative or incorrect information to parents. Until professionals are given training or they experience disability in their own family, it is unlikely their prejudices or beliefs will change. Professionals may also have prejudices or preconceived notions about the parents or about the diagnostic process. Cunningham (1995) found health professionals believed there was nothing they could do to improve the situation, and there was no good way to tell bad news (as cited in Hedov et al., 2002, p. 1348). It should be noted that considering a diagnosis as “bad news” is, in itself, a prejudicial belief. As Bingham et al. (2012) note, “We are not attributing a diagnosis of disability as inherently bad news but attending to a perception. (p. 373).” That is, most of the research treats the diagnosis as “bad news” because that is how physicians see the diagnosis. The Cunningham et al. (1984) study also found physicians believed the parents would always react angrily to the bad news. Jacobs (1977) also found physicians interpreted parents as angry and resentful when told a diagnosis and they (parents) would be dissatisfied no matter how the news was told to them (as cited in Quine & Pahl, 1986, p. 59). These attitudes stress the importance of

health professionals being aware of the research done around best practices and how best practices can influence a parents' experience of the diagnostic process.

## Chapter 3: RESEARCH METHODS

### Research Questions

This study set out to examine the experiences of parents in Minnesota. What are parents' experiences with the diagnostic process of their child's intellectual and developmental disability?

Subquestions include:

- How is this experience congruent (or incongruent) with best practices as indicated in the research?
- How does this congruence or incongruence relate to parental satisfaction with the diagnostic process?
- How do parents' experiences shape best practices?

### Participants

Participants were parents of children with intellectual and developmental disabilities who have received a diagnosis within the last three years. While the original intent was to limit this to within the last year, unfortunately, this did not yield enough participants. A total of seven parents were interviewed. Demographic information is included in Table 1. All but one parent identified as female. All parents were college-educated. All but one was Caucasian. The majority of the parents made above \$70,000 annual family income. The mean age of the parent was 46.8. The mean age of the child at diagnosis was 8.8 years old. All of the children whose parents were in the study had begun the process between the ages of birth-five years old. All but one of the children were diagnosed with either autism spectrum disorder (ASD) or fetal alcohol spectrum disorder (FASD). Parents were recruited using a local advocacy and information agency, The Arc Greater Twin Cities. Information was posted on the agency's website, and targeted parents

were sent an informational email (See Appendix D). Targeted parents were those who had contacted the agency within the past year, meaning that some of those were not eligible because they may not have had a diagnosis within the last few years. Eligible parents who responded were given the opportunity to set up an interview time within a four-week period. Seven respondents were available. All parents who participated in an interview signed an informed consent form (See Appendix A).

Table 1. Participant Demographic Information

Parent's current age	Race	Gender	Marital Status	Annual Family Income	Highest Educational Level	Child's current age	Child gender	Diagnosis	Time since dx
36	Caucasian	M	Married	Above 70,000	B.S.	5	M	ASD	1
41	Caucasian	F	Married	Above 70,000	MBA	8	M	ASD	1
53	Black	F	Single	10,000- 29,999	BA	13 15	M F	FASD FASD	7 2
54	Caucasian	F	Married	Above 70,000	BA	18	F	Early	2

								Infantile Epileptic Enceph- alopathy 4	
53	Caucasian	F	Married	Above 70,000	BS	12	M	ASD	1
49	Caucasian	F	Single	30- 49,999	BA	9	M	ASD	1
42	Caucasian	F	Married	Above 70,000	MA	8  6	F  F	ASD, ADHD, SPD  ASD, ADHD, Anxiety, SPD	<1  <1

### Methods of Data Collection

Parents were interviewed using researcher-developed interview protocols, which were semi-structured (See Appendix B). Questions were drafted to avoid being leading while focusing on areas of importance from previous research. Interviews were done in locations and at times of the interviewee's choosing.

**Procedures**

Data from interviews were recorded using an Iphone and the Recorder application. Interviews were then transcribed by the researcher, eliminating filler words or phrases unless deemed necessary for the interpretation of the statement. Names were changed or omitted for confidentiality. The researcher then analyzed the data for themes.



## Chapter 4: RESULTS

### Mixed Emotions

Overwhelmingly, parents had mixed feelings about the diagnostic process. While a parent may say s/he was satisfied or dissatisfied with the process, it was always accompanied by a “but” in the form of a frustration or stressor. All of the parents spoke throughout the interview of the stress and hardship of the process on their lives, but many would still speak positively when asked outright if they were satisfied. One parent expressed mixed emotions directly when asked that question:

In general, I am. You know, I think they did their best. I think they were human. I think they were efficient and you know, with the resources that they had. And they were very kind to the girls. They were really sweet, they made it fun, you know, so. Like I said, I didn't like the waiting room, and I didn't like the number of appointments, it's hard for a parent to take off work if they work out of the home, [pause] but other than that, you know, on an A-D scale, I think I would give this particular thing a B.

Others showed mixed emotions throughout their narratives, at one point saying they were satisfied, but at other points talking of their disappointment:

She [the woman delivering the diagnosis] was on her game. She was very professional. She didn't hold anything back. She was very clear and understanding. As a parent, and as a child, and their job as physicians to make sure that taking care of a child with FAS is going to be challenging, it's going to be difficult, and there are going to be some moments when you don't know what to do. But she said they would always be there... Well, yes, I would think that when there is information of a history when it comes down to a parent using alcohol, substance abuse, that the doctors, social workers, whoever they are, have some kind of obligation or duty to ensure that that child for one not go undiagnosed like my child was. Parents should not have to find out through the way that I found out about it. That should not happen. The diagnosis needs to be upfront from the time, before that child go home, within the first three months of the child's life. The parent or caregiver must know that this child has FAS, so if anything needs to be changed, it's the way the system is set up now, because no one should be surprised. And then kind of have to fight their way through the system afterward.

This stresses the importance of digging deeper into parents' stories. Most clear were the strong emotions that came as parents waited, not knowing:

Gut-wrenching. Gut wrenching. On the seventh day, as I held him at [Organization H], overlooking the river, I've never pleaded with God about life ever before until that moment. And it's a life altering moment. To have to have that conversation. [pause] It [pause] It feels like you are not even on the ground. You are totally disconnected from everything going on around you. And you're only focused on one single thing that you can't control. It's [pause] it's a lonely feeling. Very lonely.

Scared to death. [pause] Yeah [crying] I mean, I can go right back there. [pause] Yeah. It was, I was scared. It just started the whole process of unanswered questions. [pause] Yeah, it's just hard to like, your first thing is, what? And you know, cuz you're getting woken up and you are thinking is it, am I awake? Is this real? Its everything. [pause] And um, yeah, they, it was [pause] the immediate [pause] feeling helpless. The not knowing, I mean.

[The] pediatric neurologist, that was really kind of a scary thing, so a lot of questions were just kind of around, what's wrong with him? Like, did my kid have a stroke? And a lot of, he was really kind of allaying a lot of the fears, but also there were, he kind of brought up some other things. He's like, "He's [your son] really flexible and sometimes we see with these kids if they're really flexible, there's some brain damage that can cause that." So he's like, "That, that may be the case." This was before he got his autism diagnosis through the medical system. He was still like, "I don't think he needs an MRI but he was like, if you want to find out, we can give him an MRI." But he was like, "Even if they find out, there's not really anything you can do about it... That's just the, the way it is." And that's still an open question about whether there's something there. But, so there's a lot of questions around that. And about like "Does he have something that's going to shorten his life span significantly? Does he have some kind of degenerative disease or something like that, you know?" And, I mean, the pediatric neurologist, the visit with him, was just, very scary, you know, tense kind of a situation.

For other parents, the actual testing was intimidating. One parent spoke of the testing:

It was awful. [laughs] I, through that process, I now carry emergency chocolate with me, almost everywhere I go. Because I bawled the first time we were in the psychologist's office. And then the next appointments were better, but I went in with lots of chocolate and Kleenex. So that helped. But I found the process to be very strange, very stressful.

Several of the parents acknowledged the existence of mixed emotions throughout the process. In particular, wanting a diagnosis, an answer, but at the same time not wanting anything to be “wrong” with their child.

Then, you know, we got the diagnosis. And I remember them coming into the room and sitting down and asking me if I was ready for what they were about to tell me. And I said “I think so.” And then they told me and you just, you break down in tears, because you finally have something that you can attach hope to. That you can define...It’s tangible and real. And the biggest fear, is if they couldn’t. The biggest fear, and that’s the weirdest fear to have [laugh]. You’re...you’re joyful that they have found something and even if that something is life-altering, changing, and forever with him, you are more thankful for that than the unknown.

It’s possible that given that dichotomy, mixed emotions are inevitable throughout the diagnostic process, regardless of whether or not best practices occurred. These mixed feelings about the process seemed to mirror mixed feelings about parenting a special needs child.

And I’ll be really honest that when we got developmental delay [as a diagnosis] and I think I feel like I must have asked about autism, or maybe I ruled it out myself by looking at some of the symptoms. I know, I was like, “Well, at least it’s not autism.” I know that sounds terrible, but you know, especially in this generation with all the Jenny McCarthy things and the vaccines, like the worst thing that can happen is your kid gets autism, right? So I was like, “Well, I don’t want that to happen.” And you know, I read the book, The Curious Incident of the Dog in the Nighttime. And I was like, well, that [sigh] poor family because they have this kid that’s just so great, but they struggle. And I was like, “That would be so hard.” I remember thinking of that. And when in it, it’s not so bad on a day to day basis in the sense that our girls are amazing. And, so funny, and loving, and kind, and yet, it can be, it’s just totally exhausting. It’s exhausting... Have you heard the Holland essay? I love that essay. I cried when I read that essay. And I was like, yup its Holland, it’s not Italy, we can do this. But yep, that pain is still there.

The whole process of having a kid with you know, special needs, is something I never realized. I never could have known what it was like before. And to know what it’s like now is, it’s hard. You know. It’s great in a lot of ways. It’s great that we have so many services and supports for these kids, and on the other hand, you know, I think some people just don’t really understand it. If people don’t have someone like this in their lives, they don’t really understand that these people just

because they have a disability that doesn't mean that they're not, that they can't be just as good at everything as everybody else.

These mixed feelings seemed to come less from professionals presenting them with negative messaging (as there was often little to no information given) and more to do with their own feelings about the diagnosis, and working through those mixed emotions. That said, parents were quick to point out when a professional or a system failed them throughout the process, as was often the case, or, in the rare case, helped them:

No! [About being satisfied with the process] Because it's just a guessing game... Ultimately, I ended up in search of the right diagnosis... So yeah, I know, I think we can do better. I mean, and... why are some of these providers not more informed? I think it's best to not make statements in their records if they don't have the training, like the facial characteristics. If they don't have the training fully to understand what some of that sensory integration is, some of that what like I said, the reflex integration issues, you know, it really, it's best to not advise parents in the areas you're not an expert in. I don't want to be pointing the finger about who missed the boat, it's just we can do better. And if not for my son, for the other families that come after us.

Ha! No and yes. [Satisfied] No, because I think there was a lot of failure in it. I think people that we looked to as a society in the educational system failed [my son] and us, frankly. And when I realized that early on in that journey, that they weren't gonna, that they weren't what I thought they were, it became, and I became what I needed out of it. And I surrounded myself with professionals that could bring it home and be what I expected it to be. And [Professional H] is amazing. Amazing. And I will always hold her close to us in that. And [Organization A], my [coworker]'s wife, amazing to cut us in front of the line and to bring the people like [Professional J] together for us. And you know even [the psychologist we went to not in the field], [laugh] I mean, a brilliant doctor, we are talking probably the best, in what she does. And she's famous for what she does. Her willingness, her willingness to jump into the unknown with us. And to be a part of that. That's... that's living. If there's ever a part of life that I want, when I wake up every day and I get out that door, if someone comes to me and I'm able to help them, that I have the willingness to say yes, that is what worked during our journey. Those people. The other ones, not so much.

In their complaints of professionals, many of the same themes of best practice from the literature arose, however, the following themes seemed to be the most commonly reported: timeliness,

parental expertise (or believing parental suspicions), multiple professionals, confidence in professionals, information, services and supports, and difference between school and medical diagnoses.

### **Timeliness**

One of the main themes from best practices that appeared in the narrative was that of timeliness. Most parents waited more than five years for a diagnosis, and this time period was filled with multiple diagnoses. The average number of diagnoses for each child in this study (whether or not the diagnosis was accurate) was 6.8. This uncertainty, like mentioned in the previous literature, was stressful for families. Sometimes, the time delay was caused by uncertainty, other times it was caused by a delay in the system itself. One Minnesota organization that was mentioned several times as the gold standard for autism diagnosis often was not able to get parents in, or there was a long waiting list.

And I thought about having him evaluated at [Organization A] when I did the second evaluation but it was a really long wait, and it wasn't going to be covered by my insurance and there were a couple of other reasons that I just decided to go with the other one. So this time I decided I'm gonna wait. I'm gonna wait and I'm gonna do [Organization A]. So I had to wait until, yeah, we got in the end of January for like the preliminary thing where they decided he actually really needs an evaluation and then it wasn't until May for the actual diagnostic evaluation appointment. So at that point, they did see the autism. And, they recommended some treatment in the areas of social and communication and um self-comforting, you know, behaviors and one other that I can't think of the name of. And now it is October and we are still on a waiting list [laughs].... Um, and so, they also recommended follow-up and further evaluation with an occupational therapist. [laughs] We haven't been able to get that appointment yet, so it's kind of frustrating.

Other parents spoke of how important getting the diagnosis was, and for professionals to communicate along the way:

So then in June, we had to wait until June, you know to get in front of the evaluation people at [Organization A] and so we went in there in June and they were amazing because they not only evaluated the same day, they told you the diagnosis the same day. Whereas [our previous doctor] was like, [voice] “Oh, I need three weeks and I’ll never talk to you again and blow you off like.... like it doesn’t matter.” No, this matters more than life itself matters.

As mentioned in previous research, parents appreciated ongoing communication, as well as communication as to the reason for the delay.

When I did get that diagnosis from [Organization A], one of the things that they did mention to me is that with kids that are really high functioning autism that often they are often diagnosed late because the symptoms can look like so many other things, just like a kid who is slower to progress and there are lots of those kids.... So... you know... it helps a little bit with my frustration to know it wasn’t just negligence on the other people’s part and that it was probably just really hard to differentiate that and they were comfortable telling me at that point. So, that part really helped. I’ve been able to kind of come to terms with, ok this is the way it was supposed to be. It needed to take this long because it needed to take this long.

One parent, who had waited for sixteen years to get the correct diagnosis for her daughter had a different feeling than most parents. Because the outcome for the diagnosis was not “treatable,” she preferred not having the actual diagnosis until she had actually accepted her daughter’s life as it was.

I think I know how those parents when they were younger, like, if she was 3 or 5 diagnosed with this, I would have been devastated. So I’m pretty sure that they’re not ready to know what it’s like when she’s 18, you know. So, so I really feel for them. But, since we didn’t know, we just kept going along. And so by the time she got diagnosed, we were relieved. [laughs]...My tears are for those parents because it would have been devastating at that time to find out.

This realization was different than previous research where parents wanted a diagnosis sooner rather than later, and could have been because the mother had already waited so long for a diagnosis.

## Parental Expertise

Another best practice that came up in the narratives was professionals believing the parents' suspicions. This could also lead to the delay that many families experienced in getting a diagnosis. Across the board, families were dismissed by professionals, and on more than one occasion. This is an interesting finding, given the advent of the internet as well as development initiatives like Help Me Grow. One would hypothesize that families are more equipped than ever to recognize warning signs of development, and that health professionals would listen more to parental input. On the other hand, health professionals could be more likely to believe that parents are "WebMD" diagnosing their children, where they see one symptom and assume their child has that diagnosis. Regardless of this discrepancy, families felt that they were routinely dismissed by a variety of professionals. They were told things like "She's fine" and "Clean bill of health. There's nothing wrong with him." Most often, this dismissal came from the school system. One parent describes her interaction with her daughter's teacher:

I'll say this, I'm still mad about it. I'm trying not to be, but I'm still mad. Her current teacher... looks at me and she said, "Before we start, I just want to say, have you considered, I know that you think she has autism, but have you considered that she might just be an introvert?" And I just took a deep breath and I just kinda looked at her, and someone changed the subject. Um, but I, I was ready to fight. Like, I'm like "Oh, right, duh. Why didn't I think of that?" [laughs] Huh. I don't want [my daughter] to have autism, ADHD, and sensory processing disorder, but we took the time to get that evaluation because we see her struggling at home. We see her struggling with friendships and we see her crying and not liking herself and I worry about what I've heard might happen with undiagnosed girls. Of cutting, and anorexia, and depression, suicide. I'm worried about the future.

This dismissal led to strained relationships with the very professionals who families believed would help them. Even more extreme, families were also told that the issues that they were seeing in their child were caused by their own parenting. One mother said:

He was having some very, very difficult issues. He was not making milestones. ... it kind of went on like that until school got started. And...he started kindergarten and we was having an IEP meeting, and the psychologist, the social worker, whatever she was called, she says, "Well, your son is just mimicking you." I said "Mimicking me? How do you feel he is mimicking me?" You know, because he had some speech impairments; he was having some delayed development...I was really upset and offended because of the fact she had no idea that these were my adopted children, he was my adopted child, she just assumed that he was, you know, whatever behavior he was displaying came from me. So I took a great deal of offense of what she was saying, and I said, "No, there is something going on with this child." They were not assisting me; they were not trying to figure out what was the issue with this child.

Another mother mentioned to her doctor that her son wasn't meeting milestones. She was dismissed and insulted in one statement:

And I got the same answer every time. "Well, he's just different than your other child and you can't compare the two and he's fine and you are just a hyper-sensitive mom because he has [another disorder]." So, very dismissive.

These attacks on parenting and on the parent themselves made parents reluctant to trust professionals, and even themselves. Several parents talked about how not being believed made them doubt themselves and what they knew about their child.

It was. It was really frustrating. And each time I would think, ok this time they are going to see it. This time, you know. And then they didn't. and then I had that minute of, well, they don't see it, it must not be true. You know. It you know, I'm gonna back off I'm gonna reevaluate and I'm gonna see what it could be. And I would go through that and then I'd get back to no it's not something else. It's not.

Despite the doubts, parents stressed the importance of believing in their own gut instinct, even after being told multiple times that they were "crazy" or that "everything was fine":

Your parent instinct is big and you have to listen to it and it doesn't matter how long it takes, you have to listen to it. Because if I had stopped at the first you know evaluation I you know I... we would be in trouble you know and... And I was glad that I didn't let the fact that no one else saw it... I mean, I could take that into consideration but I could still listen to my voice that said you know they might not see it but I am mom, I see him more often. I you know I am the one who interacts with him the most and I see it. So... you know. So I would say that you know that I think that's important to tell anyone that is going through a



diagnostic process. Take what people say, take the doctors you know other peoples' opinions and you know evaluate them, but listen to yourself too. And if there is something that is telling you something, don't let that go.

Parents spoke about having to push to get a diagnosis or to get supports for their child, so that their belief in their gut instinct became more than just that- it became advocacy. Parents had to be the biggest advocate for their child, often against the professionals they thought were on their side. One parent noted of their struggle of constantly having to push, with almost every professional they come in contact with:

He goes to a social skills program during school that they've already told us he doesn't need. But, we've been told many times this. Like, you know, that he didn't, he doesn't need services from different places, like the OT at [Organization B] at first was like "I don't know what you want us to do for him. He doesn't need this." You know, until they took a bigger look at it and started, they were like, "Wow, I'm really glad we did this because we're really being able to help him. At ABA, we first...did his meet and greet where they evaluated him, they were like, "Yeah, I don't know. We don't normally do kids that are like this high functioning like that." And we really pushed. And were like, "We really need this." And then they were able to really help him a lot...The Minnetonka school district, when we first took him in, they were like, "Why is this kid even on an IEP?" And so after being told so many times, "He's fine. He doesn't need this stuff," and then finding out he did, we really pushed to keep him in the social skills program at school.

When a parent did not believe that a professional was on their side, they would often turn to someone else. Often, this led to a trail of different diagnoses and professionals involved in their child's life. This had both positive and negative effects. It could mean that a child finally gets a diagnosis or the right supports, or it could mean that another professional had failed the family. A parent spoke of changing professionals if they one they originally saw did not believe them, and of the many types of professionals she encountered:

[The] neurologist really couldn't tell us anything because all of her tests were normal. And so, through the course of a couple of years, if I had a neurologist that wasn't willing to look further as to what was going on, I would get

recommendations for a different neurologist.... Some neurologists are like “Well you know what, I don’t know what it is, so maybe you should just go home and accept it.” And I said, “I accept it. I accept my daughter. But that doesn’t mean I don’t, she doesn’t deserve, you know, to know what’s going on.” And others were like, [laughs] you give them a mystery and they want to find out what’s going on. So it’s interesting the different personalities you ran into with that.

One parent summed up what a lot of the other parents hinted at when she compared getting a diagnosis of an intellectual and developmental disability to a cancer diagnosis. Being dismissed would not be okay, and so she continues to advocate:

Like I said, the other thing I compare it to- your child or your loved one gets a diagnosis of cancer, and you can’t get to the oncologist, you can’t get referred, the pediatrician or the MD just says, its fine, its only at stage 1, you know, no worries. We’ll handle it. [*Wait a few months.*] Yeah, wait. Would that be acceptable to anybody? so that’s what drives me. Like I said I don’t have a choice, I have to speak up and I have to keep pressing on. And it’s not just like I said, it’s for our whole family, for the survival of our whole family, not just for my son.

Many of the parents continually mentioned that not only were they having to advocate for their child, but often they were the only one. This led parents to feel alone, even if surrounded by professionals--professionals who did not believe them.

### **Multiple Professionals**

Being constantly dismissed led many parents to seeing a multitude of professionals. Often, these professionals spanned disciplines, with families seeing school personnel, doctors, psychologists, neurologists, and non-profit organizations. While this was sometimes intentional, at other times it was what was necessary to get their child’s needs met. The average number of professionals that each parent mentioned throughout the course of the interview was 27, meaning that they interacted with, on average, 27 professionals throughout the course of the diagnostic process.

One parent’s short excerpt lists seven professionals:

So we continued to work with [**Organization A**] I had to work with the **district that we lived in**, because we had moved during this time. And I was trying to keep him in **the same school he was in** but I knew we couldn't so =during march, the month of march, he didn't go. I had to have the **U of MN** and his **pediatrician** write medical excuses because he wasn't eating, he refused to eat there. They called it a medical emergency intervention, and that's you know the **cops** couldn't pick me up for truancy right. To protect my own self from monsters. They [the school] were the monsters. [My son] was not. So then I went and I continued to work with the **Minnesota Disability Law Center** because they kicked open the doors on the other districts' side and I am telling you, they rolled out the red carpet [**Bold mine**].

Every service that a parent wanted to access required a new professional (or more). Each professional seemed to give a different diagnosis and often contradicted each other. As two different parents said:

Who do you believe?...In the ideal world, it would be one source where you go and you trust that they're reliable and they'll give you solid information, but we haven't had that.

In that, I got differing information. I got differing information from [Organization C] than I got from the county or the state, you know, and it was just like, alright, who do I... [laugh] who do I, you know, it's not who do you believe, but who do you trust because each one of these, if they say this is true and they say no this true, like well, if I go with this one, that could really screw us up for a little while if that's not the case, you know what I mean.

For one family, conflicting information and an incorrect diagnosis meant an unnecessary surgery for their daughter:

So anyway, it was interesting when we went out to [out of state hospital], they looked at all of her records and said, "Well, we've never seen a child tested as much as she has been without, without an answer. But we can tell you we don't think she ever needed the shunt." And I said, "Well that can explain why we never needed any correction done to it or revisions or replacing it, you know, I mean, nothing." So, but, obviously, you are not going to remove it.

Multiple professionals involved also complicated the entire diagnostic process for many families. Information would not get passed from one professional to another, and the papers would either

have to fill out the exact same paperwork, or tell their story again. This led to frustration. Even worse was when a parent went in search of a diagnosis only to find that another professional had it and hadn't communicated it clearly to her:

So, while I was sitting in the lobby [of the diagnostic clinic], right there, there was this lady who came up and she said, "You're CB's mother?" and I said, "Yes I am." And she said, "Well, you know, he was here when he was three months." And I was like, "Wait, hold up, I'm his adoptive mother. What are you talking about?" She said, "Yeah, he was here when he was three months, and he was diagnosed with fetal alcohol syndrome." and I was like, "What's that?" [laughs] and she said, "Well, [the doctor] will kind of elaborate, go into more detail." She said, "What are you for real [that you didn't know]?" I said, "I had no idea, [the county] never did reveal that to me."... So after I met with [the doctor], he said, "Yeah, I remember this little guy." So I was completely blown over by the fact that it was that part of his background was never passed down to me.

Dealing with so many professionals with different answers, as well as those who did not believe them led many families to the breaking point:

If these children, if the system would have been full cooperative, if the system of professionals were involved and helpful and you know backing the children, ok. I think all of the things that I have experienced wouldn't have been so traumatizing and I feel that the two different worlds I live in with FAS is I don't know unique maybe because I've been fighting too hard, or just fighting period. And I shouldn't be. It's been that kind of a life since 20, so for 13 years, FAS has run my life, because I have not been able to pursue a career, I have not been able to take care of myself because I have been so wrapped up in FAS. It's all I know. It's all I know, is FAS. I have, I don't have a life outside of FAS. FAS is strangling me. Ok. And it's not something that I caused, ok. But its literally tearing me apart because of the people that have disconnected or not connected to helping me and kind of like putting up barriers for me. They put up the barriers for me, that means my children can't get the help they need and if I can't get the help for them, then they are being left out.

If parents received clear, accurate answers from professionals throughout the process, the need for seeing multiple professionals would be diminished. Professionals having more in-depth knowledge and sharing that with families would help families feel less like they need to "shop around." In addition, when it is unavoidable for families to need to see multiple professionals, a

team approach would be beneficial. This would include professionals working together across professions and systems. This would also have the added bonus of families feeling less alone.

### **Confidence in Professionals**

Having to go to so many professionals caused a lot of parents to lose faith in professionals. As in the previous research, many families had the idea that professionals are the ones who are in the know, the ones who should have the answers, the cure, the fix.

No, they had no idea. And that doctor that woke me up in the middle of the night, I never saw her again. Um... cuz by the next morning, or that morning then when they started doing tests, then a neurologist was involved. I'm sure she was just the doctor on call or in the hospital that night. Probably delivering babies for all I know, I don't know. And uh... and uh... I mean she didn't, she couldn't answer anything. So you are like, totally frustrated, totally, completely scared to death. And feeling helpless and kind of pissed. You know, cuz you are like, why can't you tell me?!? I mean, you know. So. And at that point in my life, I had never been with a doctor who couldn't give me answers to everything. [laughs] You got two other kids, they are completely fine, or they've had, one had RSV, that was probably the most serious thing we had dealt with, and was asthmatic after that, that type of thing, but the doctors always knew. Knew the answers and could help you and make you feel better. And you got none of that. Absolutely nothing.

In describing the many professionals that she contacted, this parent talks about losing faith in them upon discovering they did not have all the answers:

So they did some work but they said, "Hmmm he's from eastern Europe. Have you considered that he might have fetal alcohol spectrum disorder?" And we said, "Well that's been dismissed. The U previously had looked at him, right away when we brought him home from the adoption clinic." And I look back later and they missed stuff. That was the International Adoption clinic [who] said he didn't have the facial characteristics, and the OTs, we had two different OTs say he didn't have sensory issues... so it was like, wow, you find out later, and it was like gosh, these are people that should know, you know. And we went to the very sources, you know, and um so, you know, it's really very, very hard too... That original source that we went to at five, at the U of M, was a doctor who I found out later, does the FASD evaluations. Oh my gosh! No mention of that to us. Read a couple of books and come back in six months. You think I'm going to go back to you know that, when I didn't feel like they could help us and they were credible. I mean, and like I said, I look back at the reports, and I'm like how could

the international adoption clinic have said that he had no facial characteristics and yet they weren't qualified to say we went through the process and he sure does. Oh my gosh, how could they say that he didn't have any sensory issues? We've been to several OTs. So what I would say is that some of the people that are supposed to be in the know, the key people, just aren't. And you know, I don't want to complain, I don't want to be a whiner, what I want to do is say, folks, lets come around the table and let's see where we're missing the mark, and let's do better. We can do better.

This dissatisfaction was not only with physicians or medical professionals, however. Many parents expected that the school system would be equipped to understand their son or daughter and their needs, only to find themselves let down. Many felt as though their son or daughter was the only one in the school who needed help.

Well, I first started with the school. I asked them, hey, and that's when I discovered from them, well, your child is the first child that we have here, with fetal alcohol syndrome... I'm like, "What? Out of all these kids? There's children in wheelchairs, there's kids in here with all kinds of disabilities." And she's like, "Well, yeah... your child is the first." So, I tried to start with them. Ok, that was my first place to go to, because you know, the school districts have the school psychologists, the social workers, they have a lot of resources. But I found it very difficult.

We definitely got the impression from the... school district that really they hadn't seen a lot of kids like [our son] before and didn't really know what to do, like the facially asymmetry stuff and having like, you know not really being able to do a hearing test on him, like saying he failed a hearing test, and stuff like that. Just didn't seem like they had a lot of experience with kids like this before.

Many of the parents told stories of the schools not doing what was expected of them through legislation (Individualized Education Programs, Least Restrictive Environment, etc.). This was particularly frustrating when parents felt as though they hadn't been told their rights to begin with, or were not made aware of the process. Others were angry when the school thought they would get by with an excuse:

And I said, yeah, and you guys should have been the ones to invoke this in October because of Childfind law. Because it's your job to identify this and it's

your job to enact this process that helps these kids that have issues. And “well, yes, yes. But we are just so busy.” Great. Not my problem and not my kid’s problem. You tell that district to get more people, but don’t you dare try to push it on our shoulders. So... she told me in that conversation that it was going to be a six month waiting list. And I said, well that’s funny because the law says thirty. You have thirty days.

That same parent noted that she did not expect to encounter the types of professional attitude that she did in her son’s school:

And I went to them [the school professionals] to talk. And what I received was something I never thought existed in our education system and it does. And that was ignorance. Ignorance of how to look at a person as an individual. Ignorance to look at a child and have the willingness to want to help that child in any way shape or form that a teacher could possibly want to help. So I went to them with that as my objective and got that push back. I immediately went to the administration of the school. And the administration reacted in a very “you need to come in, we’ll talk.” So I went in and they had the whole school –all faculty for second grade. All specialists. The administration, and they had the school psych... everybody was there. And I told [my son]’s story, at least the part I was aware. And there were people that were in tears, and there were people that were just not even paying attention, wanting to just get out of the room. Because their mindset was, if he’s not, and they spoke these words to me, if he’s not like everybody else, then I don’t know what to do with him. He doesn’t belong in my classroom. That was their mindset.

Parents wanted the schools to understand their child, and to understand their child’s needs. Many felt that this inability was caused by lack of education on the side of the teacher about both common diagnoses and about warning signs to look for. One parent believed that preschool teachers should be at the frontlines in regard to identifying children who need support, as well as knowing how to best support those children:

I would educate preschool teachers better in how to understand these conditions, how to help the parents know what to do next... It will be really nice if, I guess I think there’s maybe a deficiency there in the preschool programs where the teachers don’t understand the conditions, don’t understand the services. They don’t understand all of these things that go around autism, and how to help these kids. And I think that some kids, they get diagnosed way too late or don’t get diagnosed at all. And especially, I think, this probably affects kids in lower

incomes a lot more than folks like me that can go to these really... good public schools where the teachers- they have programs to deal with these kids and stuff like that.... I really hope that somehow the state or the country could help the preschool teachers really understand. Because I think they're really going to be on the frontlines.... And I think the preschool teachers are the first line to really see these kids and to really see [them] on a more objective basis like "where is this kid versus most of the kids?" and stuff like that and I look back at the first school I went to and I just don't really think they understood his condition. I think they wanted to do everything they could to help him, and I think they just didn't understand it. They didn't understand the services. And I think that just led to a lot of waste and it worries me that there are other kids in their system that aren't getting services as soon as they could be because of that.

This parent alludes to the impact that socio-economic status can play on the timeliness of the diagnosis. Because the sample size of this study was small, there were limits to the differences in socio-economic status and race/ethnicity. The one parent who identified as Black mentioned that she believed that her race played a part in how professionals treated her. Professional perceptions of the parents also seemed to play a part in those children diagnosed with FASD. Both parents of children with FASD felt that professionals, in general, did not understand the diagnosis, and that they were continually having to fight professionals and systems for understanding, primarily because of views professionals had about the mother:

And hardly, and my experience has been, hardly anybody understands and knows what that [FASD] is. And it's a lot of the stigma for the individual... You know, birth mother drank and that kind of thing. so not understanding how that affects it because it is an invisible disability. And then on top of it, with the intellect, and really the whole attitude his intellect will override the disability. And I can tell you for a fact, it won't. Unfortunately, as much as I wished it would.

I'm gonna be honest... a lot of people really kind of don't take FAS as a serious diagnosis. I think they just go, it's not autism. Everybody has autism and I think FAS is one of those types of development that they say, well you caused it. You caused the child's development. You, as the adult, the mother, is the responsible party here and now you want to get help for what you [caused], for your negligence, and for your abuse of the fetus? Ok, come on. And I think that that's one of the stigma[s] that is attached to this diagnosis, is that the parent is to blame. And so it's not like autism or muscular dystrophy or there's some genetic



anomaly that has happened that could cause this. It's basically 100% preventable. So I think that...the child born into this situation is basically, you know, that's your mommas fault, let your momma take care of you. Ok, we are not going to spend millions and millions and millions of dollars to take care of you when she should have put the drink down. She knew better.

While both parents did not disagree, they also believed that this did not mean that their child should be denied services and supports, nor should they be disregarded as adoptive parents. This led to them losing faith in professionals, and in the system.

Despite losing faith in professionals, these experiences led some parents to come to the realization that professionals are human, and there are limitations to both medical science and people's knowledge. One parent describes his experience with a neurologist who admitted to him his shortcomings as a professional. This is contrary to research that suggested that many professionals do not want to seem as though they don't have the answers:

Yeah, and even the neurologist said, "We don't understand the brain that well." And they'll, at least the neurologists I've met, will readily admit it. They'll say, like "Hey, we don't, a lot of times, we don't really find out what's really going on until the kids are like 18-19 years old...All I can really do is make educated guesses. You know. Sometimes I'm right, sometimes I'm wrong...I look back and I'm like, I'll get somebody else's patient and I'll look at the paperwork and be like I don't know how this person didn't see it, it's obviously this. But then...sometimes the same thing happens to me when my patient goes to someone else and they catch it. And they think the same thing." Um, that was a pretty scary thing.

Parents found this shortcoming to be both eye-opening and frightening. Parents believed not only did doctors have all the answers, but medical science did as well. One parent broke down in tears reliving this realization:

I think my first realization that and this is one thing I found out about especially the brain and that type of thing, how little the medical world really knows when it comes to the brain, especially. Um, and how these things work. But, anyway, yeah, it was just, uh. [long pause] Just overwhelming. [crying]

As much as families wanted health professionals and school professionals to have all the answers, in particular, some parents mentioned it makes sense to them pediatricians would not be the people to accurately diagnose their loved ones, given the limited time that a pediatrician sees a patient.

I brought my concerns up to pediatricians, and you know, she gave me referrals. She said that she didn't really see any warning signs but she also said that she doesn't spend enough time with him to really see those warning signs. .... And it's true. How often do you see a pediatrician? You don't spend much time there.

I think pediatricians could be better educated on this also. Although, at the same time, I feel like, for a pretty healthy kid like [my son], pediatricians don't see him that much, you know. And so if you are only seeing him, these doctors, they only have 20 minutes to see this kid and then they have to go to another patient. In twenty minutes, how much can you really see in a kid to tell you that they need these services. So it doesn't really. I think it would be good to educate them better, I just really think it's the preschool where it has to start.

This has implications for who emphasis is put on for training purposes. Previous research suggested pediatricians and medical professionals be the ones to receive the training. Parents in this study suggest the school system, specifically preschool and early intervention, is the place to focus training efforts.

It should also be noted that while many parents lost faith and confidence in professionals, when a professional did step up and share the journey with a parent, the parent was grateful and complimentary, even if the professional did not have all the answers. In fact, parents seemed ultimately to appreciate this.

I remember going to a parent-teacher conference, and [his teacher], I should never [forget] her name because she was such an advocate. His second grade teacher came up to me and greeted me and she just broke down in tears. Because she wanted to help [my son] in such a way and she didn't know what the answer was. And nor did I. And so we cried together.

Often, it was the breaking down of the professional wall that helped families feel that a professional was on their side. The mother above mentioned that they cried “as mothers.” This is often difficult for professionals who have worked so hard to create the image of a professional. This, as mentioned in the previous research, is also a delicate balance for professionals to strike. They need to be knowledgeable, almost to the point of specializing, but at the same time be approachable and relatable. This is also difficult when a family expects a professional to have all of the answers, because it appears that families simultaneously want professionals to know everything, but also be able to admit when they don’t. This conundrum might also be best solved by a team approach- where one professional does not know the answer, someone else will.

### **Information**

As mentioned in the previous research, parents have confidence in professionals who are able to give them information- the right amount at the right time. Information needs of parents often began even earlier than they knew their diagnostic journey was beginning, at pregnancy. None of the parents in this study remember being given information about disabilities before the birth or adoption of their child. In addition, many did not have any previous exposure to disability, and their only notion of “abnormal” development came from popular media or parenting books. This information was, at times, conflicting or negative. One parent mentioned reading Jenny McCarthy’s book on autism in which she alleges that autism is caused by vaccines and can be cured. This left parents confused, as did parenting books:

When you read a lot of the parenting books they tell you like, ok, if your kids a little bit delayed, don’t worry about it, it’s fine. But enough of that stuff started happening that she kind of raised that she really thought there was something wrong. And, um, we didn’t really do anything about it for a while, because it wasn’t anything major, you know. It was like, he was still getting along fine in school; he was doing well in preschool. Everything was going fine.

Others knew of families who had a child with a disability, but this knowledge was from a distance, or even from a book.

I hadn't really been exposed to much of anything other than just kind of cursory, like, my sister talking about this book or hearing someone talk about they saw something on a tv show. I did know that one family that [my wife] was working with, one of their sons had autism, and I didn't know much about him, just that I remember him being very hard to kind of care for in a lot of ways. Being like a real challenge. And I think he probably was not as high functioning as [my son], but I remember that too. That you know, I remember when I first heard the autism stuff with [my son], thinking about that kid and stuff like that, you know. Is that going to be our future?

Most parents agreed that they wanted information throughout the whole process, however, one parent mentioned that too much information before a diagnosis could be dangerous:

I think helping parents understand can help, but then you have parents like me that are like, "Oh, he's going to be fine." And also you don't want to you don't want to scare parents either you know because they've shown in studies, medical students, every time they find out about a new disease, they diagnose themselves as having it. I think the same thing can apply to parents. Where you teach parents about autism and all of a sudden. Every parent thinks their kid is autistic, right, and we don't need that. We don't want to clog up the system with kids that don't really need to be put through the diagnostic processes.

While none of the parents received messages during pregnancy, those who received information at the time were appreciative of the information, as long as they found it to be useful. Parents wanted information on next steps, what actions they could take, and what services and supports were available. One parent mentioned all of the things that she found helpful from the organization who gave her son the diagnosis:

When they provided the diagnosis, they took the time to answer every question, new question I had. And then they came with this sheet two sided and they had highlighted the things that "you are doing this, keep doing that. You're doing this, keep doing that. We're gonna add this and this is why. We are going to have these two new evaluations done. And we'll schedule those for you. Get in contact with this company because they will help you with this. Call the county because you

could get TEFRA. Blah blah blah blah. Then they gave us this packet 8.5x11 big binder thing and it was “The first 100 days of an autism diagnosis” which went into a myriad of things. And they knew that we had a dog- we had bought a golden retriever for [my son] because of his sleeping issues, and they um said, “Well, you can get him certified.” So they kind of helped us with that process... I mean, they were amazing. At any time, between now and whenever, if you have questions, here are our cards, here’s our direct phones. There’s our emails, you let us know. ...I’m all the time emailing with them and working with them. And what do you think about this, or what do you think about that? They’re just amazing to work with. And they’ve gone to the school; they’ve done site visits. They’ve provided recommendations to the school, you could be doing this differently, you could do this, did you know this about [my son], so that means this? I mean, they are right there in the thick of it with us.

This response was rare, however, as most families did not feel as though they received the information or support that they needed from professionals. Many felt as though they were being left to fend for themselves, and most discovered information and support on their own, sometimes unintentionally, through other parents or stumbling across it in a book or conference.

So that process [of receiving the diagnosis] seemed a little fast. They’re typing their report as we are in the meeting, and that happens. And they were very kind, sympathetic people, practitioners, but... you know, you get this diagnosis, and it’s fairly heavy. And you know you are worrying about the future, and you get a packet to read that says here’s some websites and books for more information. I understand at [Organization A], there’s a class. They give you- there’s a nice little packet, like here’s a booklet, this is what you do, this is your next step, and this is how you contact your county, and this is where all the dollars flow through. I just started reading books. And then I then I joined [Organization D] and then I went to the conference and it wasn’t until the end of the day- I went there because they had a newly diagnosed session and um, it wasn’t great, and I can tell you more about it. It was just a guy reading from slides and things like that. And it wasn’t until he said something about, he started using some acronyms and myself and another woman raised our hand and we are like, “what does that mean? What does that mean? What does that mean?” Oh, that’s and finally he mentioned “case manager” and the woman behind me said “What’s a case manager and where do I get one?” And I’m like “Me too! Where’s my case manager?” and there were case managers in the room with us and they said “Oh, dadadadada.” We had no clue. So this woman and I are writing down names and numbers and like, oh we contact the county and this is how you do it... It’s tough for a parent when you get a diagnosis like that. For me, it was definitely like... “Good luck!” So my husband and I still feel like we’re winging it. We have some resources now but we

definitely don't feel as though we have as much support as we would like. Or, I feel like I'm the center. I'm the one connecting the physicians, and the play therapist, and the OT, and the case manager, and I thought that the case manager could help me connect everything, and it doesn't work that way. And so, I'm still I'm still the person and it's, uh, it's daunting.

Another parent found out information about a therapy that might be helpful by looking at his health benefits:

I'm trying to remember how I found out. I had done a lot of research just on autism, [and] what kind of things we could do to help him. And I'd read some books. Stuff like that, since then. Written by people who are autistic. Temple Grandin is one of them and some other folks. I think I stumbled across the ABA thing by looking at my health insurance documentation actually and finding it. I was just like looking at all the services that are covered and I remember seeing "ABA for autism," and that jumped out me, cuz I was like "Oh, autism, that's what my kid has." You know, what is that? I had never heard of it before. I'm pretty sure that's how I found out about it. And then started, went from there.

Feeling as though they did not get enough information from the professionals, as one parent put it "just a glimpse", all of the parents started seeking out information on their own. This was often intense research, with parents pulling information from as many sources as possible. Sources included books, internet, conferences, other organizations—all of which they found themselves.

It was all self-motivated. You know, you would get a number from somebody and that number would lead you to somebody else, and somebody else. Sometimes it was frustrating because none of them were giving you answers, they were just giving you to the next person. [laugh] But some were very helpful. So you just, you just made every call that you could. To see where it would lead.

Yeah, I mean, a lot. Just going after [information]: doing classes. So I did [Organization D] classes. I've done training on attachment and adoption. So, [Professional who deals with attachment and behavior]- some of her training. I did a program, [Organization E] does some trainings so I tapped into that, and lots, whether it be [Organization D] conferences, whether it be webinars, lots of different things, but all either FASD, attachment, trauma, that type of thing mostly. And now, tapping into some of the ASD [resources].

Other parents were lucky enough to talk to other parents and get insight from them, whether in person or on-line. This information ranged from accessing services to the day to day care of their child.

I learned more about services to help families and help parents through other parents. I didn't learn about it at school; I didn't learn about it at through the therapists that we were going to. I didn't learn about it through [Organization A]. I learned about it through other parents. It's like, "Really? Wow, ok, who can I call for that?"

I'm finding a lot of joy in a Facebook support group. It's parent to parent support and it's fantastic. It's what I need. Because I can tune out if the world feels too heavy and I can jump in when I have a question about my daughter's chewing so much she's getting sores around her mouth, "What do I do?" "Oh, Vitamin E." I wouldn't have known that you know?

Several parents mentioned the desire to have a specific parent to talk to, or a specific group of parents who were more experienced, rather than having to network and meet other parents by happenstance. This seemed important particularly throughout the diagnostic process and shortly after receiving the diagnosis, as follow-up.

I would really love to talk to other parents. If nothing else, to give them [information], cuz originally, I also wanted to know if we were doing the right things for her. We tried every diet; we tried [laughs] wheat-free and gluten-free, and this vitamin and or 20 vitamins. You try everything when you want to help your child. And every therapy- she's still in horseback riding. You do everything you can.... Are we doing what she really needs? Or is there something out there that we can give her or do for her or get her into that uh that would help her, make her life easier?

I would like a buddy. I would like to be assigned uh a parent who has gone through the diagnosis to say, you are about to have all these meetings, my name is "Erica" and I'm going to be your friend that you can count on, from parent to parent, this is what you can expect. I can tell you my situation, it's a big spectrum, it's a big umbrella, there's a lot of things that can happen, but I'm here for you. I felt very alone, and autism is very isolating anyway.

Many parents echoed this feeling of being alone, that the professional had given them the diagnosis, given them minimal information, and then sent them on their way to figure it out themselves. Feeling alone was a common theme.

And you know, with both girls it's a relief and yet, I don't feel like we have all the support we need. We might be getting there, but yeah, back to back diagnosis. And it's interesting to be a marginalized group within a marginalized group.

I started to understand- ok, when a child is diagnosed with fetal alcohol, it comes [with] a lot of behavior, a lot of professionals. People gonna be in and out of your lives, and it's gonna be a struggle in school, home, community. So, it took me by surprise of all of the things that was going to start evolving around in my life that I had no idea was forthcoming. I didn't have no crystal ball or a person that was helping me through it. Once I adopted him, everything dropped off. Nothing. As long as he was in foster care, they were there. But the moment I adopted him, everything dropped off. None of these people were there. ... I have not really went out and found anybody to help me because I haven't, because otherwise I would be a lot happier. No, I have not found anybody to help me.

Other families tried to reach out to professionals, only to find that the professional wouldn't return calls, couldn't schedule appointments, or couldn't help. One family couldn't even get the doctor to call back or schedule an appointment to talk about the diagnosis; he simply put it in the mail:

I tried to schedule appointments with [the neurologist] to get the readout [of the evaluation]. Because I'm dying over here because school is crazy. [My son] is crazy because he's feeling unwelcome in an environment where they are treating him like a monster and an alien. And I don't know what I'm dealing with so I can't help but yet they're [the school] telling me to help. And [neurologist], you're my thread of help. So [the neurologist] never scheduled that appointment. I couldn't get ahold of his people. No one returned my calls. And I got the packet in the mail. And I remember opening it, and cutting through it. And reading all about it. And failed, failed, below average, below normal. Red flags, right? Tripping through this report as a mom who knows nothing about neurological disorders. And at the last page I get to the diagnosis. Or at least one diagnosis. It says "Executive function disorder attributed to MCAD" and it said "Come back in two years for a re-evaluation." And I just lose it. Because, number one, what the heck is executive function disorder, and number two, what the hell is two years? You are going to wait two years? You are going to sit on this kid for two years?



Another parent believed that the only follow-up the professionals would offer is if she wanted to pursue services through them, but would not take the time after that initial diagnosis appointment to answer questions and give her what she needed:

Good luck. If you need, I mean, they said, “We’re happy to see her for speech. We’re happy to have another appointment with you if you have any questions, but then it was like you had to book that appointment and it’s hard to get in with their schedules. You know, “We’re happy to see her for more services,” but that hour meeting was just like, “Here’s the diagnosis. That’s all we have time for.”

Another parent wanted both more information and services, but was unable to get either. Instead, this parent was put on a long waiting list with neither services or her questions answered.

I would have really liked [more information]... I did have some questions. I don’t remember specifically what they were. They were able to answer a couple of them and then the other ones they said really would have to be answered by the occupational therapist. When we got that diagnostic appointment or whatever. So, I still don’t really have answers to those... I am hoping that once I can get the therapy in place, a big part of it is training the family, so I’m hoping once we get that in place that they [her child’s other set of parents] will actually attend those and that will help.

Because so many of the parents felt as though they didn’t have the information or follow-up that they needed, one parent suggested she would have liked a class where she could get answers from professionals and talk to other parents. She envisioned this class as welcoming and reassuring, as well as factual. This echoed how previous research found parents wanted professionals and information to be.

I kind of wish there would have been then a mandatory class that we take afterwards so that there’s a friendly [place], comfy chairs, hot coffee, cookies, a friendly face- grandma would be awesome. A really nice Grandpa would be fine too. Just someone friendly, and listening, and nice. That would then say, cuz it wasn’t, I honestly didn’t know what to do. ...I didn’t know what to look for...it’s just so overwhelming.

A class seems to be one possible option for meeting parent's information needs. The parents in this study seemed to seek out information in multiple ways, at multiple times. It may be that the role of the professional (or the team) is to either provide that information, or provide the access to that information.

### **Services and Supports**

One of the main areas that families wanted more information on, as well as support with, is accessing services and supports. They found that getting a diagnosis was the key to accessing services, but most parents did not know where to start or, sometimes, even that they needed to or could start. This was one of the areas families were most dissatisfied with, and they tended to be dissatisfied through every step of the process.

I'm a better person for it, but it's taken me to my knees and its nearly broken our family, and like I've said, these systems that were created- are they created with the families, real families in mind?... Cuz friends and I talk and we just say, "Why?" It's such a mystery, we don't understand how these systems work and why can't it be more clear? Is it mysterious on purpose so that we'll get frustrated and we'll just walk away and we won't go back? We get denied and we just won't go back and we'll say that door was closed.

This frustration with systems was not limited to only one system. Often, parents started outside of the disability services system, with their own private healthcare. They used this to access the healthcare professionals in search of a diagnosis. Unfortunately, many parents found fault with the health insurance they had previously believed to be adequate. It's important to note that all of the individuals in the study had private health insurance, so this is not representative of the experience of someone who uses state sponsored healthcare.

The [Private insurance company]- it didn't serve us well. Fine for medical, but as far as trying to access qualified professionals that understand trauma, attachment, FASD, the complex background, was very difficult. I would call and call and call, no, not taking clients, no, don't take [that private insurance], nothing.

Ironically...our insurance cut off her therapies. Cuz she wasn't progressing. It's like, seriously, isn't that why you are in therapy, you know? [laughs] It made no sense to me and I kindly argued with them, but it didn't make any difference. So. They said, "No, she hits a [plateau], if she's not progressing over a certain period of time were not going to pay for her to go anymore."

Private health insurance often does not allow families to access all of the services that they need.

Applied Behavioral Analysis (ABA), a therapy for autism, only recently started being covered under private insurance companies, and not all the time. In the State of Minnesota, in order to access services through the county such as ABA, some therapies, in-home support or respite, an individual needs to first qualify for Medical Assistance, the state's needs-based health coverage, with a disability. If an individual is under eighteen and the family does not meet income eligibility requirements (meaning their income is too high), the individual must qualify for MA-Tefra. The family can either contact the county or use the state MNSure system to begin this process. This process proved to be both convoluted and incredibly frustrating for families.

I kind of went on two different paths to try and get this [ABA] covered. One was.. applying through MNSure for MA-Tefra, and then the other one was through my health insurance company. And it was a long slog on both fronts. Both fronts very complicated, stressful processes where you really didn't feel like you were getting anywhere for a long time. Turned out the health insurance company did eventually cover me at a clinic. I mean, one of the hardest things, too, was finding a clinic that would work with my health insurance company, and would actually take him in in time for him to get some services before kindergarten. That took a long time too, I probably called about 20 different ABA places. And a lot of them were just like, "We have a year backlog right now." Or just, "We don't work with that insurance company" or whatever. And so, the insurance, they kind of got to a point where they were like, "Alright, if you can find a clinic you like, we'll look at them and we'll see if we'll be able to make something work but you gotta find somebody first." So it took me a long time to finally find somebody and then get on a waitlist and push that through to get everything to really line up.... There are still some issues, unfortunately, with the insurance where when it actually gets billed, they are like, "Oh we don't cover this." And stuff like that, so that's a lot of fun. We're still working through that-trying to figure out if it's actually going to be covered or not. We didn't pursue the MA-Tefra part because it would have

cost us so much money that it was basically sending him to a really expensive college for a year. And so, we didn't pursue that although we may. It's such a weird process...The whole thing is just really complicated. So, that was a really stressful process. I mean, I probably spent 100-150 hours on this whole ABA, insurance, Tefra process-just trying to like work through it, figure out what's going on. It was a lot of work.

Other parents found, like the parent above, even after going through the whole process, that MA-Tefra's parental fees were cost-prohibitive. Yet, they felt that they did not have a choice because they needed to access services.

Tefra's very expensive and some families opt out. And yet I didn't have a choice. We needed it. We need it. And so that's my concern for my [son], I continue to have to continue to adjust and flex. Every time I think I've made it, you know, my son now needs this.

After getting MA-Tefra, the next step for most families is connecting with the county for services. An individual goes through an assessment process (called MNChoices as of 2015) to determine which, if any, services and supports s/he qualifies for. This, like Medical Assistance, was a mysterious process for families that they believed to be full of secrets, as though professionals were withholding key information. One parent believed that she was not given the services her child was eligible for, and questioned the county professionals:

When I asked them to send me a copy of their assessment, they sent me this document where the lettering was so small, you needed a microscope, a magnifying glass to actually look at it. And actually it was a compilation form where you needed another piece of paper to understand the piece of paper that they sent you. And which they only sent me the piece of paper that had the compilation key! [laughs] Anyway when it came back you know I said I was going to appeal it. I said, "No, this is wrong" and so I made some really serious headway. I just was not backing down, so...we had another meeting. On October 6<sup>th</sup>, I had the case manager, his supervisor, and the planner, they all came out, at one time. Come to find out the [MNChoices] person that assessed him did not include anything other than PCA...How she did the assessment was unbelievable, so I know there is prejudice when they come out and assess your child for services. That it's what they check off, [which] determines what your child receives and if they are ignoring what you are saying, and saying "Well, I'm

going to say this instead” and “I’m going to say that instead” because what they put down determines your eligibility and the budget amount.

Other families didn’t have the energy to fight being told they were not eligible for services and supports through the county:

We also went through the process with [our older daughter]. She was assessed, and she did not qualify for a case manager. And it’s-I still don’t know why she was denied while [our younger daughter] was approved. [Our older daughter] has five diagnoses, [our younger daughter] has four, and but, um, you know, I honestly don’t know why. And I haven’t fought it. I should probably fight it but. [cries]

Parents were mystified that the process was so confusing, mysterious, and difficult. Many felt as though they needed to fight to get support, which only made them more tired.

So anyway after that conversation, it’s just kinda been on this, it seems like this endless whirlpool. I mean, and it absolutely has been a struggle from then until today. Getting help through the county that I live in, getting services, dealing with the schools, it has been an absolute nightmare... I mean, it seemed like every single thing I have tried to get for him, I’ve had to fight for. I mean, literally, services he is entitled to, they didn’t give him... I had to appeal the decision to say, “Hey, he’s entitled to more,” and luckily they ruled in my favor. But it’s every single thing that I have tried to get for my child has been with a lot of “no’s” - it seems like it’s almost intentional.

I’m sorry, this is ridiculous. That we should, that families should, and most give up. And the other thing is, it’s expensive, to be honest with you. So anyways, we qualified for, we did go through an assessment, we said, we think, we qualified for a grant, but we couldn’t access the grant because then the Tefra was shut off, remember? So then last year, when he did qualify finally under his mental health diagnosis, I went after a waiver, because that’s what I was advised, so he qualified for a CADI waiver. So finally, we are getting parental pay, we are accessing services. It’s difficult though, I would say it’s difficult.

Parents wanted more transparency about everything, from the beginning to the end. Most felt as though they were searching for what they needed, fighting every step of the way. Professionals seemed to expect parents to know what to ask, what to look for, and what to request. This could

be due to professionals believing some other professional was providing that information to the family. One parent said:

I wish it was a lot more transparent, about how to go about [accessing services], and what step is next, and so it would be advocacy in the schools and understanding your rights about public education and IEPs and all that. To you know understanding how to be SMRT-ed [State Medical Review Team] and how to access county services. And where to go when you are in a crisis and you need a plan and who can best advise you and help you. There's just so many layers to support and what I'm finding is that now he did get a CADI waiver, and I am getting some supports that way, but I have still the burden to figure out. That's the thing they say, "It's your choice, you can fit whatever your child's needs are." But I'm like, "What are my options? Show me the menu." And then I have to try, so then I end up networking. So it's through these Facebook groups, through people I meet... So my kind of take is what can we do to change things. Again, I don't want to be a whiner, but we can do better. We can absolutely do better.

This points to the importance of professionals working together and having specific, designated, clear roles. Parents were also frustrated by professionals not working together, and having to fill the same information out multiple times. This could be eased by a team approach where professionals work together and share information with one another, or even as simple as having one form that is applicable to multiple professionals, rather than each having their own.

I'm not as satisfied with the wait for services, obviously. It's very frustrating and the process [for getting MA] was extremely long as well. And, in fact, there is one piece that I still don't have... Cuz they make you fill out no less than three forms that include all your medical insurance information and then at the very end they say "Well, now we have to determine if your medical insurance is cost effective." So now go through it all again. Cuz, you couldn't use any of those other three forms for that? No, apparently not.

I didn't like the fact that we filled out so [much paperwork]. I mean, the stack of questionnaires and paperwork was out of this world. It was so thick. We were always filling out paperwork and it felt to me like no one read them... So, from a parent perspective it does feel yucky that you spend all this time on all these questionnaires. I would do essay questions about what our concerns were. And it was like they didn't read it. So it was like, the appointments were tough because I was saying everything over and over and over and over again. Maybe that's part

of the process but maybe there should be better “what to expect before your diagnosis.” [sigh]

Parents all wanted to see professionals and systems work better together, rather than being at odds with one another. More than one parent noted the difficulty and monotony of accessing the different professionals and services was enough to make them give up.

### **Difference Between School and Medical Diagnoses**

Further confusing things for families and decreasing their satisfaction with the process is that different professionals required different diagnoses. A medical diagnosis is not the same as a diagnosis that qualifies for services is not the same as a school diagnosis. Families did not understand this distinction and were not sure why there was more than one required and that each had a different process and different criteria. One parent describes how they didn’t know why they needed both, but that another professional told them to:

And I said, “Why do we need an independent if the school is doing it?” And she said, “Sometimes schools miss some things and they’re only looking at it from an educational or academic standpoint. And you’ll probably be better served by going through a strong program” and [Organization A] had a very long waiting list, so we went with [Organization E].

Often, the school diagnosis was the least understood of all for parents. One parent describes how they weren’t even sure if it meant their child had autism:

We had also put him through a program in the school to basically do some testing with him and stuff like that. And they had also given him a diagnosis of ASD before the medical diagnosis. And this was an educational only diagnosis. Not medical, its educational only, and the whole reason was, this is all coming back to me now, was because we were trying to get him on, approved for an iep at school. To get him some special help. The teachers were like, “He needs help, let’s put him through this testing. Let’s see if we can shake something out.” Well, it turned out that he was scoring very high in almost every area except for one. And they were like, “He needs to fail in two areas to get him on an IEP, but if we can like, diagnose him as having ASD, then we can get him on an IEP.” And so that’s kind of what they did. They went through and alright, it looks like he has ASD. It’s not

a medical diagnosis, its educational system only... I think we weren't that surprised [with the diagnosis... Because it was this educational only diagnosis, because it was under these special circumstances, it wasn't like that he even necessarily had it [autism], you know. Even his pediatric Neurologist when we brought it up to him that he had this educational diagnosis, he was like, "I don't even know what that means." He was like, "I don't even know what it means for the educational system to diagnose someone as having autism." He's like, "I don't know if that's, I don't know if he has that or not. He may not."

While the school seemed to be flexible on the diagnosis for some, for others, it was a fight to get educational services, despite having a medical diagnosis.

And when we mentioned to school that we were going to, that we were concerned about autism with her, they flat out fought us. And they are still fighting us. They say, "No." And they say, "She's a good student, my daughter is friends with your daughter, she's one of the top readers in her class. Um, she has great behavior." And that to me, I think, is the key. She has great behavior; she's not a behavior problem. She's quiet, she does what she needs to do in school, and then she comes home, and she absolutely melts. She definitely has the diagnosis... and with my daughter right now, we pushed, and she's in the middle of an evaluation process at school where we're trying to get services and support for her. They're thinking of phasing her off her speech IEP and they say that she doesn't need any services... So we brought all that information [the medical diagnosis] into school and said, "Ok, here's her diagnosis. Can she get some support services?" And they were like, "Yeah we had a team meeting. We looked at your report, and we don't see any academic need for services. She's fine." And I said, "So we have a report, you know, half an inch thick that says she has a lot of strengths and she needs some support."

So I took the medical diagnosis that fall before 4<sup>th</sup> grade and the FASD evaluation was dismissed. The diagnosis-That's a medical diagnosis and that's not relevant to the school academics. And I'm like, "You know he needs an IEP. We need some supports. And the best they could do was maybe get him some sensory breaks, but they really kind of didn't."

Again, families wanted professionals to work together. Many felt that the school, medical, and county services were completely silo-ed, with the parent being responsible for putting the pieces together.

And I know, I realize sometimes you need a diagnosis in order to get services at school and with the state and that type of thing. I totally get it. [My daughter]



didn't need that diagnosis because her disabilities were so obvious, so, we didn't have to worry about that. But it's hard to change it once they're labeled with that too. But there again, you learned what the benefits that were available to her in school, but that didn't tell you any of the county or the state, you know, that she needs a case worker. It's like, really, why? [laughs]

While none of the parents explicitly mentioned a "key worker" as was mentioned in previous research, it may be that a key worker with knowledge of both systems would be beneficial to families. While in the state of Minnesota, this may have once been the role of the case manager, this is not the case anymore, as that person is more responsible for county funding and often has no interaction at the school, and little with other professionals, unless they are arranging for them to be paid.

## **Chapter 5: CONCLUSIONS AND DISCUSSION**

### **Conclusions**

Overall, the parents in the study were not satisfied with the diagnostic process. Many of the key themes and best practices were discussed throughout their narratives, with additional best practices emerging. Timeliness was a big concern for parents, with their search bringing them to multiple professionals. Part of the timeliness issue was professionals did not acknowledge parental expertise and believe the parents' suspicions. This ultimately led to distrust and loss of confidence in professionals. This distrust of professional competence was a new key theme in this research, although strains of it are found in previous research's discussion of manner. For the parents in this study, it appeared as though manner and setting were less important than the recognition of their expertise, information given, and the follow-up offered afterward. Families did not believe that Minnesota was meeting the information and support needs of families. In particular, accessing services and supports was a key part of the diagnostic process for families that was rarely mentioned in previous research. Parents wanted the professionals who were on the search for the diagnosis journey with them to continue that journey in accessing supports. Parents also wanted the process to be simplified at all stages, from the seeking out that first appointment to entering the school system. Most felt there were unnecessary barriers and hurdles for them to overcome, and that dealing with the emotions of the diagnosis was enough to deal with on its own. Parents would like both their emotional and informational needs met.

### **Implications and Suggestions for Further Research**

This study has many implications for practice, across disciplines. The complexity of the diagnostic process as discussed by parents suggests that simply asking parents whether they are

satisfied might not be accurate or sufficient. Further studies should take this into consideration when designing method. Ultimately, the results show that parents are still not satisfied with the diagnostic process, and that, in particular, Minnesota has areas for improvement, specifically in timeliness and follow-up.

As one parent mentioned, there is a need for more training and education of all professionals, but specifically school personnel. While many parents mentioned wonderful teachers, many also mentioned teachers who had been difficult and caused significant stress. This was mostly caused by a lack of knowledge on the part of the professional. Better education and training could help alleviate this lack of knowledge. Teachers should be trained repeatedly on developmental milestones, possible indicators of common disabilities, communicating concerns to parents, and best practices for special education. While some educational programs prepare teachers through classes that cover these topics, most teachers most likely to do not remember the details if they are not using them on a daily basis. These topics would be beneficial as a required part of continuing education for teachers with all levels of experience from early childhood to at least middle school.

The results also indicate an increased need for looking at a team approach. Parents would be more satisfied if professionals not only worked together to share/pass on information, but went one step further and worked in conjunction with one another. This could mean one location where families go to get a diagnosis, apply for services, and access services. It could also mean having professionals come to the schools and working directly with teachers. It could even be as simple as having “team” meetings where professionals across disciplines and the family come together to discuss diagnosis, options, and possibilities. An area for further research would be the

impact of ACOs (Accountable Care Organizations) on parents' experiences. However, this still would not impact the silo between medical professionals, state professionals, and school professionals. Until this becomes more integrated, it is likely that parents will be unsatisfied. This becomes difficult with money coming from various sources, and laws governing the agencies differently. Policies and funding streams would need to change to accommodate a team approach.

Information is another area that needs improvement. This research suggests that while parents will most likely seek out information on their own regardless of what the professional provides, they still appreciate structured information from professionals. As suggested by a parent, a class or cohort of parents learning together might be beneficial. Because diagnoses come from a variety of sources (schools, hospitals, clinics, etc.), until a team approach is also accomplished, it would be the most beneficial for one agency to offer this and for those sources to refer families. Another area for research might be considering if the information provided in the "First 100 days after a diagnosis of autism" booklet offered by one professional agency might make a bigger difference for families. All of the families in this study had, at some point, contacted an advocacy organization for more information. It is possible that individuals who have not contacted an advocacy and information agency might feel as though they have even less support and information, so this would be a further area for study.

Another implication that addresses both the information needs and the team approach is the idea mentioned in previous research of a "key worker." This seemed to be something that families would benefit from, and is a role some parents believed the case manager would provide. It might mean that Minnesota needs to reassess the role of the case manager to better

meet the needs of the families. This is currently under review by state agencies, however, it is likely that the change being considered will go farther from the role of a “key worker” or informant and more toward the case manager acting solely as a distributor of funds.

Finally, this study suggests that Minnesota needs to take a look at the accessibility of services and supports for families. Most families believed that accessing services and supports was a convoluted, inaccessible mystery. If the intent of these services is to provide support for families in need, it is doing the opposite by actually causing families more stress and isolation. As one family said, “We can do better.”

### **Limitations**

The limitation of this study was the study size. It was a small sample of parents, which is not an accurate representation of all Minnesotans. Because the study took place in a large metro area, it may not be generalizable to smaller, rural communities and the experiences of parents whose children are diagnosed there. In addition, primarily mothers responded, so the male perspective is not adequately represented. Parents came from primarily well-educated, middle class, white backgrounds. This is not representative of larger Minnesota demographics.

Participants were recruited from an advocacy and information organization. It could be parents who participated in the study were more likely to seek out information and help and were more savvy than the general population. It could be that accessing an advocacy organization helped eased stress and led to a more positive outlook. Contrarily, individuals who contact an advocacy organization and volunteer for such a study could be those who had a more negative experience.

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## **Appendix A: Adult Informed Consent**

### **Adult Informed Consent**

#### **Parents' Experiences of the Diagnostic Process of Their Child's Intellectual and Developmental Disability**

**You are invited** to participate in a research study of parents' experiences with the diagnostic process for their child with an intellectual and developmental disability. You were selected as a possible participant because you indicated interest in the study as a parent who fits the criteria of having a child with an intellectual and developmental disability that has been diagnosed within the last year.

This research project is being conducted by Victoria Hickenbotham to satisfy the requirements of a Master's Degree in Child and Family Studies at St. Cloud State University.

#### **Purpose**

The purpose of this study is discover what parents' experience of the diagnostic process was like in Minnesota, and whether they were satisfied with the process.

#### **Study Procedures**

If you decide to participate, you will be asked to participate in an interview lasting approximately 1-2 hours. The interview can take place in the setting of your choice. Interviews will be audio-taped.

#### **Risks and Discomforts**

Discussing the diagnostic process for some people may be an emotional experience. Participating in the interview may bring up some of these emotions for you. You may withdraw at any time if you experience discomfort that may lead to psychological harm.

For those participants who experience strong emotions, Crisis Connection is a resource to contact for 24-hour emotional support. They can be reached at 1-866-379-6363 (Toll Free – Minnesota) or 612-379-6363.

Additional resources for parents for more information and support include The Arc Greater Twin Cities at 952-920-0855 and PACER Center at 952-838-9000.

The study will take a period of your time, and it is recognized that as a parent of a child with special needs, this may be difficult to arrange. Flexibility will be exercised to accommodate for this inconvenience, including time of interview, day, setting, and the possibility of scheduling more than one session.

#### **Benefits**

The study has no known explicit benefits. Potential benefits of participation in the study could include assisting in bettering the diagnostic experience for other parents, and possible self-awareness.

#### **Confidentiality**

Information obtained in connection with this study is confidential and any identifying information will be reported under pseudonyms to prevent identification of research subjects. Although the names of individual subjects will be kept confidential, there is a possibility that you may be identifiable by your

comments in the published research. You will have an opportunity to review the text and withdraw comments prior to publication.

Interviews will be recorded on a password protected phone, and then transferred to a password protected computer. Immediately following this transfer, audio files will be deleted from the phone. Written documentation will be typed into the password protected computer, and the original paper file shredded. Audio files will be deleted after being transcribed by the researcher and at the completion of the study. All raw data will be deleted at the completion of the thesis.

### **Research Results**

As mentioned above, at your request, you may review the text and expand or withdraw comments, or note omissions prior to publication when the study is completed. Once the thesis is completed, a copy of the final version will be available at St. Cloud State University.

### **Contact info**

If you have questions right now, please ask. If you have additional questions later, you may contact me at 651-261-7988 or [vlhickenbotham@stcloudstate.edu](mailto:vlhickenbotham@stcloudstate.edu). You may reach my faculty advisor, JoAnn Johnson at [jojohanson@stcloudstate.edu](mailto:jojohanson@stcloudstate.edu). You will be given a copy of this form for your records.

### **Voluntary Participation/Withdrawal**

Participation is voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Cloud State University, the researcher, JoAann Johnson, or the organization from which you heard about the study. If you decide to participate, you are free to withdraw at any time without penalty.

### **Acceptance to Participate**

Your signature indicates that you are at least 18 years of age, you have read the information provided above, and you have consent to participate. You may withdraw from the study at any time without penalty after signing this form.

Subject Name (Printed) \_\_\_\_\_

Subject Signature \_\_\_\_\_

Date \_\_\_\_\_

## **Appendix B: Interview Questions**

### Interview Questions

*Numbered questions are those that will be asked. Indented questions are guides for follow-up, if needed.*

1. Tell me about your child.
2. What was the diagnostic process like? Tell me about it.
  - a. How long did the diagnostic process take?
  - b. What updates were you given along the way?
  - c. What testing/assessments were done?
  - d. Did you have suspicions prior to getting the diagnosis? Did you share those with health professionals?
  - e. What was the diagnosis?
  - f. Who gave the diagnosis? Were other professionals present?
  - g. Who was with you?
  - h. Where were you told?
  - i. Tell me more about the person who gave the diagnosis.
  - j. What messages did you receive about the diagnosis?
3. Was there anything you would have changed?
4. What were your first thoughts upon hearing a diagnosis?
  - a. What things had you heard about that diagnosis prior to your child being given that label?
5. Tell me about after the diagnosis? What happened?
  - a. What questions did you have after the diagnosis?
  - b. What information were you given?
  - c. What support services were offered to you? [Therapies, Specialists, Support orgs, other families...]
  - d. What actions did you take after diagnosis and how did the healthcare professional support you in those? [Looking for more info, treatments, therapies, surgeries, etc.]
  - e. Tell me about follow-up support/appointments that you had and the hand-off between professionals.
6. What was your experience with people with disabilities before your child was born?
7. What messages were you given while pregnant about disabilities and/or prenatal testing?
8. What messages did you receive about your child's future?
9. Were you satisfied with the diagnostic process? Why or why not?
10. What, if anything, would you change about the diagnostic process?
11. What has changed in your life or in the life of your family since the diagnosis?

**Appendix C: Demographic Information**Demographic Information:

Parent's Current Age:

Race/Ethnicity:

Gender:

Marital Status:

Socio-economic status: Annual income (select one):

Under \$9,999

\$10,000-\$29,999

\$30,000-\$49,999

\$50,000-\$69,999

Above \$70,000

Parent's highest education level:

Child's age:

Child's gender:

Parent's age at diagnosis:

Child's age at diagnosis:

Child's diagnosis:

### **Appendix D: Email/Website Announcement**

**We are looking to hear your story!** As part of a research study, The Arc Greater Twin Cities is looking to hear from parents who have a child with an intellectual or developmental disability that has been diagnosed in the last year. We would like to hear about the process of getting a diagnosis, whether through the healthcare or education system. We are looking for six parents to participate in interviews, lasting between 45 minutes-2 hours. If you are interested in sharing your story, please email [Victoria@thearcgtc.org](mailto:Victoria@thearcgtc.org). Please feel free to share this with anyone you think might be interested.