

**Expanded Parenting:
Fathers' and Mothers' Experiences of Parenting Young Children with Disabilities**

A Dissertation Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Juli Meagan Sams
August 2012

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Dedication

This is dedicated to the memory of Valerie Fisher Raley (1980-2009).

Acknowledgements

First and foremost, I wish to thank all of the **families who participated** in the present study.

Their willingness to share their stories and to welcome me into their lives was invaluable.

I also wish to express my gratitude to my dissertation committee: **Drs. Vey Nordquist, Priscilla Blanton, Mari Beth Coleman, and Mary Jane Moran**. I appreciate your support, availability, and insight throughout this process, leading me to my goal.

I wish to express my sincere appreciation for my recruitment team: **Agnes Fox, Sara Gilbert, Robin Hamrick, Lynne Harmon, Susie McCamy, and Pam Potocik**. Their efforts in recruitment made this research project so successful. I could not have done it without them.

I also want to thank **Rhett Billen** for his assistance with the project and discussing the findings with me. Also, **Jessica Lampley** for her assistance in the transcription of audiofiles.

I wish to thank my fellow Agraphites: **Karen Bluth, Teri Henke, MinJung Jung, Swapna Purandare, and Carolyn Spellings**. Also the support of my friends: **Lori Caudle, Sally Hunter, and Heather Wallace**. I will always value your insights and ability to help me think in a different way. And, of course, for keeping it all in perspective.

Finally, I wish to thank my husband, **Jonathan**, and our sweet daughter, **Olivia Jane**. Olivia, I have thoroughly enjoyed watching you reach your milestones and I hope, one day, you will be proud of me for reaching this milestone.

Abstract

Parenting a young child with disabilities presents unique challenges to both fathers and mothers. A comprehensive literature review revealed that there was limited information on parenting young children with disabilities and what was available was not cohesive, lacked a father perspective, and was based on quantitative measures originating from the perspective of parents of children without disabilities. Therefore, the purpose of the present study was to provide a basic, comprehensive understanding of parenting young children, birth to five, with disabilities from both fathers and mothers. A total of twenty parents (ten fathers, ten mothers) of children with disabilities participated in individual audiorecorded interviews to discuss their parenting experiences. Grounded theory techniques were used to analyze the interviews and three main themes emerged: individual meaning-making, external influences, and the process of parenting. Parents indicated they parented the same as if their children did not have disabilities, but also discussed several modifications they made in their expectations and goals as well as parenting behaviors related to structure and guidance. Accordingly, the parents appeared to be expanding their parenting practices to accommodate the children's disabilities and needed to be more intentional in their parenting approach in an effort to help their children be comparable to their peers. Also, both fathers and mothers were fairly similar in their parenting at the broadest level, but differences were evident when examined closely. Most notably, fathers were highly engaged in their parenting, but were limited by time constraints due to work schedules, which affected each area of parenting. Implications and recommendations for practice and future research are discussed.

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Chapter I

Introduction

The concept of parenting is multifarious, incorporating the relationship of both the parent and child as well as individual characteristics of each. Some aspects of parenting, such as nurturance or harsh discipline, have been linked to various child developmental outcomes, while child characteristics, such as behavior problems, have been related to outcomes in parents, mainly mothers. In other words, parenting does not exist in isolation, but is an ever-changing and transactional relationship.

Parenting often is characterized by the parent-child dyadic relationship and, most commonly, with various aspects of a parent's intent to socialize his or her child (Baumrind, 1971). More specifically, parenting has been exemplified by the degree to and manner in which a parent encourages the balance of conforming to social standards while also encouraging individuality (Baumrind, 1971). This not only incorporates the expectations for the development of children, but also the manner in which parents choose to meet those expectations through methods of discipline and nurturance (Locke & Prinz, 2002). Furthermore, additional characteristics such as child engagement, limit setting, and responsiveness are found under the umbrella term of parenting, among many others. As a result, the research on parenting has considerable breadth in relation to the depth that is present, but subsequently there also is confusion on exactly what parenting entails.

It does not appear that one characteristic is considered more or less important than another, but it seems that all parenting behaviors are part of a dynamic system of care (Baumrind, 1971; Darling, 1999). In other words, it is important, for example, to be aware of the influence of one's expectations for obedience as well as physical and verbal discipline.

Parenting also may be recognized not simply for the presence of behaviors, but the degree to which these behaviors occur or variations of method. For instance, discipline may be examined based on the level of harshness, such as, with physical discipline, a tap on the hand versus spanking. Parenting also can be defined by quality, which may encompass an array of behaviors exhibited in a variety of ways; for instance, higher quality parenting may be characterized by expressing affection demonstrated by hugging and playing (Darling & Steinberg, 1993). Interestingly, terminology associated with parenting appears to be used interchangeably within a variety of contexts, age groups, and circumstances, while the manifestation of and response to parenting may be quite different (Maccoby & Martin, 1983). At a very basic level, the term parent, for example, often appears to be synonymous with mother, yet there also seem to be different methods in which mothers and fathers socialize their children (e.g., Baumrind, 1971; Maccoby & Martin, 1983; Volling, Blandon, & Vorigine, 2006).

Purpose and Research Questions

Much of the research on parenting has focused on certain age groups (i.e., adolescence), racial groups (i.e., Caucasian), and socioeconomic groups (i.e., middle class) and there are conflicting results when research deviates from these core demographics (e.g., McWayne, Owsianik, Green, & Fantuzzo, 2008; Querido, Warner, & Eyberg, 2002). There are discrepancies and gaps in the overall literature on parenting all types of children but, of greatest interest for the present study, there is a paucity of literature on parenting young children with disabilities. Broadly speaking, the literature on the *experiences* of families of young children with disabilities suggests that the daily lives of these families are unique. For example, these families are at an increased risk for stress (e.g. Smith, Oliver, & Innocenti, 2001), low-income (e.g. Parish & Cloud, 2006), and child behavior problems (e.g. Hastings, 2003), all of which

have been linked to modified parenting expectations and behaviors in families of children without disabilities (e.g., Bridgett et al., 2009; Lugo-Gil & Tamis-LeMonda, 2008; Lagacé-Séguin & d'Entremont, 2004, respectively). However, actual parenting styles, expectations, and behaviors of these families may yield different results when examined more directly.

It is important, therefore, that a better understanding of parenting is developed as they exist for these families in an effort to avoid incongruous expectations for their unique situations. It may be that they adjust their parenting styles to match what is necessary for their children and family, given that their experiences may, in fact, be different. There appear to be differences in parenting, for example, with African-American parents when compared to what is predominant in the literature on parenting which, as previously mentioned, is largely focused on Caucasian parents (e.g. McWayne et al., 2008). It also may be that the terminology that is generalized to most families, albeit not always appropriately, may not be applicable to this subgroup of families. There may be characteristics of their parenting that are not as important for the development and socialization of their children compared to those without disabilities and, similarly, there may be parenting behaviors that are fully overlooked.

The literature on parenting of young children with disabilities, which will be explored in Chapter II, is lacking in breadth and consistency of focus, sample, methods, and outcome. There are few available studies that address parenting of this group and researchers and practitioners cannot draw appropriate conclusions regarding parenting practices of this population given the diversity of findings. Therefore, a primary purpose for the present study is the development of a fundamental understanding of parenting styles, practices, and behaviors of both mothers and fathers of young children with disabilities.

Two primary research questions directed the exploration of the present topic:

- 1) What are the parenting styles, practices, and behaviors of parents of young children (0-5) with disabilities and what are the various influences on these?
- 2) What are the similarities and differences between mothers and fathers in parenting of young children with disabilities?

Theoretical Anchor Points

Three main theories guided the present research in the conceptualization of the understanding of parenting young children with disabilities. These include Bronfenbrenner's Ecological Systems Theory, Family Systems Theory, and Metaparenting.

Ecological Systems Theory. Bronfenbrenner's Ecological Systems Theory (1977) is comprised of a series of nested systems in which each level is influenced by the others. First, an individual possesses several unique characteristics (Bronfenbrenner, 1994). In the case of the present study, this may be both child (e.g., disability status, age) and parent characteristics (e.g., gender, educational level). A *microsystem* is any immediate setting in which a person is an active participant and examples would be a parent's family-of-origin or a child's therapeutic preschool (Bronfenbrenner, 1977, 1986, 1994). A *mesosystem*, on the other hand, is the interaction between the various microsystems that potentially impact a child's development (Bronfenbrenner, 1977, 1986, 1994). They are influential independently, but also have a distinctive influence given their relationship. For example, a child is part of a family and is participating in early intervention services, such as occupational therapy, and the influence of one may affect interaction with the other.

The *exosystem* is comprised of influences that do not directly impact an individual, but potentially influence various microsystems (Bronfenbrenner, 1977). These are factors such as

policies, media, or parental work environment. For the present population, the policies related to documentation in early intervention may be considered an exosystem. A *macrosystem* incorporates the broad social and cultural values or the generally accepted beliefs of a collective group (Bronfenbrenner, 1977). This may be how other individuals in the community view a child's behavior as it relates to his or her disability.

This theory was necessary to address the various social influences on the parents of young children with disabilities and the decisions they make. In other words, it is not that a parent and child exist in isolation, but they are a part of several influences at a family, local, and broad societal level. The decisions parents make may be guided by not only the characteristics of child's disability, such as social issues or language delays, but also their spouses' support of their decisions, goals set with a therapy provider, and how disabilities are viewed by the public. The complexity of the various factors warrants attention at each level and not only within the context of the parent-child relationship.

Family Systems Theory. The Ecological Systems Theory provides an understanding of a number of potential influences on the family system and the interaction with a number of social factors. However, it only highlights the importance of the family system as one component and, accordingly, it was necessary to include the Family Systems Theory (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011) in an effort to examine the family more closely. Family Systems Theory is comprised of family characteristics, interactions, functions, and life cycle. *Family characteristics* are inputs, or traits the family members bring to the system, and include characteristics such as the family as a unit (e.g., cultural background, socioeconomic status), individual members (e.g., parental coping, nature of a child's disability), and unique circumstances (e.g., parental addiction, parenting a child with a disability).

Family Interactions are the interactions within the family system and include the relationship between spouses or partners (marital), parent and child (parental), siblings, and the extended family. As an example, it is necessary to examine not only the manner in which a father assists his child with a disability, but also how he discusses parenting with his spouse, incorporates siblings in interacting with the child with a disability, and behaves with his child when his own parents are present. Two elements are especially important in understanding interactions, which are family cohesion or the degree of closeness and individuality for each member within the family, and adaptability, or the ability for the family to change in response to a perceived stressor.

Family Functions are the outputs, or the effects of the family system, and consist of factors such as affection, spirituality, or social engagement. For example, the presence of a child's disability may make a more a parent more likely to turn away from religion because the disability is viewed as a punishment from God. *Family Life Cycle* is the manner in which the family changes over time. In other words, the family system is dynamic and experiences numerous changes including a child transitioning to school or receiving a diagnosis of a delay. This is especially important for the present study concerning the influence of the diagnostic process on parenting as well as the family's ability to set long-term expectations for their children. The inclusion of this theory as an anchor point was important given that the diagnosis of a child's disability does not only have an influence on that child's life, but also his or her family. Furthermore, the manner in which the family chooses to respond to this life change likely will influence each member of the immediate and extended family.

Meta-parenting. The previous two theories provide a framework for understanding potential influences on parenting and interactions within multiple subsystems; however, it is

important also to examine the manner in which parents elect to promote individuality and conformity in their children. Meta-parenting is “the thoughts parents have about their...childrearing” (p. 22, Hawk & Holden, 2009) and is described by various domains, which are anticipating, reflecting, assessing, and problem solving (Hawk & Holden; Nicholson, Howard, & Borkowski, 2008). *Anticipating* are preventative acts related to childrearing such as bringing toys when going in to public for a child who is overwhelmed by strangers. Unlike the foretelling nature of anticipating, *reflecting* is a parent’s evaluation of previous parent or child behaviors or interactions with his or her child. This may be related to a child’s response to a certain method of discipline. *Assessing* is related to parent’s perception of qualities related to his or her child or self, such as the manner in which she views her child’s progress towards therapeutic goals. *Problem solving* entails the act of identifying a problem and creating and executing a solution. For parents of children with disabilities, this may be recognizing that your child is behind his peers and finding services or employing activities to help him progress towards appropriate development.

The theory of metaparenting was important to apply to the present population provided that parents are parenting through a process of various decision-making processes. They make decisions in each moment based on their evaluation of and modification to each of these areas. More specifically, a parent of a young child with disabilities must both prevent and reassess the manner in which he parents based on his evaluation of his child’s abilities and the effectiveness of his problem solving strategies.

Nominal Definitions

The following terms utilized throughout the literature review and study and this is how I define them:

Parenting: The manner in which a parent defines expectations for his or her child and executes strategies in an effort to help his or her child achieve those expectations.

Parent: A biological mother or father of the child of interest.

Caregiver: Any adult who provides care to a child and is responsible for decisions in all aspects of a child's life. This includes, but is not limited to, mother, father, grandparent, and adopted parent. However, this does not include individuals such as teachers or early interventionists.

Disability: A child's diagnosis or reported delay in one or more areas of development including speech-language, hearing, vision, social, cognitive, self-help, fine and gross motor skills.

Individualized Family Service Plan (IFSP): An IFSP is a written document created collectively by parents and professionals in determining goals for a child with disabilities in each developmental domain of interest. An IFSP meeting is one in which a family of a child birth through two with a delay or diagnosis meets with service providers to discuss goals for the child. Both the family and service providers work in conjunction with each other to reach these family-centered goals.

Individualized Education Plan (IEP): An IEP is a written document created collectively by parents and professionals in the school system in determining goals for a child with disabilities in each developmental domain of interest. An IEP meeting is one in which a family of a child three through twenty one with a delay or diagnosis meets with a school system to discuss yearly goals. The school system often takes on primary responsibility for the progression towards these goals and they are educationally-based.

Chapter II

Literature Review

A literature review was conducted to better assess what is currently known about parenting styles and behaviors of families of young children with disabilities. However, first it is necessary to begin with a foundation for understanding predominant trends in the manner in which parenting has been conceptualized.

Parenting

Parenting has been defined in a multitude of ways, but the most prevalent way of examining “parenting” is through the concept of *parenting styles* (Darling, 1999; Darling, Flaherty, & Dwyer, 1997; Fox, Platz, & Bentley, 1995). The foundation of much understanding of parenting styles is based primarily on the work of Baumrind (1971). Through extensive observations of and interviews with both mothers and fathers of preschool-aged children, she developed fifteen hypothetical constructs related in some way to the manner in which they parented. These constructs are based in part on expectations of the child (e.g., participation in chores), child dependency on the parent, and the manner in which discipline occurs (e.g., punitive versus nurturing), to name a few (Baumrind, 1971).

From these broad constructs and her previous theoretical work (Baumrind, 1966), Baumrind (1971) identified three main patterns or typologies of parenting (i.e., parenting styles) which she referred to as authoritarian, permissive, and authoritative. An *authoritarian* parenting style is characterized by high expectations for the respect of authority and less dependency on a parent. Parents exhibiting this style of parenting may show less warmth to their children while being more punitive in discipline techniques, appear more rigid in their rules, and be less inclined to engage in a dialogue with their child about these rules (Baumrind, 1971). Less

parental authority and more dependency on the caregiver exemplify a permissive style of parenting. Parents employing this style of parenting may be considered warm in their affect, but are not likely to impose many rules on their children or to be punitive in their follow-through of the rules, which are in place (Baumrind, 1971).

Lastly, an *authoritative* parenting style is a combination of both parenting styles in that there is a balance in how a parent encourages a child to conform to parental expectations while rules, but allow for dialogue with their children on the purpose of these rules. In addition, parents from an authoritative style are likely to understand the value of their roles as authority figures while also maintaining an awareness of the distinctiveness of their children's contribution to the family (Baumrind, 1971). There also were a total of eight clusters within these three broader categories so that if a parent had many, but not all characteristics associated with one particular parenting style he or she may fall in to one of these clusters (Baumrind, 1971). One cluster, for example, was referred to as 'permissive, but not nonconforming' and was conceptualized as a parent who may be more lenient in some respects, but still wants his child to conform to social expectations. More recently, she has added an *unengaged* parenting style in which a parent does not assert power or support conformity, but takes a more passive role in parenting (Baumrind, Larzelere, & Owens, 2010).

The parents interviewed in Baumrind's foundational study were all Caucasian, middle-class families with children without disabilities (Baumrind, 1971). Furthermore, even within this highly homogenous sample, only 73% of the parents of boys and 80% of the parents of girls could be placed in one of the eight clusters. Interestingly, much of what is known about parenting is based on the foundation of the parents of the 174 children included in this study and the three main styles often are applied to all parents. As a result, there was a need to expand the

understanding of parenting to a more diversified population in potentially less than typical situations.

Some researchers recognized the limited nature of the findings from the original sample and sought to identify broader structures of parenting. From an ethological perspective, Maccoby & Martin (1983) proposed two observable dimensions, responsiveness and demandingness, to examine parenting within diverse samples. They also focused only on the intent of parents to promote or not promote social and personality development, with less attention on cognitive development. Maccoby and Martin's classification of parenting yielded a total of four types of parenting styles: authoritative-reciprocal, authoritarian-autocratic, indulgent-permissive, and indifferent-uninvolved, also referred to as neglecting (Maccoby & Martin; Darling, 1999). The indifferent-uninvolved pattern of parenting includes parents who do not appear to invest time or energy into insuring their children's optimal development. Although the findings are similar to Baumrind's, the manner in which these parenting patterns were derived was seemingly less complex. More specifically, instead of determining parenting style in relation to eight somewhat elusive patterns, they could be established from four possibilities based on two specific categories.

Darling & Steinberg (1993) acknowledged both perspectives on parenting and posited a conceptual model in which parenting styles may be the overall context in which more direct parenting behaviors occur. In other words, one's parenting style sets the emotional tone and broad views for a child's development for behaviors which then are linked more directly to particular goals. For example, a parenting style in which obedience is highly valued may be exhibited through parenting behaviors which incorporate verbal (e.g., multiple demands), physical (e.g., spanking), and environmental (e.g., limited child materials) prompts that promote

this desired goal. They referred to these behaviors as ‘parenting practices’ and focused on the parent-child *relationship* instead of parent *characteristics* alone (Darling et al., 1997). In addition, Darling & Steinberg incorporated the effectiveness of the parenting behaviors instead of merely the presence of those behaviors. For instance, it may be that a parent is placing multiple demands on his child (presence) but the parent is using specific language that may or may not encourage the child to comply with those demands (effectiveness).

In line with Darling & Steinberg (1993), Locke & Prinz (2002) examined two aspects of parenting, discipline and nurturance, which are commonly incorporated in the understanding of parenting behaviors. The conceptualization of parenting styles is seemingly quite complex and these behaviors are components, along with expectations, that appear in some manner in each of the definitions (Locke & Prinz). Expectations for developmental outcomes and behavior tend to be included in the understanding of parenting as these appear to guide parenting behaviors (Fox, 1992). Discipline and nurturance may be similar to the manifestation of parental expectations and beliefs and are the manner in which parents attempt to reach the developmental goals they have for their children.

Discipline can range from rule-setting with dialogue to physical techniques, such as spanking, and has a primary purpose of *discouraging* certain behaviors in an effort to set boundaries for a child (Locke & Prinz, 2002). For example, if a parent does not want her child to bite another child, she may use time-out, redirection, positive reinforcement or spanking, among other techniques. According to Locke & Prinz, discipline generally is evaluated by the effectiveness of these methods, or whether or not the undesired behavior is, in fact, thwarted by a technique selected by a parent. Nurturance, on the other hand, is the method for *encouraging* growth within those boundaries and is quite similar to the emotional climate described by

Baumrind (1971). Nurturance may be exhibited through behaviors referred to as instrumental acts, or spending special time with a child, or as emotional expressions, such as hugging (Locke & Prinz). Discipline is evaluated based on the discrete view of effectiveness; whereas nurturance is thought to be on a continuous range of parent behaviors all of which may have some effect on child outcomes and generally are evaluated accordingly (Locke & Prinz).

In an effort to better understand parenting of young children with disabilities two reviews of literature were conducted. Both reviews are limited to research published in 1990 or later and focus on or include young children (birth to five) in the sample. The first is an illustrative sample of research on parenting young, children without disabilities as it relates to the context of parenting styles and practices, expectations, nurturance, and discipline. This is meant to include more predominant trends in reference to sample characteristics, purpose, methodology, and general findings. The second is a comprehensive review of literature that examines parenting of young children with disabilities within the same previously described context. Similarities and differences of the available research for each population will be highlighted throughout the summary on young children with disabilities.

Parenting Children without Disabilities

An illustrative review of available literature was conducted on parenting young, children without disabilities. Inclusion criteria were as follows: a) the research was published in the year 1990 or after, b) the sample included children birth to five years of age; however, it was not necessary that this age group be the sole focus of the study (e.g., an article was included if parents of toddlers through middle childhood were examined), c) the research included some type of measurement of parenting related to the previously mentioned parenting styles, practices, and behaviors (e.g., an article focused exclusively on parental stress was excluded), d) the

research was peer-reviewed and empirical and, as a result, research such as dissertations and theoretical articles were not included, and e) none of the children in the sample were identified as having some type of disability or diagnosis. The articles will be discussed from the broadest view of parenting (i.e., parenting styles) to more specific parenting behaviors. This section will conclude with a discussion of the overall findings related to focus, sampling, methodology, and findings.

Parenting styles. Parenting styles provide the emotional overtone and direct parenting behaviors that parents employ in an attempt to socialize their children. The main typologies are permissive (e.g., lax on rules, child-directed), authoritarian (e.g., firm on rules, parent-directed), authoritative (e.g., parent sets rules but allows child input), and neglectful (e.g., limited rules or involvement). The following are studies that exemplify parenting styles associated with young, children without disabilities. Casas, Weigel, Crick, Ostrov, Woods, Yeh, and Huddleston-Casas (2006) examined the relationship between parenting styles and aggressive behaviors of children between the ages of two and six. The majority of the families were Caucasian (87%) and middle to upper income. Parents, 85 fathers and 119 mothers, of 122 children completed questionnaires assessing the level of relational and physical aggression and attachment of their children. In addition, parents completed the Parenting Practices Questionnaire (Robinson et al., 2001) to measure parenting style of both themselves as well as their partners and a Psychological Control measure (Barber, 1996) for the purpose of examining parental psychological control. The Parenting Practices Questionnaire consists of authoritarian, authoritative and permissive subscales and alpha coefficients ranged from .65 (permissive, mothers) to .85 (authoritative, fathers). The Psychological Control measure consisted of seven subscales, only five of which were included due to low alpha coefficients. The final subscales were erratic emotional

behavior, love withdrawal, guilt induction, invalidating feelings, and directiveness and these subscales had alpha coefficients ranging from .64 (invalidating feelings, mothers) to .79 (guilt induction, fathers).

There were variations in the findings related to both parent and child gender, yet the distribution of parenting styles was quite similar between both mothers and fathers (Casas et al., 2006). Permissive parenting from mothers was associated with sons being relationally aggressive (i.e., verbally or socially aggressive) and daughters as being both relationally and physically aggressive. Authoritarian parenting from mothers also was related to relational aggression in daughters, yet authoritarian parenting from fathers was related to relational aggression in both sons and daughters. Parental psychological control was associated with both relational and physical aggression in daughters, but the findings were inconsistent for sons (Casas et al.).

Lagace-Seguin & d'Entremont (2006) assessed the relationship between mothers' disciplinary styles, and children's negative affect and play behaviors. A total of 98 mothers of children between the ages of three and five completed questionnaires regarding child characteristics and their parental emotional and disciplinary styles. More specifically, for disciplinary or parenting styles, they completed the Parenting Practices Questionnaire (Robinson, Mandleco, Olsen, & Hart, 1995) which is a 62-item self-report questionnaire with subsections of authoritative, authoritarian, and permissive subscales. Internal consistency alpha coefficients were .84, .78, and .64, respectively. Child negative affect was negatively related to an authoritative parenting style, yet positively related to both authoritarian and permissive styles of parenting. In other words, a mother who employed an authoritative parenting style was less likely to have children who exhibited aversive emotions than mothers who applied either a

permissive or authoritarian style. Furthermore, for both authoritative and permissive parenting styles, a higher degree of child negative affect was related to lower levels of solitary-active play.

In the previous two studies, researchers investigated parenting styles in relation to the possible influence of parenting style on children, yet in the following study, parenting styles were examined in relation to predetermined styles of child behavior. Cornell and Frick (2007) assessed parenting styles, disciplinary practices, and child characteristics of mothers of 87 preschool-aged children who were deemed by their preschool teachers as either behaviorally inhibited or uninhibited. Families were recruited from local preschools and were only included if the children did not have a delay. The majority of the families were Caucasian (95%), middle to upper income (85%), and all mothers. Mothers completed questionnaires on characteristics of their children as well as two questionnaires to assess their parenting. They completed the Alabama Parenting Questionnaire (Shelton, Frick, & Wootton, 1996), which is applicable to parents of children with conduct issues, to examine discipline practices through the use of positive reinforcement, corporal punishment, and the consistency of the method. Alpha coefficients for reinforcement and consistency were .72, yet for corporal punishment it was .42; however, the authors included the three items irrespective of the low reliability. The mothers also completed the Ideas About Parenting Scale (Heming, Cowan, & Cowan, 1990) to examine parenting styles with subscales of authoritative, permissive and authoritarian and was meant to support the findings from the Alabama Parenting Questionnaire. Some items were deleted yet some of the remaining items still yielded alpha coefficients as low as .55 (authoritative). The likelihood of child guilt declined for inhibited children in relation to inconsistent discipline, yet increased in relation to authoritarian parenting. There was a trend of lower levels of empathy in children overall related to authoritarian parenting style or reports of higher use of corporal

punishment.

Expectations, discipline, and nurturance. Expectations are behavioral or developmental goals that a parent sets for his or her child and discipline (e.g., spanking, time-out, rule-making) and nurturance (e.g., hugging, praise, special time) are methods for achieving those desired goals. Nicholson, Fox, and Johnson (2005) investigated parenting behaviors and the relationship to child behaviors from a sample of two- to five-year-old children who displayed externalizing behaviors ($n=30$) and those who did not ($n=30$). The majority of the sample was Caucasian (93%) and was from all levels of income. Mothers completed self-report measures regarding their children's behavior as well as the Parent Behavior Checklist (Fox, 1994) which examines parents' expectations for their children as well as parenting behaviors. The three subscales in the 100-item self-report scale are expectations, discipline and nurturance with alpha coefficients of .97, .91, and .82, respectively. Mothers of children who exhibited externalizing behaviors were more likely to report using punishment ($p<.01$), verbal and corporal ($p<.01$), when compared to mothers of children who did not exhibit externalizing behaviors. The two groups did not differ, however, on expectations or nurturing behaviors.

Nicholson et al. (2005) was unique in that the authors focused on discipline, nurturance, *and* expectations. Dowling, Slep, and O'Leary (2009), on the other hand, examined the relationship between child misbehavior and parenting related to preemptive techniques, discipline, and praise of 40 mothers of two- year-old children. In a laboratory setting, mother-child dyads were observed for approximately 30 minutes in three tasks with the purpose of eliciting misbehavior and, subsequently, discipline. Preemptive parenting and discipline were coded on global rating scales, whereas praise was coded using a time-sampling technique in which behaviors were coded in ten second intervals. Interobserver reliability ranged from .83

(praise) to 1 (lax discipline). Mothers that were more likely to incorporate preemptive parenting were less likely to utilize lax discipline, regardless of child misbehavior. However, mothers that were more likely to utilize preemptive parenting were less likely to incorporate overreactive discipline but this relationship was mediated by child misbehavior.

Dowling et al. (2009) addressed both discipline and nurturance, yet only discipline was highlighted in their findings. Regalado, Sareen, Inkelas, Wissow, and Halfon (2004) also assessed the relationship between discipline techniques and factors associated with the child (e.g., child age), parent (e.g., mental health issues), and family (e.g., income). A total of 1768 caregivers of children, four months to three years, participated in phone interviews regarding frequency of the use of aversive and nonaversive discipline techniques as well as individual and family characteristics. Parents were asked about their concerns regarding their children in each developmental domain (e.g., speech-language, social). The majority of participants were mothers (87%), yet fathers comprised 11% of the sample. The most common method of discipline, overall, was reasoning (90%) and the least common was spanking (26%), although these categories were not mutually exclusive. There was an increase in the report of the use of yelling and spanking between the ages of four and nineteen months. Parents who identified themselves as Hispanic, Spanish-speaking families were least likely to report utilizing time-out or toy removal and those who identified themselves as Black families were most likely to report spanking. Parents of children that were deemed *at risk* developmentally were more likely to report yelling and spanking compared to parents of children with no risk. Overall, parents who reported frustrations with their children's behavior were less likely to report discipline techniques that would be considered reactive.

In another article, the researchers examined variations in nurturance and other parenting behaviors. Honig and Park (1993) investigated the relationship between parenting practices and childcare placement in a sample of 105 preschool aged children. Children were in full time care either before or after nine months of age or were not in a childcare setting. Mothers completed the Parenting Dimensions Inventory (Slater & Power, 1987), a 47 item, six-point likert scale and five of eight constructs were included in the present study. They were nurturance, responsiveness, consistency, and amount and type of control. No information on reliability or validity was included. Mothers of children who were in full-time care prior to 9 months were more likely to reason with their children. All families reported high levels of nurturance and responsiveness. Mothers whose children attended childcare were more likely to incorporate inductive reasoning compared to mothers who did not.

Parenting behaviors. In the following articles, a variety of parenting behaviors was the focus of more specific manifestations of parenting. In other words, discipline may be manifested by behaviors such as negative control (Volling et al., 2006) or spanking. Volling et al. observed parental gentle guidance and children's compliance in 59 families of 16-month-old children and their older siblings. The majority were Caucasian (90%) and middle to upper income. A family was observed in a laboratory setting during a five-minute clean up task that occurred at the end of a 90 minute visit. The observations were video recorded and coded using time-sampling procedures with 60 second intervals. Four behaviors related to parenting were coded: no involvement, social exchange, gentle guidance, and negative control. The coders were reliable with greater than 80% agreement. Both mothers and fathers were less likely to utilize gentle guidance with the younger sibling compared to the older sibling, yet fathers were less likely to incorporate gentle guidance than mothers. Mothers' use of gentle guidance was related to more

compliance in the younger children regardless of the guidance provided by the father. However, this was not the case for the older siblings in which father gentle guidance in combination with mother gentle guidance was related to increased compliance.

Warash and Markstrom (2001) examined what they referred to as parenting styles and academic self-esteem in a sample of parents of 40 preschool age children. Mothers and fathers, although the exact number of each was not specified, completed a self-report questionnaire on their children's self-esteem as well as the Parent's Report (Cohen, Dibble, & Grawe, 1977). The Parent's Report is a 47-item, seven point likert scale with five subsections that are respect for autonomy, control through guilt and anxiety, consistency in parenting, warmth/child-centeredness, and parental temper/detachment. Alpha coefficients for the five subsections ranged from .42 (fathers, warmth/ child-centeredness) to .84 (mothers, autonomy and control). The coefficient was so low for the warmth/child-centeredness subsection that it was considered unreliable, yet it was still included in the analysis. Consistent parenting from fathers and temper/detachment from mothers was related to increased levels of self-esteem in daughters, but the same was not true for sons. For sons, autonomy, control, and temper/detachment from fathers and only autonomy and control from mothers was related to higher levels of academic self-esteem.

Rubin, Burgess, and Hastings (2002) investigated child temperament, behavior problems and parenting behaviors in a sample of children at the age of two and again at the age of four. The sample at the age of two consisted of 108 children and their mothers and at the age of four there were 88 children and their mothers. Children were observed in a variety of tasks to assess many behaviors, but parenting behaviors were examined during clean-up, free play, and snack only. Behaviors related to unsolicited assistance, affection and scolding were coded using time

sampling procedures with one minute intervals. Interobserver reliability ranged from 82% during clean up to 91% for affection. The relationship between inhibited temperament at two and reticence at four was moderated by mothers' use of intrusive behaviors or derisive comments. More specifically, mothers who were observed to be more intrusive in parenting were more likely to have children that were socially inhibited.

The authors of the previous two studies examined the relationship between parent and child behaviors, yet the author of the following study investigated more external influences on parenting behaviors. Rodgers (1993) assessed the impact of stress and social support on parenting behaviors in a sample of 85 mothers of preschool-age children. The mothers completed scales related to levels of maternal stress (main effect) and symptomology (mediator), perceived social support (moderator), and the Management of Children's Behavior Scale (Rodgers, 1993). This 35 item scale was informed by other measures of parenting behaviors that appear to be impacted by stress and consisted of five subscales which were punishment, inconsistency, parental-coldness, sensitization, and rejection-oriented behavior. The Chronbach's alpha for the measure as a whole was .89. Parenting stress directly affected parenting behaviors as did symptomology to a lesser degree ($p=.06$); however, social support did not appear to impact parenting behaviors. Overall, mothers reported parenting behaviors that were deemed 'desirable' by the authors.

Analysis of literature on parenting children without disabilities. The literature on parenting of children without disabilities was largely focused on child behaviors (e.g, Casas et al., 2006; Dowling et al., 2009; Nicholson et al., 2005) and temperament (e.g., Cornell & Frick, 2007; Lagace-Seguin & d'Entremont, 2006; Rubin et al., 2002), both of which generally are considered problematic. Sample sizes ranged from 40 (i.e. Nicholson et al.) to 1768 (i.e.,

Regaldo et al., 2004) and included children from one to five, with somewhat more of a focus on preschool age. The majority of the participants were mothers, but fathers were, at a minimum, represented in five of the eleven studies (i.e., Casas et al.; Dowling et al. 2009; Regaldo et al., 2004; Volling et al., 2006; Warash & Markstrom, 2001). Data were gathered through either self-report questionnaires or observation, with the exception of one study which utilized interview procedures (i.e., Regaldo et al., 2004), yet the variations within these methods as well as the findings warrant additional attention.

Methodology. Two of the studies utilized the Parenting Practices Questionnaire to examine parenting styles (Casas et al., 2006; Lagace-Seguin & d'Entremont, 2006), yet there were a variety of other questionnaires regarding parenting styles and behaviors. In addition, two of the studies used more than one questionnaire to assess parenting (Casas et al.; Cornell & Frick, 2007). The alpha coefficients ranged from .42 (corporal punishment; Cornell & Frick) to .97 (expectations; Nicholson et al., 2005) and, interestingly, subscales generally were still included even when coefficients were considered unreliable. As previously mentioned, one study (Reglado et al., 2004) utilized a phone interview and the parenting questions were related the frequency of predetermined discipline techniques. The additional questions originated from self-report questionnaires that were read to the participant. The observations all occurred in laboratory settings in predetermined tasks and, consequently, with select materials (Dowling et al., 2009; Rubin et al., 2002; Volling et al., 2006). There consistently were multiple tasks, some of which were evaluations and responding to questionnaires, over the course of a 30-90 minute visit. Time-sampling and global ratings were utilized to code parenting behaviors. Intercoder reliability always exceeded 80% and varied based on the behavior that was observed.

Findings. The distribution of parenting styles was similar between mothers and fathers, yet the child's response was specific to the gender of the child (Casas et al., 2006). Overall, a permissive parenting style was related to aggressive behaviors in children when mothers exhibited this style (Casas et al.) and solitary play behaviors of children with higher levels of negative affect (Lagace-Seguin & d'Entremont, 2006). Similarly, an authoritarian style of parenting was related to an increased likelihood of relational aggression (Casas et al.) and child negative affect, lower levels of solitary-active play (Lagace-Seguin & D'Entremont), as well as higher levels of guilt and lower levels of empathy compared to other parenting styles (Cornell & Frick, 2007). An authoritative parenting style, on the other hand, was related to a decreased likelihood of child negative affect.

Mothers of children who presented externalizing problem behaviors had similar expectations to parents of children who did not and, similarly, nurturance did not vary across the two groups (Nicholson et al., 2005). Discipline, however, varied as a function of children's behaviors with mothers reporting higher levels of punishment for children who exhibited externalizing behaviors (Nicholson et al.). There also were several additional factors related to discipline techniques such as child age, ethnicity, and parental frustration (Regaldo et al., 2004). In addition, parents who were observed using preemptive parenting techniques were less likely to use over reactive discipline techniques (Dowling et al., 2009).

The findings on parenting behaviors were a little more varied than the other conceptualizations of parenting in relation to the focus of the study, yet some noteworthy findings emerged. First, mothers were more likely to use gentle guidance than fathers and both parents were more likely to utilize gentle guidance with older children compared to younger children (Volling et al., 2006). These findings may have been due, in part, to behaviors that were

highlighted and sampled as well as parental expectations of their children. Second, there were variations in academic self-esteem in children related to parenting behaviors associated with encouraging autonomy, control, and temper/detachment (Warash & Markstrom, 2001). Third, parental intrusiveness in an observed task at two years was related to social inhibition at four years (Rubin et al., 2002). Fourth, parental stress (Rodgers, 1993) and childcare status (Honig & Park, 1993) were related to modified parenting techniques.

Implications for the present study. When viewed collectively, it is clear that a parent's method of aiding in the development of his or her child does, in fact, influence that child's development. There also appear to be characteristics of both the parent (e.g., gender) and child (e.g., behavior) that, in turn, influence the decisions or application of these parenting choices. Parents of young children with disabilities may need to make additional accommodations to assist in the advancement of their children's development given the delayed nature of their progress.

Parenting Children with Disabilities

A systematic review of available literature was conducted on parenting young children with disabilities. A systematic review is one in which available literature on a topic is systematically and comprehensively reviewed and similar outcomes could be obtained by multiple researchers (Littell, Corcoran, and Pillai, 2008). Therefore, there is less risk of error or bias in the available information when compared to narrative reviews or meta-analyses. Inclusion criteria for the present study were as follows: a) the research was published in the year 1990 or after, b) the sample included children birth to five years old; however, it was not necessary that this age group be the sole focus of the study (e.g., an article was included if parents of preschoolers through late childhood were examined), c) the research included some type of

measurement of parenting related to the previously mentioned parenting styles, practices, and behaviors (e.g., an article focused exclusively on parenting self-efficacy was excluded), d) the research was peer-reviewed and empirical and, as a result, research such as dissertations and theoretical articles was not included, and e) at least a portion of the sample of children were identified as having some type of disability or diagnosis. No additional exclusion criteria, such as severity of disability, were included for the literature review.

Several steps were taken to ensure a systematic review of literature on parenting young children with disabilities. Academic Search Premier, Google Scholar, ERIC, and PsychoInfo databases were examined with all practical combinations of the search terms listed in Appendix A. Generally speaking, it was common, as an example, to include ‘parent’, ‘preschool’, and then each diagnosis separately and this process would then be repeated with interchanging ‘preschool’ with ‘toddler’. Next, each article was reviewed both for cited references as well as a reverse search in which each article was reviewed for additional articles in which it was cited. Then, this process was repeated until no additional articles surfaced. Finally, an independent research assistant completed a separate search following the same criteria that yielded no additional articles.

Eighteen articles were found that examined parenting of young children with disabilities. There was much diversity in the findings of the review of literature on nearly every aspect (i.e., focus, sample, measurement, findings) and, as a result, it is necessary to begin by examining each article independently. The articles will be discussed from the broadest examination of parenting, i.e., parenting styles, to the more specific parenting behaviors, e.g., parental warmth. However, it is not possible to fully disentangle these concepts as they are complementary, not contradictory, of one another. This section then will conclude with a review of the body of

literature as a whole. It should be noted that the literature on parenting young children with disabilities is so varied that it is difficult to draw any accurate comparisons between the studies. In an effort to guide the reader through this intricate body of literature, associations will be made throughout the following sections to best describe the availability of information on the present topic.

Parenting styles. Parenting styles encompass the emotional tone, expectations, and behaviors associated with how a parent chooses to promote development in his or her child. The main parenting styles in the literature on parenting are permissive, authoritarian, authoritative, and neglectful (Baumrind, 1971; Maccoby & Martin, 1983). Only two of the eighteen articles focused on these previously described *parenting styles* of young children with disabilities and both used the same measurement instrument to examine these constructs. Rutgers et al. (2007) examined parenting styles, parenting self-efficacy and attachment of parents with young children with disabilities (n=64) including autism, what they referred to as “mental retardation”, language delays and children without disabilities (n=25). No information was provided on the proportion of mothers and fathers. Parents of two- to three-year-old children completed a battery of self-report questionnaires regarding child behaviors in addition to the Child Rearing Practices Report (Block, 1991) which is a 100 item, likert scale that measures authoritarian and authoritative parenting styles. The authoritative subscale was utilized in the present study with a Cronbach’s alpha of .74; the authoritarian subscale was not analyzed because the Cronbach’s alpha was only .53. Parents of children with a diagnosis were less likely to report utilizing an authoritative parenting style compared to those with no diagnosis. This trend was maintained when parents of children with autism only were compared to parents of children without a diagnosis, but there was not a significant difference in parenting styles between children with autism and other

diagnoses. When examined overall, parents who reported higher levels of parenting self-efficacy also were more likely to report authoritative parenting.

Woolfson and Grant (2006) evaluated parenting styles and levels of stress of parents of both children without disabilities (n=60) and those with developmental disabilities (n=53). Their sample consisted mostly of mothers (88%) of four groups (N=113) separated by age, preschool (3-5 years) and late childhood (9-11 years) and disability status. Young children with disabilities comprised 29% of the total sample. Woolfson and Grant utilized a modified version of the Child Rearing Practices Report (Rickel & Biasitti, 1982) which is a 40-item, likert-type scale that has two subscales: restrictiveness, with an alpha coefficient of .89 when applied to parents of children with developmental delays, and nurturance, with an alpha coefficient of .80 with the same group. Scores on the subscales are evaluated and then are classified by different combinations of the ratings on the subscales as authoritative (high restrictiveness, high nurturance), authoritarian (high restrictiveness, low nurturance), permissive (low restrictiveness, high nurturance), or neglectful (low restrictiveness, low nurturance). They found that parents of younger children with developmental delays were more likely to report using an authoritative parenting style than parents of older children with developmental delays. When compared to the young children without disabilities, parents of young children with developmental disabilities were four times more likely to report using an authoritative parenting style. Interestingly, however, this style also was linked to higher levels of stress for the parents of children with disabilities as a whole. It may be that it is more stressful for a parent to implement a parenting style that is inconsistent with the needs of his or her child, but this has not been supported empirically.

Miles and Holditch-Davis (1995) did not focus on the previously defined parenting styles, but discussed the possibility of another type of parenting style, referred to as compensatory parenting style. The sample consisted of twenty-four mothers and three grandmothers of 30 children who were born premature but were three-year-olds at the time of the study. The caregivers completed likert-type scales related to their attitudes toward their child, level of vulnerability and social strengths in addition to a semi-structured interview related to their experiences of the birth, hospitalization, transition home, and parenting of these children. Constant comparative method of analysis was used to examine the interview data. Two main themes emerged from the interviews in which the caregivers reported their children as being both normal and special. More specifically, they felt that their children were similar to peers without disabilities, but also reported that they were vulnerable to various threats to health or other problems. As a result, caregivers reported they felt they were less likely to set boundaries than they would if their children did not have disabilities, and were possibly more protective and stimulative in their interactions related to factors such as the child's past medical experiences and the loss of other children (i.e., twin sibling). From this information, Miles and Holditch-Davis posited that there may be an additional parenting style, compensatory, in which parents of children who were born premature must compensate for their children's disabilities in their parenting.

It is necessary, at this point, to discuss the findings for parenting styles of parents of young children with disabilities. The first two articles present contradictory findings with regards to parenting styles of young children with disabilities. When compared to children without disabilities, parents of the toddler aged children reported that they were less likely to use an authoritative parenting style, whereas parents of preschool aged children reported that they were

more likely to do so. Woolfson & Grant (2006) suggested that there were variations in parenting style between preschool aged children in comparison with school aged children, yet it remains to be seen whether or not parents of younger children (birth to five) differ on parenting style. With that said, it is not possible to make accurate comparisons based on the research as there were only a total of 117 children, with only a few types of diagnoses, in both studies combined. Furthermore, the samples consisted of different age groups (toddler versus preschool), diagnoses (developmental delays to autism), measurement methods, and focus (stress versus self-efficacy). The third article does not directly address the other parenting styles, but instead suggests that another style may exist when the circumstances of a family are unique.

Expectations, discipline, and nurturance. Expectations, nurturance, and discipline are parenting processes, which are incorporated in many definitions of parenting. Expectations are the short- and long-term goals one sets for his or her child and nurturance and discipline are the manner in which one encourages a child to meet those goals. Nurturance generally is associated with behaviors that encourage a child, such as physical affection, whereas discipline is more focused on setting boundaries. A total of seven articles were found that focus on a minimum of at least one of the three components of expectations, nurturance, and/or discipline.

Keller and Fox (2009) assessed parental expectations and ratings of discipline and nurturance within a sample of 58 parents of two-year-old children with behavior concerns. The majority of these children (77%) were identified as having a developmental delay. The caregivers completed the Parent Behavior Checklist (Fox, 1994), a 32-item scale that measures expectations, discipline, and nurturance, and the Parent-Child Relationship Inventory (Fox & Nicholson, 2003), that measures the quality of the parent-child relationship, to better understand their parenting practices. The majority (85%) of the *primary* caregivers was mothers, yet it was

not explicitly clear who was responsible for completing the questionnaires. The caregivers of children with a delay reported higher expectations of their children when compared to those without a delay; interestingly, they also were more likely to report higher levels of child behavior problems. For the sample as a whole, higher expectations were related to higher use of punishment and less nurturing practices compared to lower expectations.

Tucker and Fox (1995) investigated the same parenting behaviors with a sample of preschoolers both with and without mild diagnoses, or what they referred to as “handicaps”. The sample was composed of 125 families of children between three and five, 65 of which were diagnosed with delays in vision, language, motor, or social development. Mothers completed the Parent Behavior checklist (Fox, 1994) in addition to a demographic and child behavior questionnaire. Mothers of children with mild delays reported lower expectations for their children, yet comparable levels of discipline and nurturance when compared to mothers of children without disabilities.

Carson, Carson, Klee and Jackman-Brown (2007) also examined parental expectations, discipline and nurturance in the context of behavior problems of two-year-old children but focused on those with and without language delays. Forty-seven parents completed the Parent Behavior Checklist (Fox, 1994) among other self-report questionnaires and interview questions, which examined child temperament and development. No specific information was provided as to whom the term ‘parents’ encompassed. Parents of children without disabilities reported higher levels of nurturance and lower levels of punitive discipline than parents of children with language delays. However, there was little variation on expectations between the two groups.

It is necessary at this point to describe the preceding findings in light of the similarity between the samples and measurement, as this is the only time when such similarities exist

within this body of literature. Like the findings on parenting style of parents of young children with disabilities, these preceding articles also illustrate disparate findings; yet, unlike the studies on parenting style for parents of children with disabilities, these studies were fairly homogenous in nearly every respect. They focused on two-year-old children with behavior problems with more mild delays and utilized the Parent Behavior Checklist to examine parental expectations and the parenting behaviors of nurturance and discipline. With regard to parents' report of expectations, specifically, Keller and Fox (2009), Tucker and Fox (1995), and Carson et al. (2007) found that there were differences between parents of children with developmental versus language delays. When compared to those without disabilities, higher expectations were reported for children with developmental delays, but this was not the case with children with language delays as they were reported to be both lower and comparable to children without delays.

The following study also utilized the Parent Behavior Checklist but with an older group than the previous three articles. Carson, Perry, Diefenderfer, and Klee (1999) investigated parenting in a sample of 64 two-year-old children with (n=53) and without (n=11) language delays. Parenting was reevaluated with 26 families between the ages of five and six. When the children were two, parents completed questionnaires related to family functioning, the Family Evaluation Form-Revised (FEF-R; Emery, Weintraub, & Neae, 1984) and the Mother-Child Relationship Evaluation (MCRE; Roth, 1980). Five subscales from the FEF-R were used in the present study: nurturance, independence training, effective discipline, strict/punitive discipline, a negative style. Four subscales from the MCRE also were included: maternal acceptance, rejection, overprotection, and overindulgence. At age five or six, parents completed the Parent Behavior Checklist (Fox, 1994) which included subscales of discipline, nurturance, and

expectations. No reliability or validity information was provided. When compared to mothers of children without language delays, mothers of children with language delays were more likely to report that both they and their spouses were less nurturing and their spouses were more likely to use punitive methods of discipline. Fathers of children with language delays were more likely to report that they used independence training and effective and punitive discipline compared to fathers of children without language delays.

These articles provide information on the variability within each area (i.e., expectations, discipline, and nurturance), but do not provide details as to the impact of these parenting choices on a mother. Johnson (2000), on the other hand, utilizing grounded theory, conducted telephone interviews with ten mothers of children between the ages of three to nine years who had mild to moderate physical disabilities. The focus of the interview was on discipline, nurturance, teaching, and expectations, among other factors such as social support and self-efficacy. No information was provided that described variations related to the influence of child age on parenting. This is an important factor in interpreting the findings in light of the results reported by Woolfson & Grant (2006) in which there were differences in parenting styles of young (three- to four-year-old) children compared to older (nine- to eleven-year-old) children with disabilities. More specifically, parents of younger children with developmental delays were more likely to report using parenting practices consistent with an authoritative parenting style than parents of older children.

Johnson (2000) found that some mothers reported high expectations of their children while others reported low expectations, yet only mothers who reported low expectations regretted their decision. Their expectations appeared to be related to the need to normalize the child's development and, furthermore, some of the mothers also mentioned that they attempted

to view their children as separate from the disability. In other words, it appeared that, for some, disability had little direct influence on how they parented, yet they chose not to parent in relation to the disability. Nurturance, for the present sample, was suggestive of validation and intrinsic worth of the child. The mothers reported that discipline was specific to the child's needs, yet no information was provided as to how they determined what the needs are for either the child or the discipline techniques.

In two of the eight articles, researchers examined discipline techniques specifically. Knutson, Johnson, and Sullivan (2004) assessed parents' disciplinary choices of children with ($n=79$) and without hearing impairments ($n=27$). The sample participants, composed of 106 mothers of children between the ages of two and twelve, completed an analog parenting task in which they viewed pictures of children misbehaving and indicated the method of discipline they would choose in that situation. Specifically, Knutson et al. were interested in the use of physical discipline compared to other forms of discipline and how discipline techniques escalated in relation to children's behaviors. Overall, mothers of children with hearing impairments were more likely to report the use of physical discipline and to escalate their discipline techniques when compared to those without hearing impairments. With that said, similar to Johnson (2000), the sample in this study ranged from toddlerhood to middle childhood and, as a result, the depicted scenes and subsequent interpretation may not have been necessarily accurate for parents of all age groups.

Little (2002) investigated the disciplinary strategies of 411 mothers of children between four and seventeen years old with Asperger's ($n=308$), nonverbal learning disorder ($n=62$) or a combination of the two ($n=41$). Mothers completed the Conflict Tactics Scale-Parent Child Form which is a frequency rating scale ranging from never to more than twenty times within the

previous twelve months. Items were grouped into psychological, or nonphysical, aggression ($\alpha = .68$) and corporal punishment ($\alpha = .58$). Mothers of four-year-old children reported the highest levels of corporal punishment of all age groups, which declined over time. Both mother and child age was related to either form of discipline, yet disability status was not.

The articles on expectations, discipline and nurturance yielded different findings in every respect. Reported levels of expectations were different among the studies, even when certain components (i.e., child age, severity of diagnosis) were controlled. Discipline strategies varied in relation to child age, source of parent report (mother versus father), and child diagnosis. There was minimal information on setting expectations, actual discipline techniques and the reasoning behind choosing them, or details on nurturing behaviors and other methods of expressing love.

Parenting behaviors. The remaining eight articles incorporated operational definitions, which appeared to be more specific than the previously described parenting styles and processes (i.e., expectations, discipline, and nurturance). These articles were included in the literature review for two reasons. First, the researchers identified the behaviors as ‘parenting’ and this provides a basis for understanding how parenting is being defined by researchers when examining children with disabilities. Second, some of the behaviors may be physical representations of previously described parenting processes. For example, nurturance may be manifested by ‘parental warmth’ or hugging (e.g., Lomax-Bream, Taylor, Landry, Barnes, Fletcher, Swank, 2007) and expectations by ‘pressure to achieve’ (Button, Pianta, & Marvin, 2001) or directives (Roskam, 2005; Roskam & Schelstraet, 2007).

Four of the articles focused on observation of parenting behaviors during parent-child interactions. Lomax-Bream et al. (2007) investigated parenting and motor skills of 165 children with ($n=91$) and without ($n=74$) spina bifida between the ages of six months to three years. The

children's developmental skills were assessed with a battery of evaluations and a fifteen-minute videotaped, play observation occurred between mother and child in a laboratory setting. The observers evaluated parental warmth (e.g., hugging, praise), responsiveness (i.e., responding to child's needs), and a mother's ability to maintain her child's attention (i.e., responding to child's interests) during the mother-child interaction, which they often referred to as parenting styles. The behaviors were rated on a global rating scale following the observation and had intercoder reliabilities of .87 for warmth, .63 for responsiveness, and .89 for maintaining. Higher quality parenting, as defined by the observed behaviors, was associated with higher level of scores for both groups on cognitive, language, and physical domains, but only for children with spina bifida in the area of daily living skills. It is worthy of note that, overall, when parenting was examined at six months, it appeared that there was a bi-directional relationship between mother and child, but at two years it became a mother's influence on her child.

Button et al. (2001) incorporated self-report questionnaires, interviews and observations to examine parenting of young children with disabilities. The sample was composed of 112 mothers of children between one and four years of age with cerebral palsy (n=58), epilepsy (n=19) and without disabilities (n=35). Fathers were included when available, but the exact number was not indicated. The mother and child interacted during a videotaped problem-solving task in which the researchers examined behaviors including sensitivity, affect (positive/negative), support (total, non-, and for task completion), pressure to achieve, over involvement, and neglect. In contrast with Lomax-Bream et al. (2007) parental behaviors were not contingent on child behavior, but were focused solely on mothers' choices. All behaviors were rated on seven-point rating scales following the observation and interrater agreement was 80% or above. Mothers who reported being concerned about their children's futures were less sensitive and

supportive during the parent-child interaction when compared to those who worried less. In addition, if a mother expressed concern about boundary issues, she was more likely to pressure her child and become over involved during the task.

Lojskasek, Goldberg, Marcovitch, and MacGregor (1990) assessed factors related to maternal responsiveness and other maternal behaviors in a sample of mothers of 109 preschool-aged children with Down syndrome (n=40), neurological issues (n=29), and unknown delays (n=40). Both parents completed questionnaires related to child behaviors and parental attitudes and the mothers and children participated in an observed free-play task. The videotaped task lasted 7 minutes and was part of a longer observation and interview. Maternal responsiveness was coded and included positioning, facial expressions, vocal expressions, vocal appropriateness, and pleasure with child and was coded on a five point, global rating scale ranging from low to high. Maternal age was the best predictor of maternal responsiveness with older mothers being more responsive than younger mothers. Developmental status did not influence maternal responsiveness for any of the groups.

Brown, McIntyre, Crnic, Baker, and Blacher (2011) examined the role of negative parenting in a sample of 260 children between the ages of three and nine. Nearly half (40%) of the children were considered developmentally delayed whereas the remainder (60%) were considered typically developing. Both mothers and fathers participated in the overall project, but only mothers were included in the observation of negative affect and intrusive interaction behaviors. These observations occurred when the child was four years old and both the mother and child participated in cleanup and problem solving tasks. Their behaviors were rated on the Parent Child Interaction Rating System on a five point scale ranging from low to high intensity/frequency. Child related risk and child demandingness also were examined with

observations and questionnaires between the ages of three and five. Children with developmental delays were more likely to have mothers who exhibited negative parenting behaviors.

The previous four articles used observation techniques and the following two articles utilized interviews, yet these all examined predetermined parenting behaviors originating from children without disabilities. Roskam (2005) examined the influence of child personality as well as mothers' beliefs about their children's development and their parenting behaviors. The sample consisted of 102 mothers of three to six-year-old children with mental delays (mild, $n=18$; moderate, $n=23$; severe, $n=19$), sensory delays ($n=19$), most of whom had hearing impairments, and developmental delays, including issues with hyperactivity ($n=23$). The mothers participated in interviews in which they were asked to provide specific examples of recent parenting behaviors related to directive (social norms, dependent behavior), stimulating (promotes development, autonomy), supportive (emotional, respond to child's needs), and maturation (develop at child's pace) behaviors. The responses were rated on a likert scale and interrater agreement was .87.

Disability status was related to variation in the combination of stimulating and directive behaviors (Roskam, 2005). More specifically, mothers of children with severe mental delays were more likely to discuss using directive behaviors, whereas mothers of children with sensory delays were more likely to mention utilizing stimulating behaviors. Furthermore, overall, mothers with less education were more likely to report directive behaviors than those with more education.

Roskam & Schelstraet (2007) investigated childrearing behaviors, or more specifically, controlling versus autonomy, of young children with a variety of disabilities. The sample

consisted of 31 mothers of children between the ages of three and six with a variety of disabilities, ranging from, what they referred to as, mental retardation (n=23), multiple disabilities (n=11) and sensory delays, also referred to as hearing impairments (n=7). Mental retardation and hearing impairments were separated based on severity. The mothers participated in interviews (inspired by Honig & Caldwell, 1965) in which they described recent, specific parenting examples and their speech was analyzed for eight specific categories of behaviors which were rated for their level of control and autonomy. Responses were rated on a likert scale with nine points. Some examples of these categories are explanations, directives, and managing strategy and these were placed on an axis with the two extremes being coerciveness and inductiveness.

Disability status was related to varying parenting behaviors; in particular, mothers of children with mental or multiple delays were more likely to discuss directive parenting behaviors and to report providing less explanations to their children than parents of children with hearing impairments (Roskam & Schelstrat; 2007). This is interesting in light of Knutson et al.'s (2004) findings, in which mothers of children with hearing impairments reported that they were more likely to utilize physical discipline when compared to parents of children without disabilities. It remains to be seen how discipline techniques would be distributed among the variety of disabilities, including some being more severe.

Two remaining studies used questionnaires to examine parenting and incorporated terminology that was specific, but seemed in line with several characteristics associated with *parenting style*. Osborne and Reed (2010) investigated stress and parenting with 149 parents of children with autism between the ages of two and sixteen, 63% of which were between the ages of two and six. Parents, although it was not specified whether it was mothers or any other

parental figure, completed the Parent-Child Relationship Inventory (Gerard, 1994) using a four point, likert scale ranging from strongly disagree to strongly agree. The authors utilized four of the seven subscales which are parental involvement, effectiveness of communication, limit setting (discipline) and autonomy (promote independence). Internal reliability coefficients ranged from .76 to .88. The three additional subscales were more focused on distal factors of parenting such as parental self-efficacy and, as a result, were excluded from the study. The parents and children were evaluated twice over a nine to ten month period in which the authors examined stability of parenting behaviors.

Parents reported behaviors that were in line with what was considered “good parenting” (p. 4) for the purposes of the instrument (Osborne & Reed, 2010). In other words, the parenting behaviors were similar to the trends associated with parents of children without disabilities. Collectively, parents reported difficulties with communication, but none of the other constructs. Parents of younger children indicated more stress than parents of older children, which the researchers surmised was related to the increase of the reported effectiveness of communication as children developed. In other words, as children’s verbal skills improved, parenting became less stressful.

Gau, Chiu, Soong, and Lee (2008) investigated parenting of 95 families of children, between two and fifteen, with Down syndrome (n=45) and their siblings as well as peers without disabilities (n=50). Both mothers (n=93) and fathers (n=87) completed questionnaires related to family and child characteristics in addition to the Chinese Parental Bonding Instrument. This is a modified version of the Parental Bonding Instrument and is a 25 item, four point likert scale ranging from very likely to very unlikely with three dimensions (i.e., subscales) which are care/affection, overprotection and authoritarianism. Parents of children with Down syndrome

were more overprotective and were more likely to be controlling (i.e., authoritarian) the children with Down syndrome compared to their sibling. Fathers of children with Down syndrome were more likely to report being overprotective of their child with Down syndrome compared to fathers of children without disabilities. Mothers of children with Down syndrome reported less affection compared to mothers of children without disabilities (at $p < .1$).

Each of these studies concentrated on different definitions of parenting behaviors, yet they may have, in fact, been observing some quite similar behaviors. For example, expectations may be manifested by pressure to achieve (Button et al., 2001), directives or maturation (Roskam, 2005), and autonomy (Osborne & Reed, 2009). Nevertheless, there were variations in the findings. Parents of children with mental (Roskam, 2005; Roskam & Schelstrat, 2007) or multiple (Roskam & Schelstrat) disabilities were more likely to utilize directive behaviors (i.e., promoting dependence) when compared to parents of children with hearing impairments. Yet, parents of children with autism, which generally is associated with delays in multiple domains, appeared to follow similar patterns to children without disabilities with regard to autonomy (i.e., encouraging independence; Osborne & Reed). It is unclear as to the reason for the dissimilarity as age is accounted for in each of the studies. It can be said of these articles, that the presence of a child's disability does appear to have some influence on parenting behaviors, but may be moderated by factors such as severity of diagnosis or parent gender.

Analysis of literature on parenting children with disabilities. Much of the research on parenting young children with disabilities was not conducted with U.S. samples; six of the studies originated in other countries, such as South Africa or Belgium. Although it does not appear to be the case at a surface level, it is quite possible that the social construction of parenting may vary across countries. This also is important in that it was necessary to expand to

a more global search to attain even this limited amount of information on parenting young children with disabilities. In addition, the majority (83%) of the studies was published within the last ten years and 67% were published in the year 2005 or later. This demonstrates a possible upsurge in the interest in parenting within this subgroup which supports the need for the development of a fundamental understanding at the present time.

Focus of the studies. Half of the studies incorporated some type of additional component to the research and two main foci emerged. The first focus was on parenting variables primarily in relation to parental mental health. The factors which were highlighted were stress (Button et al., 2001; Osborne & Reed, 2010; Woolfson & Grant, 2006), and child variables related to personality (Button et al.; Carson et al., 2007; Roskam, 2005), attachment (Rutgers et al., 2007), or behavior problems (Osborne & Reed; Roskam & Schelstraet, 2007). Only one study incorporated child outcomes which was development in language, cognitive, and self-help domains (Lomax-Bream et al., 2007). The foci of these studies varied from the literature on children without disabilities which focused almost exclusively on child behaviors and temperament. It may be that these different foci represent a different set of experiences, such as the additional stress that often accompanies a child's diagnosis.

The inclusion of these variables is of importance primarily for two reasons. First, there clearly is not a solid understanding of parenting within this subgroup. This is important, not only because a cohesive, reliable understanding provides a foundation on which to build knowledge but also because a basic understanding is a logical point from which to start. Second, any findings based on the inclusion of mediating and/or moderating variables may be erroneous as they may be measured against inappropriate standards of parenting for this specific population, given this lack of a basic understanding. For example, it may be that an authoritarian parenting

style is ideal for parents of children with certain diagnoses. Examining the influence of stress with the expectation that an authoritative style of parenting is optimal might yield skewed findings.

Sample. The sample sizes overall are quite small, ranging from 10 (Johnson, 2000) to the 411 participants (Little, 2008). Furthermore, twelve of the eighteen articles are comprised of parents of either children with disabilities and children without disabilities. As a result, children with disabilities still only comprise 59% of the total number of participants when all samples are combined, for a total of 1479 participants. This, in turn, limits the data and statistical robustness necessary to draw conclusions on parenting young children with disabilities. This is in contrast to the samples consisting exclusively of children without disabilities that ranged from 40 to 1768. In addition, there seems to be an assumption that parents of children without disabilities should serve as an optimal standard for comparing parents of children with disabilities, yet parents of children with disabilities may have different styles and practices that function just as effectively. For example, it may be that parents of children with disabilities are more adaptable than parents of children without disabilities and, as a result, utilize practices that are more “authoritarian, but still effective or may be able to move seamlessly between various approaches.

Mothers clearly are the focus of research on parenting young children with disabilities as researchers of six of the articles overtly indicate that they are examining mothers, similar to the trends in literature on parenting children without disabilities. The authors of only three articles (i.e., Carson et al., 1999; Gau et al., 2008; Lomax-Bream et al., 2007) explicitly mention the inclusion of fathers as participants, yet in one they comprised only 11% of the overall sample. In other articles, one can only assume that fathers, grandparents, and foster parents were included in the catch-all term of ‘primary caregiver’ or ‘parent’, but their role was not specified at all. As

discussed above, for children without disabilities, differences were found between mothers and fathers in parenting styles and behaviors, discipline techniques and nurturance (e.g., Burbach, Fox, & Nicholson, 2004). For example, fathers of toddlers were found to be less likely to provide gentle guidance to their children during a cleanup task than mothers (Volling, Bandon, & Gorvine, 2006). Therefore, it is important to not only include fathers in our understanding of parenting styles and behaviors, but also to distinguish them as a separate group from mothers.

There was no single diagnosis that appeared to be prominent in the research on parenting young children with disabilities. Developmental and language delays were included most often, but they generally were part of a larger sample that included additional diagnoses. One can only speculate about the selection of the diagnostic categories, but it is clear that no conclusions can be drawn about the differential effects of one or more categories or specific parenting practices. For instance, it may be that the presence of a physical disability is related to modification of certain parenting behaviors, which are different than variations of parenting behavior in relation to intellectual disabilities.

Interestingly, half of the samples spanned from early childhood to middle childhood and findings were not always discussed with different developmental periods in mind. The literature on parenting of children without disabilities, on the other hand, was focused solely on children prior to school age, with many including children of preschool age. On the rare occasions when age groups were separated and compared (i.e., Osborne & Reed, 2010; Woolfson & Grant, 2006), there consistently were differences between parenting younger and older children with disabilities. Therefore, it is necessary to exercise caution when interpreting findings on parenting as age likely is one of the many factors influencing parenting. Furthermore, some of the researchers supported their assumptions or hypotheses of parenting younger children by

discussing findings for older age groups in their literature review (e.g., Lomax-Bream et al., 2007). It also should be noted that, although the focus of the present literature review was intended to be solely on younger children (birth to five), it quickly became apparent that the focus needed to be expanded to articles that simply included this age group.

Procedures. Similar to the research on children without disabilities, research on young children with disabilities was predominantly quantitative in nature and half of the researchers used self-report questionnaires to examine parenting styles and behaviors. Interviews were utilized in five studies and generally were less from an emic perspective (i.e., Johnson), incorporating participants' words and directions of insight, compared to a more etic perspective, utilizing predetermined categories. Observations were used in four studies, all in laboratory settings with specific tasks and predetermined categories of behavior. None of the articles employed more than one method (i.e., questionnaire, observation, interview) to examine parenting behaviors or styles and only two (Carson et al., 1999; Keller & Fox, 2004) provided more than one measure of parenting. The trends in methodological approach for parenting young children with disabilities (i.e., self-report scales, observation and etic interviews) varied somewhat from the research on children without disabilities (i.e., self-report scales and observation).

Even with such a small number of research articles there was considerable variability in the measurement methods. One measure, the Parent Behavior Checklist, was utilized four times and the Childrearing Practices Report also was used twice, but with two distinct versions. For the self-report questionnaires, the alpha coefficients associated with internal consistency ranged anywhere from .53 (i.e., Childrearing Practices Report, Authoritarian subscale) to .97 (i.e., Parent Behavior Checklist, Expectations subscale). The Parent Behavior Checklist had the

highest internal consistency coefficients overall. This instrument was developed for parents of children prior to the age of five. Limited information was available for any measure with regard to validity and normed references, but the majority had not been utilized or evaluated for their psychometric properties with parents of young children with disabilities prior to the present studies. It is not the purpose of the present study to comprehensively evaluate the psychometric quality of the available research, but basic information will be discussed.

Of the studies that relied on interviews, interrater reliability was only reported by Roskam (2005) with a beta coefficient of .87 and internal consistency for Roskam & Schelstraet (2007) with a beta coefficient of .84. For the observations, interrater reliability ranged from .63 (i.e., responsiveness; Lomax-Bream et al., 2007) to .87 (i.e., warmth; Lomax-Bream et al.). Unfortunately, the psychometric properties of the measures used in this body of literature were comparable to the literature on parenting children without disabilities. Reliability coefficients generally were low and validity information was lacking. Moreover, the measures utilized with parents of children with disabilities were not developed for parents of young children with disabilities nor were they, as a whole, previously utilized and evaluated using samples of young children with disabilities.

Findings. The following is a discussion of the findings within the literature of parenting young children with disabilities.

Parenting style. There were conflicting results on parenting style for young children with disabilities although only three studies focused on this broad aspect of parenting. Higher levels of authoritative parenting were reported for parents of children with developmental delays (Woolfson & Grant, 2006), but lower levels were reported for parents of children with autism, language delays, and mental retardation (Rutgers et al., 2007) when compared to children

without disabilities. This *may* be related to the type and severity of diagnoses that are being compared, but this possibility was not formally examined. It does, however, appear that higher levels of self-efficacy (Rutger et al.) and stress (Woolfson & Grant) are associated with an authoritative parenting style for parents of young children with disabilities. In addition, it may be that there are additional parenting styles, such as the compensatory parenting style, that are more applicable to the unique lives of parents of children with disabilities (Miles & Holditch-Davis, 1995).

Expectations, discipline, and nurturance. Parents of children with disabilities reported various findings on the expectations they had of their children. When compared to those without disabilities, caregivers of young children with developmental delays reported higher expectations (Keller & Fox, 2009), those with mild delays reported lower expectations (Tucker & Fox, 1995) and those with language delays reported similar expectations (Carson et al., 2007). Furthermore, parents of children with physical disabilities, between three and nine, reported having either high or low expectations for their children, but regretted having low expectations for their children (Johnson, 2000). The reason for the inconsistencies may be related to a number of factors, such as a child's diagnosis or the age of the child, but it is of interest that expectations ranged from low to high for this population. For instance, it was not that they simply were lower in relation to a child's disability. In addition, parents of children with language delays (Carson et al.) reported lower levels of nurturance when compared to those without disabilities as did parents of children with developmental delays (Keller & Fox).

Mothers of children with high expectations of their children with developmental delays (Keller & Fox, 2009), speech-language delays (Carson et al., 2007) and hearing impairments (Knutson et al., 2004) reported using more punitive, or strict, forms of discipline compared to

parents of children without disabilities. Carson et al. postulated that this was due to the fact that the parents in these subgroups generally are more stressed, whereas Knutson et al. posited that it was the only effective way to get a child's attention. This is one example of the possibility that parenting behaviors may not be altered simply by the presence of a disability, but also by the type of diagnosis. There also may be additional factors associated with the diagnosis, such as a child's frustration with not being able to effectively communicate and thereby leading to an increase of behavior problems which, in turn, increases the likelihood of physical discipline. In addition, mothers of children with mild to moderate physical disabilities indicated that they disciplined their children based on their specific needs (Johnson, 2000). Yet, parents of children with mild delays reported similar levels of discipline and nurturance (Tucker & Fox, 1995) when compared to those without disabilities. There also were variations in levels and methods of discipline based on mother versus father reports (Carson et al., 1999) and child age (Little, 2002).

Parenting behaviors. There were a variety of findings within the context of parenting behaviors which makes it very difficult to summarize them. However, overall findings will be presented and discussed. First, parents of young children with spina bifida reported that high quality parenting influenced child outcomes and they only differed from parents of children without disabilities with respect to daily living skills (Lomax-Bream et al., 2007). Second, both maternal concern (Button et al., 2001) and disability status (severity) were related to modifications in parenting behaviors (Gau et al., 2008; Roskam, 2005; Roskam & Schelstraet, 2007), with one exception (i.e., Lojskasek et al., 1990). In particular, higher levels of concern and a more severe diagnosis were related to more directive or pressure inducing forms of parenting behaviors whereas lower level of concern and less severe diagnosis were related to

more stimulating and supportive behaviors (Button et al., Roskam; Roskam & Schelstraet). Third, in contrast with the previous findings on severity of the diagnoses, parents of children with autism between the ages of two and sixteen reported behaviors that they engaged in were similar to parents of children without disabilities, with the exception of the effectiveness of communication (Osborne & Reed, 2010). Fourth, mothers of children with Down syndrome indicated that they were less affectionate than mothers of children without disabilities, yet, fathers said they were more likely to be overprotective of their children with disabilities compared to fathers of children without disabilities (Gau et al., 2008). However, variations in focus, age span and diagnoses as well as operationalized terminology rendered interpretation virtually impossible.

It would be quite difficult, if not impossible, to draw any accurate comparisons between the bodies of literature of parenting young children with and without disabilities with regard to findings as the foci of varied within each body of literature as well as between them. Research on parenting of young children with disabilities has very diverse findings and is actually contradictory in a few situations. The literature on parenting of young children without disabilities, on the other hand, follows similar patterns in which it appears that parents may be influenced by the behaviors and temperament of their children, at least in problematic cases. This is interesting in relation to the varied behaviors that may be related to the presence of a disability. For instance, a child with a language delay may act out in frustration from not being understood, thereby increasing the chance of behavior problems. Furthermore, one can see from the literature on parents of young, children without disabilities that there are differences related to parental gender. The father role in parenting of young children with disabilities appears to have been completely overlooked.

Implications for the present study. Much of our understanding of parenting young children with disabilities is based on scales designed for parents of children without disabilities, many of which have questionable psychometric properties. In other words, virtually nothing is known about the common or unique parenting qualities for this specific population. Unlike the samples in the literature on parenting young children without disabilities, there is very limited information that focuses specifically on children younger than age five. It is not surprising, therefore, that the findings are not consistent and, at times, contradict one another. In an effort to fill this void, it is imperative that an understanding is developed from the ground up to advance our knowledge of parenting of mothers and fathers of young children with disabilities.

The literature is almost devoid of a father perspective on parenting of young children with disabilities. As one can see from the findings based on children without disabilities, fathers provide a distinctive set of parenting behaviors that is comparable to mothers in many respects, but also distinct in others (e.g., Casas et al., 2006; Volling et al., 2006); therefore, it is essential that one includes fathers' perspectives in an examination of parenting young children with disabilities. Overall, the literature lacks a clear theoretical perspective. Theories that were derived from research on parenting children without disabilities simply are applied to parents of children with disabilities without due consideration of the unique circumstances of these families. A theory of parenting that emerges from research on fathers and mothers of young children with disabilities is necessary to fill this gap in our understanding of the manner in which parents of children with disabilities attempt to promote optimal development. The present study was designed to address each of these limitations, but only in an exploratory manner. Findings that emerge from small scale, qualitative studies often serve as a basis for the development of

more comprehensive studies. This was a future purpose of the present study as it seemed premature to designate it as the primary goal.

Chapter III

Methods

Research Design

In an effort to address the research questions, a qualitative, grounded theory approach was employed. More specifically, in-person interviews were conducted with mothers and fathers of young children with disabilities to learn about the process of parenting for their families. Personal reflections were incorporated throughout the data collection and analysis phases.

Qualitative research. A qualitative methodological approach was utilized in the present study for two primary reasons. As previously stated in chapter two, the majority of the previous research is largely quantitative in nature and generally composed of predetermined categories originating from children without disabilities. Although a quantitative approach has the potential to provide valuable information, a qualitative approach is important to compliment what can be learned from quantitative measures. It is not clear if the parenting styles and behaviors accurately represent the experiences of families of children with disabilities and, therefore, it is imperative that an understanding be developed from the population of interest (Charmaz, 2000; Mills, Bonner, & Francis, 2006). Parents of young children with disabilities face unique circumstances (e.g., Hastings, 2003; Parish & Cloud, 2006; Smith et al., 2001) and a qualitative approach better enabled me, as a researcher, to develop an understanding *from* the population of interest instead of *for* the population. Given that a primary purpose of the present study is to develop a fundamental understanding of the topic of interest, a qualitative approach enabled me to begin at this foundational level and to limit the inclusion of preconceived ideas about parental experiences. This also was true for the inclusion of fathers as little is known about their experiences of parenting young children with disabilities.

Another key reason for the utilization of a qualitative approach was the potential benefit to practitioners such as early interventionists, therapy providers, and early childhood special education professionals. It is essential that practitioners are setting reasonable expectations for the parents with whom they work and that parenting interventions are aligned with the population for which they were designed. For instance, it may be that a more directive approach to parenting is ideal for parents of children with autism, yet more of a guidance role is necessary for parents of children with Down syndrome. It may be unrealistic and unnecessary to promote more authoritative practices for parents of children with specific diagnoses. Information derived from the present study may provide a basis of understanding expectations and practices that are compatible with parents' lived experiences. A qualitative approach also allows parents to describe barriers and unique influences on their parenting that may not have been previously addressed in quantitative studies. This potentially new knowledge could be useful in highlighting areas of interest. Practitioners then would have the opportunity to interpret the new knowledge for their work with parents.

Positioning. I approached the present research from a subjectivist position due to the individualized nature of both the subject matter (i.e., parenting) and the population (i.e., disabilities) (Daly, 2007). I attempted to assist the family in developing a reality of their lived experiences within the context of the research focus. My understanding of reality is from a social constructionism perspective in which I believe that there may be one reality, but it may be perceived differently by individuals. Therefore, I believe it is necessary to explore the process of meaning-making by speaking with a group of families who experience a similar situation (Daly). In the present study, parenting a young child with disabilities constituted the primary experience.

Grounded theory. The grounded theory approach to interviewing and data analysis was selected for the present study for several reasons. Grounded theory generally is a logical starting point for areas of interest where little research has been conducted (Chenitz & Swanson, 1986). As one can determine from the literature review on parenting of young children with disabilities, there is limited research overall and what is present lacks psychometric strength and consistency with regard to focus, sample, methods, procedures, and findings. Furthermore, researchers previously attempted to identify parenting of young children with disabilities based on an understanding of and categorizations originating from parents of children without disabilities of varying ages. A basic level of understanding is necessary which is not yet present from the limited, inconclusive literature.

A grounded theory approach enabled me to define parenting of young children with disabilities based on the statements from individuals who are responsible for the care of these children on a daily basis. By using a grounded theory approach, Strauss & Corbin (1994) argued that theory is not derived from previous knowledge, but is based on individuals who experience a phenomena (Creswell, 2007). A grounded theory approach provides the structure to stay within the broad construct of parenting while providing the flexibility to allow previously unidentified knowledge to emerge (Charmaz, 2000).

There are a variety of approaches to grounded theory which are guided by one's ontological and epistemological positioning. For instance, Glaser and Strauss provided the foundational support for the approach from a positivist perspective (Charmaz, 2000). My ontological (relativist) and epistemological (subjectivist) positioning are most closely aligned with the approach to grounded theory discussed by Charmaz. From a constructivist position, Charmaz believes that realities are co-constructed and that there is not one single reality

(Creswell, 2007). From this perspective, it can be assumed that the researchers “*define* what is happening in the data...[whereas] objectivist grounded theorists assume they *discover* what is happening in the data” (p. 684, Charmaz, 2002), thereby providing more authority to the lived experiences of parents of young children with disabilities. This particular approach was selected not only because of the close alignment with my theoretical perspective, but also because it allows the most voice to parents of young children with disabilities. Therefore, I viewed myself as a catalyst in the development of theory on parenting of young children with disabilities based on parents’ lived experiences.

Limitations to grounded theory. There are limitations to the grounded theory approach that need to be taken into consideration when making decisions regarding the best methodology for the present study. First, there is a considerable amount of time involved in utilizing this type of methodology. It not only takes considerable time to establish rapport with stakeholders in the community (i.e., recruitment team) and locating willing families, it also takes time to collect and analyze data. The constant comparative process of analysis requires the researcher to continuously go back and forth multiple times. If the analysis is done appropriately, the data should provide rich descriptions of lived experiences as well as useful and novel information, it is still possible to lose sight of the larger picture. To minimize this possibility, it was necessary to maintain notes and allow for others’ contribution throughout the process.

Grounded theory involves the use of theoretical sampling and an expanding list of questions and topics that evolves throughout the process. This approach is useful in identifying diversity within the topic of interest, yet it does not necessarily contribute to diversity in findings. There are several factors that may appear less important and reduce, to some degree, the ability to generalize the findings to other families. For instance, in the present study, it may

be that parents may have similar responses because of the state's early intervention system, whereas parents in another state with a different system may have distinctly different experiences. These limitations to grounded theory were taken into consideration, but this methodological approach was deemed best due to the richness of information that often is derived from interviews and possibly of developing a solid foundation of information from which to draw conclusions about parenting experiences.

Sampling

Theoretical sampling was used, as much as was possible, in the present study “to develop the researcher's theory, not to represent [the] population” (p. 689, Charmaz, 2002). This method of sampling is recommended by grounded theorists (Charmaz, 2000, 2002; Daly, 2007) to allow participants to determine important areas and influences on their parenting beliefs, behaviors, and practices and to allow for further exploration of these influences. For instance, it may be that the presence of another sibling appears pivotal in parents' decisions regarding their child with disabilities. As a result, it would be important to also interview parents of children who have only a child with disabilities. Participant sampling was determined throughout the data collection process. This provided a more holistic understanding of the lived experiences of these families and it allowed discussions of variance and bridging of gaps in the theory (Charmaz, 2002). It is more important to sample based on the development of a concept than based on individual features (Daly, 2007). Consequently, it was necessary to make decisions regarding questioning within the group of individuals willing to participate.

Although it was not possible to fully utilize theoretical sampling at the individual level due to a relatively low number of available, willing participants, recruitment sites were determined based on characteristics associated with previous participants. For instance, when it

became clear that many of the parents had children with hearing impairments, a therapy provider who works almost exclusively with children with autism was asked to assist in the recruitment process. Additionally, it was difficult at times to determine these characteristics through the initial contact with prospective participants. Through very limited inclusion criteria and constant comparison of emerging data and analysis, it is believed that these avenues were explored within the sample of available participants. In other words, if one individual discussed a topic of interest it was pursued with future participants regardless of intentionality in the method of sampling.

Recruitment. The sample was identified in partnership with the local organizations serving young children with disabilities. The recruitment process evolved throughout the course of the study. The first stage involved professionals at Little Tennessee Valley Educational Cooperative (LTVEC), University of Tennessee (UT) Center on Deafness, and Friends of Tennessee's Babies with Special Needs (FOT) who assisted me in identifying and recruiting available families. The LTVEC Birth-to-Three Program serves approximately 45 to 50 families with young children (0-3) with developmental delays. The UT Center on Deafness serves individuals of all ages, but provides a newborn hearing screening and other services to families of young children and FOT provides various support services to families of young children with disabilities.

The next stage involved the inclusion of three additional professionals at Parent-Child Services Group (PCSG), a board certified behavior analysis (BCBA), and a speech-language pathologist (SLP). PCSG provides a variety of therapeutic services to children of all ages including, but not limited to speech, occupational, reading, and physical therapies. The BCBA private business owner provides applied behavior analysis services to approximately ten to

fifteen children of all ages primarily with autism and the speech therapist private business owner provides speech therapy to children with varying diagnoses and ages.

As previously mentioned, participants initially were recruited through the LTVEC, UT Center on Deafness, and FOT. Flyers (Appendix B) were given to professionals in these areas and they distributed the flyers and discussed the project with potential families. Potential participants were asked to contact me via phone or email to discuss the study in greater detail, ask any questions they might have and to set up an interview time and location. When applicable, the professionals provided me with contact information for interested families.

A representative from UT Center on Deafness provided contact information for families, through which one family agreed to participate, and also invited me to attend a social event hosted by the East Tennessee chapter of Hands and Voices. Hands and Voices is a non-profit organization designed to provide support to families of children who are deaf or hard of hearing. At this event, I was able to provide flyers to families that fit that criteria and was personally introduced to families by the UT Center on Deafness professional. Three couples were recruited at this event. She also referred me to a respite event hosted by FOT. I provided flyers to individuals during their arrival at the event and was able to discuss the study with them in greater detail as I escorted them to their children's classrooms for the day. There was some overlap in families attending both events, but I was able to recruit one additional family through this event.

At this point, all families had young children who were deaf or hard of hearing. In an attempt to diversify the diagnostic features of the sample, I contacted several other professionals that were not as directly associated with hearing loss. Three additional professionals that provided a variety of therapeutic services agreed to assist in the recruitment process at this point. Three additional couples were recruited from the BCBA, who discussed the research project with

both current and new clients and provided families with flyers. All of these children had a diagnosis somewhere on the autism spectrum. Three additional families contacted me based on flyers they saw posted at one of these organizations and two of these families were able to schedule interviews. One child had a diagnosis of congenital hypothyroidism and the other had global delays associated with a rare genetic disorder.

Targeted parents had a child between birth to five years of age with any type of diagnoses/developmental delay in the eastern portion of the state of Tennessee. Type of diagnoses was not limited because this methodological approach allowed me to examine parents' perceptions of the potential influence of severity or type related to varying types of parenting practices and behaviors. At this point, variations in parenting related to severity or type of diagnosis is not clear and, therefore, all possibilities were examined. The presence of a child's disability was determined by a family's participation in any of the programs serving children with disabilities, yet a more specific diagnosis was obtained by parent report during the interview and on the brief demographic form (Appendix F). Age was limited to five years because there appeared to be variations in parenting of children of varying ages as determined by the literature review. It is believed that there may be more marked differences between school age and not school age given the differences in experiences.

Every effort was made to encourage both a mother and father from the same family to participate, yet they ultimately were not required to be from the same family. Based on previous research with a similar population, it was felt that father participation would be quite a challenge (Dolezal-Sams, Nordquist, & Twardosz, 2009) and I did not want to limit mother data by basing one parent's participation on the participation of his or her spouse. Nevertheless, a few strategies were employed to potentially increase the likelihood of father participation. The importance of

father participation was conveyed to the organizations that assisted in the recruitment of participants. All participants were entered into a raffle for football tickets as it was my hope that this type of incentive would be useful in targeting fathers. On the flyer, fathers were listed first and pictures including fathers and a football also were included with the hope of drawing their attention. Because fathers clearly are not represented in the literature, participation of an equivalent number of mothers and fathers was considered ideal, which turned out to be the case.

Interviews continued until saturation was achieved, or until no new information was attained from the interviews (Charmaz; Creswell). Saturation was determined when no more than one code emerged from the data analysis. The analysis was conducted concurrently with data collection.

Participant information. A total of twenty individuals (ten couples) participated in the study. All names are pseudonyms and are listed alphabetically based on the order of interviews. For instance, Alex and Alexandra were the first father and mother to be interviewed. Basic demographic information on parents can be found in Table A.1. Information on children is located in Tables A.2 (demographic) and A.3 (disability information). More detailed descriptions of each family are located in Appendix C. All tables mentioned in the methods section are located in the appendix.

All but one of the couples was married; the remaining couple had lived together for a period of six years. The range of the marital period was two to thirteen years, and the average range was seven and a half years. Of the mothers, seven were stay-at-home moms, one of which was a full-time student, whereas the remaining three were employed full-time. Of the fathers, two were unemployed at the time of the interview, one was a full-time student who also worked, and the remaining seven were employed full-time. The educational level of the parents ranged

from a high school diploma to a doctoral degree. One family was Asian while all remaining families were Caucasian. Fathers ages ranged from 28 to 45 with an average of 35.5 years; mothers ages ranged from 25 to 42 with an average age of 34.4 years.

All but one of the families had more than one child, but only one family had two children with disabilities under the age of six. Therefore, a total of eleven children between the ages of 9 and 67 months ($\bar{x}$ =34 months) were the focus of the ten couples' interviews. One family (Eric and Erica) also had an older child (nine years old) with a rare genetic disorder. Six of the children were male and five were female. All of the children with autism were male. The majority of the children had a hearing loss ($n=6$) or were diagnosed with Autism Spectrum Disorders ($n=3$). The remaining two children were diagnosed with congenital hypothyroidism and apraxia associated with an anxiety disorder. With that said, through discussion in the interviews and review of the type of services the children were receiving, it was clear that generally there were additional delays in many of the children. The majority of the children also had language delays, regardless of their primary diagnosis. One child (Family 5) had global delays associated with a rare genetic disorder which included service provision for vision, cleft palate, braces for her legs, and a complete loss of hearing, which required that she and her parents participate in an intense sign language program.

Procedures

The research team consisted of myself, Mr. Rhett Billen, a Child and Family Studies Master's student, and Dr. Vey Nordquist, my major advisor. I was the principal investigator and was responsible for developing and managing the entire project. Mr. Billen completed a portion (40%) of the interviews, reviewed all transcripts, and discussed his reflections with me. Dr. Nordquist provided support on the overall procedural development of the project, reviewed a

portion of the transcripts and discussed his reflections.

Potential participants either contacted me via email or phone or were referred by one of the individuals on the recruitment team. When contact was established, I provided additional information about the study and a day, time, and place were determined for the interview. Contact was almost exclusively made with the mothers, which necessitated that I gain father contact information from the mother. The interviews were counterbalanced based on interviewer and parent gender as much as was possible (see Table A.4).

Interviews took place in the parent's home if he or she did not anticipate other distractions, or on the University of Tennessee campus in the department of Child and Family Studies in Jessie Harris Building. These two locations were selected to limit the options to places that potentially reduced external noise and other distractions, yet also provided a sense of comfort and choice for the participants. The families determined which of the two locations was more comfortable and convenient for them. Eleven participants chose to complete the interviews in the home whereas the remaining nine elected to conduct the interviews on campus. At least one child was present at nine of the mother interviews, yet this was only the case during three of the father interviews. During these father interviews, the children were present in the home but were cared for at least part of the time by the mother. If the child was present during an on-campus interview, age appropriate toys were provided to entertain them as much as possible. Nevertheless, in each case the parent needed a break at least once and often went back and forth between the child and interviewer.

After the initial contact was made and the interview was set, a welcome packet was sent to each parent that included a welcome letter with interview information (Appendix D), an informed consent form (Appendix E), and a brief demographic form (Appendix F). Parents were

asked to review and complete the informed consent form prior to beginning the interview. The interviewer brought two additional copies of the form to the interview to insure that one was signed and filed while the other was provided for the parent to keep for their records. On the day of the interview and upon a parent's consent, the audiorecorded interview began and generally lasted approximately one hour (range: 32-91 minutes; average: 62 minutes). Upon completion of the interview, the participants were asked if they had any additional information to provide or questions regarding the study. At this point, the audiorecorders were turned off and the interview was over. The parent then was asked if he or she would be willing to participate in the follow-up couple interview and, if he or she was willing, the appropriate informed consent form was reviewed and signed. Follow-up interviews were not scheduled until transcriptions and preliminary analyses were completed.

Very soon after the individual interview, in a separate location, the interviewer recorded her/his thoughts and impressions regarding the interview as well as possible codes and other information pertinent to the study (reflective memoing; Daly, 2007). The interviews then were transcribed and analyzed following grounded theory guidelines of coding. In line with recommendations for constant comparison and theoretical sampling, interview questions (discussed in the following section) were modified as needed. This included deletion, addition, substitution, and reordering of the guided questions. As themes began to emerge from the data, potentially new avenues of inquiry were further explored with the next participants. Parents had the option of participating in a secondary couple interview after both mother and father interviews were completed. However, the secondary interviews are not the focus of analysis for the present study.

Interview questions. A list of interview questions was orally presented to all parents in an

effort to address the overall construct of parenting, yet there was flexibility in the questions as parents determined what they thought/felt was important with regards to parenting of a young child with disabilities. The preliminary questions were developed through review of the literature on parenting, knowledge of the population based on professional experience, consultation with an experienced qualitative researcher, and by examining constructs from available scales on parenting. The interview questions were expanded through additional prompts for further clarification, such as ‘tell me more about...’. Charmaz (2002; 2006) recommends a series of questions that initially are broad and open-ended, followed by intermediate questions and then concluding with more specific questions. The preliminary questions followed this pattern (Appendix G).

The questions changed throughout the data collection process as I constantly compared emerging codes and themes. In other words, I modified the questions based on information gleaned from the parents. After the first interviews, it was apparent that a few additional avenues needed to be explored. For instance, Alexandra discussed the importance of the Individualized Family Service Plan (IFSP) in setting goals for her child, which is unique to the present population. As a result, the questions were modified after this visit and again about half way through the study. Both of these revisions are indicated in the Appendix G. I also was regularly reviewing and analyzing these themes throughout and discussing them with others on the research team and, as a result, the interview process seemed to become more fluid as the study progressed.

The questions often were asked as the parents presented information that led to a natural transition into another area. For example, if parents discussed how they set goals for their children and mentioned collaboration with professionals, it was common to discuss the IFSP at

this point. Also, the language and sentence structure that was used when presenting the question changed in response to requests for explanation from parents. As an example, “How do you express your care and concern for your child?” often was followed up by “How do you show him (or her) that you love him (or her)?”

Specific interview techniques and questions were incorporated to encourage father participation and enhance the level of comfort during the interview process (Schwalbe & Wokomir, 2002). More specifically, I allowed for potentially lengthy pauses, conveyed to the father that he is the expert on his child, and attempted to encourage ‘stories’ instead of asking direct questions (Schwalbe & Wokomir). Similar strategies were utilized with mothers, but not to the same extent because it is likely that woman may be more forthcoming with information than men.

Compensation. At the beginning of the visit, each participant received \$25 in cash for his/her participation in the individual interview. In addition, every individual that participated was entered once into a raffle drawing for one set of two tickets to one of three UT football games. This incentive was included in an effort to promote father involvement.

Memoing. Memo writing occurred throughout data collection and analysis as this “links coding to the writing of the first draft of analysis” (Charmaz, 2002). As I was coding the data, I kept a record of thoughts that I had regarding concepts or new ideas. This was done in an effort to be reflective throughout the process and better enable me to inform the ongoing data collection and analytical process. After each interview, the interviewers (i.e., myself or Mr. Billen) provided audiorecorded reflections of our experiences during the interviews. This included information such as our reflections on the pragmatics of the interview (e.g., the father seemed nervous), critiques of our interviewing (e.g., felt I rushed through a certain question) or

topics or early themes that seemed especially important (e.g., I noticed the mother spoke a lot about being physical in teaching).

I also made notes as I was analyzing that centered on whether topics were relevant, too broad, or other various factors. I made notes in the documents as I transcribed in which I responded to statements they made. As an example, when a parent spoke about using his younger child as a peer model, I made a note about the responsibility for this child. In my discussion with Mr. Billen, I reflected on issues that emerged that were important to him.

Data Analysis

Data were analyzed in line with the grounded theory approach. Data analysis began immediately after the first interview (Creswell). A constant comparative method was employed throughout the process of data analysis in which I compared codes and themes emerging from analysis with the data collection process (Chenitz, & Swanson, 1986; Creswell; Ryan & Bernard, 2000). The analysis informed future interviews which in turn influenced data analysis. Due to the richness of data, I elected to reanalyze the data once all interviews were completed. This second process was somewhat more systematic but, as expected, no new themes emerged. It was simply an effort to reemerge myself in the data and to confirm, to some degree, what I was finding throughout the data collection and analysis process. Furthermore, grounded theory is not a linear process; it is common to follow a meandering path throughout the data collection and analytic process.

After each interview, I transcribed the majority (68%) of the audiofiles while the remainder was transcribed by an undergraduate student. Following transcription, each line was examined to begin to determine initial codes, or a label for what was being described, in the data which allowed a close examination of the words and meaning parents use to describe their

parenting behaviors and decisions (Charmaz, 2002). In other words, I read each transcript line-by-line and drew conclusions regarding that specific line about “What is going on here?”. I made notes in the margins of the printed document reflecting what I felt the parents were saying. After each interview I updated the interview questions based on similarities in concepts that emerged from the responses.

Open coding occurred next in which major categories emerged from the data (Creswell, 2007; Daly, 2007). During this stage of analysis, I began to classify the findings from the line-by-line analyses into conceptual grouping that allowed themes to begin to develop. I began to reflect on groupings and found it necessary to create lists on separate pages to best examine the themes. For instance, when parents discussed lack of materials on parenting or pursuing the internet for resources, I began a list of ‘self-guided learning’ that the parents discussed. I then added to this list as I reviewed the transcripts and found additional characteristics that were attributed to the child. Once a category was determined, I then used as a standard with which to compare other statements. This process is referred to as the axial coding stage of analysis (Daly, 2007). Additionally, one of my research questions addressed the similarities and differences between mothers and fathers responses, as a result, I underlined codes that were unique to either mothers or fathers at this stage. For instance, a father discussed “be(ing) fair and balanced”, but mothers did not mention this and, as a result, it was underlined in the father file. I was then able to examine the differences within the larger categories that were emerging.

Selective coding allowed me to develop hypotheses regarding the parenting young children with disabilities by which I developed three central themes (Creswell, 2007). I was able to refine and, to a limited degree, define each broad theme. I reviewed all of the categories such as ‘social support-formal’ and ‘context-time’ and created a larger category of ‘external

influences on adaptation’. I then reviewed all of the categories and added to the three largest themes. During this stage of the analytic process, I began to develop a theory to describe parenting of young children with disabilities by identifying core elements that were identified by participants.

Trustworthiness

In qualitative research, it is important to establish trustworthiness or support for the accuracy of the findings and the soundness of the methodological procedures. In the present study multiple techniques were employed to address four main areas of trustworthiness: credibility, transferability, dependability, and confirmability.

Credibility. In qualitative research, credibility refers to the accuracy of the representation of the findings in relation to the real experiences of the participants. To address this issue, I examined the original findings from individual interviews with a subsample of couples in order to increase the accuracy of the interview data. More specifically, I reviewed individual interviews and made notes on similarities and differences between mothers and fathers as well as areas I wanted to further clarify. I then reinterviewed five of the original ten couples and focused these areas of interest. In addition, after all twenty interviews were completed, I emailed a brief follow-up list of questions to the participants that addressed areas that needed further clarification that came up near the end of the interview process (Appendix H). A total of four individuals completed and returned these documents. I also provided the participants and recruitment team with a brief list of the overall findings (Appendix I) and asked them to provide feedback if they wished. No parents provided any additional information, but two of the members of the recruitment team verified that what was presented was aligned with their experiences working with parents.

I was the primary researcher in the present project, yet I had the support of Mr. Billen, who also reviewed the transcripts. We discussed participant responses throughout the data collection process in an effort to expand the questions and identify areas that needed further exploration. Also, my major advisor, Dr. Nordquist, independently reviewed a portion of the transcripts for overall analysis and provided feedback on areas he found especially important, such as siblings or the couple dynamics. I also provided descriptions that were detailed enough that it should provide enough background that one could draw similar conclusions on the findings.

Member checks, or confirming what the parents intended, occurred both during the individual interviews, couple interviews, and follow-up. Throughout the individual interviews I used terminology such as “it sounds like...” to help clarify what the parents were saying. During the couple interviews, I reiterated how I interpreted the preliminary themes that emerged from their individual interviews; however, responses may have been altered somewhat by the presence of the other parent. In the large majority of cases, the original findings were confirmed and further explored. As previously mentioned, I also provided all parents as well as members of my recruitment team with a list of preliminary themes and asked for unstructured feedback.

Transferability and dependability. Transferability is related to the application of the findings in similar contexts whereas dependability refers to two researchers drawing the same conclusions if similar procedures were followed in the exact same manner (Lincoln & Guba, 1985; Shenton, 2004). Similar methods were employed to address both processes (Lincoln & Guba). I provided detailed descriptions of the research process including data collection and analysis as well as reflections, throughout the course of the study. I created multiple documents during the analysis process, both in short-hand and electronic documents. Throughout much of

the transcription process, I placed various highlighted notes within the documents to remind myself to pay close attention to certain areas. More directly, I left a sort of ‘paper trail’ in which I assigned the stages of analysis into steps (Shenton). For example, in Step II documents, I identified key words that I subsequently placed into larger categories.

Confirmability. Confirmability in qualitative research is a process that helps to limit the researcher’s biases and render the findings as objective as possible (Lincoln & Guba, 1985; Shenton, 2004). After much consideration, Mr. Billen and I decided not to complete bracketing interviews prior to data collection. A bracketing interview is one in which the interviewer is asked his or her opinion on the guiding questions so that the interviewer becomes aware of potential biases on the subject matter. I did not feel I had biases on the present topic other than the expectation that I would find some differences in parenting between these parents and parents of children without disabilities. I did find it important during the analytic process to reflect on the families themselves and document my impressions of their characteristics. For instance, I noted that one father appeared to be “an alpha male”. I did not feel my initial impressions of the individuals affected the development of themes, but I believe it was necessary to be aware of my opinions. I also believe that the multiple steps that were taken to confirm the findings with the participants and other researchers increased the objectivity of the present research.

Chapter IV

Results

Parents of young children with disabilities explained various aspects of parenting and three main themes emerged: individual meaning-making, external influences on adaptation, and the process of parenting. Families discussed two main aspects to their parenting in nearly every area that included details that were fairly standard and those that were more related to having a child with a disability. To the degree that it is possible, the findings will be presented accordingly with more general, typical findings presented in each area first and then unique contributions to their parenting related to the presence of a child's disability. Also, fathers and mothers were fairly similar in a broad sense with most aspects of parenting, but did present some distinct viewpoints. Findings for both will be presented first in each section, and then fathers will be discussed, followed by mothers. These also are presented in Table A.5 in the appendix.

The quotes provided throughout the results section are meant to be representative examples of what the collective group of parents expressed during the interview process. In other words, the selected individual quotes within each section best capture what parents expressed collectively. The quotations were taken directly from transcripts and are the exact expression of participants' personal patterns of speech. This may not reflect what is accepted as correct grammatical usage in formal written English. It was important to retain their original language because it is necessary to communicate their perspectives. In line with grounded theory, in-vivo codes derived from the participants' own words were incorporated in the analysis and writing of the findings (Charmaz, 2006). Thus, a specific phrase provided by a parent that accurately captures a category is utilized to explain that code (e.g. "They're experts...?: Formal social support"). Table 1 is included as guide given the complexity of findings.

Table 1		
<i>Heading Guide</i>		
Level One	Level Two	Level Three
Individual Meaning-making		
	Personal beliefs about family and parenting	
	Personal beliefs about disability	
		Parental perspective
		Disability as an excuse
		Same, but different
External Influences on Adaptation		
	Context	
		Place
		Time
	Social support	
		Informal social support
		Formal social support
		Peer support/social aspect of child
	Other external influences	
		Self-guided learning
		Various influences
Process of Parenting		
	Awareness/intentionality in parenting	
	Expectations and goals	
		Long-term expectations
		Can't versus won't
		Short-term goals
	Structure	
		Boundaries
		Discipline
	Guidance	
		Teaching
		Care and concern

Theme One: Individual Meaning-making

One of the three main themes that emerged from the data collection and analytic process was the discussion of meaning-making process for the individual parent. All twenty individuals discussed general beliefs that indirectly affected parenting choices within this group and encapsulated the feelings of parents on their role within the family system or of their children's disability. These represented psychological factors in their experiences of parenting.

Personal beliefs about family and parenting. All of the parents discussed their personal beliefs on components of daily life that were central to the functioning of the family as well as their roles within the family and as a parent. Fathers and mothers expressed broad views on the dynamics of the family such as the value placed on routines (e.g., mealtime, bedtime) or staying active. Fathers also mentioned that they were gone much of the time due to work and felt their primary responsibility to their family was to provide. In many cases, mothers indicated they stayed home with their children, often due to their children's disabilities, as they felt that this was critical for their children's development.

Georgia: I guess our biggest modification is that I would probably be working now and she'd be in daycare...the reason we're not doing that is because she needs that, now is the time when kids are absorbing everything and just, you know, their minds are little sponges. We want her to have the accessibility to somebody one-on-one with her all the time. So, I'm a stay at home mom.

Fathers revealed that their role as a parent was to set expectations and then provide their children with the supportive tools to reach those expectations.

Eric: The biggest responsibility, the biggest privilege in being a parent is knowing that in the most, uh, formative years of, um, a person's existence, you have the opportunity and

the chance to, um, mold them, um, um, to be good people...I think, um, that is perhaps, um, the most, um, God-honoring thing we can do with our lives.

A couple of the mothers explicitly stated that their lives revolved around their children, although many of the parents inadvertently expressed this as well. The parents expressed a broad array of characteristics in how they defined what parenting meant to them.

George: [in reference to the term parent] Just overall interaction between us and our kids in every, every aspect of it. It's from providing, to nurturing, to feeding, just everything. There's not one set thing that comes to mind.

Fran: [in reference to the term parent] Parenting is caring for your child's physical, emotional, intellectual and social needs in the best way you know how. It is looking out for your child's best interests and safety at all times.

Georgia: [in reference to the term parent] I guess the word love just comes to mind. Just, um, love, responsibility, just being the best role model and teacher and friend, not friend as in 'oh, you're my buddy' kinda thing. But just, you know, the constant companion...I actually get a little worked up when I hear the word. It's just, there's just such a, the word love is just not even, such a supreme kind of love. Just an all-encompassing kind of love. And just being the best you can and doing the best you can for your children.

Many of the parents implicitly expressed the high level of sacrifice for their children with providing all their needs, no matter what the cost or change for their family.

Chris: And that was the commitment we made. If we had to drive to, you know, Nevada, we'd go.

Donald: I should satisfy, sacrifice my life to take care of my baby and also my wife also sacrifice her life to take care of baby... The USA is a better than [country of origin]. So

my parents and parents-in-law are want us to stay in USA. Because when you come back, my neighborhood, neighborhoods come and ask me ‘what happen?’ and then they have some caution... ‘He is very, looks very ugly like a strange face and it’s, he cannot hear.’ ...So, then my family and I will get hurt. So I don’t like that situations. And also my sons should go to the, not normal school, but the special school. So, which means that my son will be treated as a normal person. Not special person, but a normal person. So I don’t like that situation so I try to stay in USA to take care of my baby.

Personal beliefs about disability. All of the fathers and mothers expressed their general beliefs of what a disability means for their children and their family including maintaining a certain perspective on the matter, the risk of viewing the disability as an excuse, and the distinction between treating their children the same or different as others. The following quote best captures this section as a whole as it demonstrates the conflicted nature of their views.

Alexandra: You want your child healthy, happy, you know, I mean, I hope I don’t start crying on you but when you ask for a kid, you don’t ask for deafness or blindness or Down syndrome, but you love them just as much if they have it. You know what I mean? So that’s where we stand... I just think, in general, kids with disabilities are horses with different colors.

“That’s all it is”: Parental perspective. The families mentioned various perspectives related to the presence of a child’s disability that appeared to be significant in caring for young children with disabilities.

Georgia: I got over the initial shock, called my husband, and told him what they found and he said ‘oh, alright. Well, if that’s all it is, we’ll deal with it.’ I wa-, I was like, ‘what do you mean ‘if that’s all it is, we’ll deal with it?!’ And he said ‘Sweetie, look around

you. Look at the babies that are in there that have so many other problems. Life-threatening problems that are, have had open heart surgery and are only a month old’.

And that just, it slammed me against a wall, it threw it into perspective. And I said ‘You’re right. That’s all it is. It’s a hearing loss. We can deal with that’.

Fathers, more so than mothers, did not always see their children as having disabilities and were not always convinced of the actual diagnosis or delay. Many of the parents felt that their children’s conditions were milder than what was experienced by other children with similar disabilities.

George: One of the, the main influence was we don’t see it really as a disability right now. You know, she still functions, she still communicates, although it may be in a different way, through sign language. There’s nothing, nothing there that says that, to me, that she’s disabled, although by definition she is, but I don’t want her to see herself as, ‘this is holding me back because I have a hearing loss.’ It’s not holding you back, you just got to find your way of doing it.

Henry: He’s not one of those autistics that, that is like in his own world, you know. He’s, he’s very loving, very playful, and uh, he knows who his mom and dad are, he knows who a lot of people are. Um, he loves, be-because of his autism, he’s a lot sweeter than a lot of kids. He loves unconditionally, and he’s friendly to everybody.

Mothers indicated that they recognized it could always be worse than their situation and it was a matter of not lessening, but simply changing the manner in which they viewed their children.

Irene: I think that you have to try really hard not see your child as “less”. They’re not “less” than a person, you know? They’re still a person and they’re still your child

(laughs). And they can, they can still achieve really great things, you just have to shift your focus a little bit... it teaches you to, uh, to view everything in life differently and to slow down and, uh, and just, it makes you less judgmental (laughs). So it really is a privilege even though it doesn't seem like that at all at first.

There also appeared to be a process of how parents viewed having children with disabilities in their family, much of which centered on the diagnostic process.

Henry: For a long time, I took the route as God was punishing me, him, for something I did, you know? But as time went on, uh, I began to realize that uh, [focal child's name] was a blessing to begin with...having an autistic child, at first you thought it was a curse, when you first found out. But you come to realize, it's a gift.

Christy: It's always kind of been my passion and, um, and I know God gave me these kids because I can help them and, you know, I think it's been as much a blessing for me as having a typical kid because it just makes it a little more special knowing what they've been through.

Irene: Someone else said this to me when I was really low about, about his diagnosis, that what you, what you get to do is a very unique experience to be a parent to a kid with special needs, especially with autism because it's so very, it's, it's parenting a truly unique individual. It's, it's learning a new language, it's, it's, uh, you know, it's just, it's experiencing life in a completely different way. It's slowing down and noticing the most mundane things like the lines of the wall and, and the way the light shines out the window. It really teaches you to focus on small details...it teaches you to, uh, to view everything in life differently and to slow down and, uh, and just, it makes you less

judgmental (laughs). So it really is a privilege even though it doesn't seem like that at all at first.

“Nothing should hold him back”: Disability as an excuse. Many of the parents mentioned that they did not want to use the child's disability as an excuse. They did not want to allow the presence of the child's disability as an excuse for potentially disruptive behaviors or lowered expectations.

Chris: He's not any different than somebody else that has perfect hearing and that he can face the challenges that's set in front of him. You know, through school and through life. Um, you know that doesn't make a difference that he, he has a hearing issue. He can still be what he wants to be in life. Nothing should hold him back.

Some parents expressed that they do this because it would not be realistic of what they will experience outside of their family and others mentioned that it was not fair to their siblings.

Alex: I try to treat it just like I would the boys. . . I try not to give her an advantage over, you know, like, the boys were able to do this, I'm gonna try and let her by with something that I wouldn't let them by with. So I try to set the same boundaries, even though, like I said, at first it was a little bit, I guess, a challenge of not having that communication, I still don't let her by with more than what I would let the boys by with.

Georgia: We don't give her special treatment because she's not going to get that all her life, so as far as her hearing loss, she can hear, you know, she just doesn't have that crisp clear hearing.

Fathers especially mentioned the decision to not use the disability as an excuse. For some fathers, the perception of their children's disabilities influenced these decisions, such as not seeing the child as having a disability or that every child has some aspect that may be limiting.

Brandon: I think every child probably has something whether...it's a physical mobility, if it's a speech problem, sight, hearing, so, um, while I'm, I try to be aware of his condition, I don't want to use it as an excuse to enable him or caudle him too much, but I think he's adjusted like any other child would, as far as I know. Just cause, once he was born, I mean that was the condition we were faced with, so to us it is normal. I don't know how it would be other than that.

The fathers did not want their children to isolate themselves, but hoped they would use their disabilities as an advantage.

Brandon: Rather than use it as a crutch, I want him to use it to his advantage. He, he may not be able to hear as well without aid, but, um, he can do other things. I don't know that yet, maybe his vision is better, maybe his lip-reading is better, maybe he can do other things, um, with musical instruments.

A couple of the mothers did not want to use their children's disability as an excuse because they did not want for it to become a self-fulfilling prophesy.

Fran: I want to push her and I want her to feel as normal as possible. And not label herself so that she lowers her own standards of what she can be without her labels.

“The only difference is...”: Same, but different. Most of the parents mentioned that they treated their children the same, but then proceeded to explain various differences in their parenting. This was enduring throughout all levels associated with the process of parenting including expectations, structure, and guidance. Most of the parents with other children indicated that they parented all the children in the same way, but also discussed various modifications they made for the children with disabilities. For instance, parents discussed that they interacted in the same way, but needed to speak louder or be more physically direct. These

are just a few highlighted examples from both fathers and mothers:

Chris: I don't think it changed. I think it would have been the same. Um, if both of them were perfectly healthy, I think it would have been the same. The only difference is...I think me personally, I reinforce more. Um, in reference to everything because now I know the challenges in life for [focal male], you know, or [focal female], you know, um, are going to be a lot tougher then if, you know, I think that's more of social and...I don't think it would change, I just think I've, I really focused on it.

Donald: I just I've treat, take care of him like a normal. I, which means that I cannot give him the other special care. Because so far he's normal, excluding the ear, hear, hearing. So now it's just I feel normal to him.

George: We try to show her no different than [sibling's name], um, she's, you know, we obviously have to speak a lot louder to her, and sometimes things come over more, um, I guess not aggressive, but more stern when we're talking to her.

Alexandra: I just treated her like I did my other two. Except she's just not hearing.

Brandy: Just two typical boys. Um, but with a hearing loss.

Georgia: As long as she's getting that information, we expect the same on her as a typical child.

Many of the fathers described the importance of treating all the children in the same way to be fair, but did not always achieve this.

Alex: I mean the original plan, I guess, what just like the way we deal with the boys, just, um, just a normal discipline we had for them. Which is the same way I discipline her. So I can't really tell that I've modified it in changing discipline patterns for then the boys, because the boys, uh, I mean other than with her I use, sometimes I use the sign

language...before we found out you know we just always assumed that everything would be as it was with the boys. Um, but then after her diagnosis we didn't know what to expect, so I guess for the first little while there was that up, you know, in the air of, um, you know 'Do we need to be more lenient with her?', 'Do we need to give her more of a benefit of the doubt?'...and that's why we finally came to the conclusion after a lot of thought and stuff that, you know, we, we need to be fair. And you know, balanced. And, just as strict with her as we would with the boys and treat them all the same. Um, but I don't feel like my parenting has changed other than just having to interact myself more with her to teach her and, um, try to get her paying more attention to stuff and in that area.

A couple parents even discussed how professionals in the field explained the importance of treating them as if they did not have a disability.

Alexandra: From day one that we started therapy I was told to treat her just like I treat my other two. Because she has a disability, you know, sometimes it's harder for parents to discipline but she said, 'she has a disability, she's always going to have a disability, but if you treat her like she's got a disability then that's when you're gonna have trouble.'

Even though these parents felt it was important to treat their children the same, they all discussed modifications they made in their parenting related to their children's disabilities.

Theme Two: External Influences on Adaptation

Another main theme that emerged was the discussion of external influences on a family's adaptation to the presence of a child's disability. Unlike the internal process of meaning-making discussed in theme one, these were peripheral influences on the manner in which the family was able to make appropriate adjustments to accommodate changes associated with the delay. All

twenty parents discussed a variety of specific factors that either indirectly or directly influenced parenting choices within this group. The families described the influence on parenting of context, social support, and additional external influences (e.g., religion, forums).

Context. Two main contexts appeared to be influential to their parenting in that they often needed to make adjustments based on the place and the time of day or day of the week.

“And they don’t understand”: Place. Parents indicated that there were differences between parenting at home versus in public. Some fathers and mothers discussed the importance of treating their children the same in public versus home, but most acknowledged that this was not always successful.

Chris: It should be constant. What I mean by that is, it shouldn’t change in reference to the way you do it, if you’re out there or in our home...in my opinion, it gives the child that way of finding ways to break through that. You know, um, manipulate that as I can say. Um, so I think it should be constant, if, if there’s hitting here or if there’s hitting there. It’s just the same way.

Brandy: Although, I really should just remove him from the store if...he’s not gonna behave, but, uh, you know, you don’t want to, if you’re in a store, you can’t be that loud and if he can’t hear me or he’s taken his hearing aid out or something, it’s definitely, you do act a little bit differently in public than he would at home (laughs).

Some fathers were more likely to caudle their children in public than at home. A few of the fathers interacted differently at home because they could be more relaxed in their interactions (e.g., roughhousing) and there were more distractions thereby limiting the need for constant discipline.

Brandon: Initially we would have the same approach in public or in private but if we're out in public and he continues to throw a fit and kind of escalates to where he's in one of the moods, to where he starts grabbing stuff and throwing it around or lashing out, then I'm not, I mean, I think that I've moved past being sympathetic ...where 'you need to stop acting this way, we're out in public, um, you know this is not acceptable behavior'. And if he continues to do it, then he's punished, where if we were at home, I think we have a lot of other things that, I don't want to use the word 'distraction', but we could, we could offset his focus from what he's not being able to do and get him involved in something else that he may be able to do.

Several of the parents also recognized a number of ways in which the children's disabilities varied in relation to context. A couple of the parents felt that their children worked so hard in therapy that they wanted home to be a place to relax and only work on goals more casually.

Irwin: We do a good bit of downtime at home just because he's in, what, it's like 15 hours or something, 17 hours of, um, therapy a week. So he's got like a part-time job, you know (laughs). Some of what he does, I'm sure he finds fun and some of it, I'm sure he finds to be miserable in terms of just being boring work. He has to cause, um, he's trying to work at something. So he's got a part-time job, so we let him, uh, let him do a lot of down-time at home.

Some of the parents also expressed there were differences in the public perception of their children's disabilities and the judgment they felt when their children's disabilities were not clearly recognizable.

Christy: There's still that social pressure of every, you know? I've had people come up on a particularly bad sensory day in Food City and it took us 2 ½ hours to get through. And I, 3 people come up to me 'do you need help?'. And it wasn't like 'oh, bless your heart, you need help', it was like get this screaming kid out of the store (laughs). So, yeah, you basically have to react differently because you don't want people to think badly of you or people to think badly of your kid. And they don't understand, you know? Like they don't have Down syndrome, like there's something you can see going on or autism where they can wear a t-shirt that says 'I have autistic' - 'I have autism, I'm not bad'.

Parents also discussed the implications of the children's behaviors associated with the disabilities, such as being loud when the child had a hearing loss.

Alexandra: With the other two, they were, most of the time they're good and like we go out in public and people comment on how good they are and it's like, I take her and, you know, she's loud and then because of her non-hearing she's 20 times louder than the normal child, because she don't hear herself. So everybody's looking at us. And I'm not used to being the, I'm not usually the one people looks at because, you know, the kids are out of control, but she (whispers, laughs) sometimes makes me look like that... I think just when she's really loud and I think that's just in public. It's just really hard because people don't understand and whether she's loud or she ain't loud, it's cause of her deafness or it isn't, she's really not old enough to understand that she's too loud anyway.

Mothers also had much to say about various contexts and the manner in which they interacted with their children. For instance, some were more likely to sign in therapy, but less so in public and described the difficulties of communicating (i.e., signing) in the car. At home, mothers utilized certain techniques to help their children such as squishing her child's head.

Erica: I'll probably, you know, do a little bit to just get, you know, whatever I need, you know, be, be sure to tell her something, but there's not as much, um, signing going on, I guess, when we're out and about... I mean, I do sign at therapy, you know, like therapy times is a really good time to sign through therapy, and all that stuff. But, you know, I can take a walk, and every once and a while, I'll stop and kinda get in front of her, and sign something we see when we're taking a walk, you know... And I know when I'm driving the car; I can't just say, you know, something (laughs). I got to like have her attention, and sign at maybe the mirror.

“Cause you're exhausted, tired, and you catch everything”: Time. Parents also discussed various factors related to the time of day or day of the week that potentially affected the manner in which they parented their children. Many of the parents were more tired at the end of the day and end of the week. Fathers were more likely than mothers to attribute this to work, whereas mothers were more likely to ascribe this fatigue to caretaking and/or going to therapies. Some of the parents felt they noticed more misbehavior at night while others were less likely to discipline due to this fatigue. The following are examples of the influence of time on parenting.

Chris: There's a possibility that there could be a difference of what, what really bothers you more. And, and what I mean is the little things of maybe say something, name calling. Or something in the morning may not bother you as much as it does at night. Cause you're exhausted, tired, and you catch everything. And, you know, you're just ready to start over again.

Christy: I think it depends a lot on the day and if I wake up and I'm still exhausted then I'm more likely to let her, to let her get away with some of her stuff that probably is not, is just wanting me to be their mom.

Social support. Parents described both informal and formal forms of social support that, for the most part, were beneficial in parenting their young children with disabilities. At times, they also discussed the implications of the absence of social support and potential difficulties associated with less than positive forms of social support.

“Coming together in unity”: Informal social support. Many of the parents mentioned that their spouses were a source of social support for them and they tried to be in tune with one another on all aspects of parenting.

Alex: If Alexandra is trying to discipline them, you know, and then they’ll come to me and I’ll say ‘you know, what’s wrong with?’. I’ll go to Alexandra and she’ll say, you know, ‘this is why’ or ‘she’s in trouble’ or this or that. So we’ve always come together as together. So that’s a factor being, coming together in unity in everything we do with our kids. So. All that is factors in how we parent and discipline and raise our kids.

Christy: So sometimes it helps to have other people here, like my husband, and have him say ‘I’ll take [focal male], you take [focal female].’ And then kind of divide and conquer.

As previously mentioned, many of the mothers stayed home with the children and most of the fathers worked outside of the home full-time. Many of the fathers contributed to the caretaking, but most felt their wives did more of the caretaking, managing of appointments, and other tasks related to the children’s diagnoses.

Eric: She knows what she’s doing (laughs)...I always have to, um, ask because I’m not always up on what she can and cannot eat. And I, she does have a, um, dairy allergy...I don’t know how the clothes are organized in the closets...[or] how much, she, uh, typically eats at a meal. Um, there’s, um, I’m not as in tune...I help out in other ways, but

um, um, as far as, uh, picking out clothes and preparing meals and bathing [focal child], for instance, my wife does those, um, primary tasks.

Several of the fathers attributed their felt lack of knowledge on their children's development and therapies given their wives constant involvement with the children.

Brandon: I am at work during the week and I rely a lot on what my wife says, what [focal male] did, and his behavior... Maybe it's because I don't get to spend as much time with him as my wife, who stays at home with our children.

Eric: My wife, in particular, has worked with the TEIS [Tennessee Early Intervention System], um, representative, I guess. Um, and, uh, I'm trying to remember. I think I was probably involved in one of the first meetings. Uh, but really it's been, um, more my wife's job, I guess.

Many of the parents did recognize the contribution of the fathers when they were with the children and they appeared to be highly engaged with their children when home.

Donald: And so actually if, and especially Saturday or Sunday I, uh, play with him. Uh, especially on Saturday, my wife go shopping by herself, alone. And I take care of the son and my daughter at home. Or you can, we go out, we can, we go outside and we just, uh, walk. Or we go to the playground with my, just so my son, my daughter and me. We just go outside and play for 2 or 3 hours...only three (laughs).

Georgia: And my husband's EXTREMELY involved, he's not usually here for the IFSP meetings, but, you know, he always gets all the details out of it...so he's very involved when it, how things are working and working what they're towards all her goals, too.

Jaclyn: Jack influences me. You know, sometimes I might respond a certain way, I might not be as firm as I need to be or, you know, I was kind of lax with time outs and he's, he's helped me in that regard.

In one family, the child's grandmother took the child to many of her appointments, but some of the parents discussed their lack of social support in relation to distance from family and friends.

George: We're both from out of town, we don't have family around here, we don't have too many friends around here that don't have kids, so we are fairly isolated to our neighbors, and we got good neighbors.

Donna: There's nobody taking care of her because we have nobody. I don't have any siblings over here.

For one couple, the rarity of their child's diagnosis limited their ability to seek out the help of others.

Fran: It's [congenital hypothyroidism] very rare...it was hard when she was diagnosed, because we didn't know anybody that had been in the same situation to go to and say, 'like what is your experience?'...but, um, I guess that is kind of isolating...there's no sort of parent support group or websites or anything just dedicated to this.

Many of the parents discussed the supportiveness of other parents of children with disabilities in the community or online forums and felt it opened them up to relationships and experiences they did not feel they would have otherwise.

George: Just to get out and, and meet different people and experience different things, and it's very helpful, and a lot of the group members and the adults do a lot of sign language.

Irwin: It is really nice to know that there are people out there who are going through the same struggles. And it's also interesting, too, to kinda share the, you know, share in other people's joys. When their kid makes the breakthrough then it's exciting to, to hear. Um, and you feel good for them and, um, you know, it helps to get hope that [focal child] makes these breakthroughs, too.

Childcare and local churches provided a source of support for some families although there were added complexities associated with having children with disabilities. For instance, Fran indicated that it was difficult to be the liaison between what therapists and doctors wanted and the level of assistance and feedback her childcare provider was able to offer. Another mother commented on the difficulty in finding a church in which she could leave her son during the service.

“They’re experts...?”: Formal social support. Both fathers and mothers mentioned several professionals or service providers that provided some sort of formal social support for them and their children with disabilities. Parents distinguished between medical versus early intervention professionals and, for many, the diagnostic process led to some mistrust of medical professionals given the initial delivery of their children’s diagnoses. Other parents had one or two professionals that they trusted enough to let them guide them in making certain decisions for their children. For fathers especially, there were mixed perceptions on the roles of the doctors and therapists with some referring to them as experts and others feeling that they are just taking a good guess.

Brandon: I feel like I’m the student all over again so I just follow instructions and do what they, they suggest because obviously they’re, they’re experts in this and if they feel it has a potential benefit for [focal male], then I don’t want to neglect him of that.

Chris: Many people are out there trying to, you know, pinpoint which direction you need to go. You know? Your kid should go in this direction, your kid should go in this direction. But, you know, a parent should do what's best for their kids. Um, you know, they're not, they're not perfect.

Frank: I'm also not qualified, I attended to all the questions, even doctors' diagnoses and stuff...I sometimes think they're, I think they're probably taking a good guess, too. And they're trained in all that but sometimes I'm always just like 'man, I see her and I don't', nothing that she does or doesn't do right now, I don't, jumps out at me as like terribly different than my other kids.

Fran: Even though she's diagnosed with it, I've learned enough about the medical profession since having [focal child] (laughs) to know that if you see 2 different doctors and get 2 different diagnoses and thoughts on how you're doing things. And I just try to be really cautious about permanently latching on to these labels because that's just like someone's opinion and if that informs the way we can help her, then that is fine, but, um, I don't just want to become obsessed with like, you know, (laughs) a self-fulfilling prophesy.

At times, there were barriers to accessing formal support in the way of language or location. Some families would drive to middle Tennessee for evaluations, to weekly therapy visits over an hour away from their homes, or even change school systems so that their children could have the best services they felt possible. Nevertheless, mothers discussed the collaborative process with many of the formal support providers in decisions regarding their children's progress and developmental goals.

Georgia: They're very, very helpful with everything... but it's really good that, um, her caseworker is really able to say 'okay, we're done with that goal. Let's, you know, get a new one in here for the next 3 months'. So, it gives us all something to work towards. And then it gives me and the early interventionist some, a common goal or goals. To work together towards, so she's kinda getting it from all directions.

Parents revealed several specifics regarding their relationship with the therapists and interventionists that worked with their children. Most of the parents recognized the contribution of teaching the parents various activities to help their children make progress developmentally. For some parents, they felt that their role as a parent went beyond this.

Brandon: In terms of parenting techniques, they've not really changed anything other than the activities that we've, that we should work on with him.

Brandy: Most of our goals have been helped with the therapist, you know, along the way. I think it really would have been hard to be where we're at with his speech without him having that constant therapy for the past 4 years. Um, he was diagnosed early, so that helped a lot... definitely with his early interventionist. They teach you parenting skills as well as learning skills. So, they definitely recommend singing to your child, reading to your child, um, different activities to play with them and help them. But I, for the most part, as far as caring for them - I mean, that's kind of your job as a parent, too, to do that.

Irene: I also learned a lot of stuff from, he had an early interventionist, when we was really little, and taught me a lot of things that would calm him, like brushing and compression...and his occupational therapist, um, also helped us with that.

Fathers and mothers recognized that there were certain characteristics of the therapists that made them especially helpful in their supportive roles. Parents wanted the interventionists and therapists to have some experience in the field.

Irene: A couple of the therapists, we, we just, we just didn't click as well. And, I've never, we've never had a bad experience...there were a couple of people that I saw who were like REALLY young, like, right out of school, um, and, obviously they didn't have kids (laughs). Um, so they were really helpful like in a clinical setting, but then, um, translating that to parenting in the home, you know, they didn't really have any experience in that and they didn't have any experience with a lot of parents because they had just come out of school.

Fathers wanted therapists to enjoy what they were doing, love their children, and have some level of passion for their work. Several of the mothers felt they benefited more from interventionists who had children of their own because they were different in their approach to completing weekly activities with the children and set more reasonable expectations for the parents.

Alexandra: ...depends. For the ones who have kids most of them kind of do like I do. I've found out. But the ones who don't have kids kind of have a different take on parenting. But until you're a parent, you really can't judge how to parent until you've been there.

Christy: The people that don't have kids just say 'this is what you need do' (laughs) and, and not, they, they definitely don't give examples or have that sympathetic ear maybe, or and then the people that do have kids, they say 'oh, I know it's hard. Can you try to do this?'. And they'll be more specific with their examples, but it's still something they want

you to do and then like OT, she's got some kids at home, other things going on, too. So she'll say 'hey, if you get to it this week (laughs)'. You know, it's just in how they present it to you.

Mothers received feedback from professionals on every aspect of parenting such as teaching, setting boundaries and expectations, and strategies for discipline. Jaclyn felt that the therapists were able to recognize subtle accomplishments in her child that she had not previously noticed and felt she received therapy as much as her child.

Jaclyn: I think they've helped, I mean, they've been able to have a different perspective, um, you know, they can see changes in him probably more easily than I can. You know, for me it just seems so gradual, but you know, a lot of times with them, you know, he's changed so much, he's doing this, and certain things they, they can recognize in his development that I might not, you know, it might be more subtle to me or I might not even realize that, you know, he's able to say a certain sounds or letter combination, constant, or whatever. You know, for the therapist, they might realize that that's a big accomplishment...they are encouraging in that respect.

Christy and Donna both felt that having multiple therapists required that they do too much.

Donna: I was really stressed because I should do this, this, this. Following this, their orders, because they're giving me 2 places, different order and then the other orders from other places...many orders from them, so I'm kinda burnt out. I, I don't do anything ...

“I want him to be in the middle of it”: Peer support/social aspect of child. A social aspect of parenting related to the children's development emerged in several of the conversations with families. This section was included as an influence to parenting because the concern for the

social development of their children shaped many of their parenting decisions. This is not to say that other areas of development were not of concern to the parents, but this area of development, in particular, emerged throughout the interview process. There were two main paths of discussion with some mentioning the importance of playgroups and siblings in promoting development while others expressed concern now and in the future with issues related to bullying.

Both fathers and mothers mentioned the importance of including the children's siblings in therapy sessions as a sort of peer model. They also discussed the necessity of teaching the siblings of the children with disabilities methods for communication and interaction.

Georgia: Then we realized we kinda have a little group here with her sister. So we got, like as a group, kinda put her in a group setting. We put her sister in speech lessons with her and it motivates her to kinda keep up with [sibling's name]. She, you know, if she's not answering the question and then her sister does and she, kinda, you know 'oh, I can do that, I can do that, too'.

Parents also were concerned about their children's interactions with others in relation, at least in part, to their disabilities. For some, they felt that their children were too friendly and did not recognize danger, did not engage in social behaviors, and/or displayed behaviors that were not typical.

Henry: Because of his autism, he's a lot sweeter than a lot of kids. He loves unconditionally, and he's friendly to everybody. And in a way that worries me sometimes because to him there are no strangers, and you can't, you can't explain to him, you know, don't talk to strangers... one of them asked, at one point, 'why is he hugging me?' Well, he couldn't really tell him that he...was glad that they were there, so that was his way.

Irwin: In terms of like social boundaries, we're having some difficulty right now with one of his favorite things to do with people is to, um, is, you know, so he's like getting tall and so he'll go up to someone and just wrap his arms around them and rubbing his face in their crotch (laughs nervously). Um, and I think he just, you know, it's either a stim or he's just trying to express affection through a hug or something. But it's awkward (laughs).

Georgia: She doesn't care so much to interact with the other kids and I don't know if that's part of her hearing disability or if that's just her personality. She likes to BE in the play areas. But as far as interacting with any of the other kids, not a very big thing to her. Other parents mentioned the process of explaining the children's disabilities to other children or adults.

Brandy: One of my friends, her little girl, [friend's name], who's about a year older than [focal child's name] calls 'em his ear plugs because she has to wear earplugs when she swims. So she's like, 'why does he have earplugs in?', you know, that kind of, she's always had to ask that when she was younger. So other kids are definitely, sometimes aware and sometimes they don't notice.

Donald: Sometimes when he play with his friends then I feel some sad because when, when he play he's wearing the, wearing the band, like a hearing aid bandage so some people, some adults, parents, other parent come to me and watch that. Or some kid's come or because they are curious the bandage, the aid hearing aids, then at the time, I feel some sad to answer them. And some kids, ask, the kids, 'he has no ear!'. At the time, I feel a little sad about that.

For other parents, there was an expression of concern with how other children would perceive and react to their children's disabilities. There was long-term concern of bullying, especially when the children's disabilities were more recognizable, such as having hearing aids.

Brandon: While my wife and I may expect some type of teasing and ridicule from his peers throughout the remainder of his life, at some stage he's going to have to get used to that and learn how to deal with it and so we want him to be as involved today as when we did before he was ever conceived or before he was ever born.

Brandy: I think as he gets older they'll notice more... well, a big thing, and I think it's hard with any parent, is, um – I dread the day when he gets made fun of or different things like that. As a parent, even kids that aren't even making fun of him as a, for hearing aids, they might say, and, you know, this is just an example, laugh at his shirt.

Henrietta: I worry about when he gets older, when kids start being mean, and I just, I would like to see him just, Bam! He's just as good as the rest of them, and better, you know, so people don't call him names, and (sighs), all that kinda stuff.

In an effort to limit the impact on their children, parents took steps to build up the children's self-esteem and exposure to children of all levels of ability. They made decisions with regard to playgroups and schools so that their children would either be with peers with a variety of disabilities or those without.

Brandon: I want him to get involved in sports, not, not with the expectation of him becoming a million dollar athlete one day or winning a scholarship for a college. It's just, I like the discipline and more the, um, team-building skills of interacting with other peers his age. I, I think that's important for him because I don't want him to be a hermit, I don't

want him to use his hearing loss as an excuse to isolate himself from society. I want him to be in the middle of it.

Other external influences. The families discussed other external influences to their parenting choices including self-guided learning and various influences (e.g., religion, own parenting).

“Every single child is unique”: Self-guided learning. Fathers and mothers discussed taking the initiative in finding several methods for learning parenting techniques. This was included in the influences on parenting section because this illustrates a variety of methods for how these families learned how to interact with their children with disabilities. Parents learned through trial and error, other parents, and parenting books. Fathers also learned techniques from the mother. Mothers simply observed their children and/or relied on intuition. Resources often were lacking in how to parent a young child with disabilities and that information that was available was more medical than helpful as far parenting strategies. At times, the rarity of the diagnosis left them with no available resources.

Fran: I asked ‘is there like a book I could read?’ You know, I just want information I could put my hands on. ‘No, not really’ I mean (laughs), so, um, you just have to put a lot of trust in what our doctors are saying cause there wasn’t any parents or other sources of information.

Parents also relied on previous experience with their children and children’s videos (e.g., signing).

Erica: I think, we realized early on, how much expressions affect them and children. She watches a lot, so like yeah, if she sees me do something, she’s kinda curious, like what is that about. So, you learn it, and then, I know when we were watching some signing

videos where people were signing books. The, a lot of expressing what's happening in a book is not necessarily reading word-for-word what the book says, but showing what is happening in the book. Which is like, so not me, I'm not usually very dramatic (laughs). So, it's like, I'm having to learn, you know how to express stuff, so that she can grasp it.

Fathers, especially, discussed spending time researching the internet for parenting forums and other resources for working with their children with disabilities (e.g., parenting strategies, forms of therapy). A few fathers felt each child is unique and, accordingly, resources would not necessarily apply to their children regardless of the children's disabilities.

Brandon: I'd like to say that I've read a book on it and was master on it from the beginning. Um, it's really, it's, it's constant learning. Um, today is different from yesterday and while everybody can give you advice on what to expect, and what it's going to be like, every single child is unique.

“And Let That Guide the Way”: Various influences. In addition to the previously described influences on parenting, there were many additional factors that were not represented collectively but a few parents discussed each of the following as influential to their parenting. Fathers and mothers discussed the influence of the manner in which they were parented. Some parents felt that it was the standard by which they wanted to parent their own children whereas others wanted to correct the perceived mistakes made by their parents.

George: My upbringing was very not lackadaisical, but, you know, we were allowed to explore, we were allowed to do anything, the parents weren't strict on any, on very many things. So, it was, and they did same thing, they gave us the tools that we needed to make our own wise decisions. And as we grew older, you know, our viewpoints may differ on some things, but for the most part, I'm raising the girls similar to how I was raised.

Chris: My father was always like ‘you can do it. You gotta follow through with it’. Um, but with [focal male], I’m more of sitting down and saying ‘okay, let’s stop. Let’s think about this. Where, where’s the situation, what’s happening here? How do we fix it?’ . And, and let him think it through so he can do it.

Donna: I was growing opposite way. I was really forced to do EVERYTHING with my parents. They really stubborn and then they’re growing me old ways. So I don’t have good memory with that.

Mothers felt that they were able to take their job or educational experience that related to children and apply that to their own children. Many of the mothers had experience as a nanny, childcare worker, teacher, or, in one case, early interventionist.

Georgia: I nannied for 10 years for a family and I saw, being the nanny of 2, for 2 successful parents, watching, watching how they bought their kids, basically. They didn’t take that quality time, but Christmases were over the top...when they’re, they’re supposed to be studying for a test, you know, ‘come on, let’s go take a break for ice cream’. I mean that just made ‘em smile for 2 days, you know...I wanna create memories. You know, you’re not gonna remember that American Girl doll you got when you were 4 years old, you know. You’re gonna remember the trips to the zoo, flying a kite in the backyard.

Most of the parents discussed the role of religion/spirituality in their decisions as parents. As discussed previously (see “Perspective” section), a few parents felt that having a child with a disability was a punishment from God when they first heard the diagnosis. However, for many parents, the influence of religiosity ranged from wanting their children to be moral to a deep sense of spirituality that was pervasive throughout their lives.

Alex: We just try to hold [our children] to that moral standard. And let that guide the way that we, um, teach our kids, and parent our kids and stuff.

Eric: One of the things that, that we can do is, um, offer some perspective. Um, because, uh, you know, when a parent has a, um, handicap child some way, -that's a emotionally, um, um, i-i-it hurts a parent and they have a, may have trouble coming to grips with that and, in a situation like that, you know, you can offer perspective, um, uh, but, um, you know your perspective is grounded in, um, uh, first principles. In what you know, uh, what life is all about and, uh, your faith in God and things like that...if you're dealing with a parent um, um, who believes in God or has a Christian world view in particular, um, it's much easier to give a person like that, to share your perspective with them.

Because, you know, you think in terms of, uh, not just an earthly life, but in terms of an eternal perspective.

Parents also discussed the path to becoming a parent through various factors such as wanting to have children and/or difficulty in conceiving.

George: Just the excitement of having kids, it just, I just really wanted kids, so it wasn't, whatever it took was gonna, it was gonna happen.

Christy: We tried 5 years to have them and I think that's what changed me as far as being a parent. Because we just waited so long for them and we had so many complications and I don't think that, if I had just been able to have babies when I wanted to have babies, I wouldn't have been as patient or as, um, I don't know. Cooperative, maybe, is not the right word, but like I thought I would be a parent that just said 'no, this is what we're doing and this is how we're going to do it'. And I'm just not and maybe that's because of

waiting. Maybe that's because of who they are. I don't know. But maybe I would have been like that anyway. I don't know.

Other parents felt difficult pregnancies and/or labor and delivery had an influence on their parenting.

Donna: I have a hard time pregnancy, during my entire period, and then I didn't know his issues until he was born and then they found that he doesn't have an outer ear and ear drum, so he cannot hear.

Chris: Overall, I think I'm a lot hard(er) on [focal male]...I believe that what he went through into this world, um, to get here, is there's a purpose for him, um, to be here...I'm a lot tougher on him in reference to, um, making sure he grows up to be, um, a strong man that, that's, you know, makes a difference in the world... from going to not having a heartbeat to making it through that and making it through a NICU. And then making it through hot, heart monitors during when he was at home. I just think there is a purpose for him in life. And I feel that it's important for me to guide him the right way so, you know, so that he makes the right choices.

Frank: You just kind of think back to all the mess that she was in, I mean, she was just hooked up to all this stuff. You know, I'll have little flashbacks to that sometimes and I'll just wanna, you know, maybe when she's being a little fussy, I've kind of got that to fall back on.

Fran: Seeing how there was a period there where we didn't know she was gonna live. And so, we, you know, having come from that point. I mean, it does change the way you see her, you know. She just seems more fragile and delicate and it makes me probably, you know, more worried about her.

Both fathers and mothers attributed some of their children's behaviors to various child characteristics not associated with the children's disabilities. A child's personality (e.g. "she's feisty"), age ("he's too young to understand"), gender ("he's all boy"), and/or birth order ("she's the baby") all were discussed as possible reasons for children's behaviors or abilities.

Frank: Aside from all the therapies and whatnot, she's been so much easier. She seems like she's really (laughs), she is really, just a lot more content.

Jaclyn: I think I've always had the autism on my mind, that everything is due to that, and it's been harder, previously it's been harder for me to see that well, that has his age that's pretty normal.

A couple fathers also felt that the children's interest in a particular parent guided some of their interactions. For instance, Chris stated that his son preferred him and that his daughter preferred his wife, Christy, so he was more likely to engage with his son as a result. However, several parents indicated that all children simply are unique.

Eric: You just cannot treat, um, treat a child with a handicap like that, in the same way as you would another child. Um, um, they're all individuals. And, um, you know you can't parent in a cookie cutter fashion. You have, um, I think adjust to a particular child.

Theme Three: Process of Parenting

A final major theme that emerged throughout the process was the discussion of the actual process of parenting a young child with a disability. All twenty individuals expressed their broad expectations for children as well as more direct behaviors associated with structure and guidance. This section represents the manner in which parents attempt to socialize their children while developing children's autonomy.

Awareness/intentionality in parenting. Both fathers and mothers discussed that they needed to be more intentional in their parenting of their young children with disabilities than if their children did not have disabilities. This was pervasive throughout all aspects of parenting and served as a sort of filter within the decision-making process related to parenting. More specifically, nearly every parenting decision and action required some form of additional thought in an effort to adapt to the presence of a child's disability. They discussed this in different ways as fathers were somewhat less direct in their discussion.

Fathers discussed the awareness of their interactions with their children in drawing attention to sounds and working on skills daily.

Alex: If you have to learn yourself to do that, I guess, you know, just to keep reminding yourself to draw attention to that, draw attention to that, draw attention to that. I've never found it disruptive. But it just, it takes time to, um, to learn yourself to do that.

Brandon: I'm much more inclined to, to kneel down to him, to look face-to-face to communicate so that not only am I ensuring that my voice is projecting where he can hear, but he can possibly read my lips if need be. With my younger son, [sibling's name], who has normal hearing, um, our knee jerk reaction is if he's doing something, we might instantly shout out (snaps) 'don't do that'. And he can hear us whether he's looking at us or not, but [focal male], I want to make sure he gets it. So communicating much more closely to him.

Chris: I don't know if I'd be the same. You know if I had, if he didn't have any hearing issues...I don't think I'd be more of really working as much or harder as I have to now. To make sure he understands and goes the right way.

Mothers, on the other hand, addressed that everything required extra attention. Brandy mentioned that it did not occur to her to parent differently, but the majority of mothers indicated that they were more aware of their parenting decisions.

Fran: [Middle child's name] she's just always been, you know, really bright and just, you know, you almost didn't even have to do anything. Like she was wanting to learn her letters, she's wanting to learn how to add, she wants to learn about everything and just questioning everything. With [focal child], it's more, there has to be a little bit more intervention to make sure she's on track. We have to make sure we watch her a lot closer so. And I worry about her more (laughs lightly).

Mothers felt they were more articulate in their speech and more precise in their teaching than if their children did not have disabilities and revealed that each moment required thought.

Irene: I do the same thing with [focal child's name] only you have to do it in kind of different ways, like you need to really get down in his face when you're talking to him, so he knows that you're talking to him, and um, point out things that are closer because he can't see that far away... I really have to think through, every tactic, I mean, like anything from the way ...that I serve his lunch, like just everything has to be a little bit more mindful than it would have been otherwise.

The mothers felt that it took more initiative on their part to help their children learn skills that should come naturally and often felt they needed to purposefully push their children in areas that potentially made both parent and child uncomfortable.

Georgia: It's just whatever she's looking at, we verbalize what it is. And where [sibling's name] my point to that piece of cake up there, um, say 'here you go' and she'll take it and say 'cake' and walk away. Where [focal child] will say 'You want the CAKE, here's the

CAKE, [focal child]'. So it's more, we're really just trying to verbalize as much as possible, which, you know, can get kinda long-winded during the day (laughs).

Expectations and goals. Parents discussed both long-term expectations and more short-term goals they had for their children that guided the manner in which they interacted with them.

“Capable, but different”: Long-term expectations. Fathers and mothers were similar in many ways in the long-term expectations they had for their young children with disabilities. Both fathers and mothers mentioned that their expectations remained the same regardless of their children's disabilities. They wanted their children to be their best, be good, loving, independent, and happy.

Christy: I think I still have the expectations that I would if they didn't have special needs. I think I still want them to be good kids. You know, to be happy and loving and productive members of society. I don't want them to be bullies, you know, and if they have friends that are different, then we talk about why that friend is different. And not make fun of him, or her, um, so I think I realized as a parent that I don't really care if they're popular or good at sports.

Fathers wanted their children to be strong, follow their own paths, and lead stable and fulfilled lives and mothers wanted their children to have a family of their own. Academics were important to many of the families and a few of the parents expected their children to graduate high school or go to college, but often within the context of it was the children's desire.

Frank: Expectations, um they are the same with all my children, which is I want them to have a happy life, you know, and um, that's just more important to me than anything else, you know...if they're happy, as long as their trying like excel at it, and not just be, you know, um, I want my kids to be, you know, not be implacent and always be learning,

that's my main thing for the kids. I'll always want them to, to love (pause) love learning and to love, and to realize like just because you finish school doesn't mean you're done learning.

Christy: I just want them to be smart (laughs). Like that, like I didn't know that about myself, that I had so much concern for how I, how academically successful they are. But, but I do. I want them to be okay in school. And if C is the best that they can do, then that's okay with me. I want them to be able to do their best.

The parents also had many expectations that were specific to the fact that their children had disabilities. Both fathers and mothers recognized that it was an ever-changing process of identifying expectations for their young children.

Alexandra: You're nervous and you don't know what an outcome will be and I guess, finding out when she's a newborn was, of course, devastating. I looked at my newborn who is everything you wait for for 9 months and you look at 'em and they're not hearing and you think 'she's never gonna know I'm her mother, she's not gonna know my voice, she's not going to be able to tell me she wants this or she wants that.' Then she's 18 months old and she can do just about anything my boys can do, but hear and speak. I mean, she is very, I mean she don't sign a whole lot yet, but she gestures. If she wants something she's going to let you know. She don't have to speak to let you know.

Throughout the diagnostic process, some of the parents felt as if they gave up certainty and that their children may not actually achieve the milestones that they simply assumed they would reach.

Irene: I think I gave up certainty because, you know, when you have a baby, you're certain they are going to learn to talk, they are going to learn to walk, they're going to go

to school, you know, they're going to do all of these sort of things, they are going to learn to ride a bike, all that kind of stuff. Um, these are just things you take for granted, and so I, we had to kinda learn, not to take that stuff for granted. Not to be like, oh yes, he's absolutely going to, you know, go to a typical classroom and graduate from high school. I mean, he's going to graduate from some type of high school, but it might special Ed. So, uh, yeah, I think that, that was the biggest thing, that to just give up the certainty of things that everyone expects their child to be doing, and doesn't even think about it.

The parents indicated that it took time to decide their expectations and expressed concern for choices made now and their future impact.

Alexandra: When you're a parent, you kinda make the best decisions you can for your child. You don't know what's right sometimes, like I was afraid of a cochlear because I was afraid she'd think that I didn't love her and what she was, no matter what...when you are dealing with a child with hearing loss you, you don't have a lot of time to decide, you know what I mean? Cause if I wait until she says 'okay, momma, I want to be hearing', well the chance is probably done passed her by...I either have to make a choice for her or make it and that means that she is, that she's probably not gonna be happy with that choice, you know what I mean?

There also was some apprehension about placing labels on their children as they did not want to create self-fulfilling prophesy. A couple of the parents hoped their children would enter professions in which they helped others in a similar situation, such as an audiologist. One father realized his son may always be dependent on him and another wanted his son to play football, but recognized that this may not be a possibility after he heard the diagnosis of his son's autism.

Irwin: That's a difficult question. One in which my wife and I have grappled with, what our expectations for him. And I think at this point, I mean, I go back and forth because some people have said that I, he could be anything. He could be exactly the same.

Nonverbal, needing help with most every day activities, you know, so serious intervention, assistance as an adult. Or he might be high-functioning...he might have caught up developmentally by the time he's 18 or something...and our, our expectations are that he'll be happy and healthy and (laughs) beyond that, you know, doing our best to prepare for ourselves for the possibility that he may not make a lot of progress.

Some mothers had to shift their expectations, while others tried not to set them too high.

Alexandra: Now I do think that when I first found out, that she was diagnosed, I didn't lessen my expectations, but I guess I didn't know what to expect, if that makes sense. I didn't know if she would...I didn't know how it would be ... Of course, I want her to be hearing and speaking because we're hearing and speaking and my family's hearing and speaking and you don't love them less because they have a disability.

Henrietta: Sometimes I'm afraid, to expect, what would be best to expect, does that make sense? It's like I'm afraid to set myself up for major disappointment, so, I guess I'm trying to limit, in my mind, what his potential may actually be, even though when I look at him I'm thinking Wow! But I don't want to be crushed if it turns out he can't...it's more of a defense mechanism on my part. But, truly when I look at him, and I hold him, and I watch him, I think Wow! If there was just some way to unlock what's blocking him, he could just be amazing. Cause he already is, you know, in my mind... I would like to expect the ultimate, but I try to tone it down in my mind, in case it don't happen because it breaks my heart.

Jaelyn: I just want him to do this best that he can do. I mean, you know, he's, I can't imagine, you know, everything that he's been through in his life, um, I don't really have high expectations. I just, he's a child, you know.

“I’m always wondering”: Can’t versus won’t. The parents mentioned the constant struggle in determining a child’s abilities and this guided most of their in-the-moment decisions related to short-term goals. In the process of setting goals, many of the parents expressed difficulty in determining whether their children were not capable of tasks or were choosing not to do them.

Eric: I think one of the biggest challenges is figuring out, um, you know understanding, trying to figure out what the child can and cannot comprehend and understand. Because that has a big effect on how you discipline your child, how you teach them what, um, um, what sort of expectations there are.

Brandy: That’s why I’m still trying to read parenting books, to figure out. I do find it’s hard sometimes, for instance, if it’s summertime and we’re at the pool he can’t hear me, so I’m either screaming at him and then there’s times I don’t know if he can hear me or if he’s choosing to ignore me. But when he doesn’t have his hearing aids in, it’s hard to know, well, did hear what I just warned him of or told him, and then he’s doing it. So with him, with [sibling’s name], my youngest, I know that I won’t have to think about that. With [focal child’s name], I’m always wondering, it’s so hard to talk to him because sometimes I don’t know if he’s hearing me.

The parents often relied on the child to demonstrate this in some way, but many gave additional chances given the lack of clarity on their children’s abilities.

Georgia: There are times where, you know, we wonder if it's just her personality or if it's her hearing loss that causes some of the frustration that she gets...so, if she's capable of it, we'll expect her to do it and I feel as parents with all the, um, you know, testing and everything that she does and just that 'okay, are you being serious or are you pulling our leg here, trying to get a little something'. You know, being on the ball with that. That we should know what she is capable of.

Also, the majority of children were delayed in their development of language so this lack of ability to express oneself made it especially difficult for the parents to determine what the children understood.

Jaclyn: I just try to figure out what he's trying to communicate and provide, you know, his, um, (pause) his needs that way. It's hard because I don't, you know, we don't always know what he wants, it's easier than it used to be since he has signs and some words, you know, his communication has improved.

One father mentioned it was particularly problematic due to the fact it was his first child and he did not have a framework for what was typical.

Irwin: I feel like one of the difficulties is that since there is that lack of expressive communication back that it's MORE difficult for us to know if he's getting the message. But again not having raised a neurotypical 3-year-old yet, um, you know, that may not be possible period.

Fathers described several methods for trying to determine their abilities such as waiting for the child to request help, letting the child attempt tasks first, or discussing progress with the children's therapists. They also were more likely to interact with children in ways they were fairly confident their children understood, such as getting directly in their children's faces.

Alex: Just trying to spend as much face-to-face time, you know. With her you need to make sure she's looking at you. That you've got her eyesight. Because, you know, if she's not wearing her implant, she can't hear you. Uh, if she is wearing her implant, uh, she isn't good at localizing sounds where they come from, so it's good to make sure you've got eye-to-eye contact with her. And you know, that's just the way I always try to deal with her. Eye-to-eye contact.

Mothers, at times, expected their children to understand because they compared them to their siblings without disabilities or because the children with disabilities previously had demonstrated that they knew a rule. Nonetheless, they discussed the conflict of determining when they should push their children and when they should caudle them.

Christy: ...it's hard to distinguish sometimes between what she can't do and what she's just not willing to try. She's a pretty cautious kid and, um, so I don't know [if she] doesn't want to do it or if she's really scared to do it. And some of that is the apraxia, not knowing what her body can do, and some of it's the sensory integration, not knowing where her body is in space. So, um, she's more of a challenge to parent as far as much to push her and when to push her and when to kind of caudle her and to pick her up...in every other way a very typical little girl... it's rough (laughs, speaks to child). Um, with her especially, when she, when she gets upset, she's so clingy and so vocal. It's very screaming, 'I'm terrified', it's scary stuff. And, so it's hard to kind of step back and say, 'okay, is she really scared or is she really just kind of thinking she doesn't want to try it at this point.'

“Bring her up into the window...where she's just normal”: Short-term goals.

Overall, the short-term goals that fathers and mothers set were related to learning and to building

their children's confidence and self-esteem. Fathers wanted to work on preparing their children for school, whereas mothers seemed more focused on keeping the children comfortable and happy. Parents also had several goals related to their children's disabilities, but their two primary goals were to have appropriate interactions with others and to make advances in language development and this was universal across disability type.

Brandon: Since finding out at an early age of his diagnosis, I've looked at our plans for him and I guess more of a short-term sequence than what I want him to be when he's 25, 30, 50. Right now, I'm focused on making sure we do everything we can and to build up his speech.

Irene: The one thing that, that I would like for him to be able to achieve is to, he really, he desperately wants to make social connections with people, he seeks them out, but the ways in which he does it, it's, it's not going to (laughs) um, foster, sort of, close relationships because he likes to, you know, go out and point people in the eyes (laughs) and stuff like that, that's fun for him (laughs). So, um, we, we are trying to (pause) sort of re-train the way he acts with people, so he can have close friendships and things like that. But other than that, we really just want him to grow up and be able to do whatever it is that he wants to do and be happy.

Some parents wanted their children to "be normal" and be at the same level as their peers.

Frank: We're trying our best to, you know, to get her, um, you know, in, in a window of development, I guess, that's more consistent with (pause) with what they consider normal, I guess...And my broad goals are just to kinda bring her up, I guess, the broadest goal is to bring her up into the window where, you know, she's just normal across board, she's developing at a normal, a normal rate for kids her age.

Fathers also mentioned increased independence and progress with self-help tasks. Mothers wanted their children to demonstrate their abilities (e.g., hearing, comprehension of concept) in some way. Some mothers expressed that building their children's level of confidence was an important goal.

Brandy: Definitely, more intonation in his speech, pronouncing consonants and, um, different words a little bit better, more clear. Um, trying to get him to behave (laughs). Overall, I just want to get a little bit more confidence and self-esteem in him built up, um, but day to day it's mostly my broad goals is speech and language.

One father discussed the importance on not setting limitations on his child because his child makes progress.

Irwin: I think one of the things that I've learned so far in this process is just that he will continue to surprise us and that we really shouldn't set these kind of limitations.

A few of the mothers felt that the accomplishments were bigger when reached compared to their other children. Mothers, unlike most fathers, also discussed the process of setting goals for their children and these often centered on their interactions with Tennessee Early Intervention System (TEIS) and the Individualized Family Service Plan (IFSP) or the school system and Individualized Education Plan (IEP) meetings. As a reminder, six of the eleven focal children were under the age of three and, therefore, were receiving early intervention services and that were guided by an IFSP. The remaining five children were in the school system and had an IEP that specified learning goals and teaching strategies.

Some of the mothers expressed the process of setting goals on their IFSP either too high or too low. They consistently were surprised when their children achieve the goals they originally felt were too high.

Georgia: For her last review, we realized we set her goals too low. We put her vocabulary at 50 words by the time she was 2 and she's already at 50 words now. So we jumped that up. They're very, very helpful with everything...it often gives me hope, like 'you know, okay, I know we set this goal high, but I know she can do it'. Where normally, for like the last one, we were like '50 words by the time she's 2' because she wasn't really speaking any words by her first birthday besides 'momma' and 'dadda'. And I was like 'okay, 50 words, that's good'. Well, now, I mean, she sees flower, water, outside, plane for airplane. So she's got all these verbal skills that I wasn't expecting. A few of the parents indicated that having the IFSP/IEP forced them to push their children in directions they would not have gone without it.

Christy: There will be situations where normally I wouldn't have asked him to talk to a stranger, but that's an IEP goal. Um, and I wouldn't typically say he has to say hi back to someone that says hi back to him or that says hi first to him, but, you know, the only reason I think of it is because I want him to achieve that goal in his IEP. And it's the same with her. I typically wouldn't make her walk into Walmart, but she needs to be able to walk in places that are not familiar to her or are scary to her and so there are people staring at me like I'm a horrible mom or like she's a horrible kid, but you just have to do it, you know? She just has to do it and I just have to not care what other people think (laughs).

The mothers also discussed the process of establishing goals with professionals and felt that, for birth through two, it was a very collaborative process.

Fran: That wasn't that different from how we would've treated any child with, with or without an IFSP. I guess it's made us more aware of, you know, people from Birth to

Three and TEIS and all the people, you know, it makes us more aware of what she should be doing to make sure she stays on track.

Both fathers and mothers expressed their reduced role when the children were in the school system.

Jack: The IEP, it's sort of out there. Something the school deals with and I, honestly, we try to drive that as much as we can. But it, it's sort of like it doesn't really come into play for us at home.

Irene: When you create the IFSP you have to come up with specific goals for the family, uh, to implement in the home so that, you know, that made Irwin and I sit and think "Okay, well what, what is our goal as a family? What, what do we want his role to be in the family? How are we going to facilitate that?" It was super helpful. And then the IEP is just, uh, you know, we, it's more about school setting but, then we see what they want him to do and then we see how we can, um, help that to happen at home.

Structure. Parents discussed the manner in which they provided structure or limitations for their young children with disabilities. All of the parents mentioned factors related to setting boundaries and enforcing discipline.

"They're too dangerous, so then we give him some limits": Boundaries. Fathers and mothers both were consistent on behaviors that they considered inappropriate and required some method of discipline. If the child was engaging in any activity that hurt him or herself, others, or property, they were disciplined.

Georgia: Yeah, when she's physical towards her sister. Not just when she's being rambunctious or getting into something, it's more of pulling hair, if she's biting her, or, or something physical on that end that's one directed...if they're both wrestling with each

other and someone, something happens then it's no big deal. But, when she's physically aggressive then we put her in timeout.

Also, parents provided several examples of safety related issues that required their prompt attention and was a clear boundary such as, turning over a lamp or touching a hot stove. One father mentioned that name calling or spitting were not allowed in his house.

Chris: No hitting, um, no name calling, um, you know, (sighs), you know, the normal stuff. No spitting, you know all that kind of stuff that for young kids, um, I just think that, um, in reference to those, [focal female] can get away with name calling a little bit more than [focal male] would.

Christy: The other thing is like standing on tables, because he likes to jump. So he'll jump from one thing to another thing to another thing. And some things are okay to jump from, some things are not. They're too dangerous, so then we give him some limits. 'You can jump around here to the couch' and if he jumps from the table to the couch again then, you know, that's a timeout. But if it's not dangerous, it's not a regular offense.

Fathers and mothers set the same boundaries for their children with disabilities as they did for their siblings without disabilities, yet discussed some unique differences. One couple mentioned that they would discipline their son with autism for self-stimulatory behavior. Fathers also discussed that discipline was necessary to establish the social boundaries that were unique to their children with disabilities. More specifically, parents would discipline if their children hurt peers' feelings or, for two of the children with autism, if they did not recognize the social boundaries, such as hugging a strangers crotch.

Irene: We do try to limit disruptive behavior, you know, I'm not just going to let him run around wild and say oh he's autistic, you know. We, we try to limit that, but then we have

to realize you can't push him past a certain point. You know, we can't take him out to a really crowded, noisy place when he's really hungry and tired, and expect him to behave himself, which is kind of true of any kid.

“I can't just say something”: Discipline. Fathers and mothers mentioned several techniques for disciplining their young children with disabilities which ranged from redirection and positive reinforcement to timeout, shouting/verbally stern, removal of reinforcement, and spanking/smacking the child's hand. Many of the parents acknowledged the importance of being consistent with the method they chose and that it also was necessary to follow through with their methods of discipline.

Chris: The key is, to discipline, is follow through on what you need to do. You know, follow through in putting them in timeout. If they're gonna hit every time, then it's important to put them in timeout. You can't let them hit one time and then not the next.

Henrietta: When it's really a safety risk I'm better at discipline...and he'll do that for Henry because Henry has disciplined him consistently...but not me, I'll just want to be where he's at, so I'll just let him, do what he wants, and that's not working out real good, and I'm aware of it. But, it's, it's my weakness, not [focal child's name] (laughs).

In many cases, there were specific methods of discipline based on the area of misbehavior. For instance, a father may only spank when the child was behaving in a way that endangered him or her. Fathers would get on the children's level and felt that repetition was key in disciplining their children. Some fathers would explain the reason behind their discipline, while others simply stated “no” when the child was misbehaving.

Alex: Different situations call for different things. If it's something that she's touching that she's not supposed to then I'll hit the top of her hand, just 'no!' (slaps hand). You

know, it's, um, you know something like going outside when she's not supposed to, sometimes that screen door doesn't latch all the way. The boys come back in, you know, I don't go out there and hit her hand (hits hand) cause she's not touching stuff. She won't understand that. You know, I'll go out there and I'll say 'no, no. Don't be outside' and then I'll just bring her back in and set her inside and shut the door. Let her know that she's not supposed to be outside. So I guess it's just different things for, um, you know, what she's actually doing.

Chris: We were raised as, um, when we were kids, we were always spanked as kids. So we really stayed away from that. Um, you know, when we've, when it's been to an extreme, when they, something. We slap their hand. Um, but, um, we try to stay away from the spanking part. Um, and that's just because of the way we were raised. You know, uh, my generation was, you was spanked and then a lot of times you never knew what you did. You know, you were like 'okay, well'. It's just much easier to put them in timeout in their area and then go over what they've done wrong, so they learn that.

A couple of the fathers felt they were more lenient with one child than another, but also felt the mothers were more lenient with a particular one as well.

Alex: I guess at times as much as I try to say that I, I've held her completely to the same standards, I guess there's been times where, I guess, that I, I may have kind of let her slip a couple times with stuff that I wouldn't have let the boys slip with. . . like with the boys, I always tried to, if I tell them to do something, the first time I expect them to carry through with it. And with [Focal Child's Name], I know that she can't always, you know, always understand what I'm trying to get her to do...sometimes it takes a repeated action, uh, uh, you know, or, uh, trying to show her something, you know, to get her to

understand it because of that. So I would, maybe, modify a little bit with her giving her more of a chance to understand it before I would strictly enforce it.

Some mothers selected discipline techniques based on consequences they knew they could keep, whereas others selected techniques based on what was most effective with their children.

Both fathers and mothers discussed the importance of both signing and speaking to their children when they were disciplining them as well as being more expressive. One father (Henry) of a child with autism mentioned that it helped to get his child to count to ten in order to calm down enough to respond to any method of discipline. Mothers mentioned the importance of being much more physical in their discipline techniques in that they often had to run across the room, stomp their feet, and/or get in the children's faces when disciplining them.

Erica: She'll stand on the couch and maybe want to reach for the lamp...and this has been so hard just realizing I can't just say something. I've gotta get to her because she's not going to respond to me saying something (laughs). And if she's not looking at me or I'm not in the near...in the room...that's, that's one of the things I like whoa, because I can't like quickly respond like I normally can with another kid...it looks like she's about to do something dangerous, and I'm like running through the house...I'll stomp my feet, so she knows I'm coming! Or that something serious, and so, I've had to figure out ways to let her know, um, through feeling it, or you know, something, and uh, if I can get to her fast enough, then great. But, um, so she knows (laughs) when we're stomping our feet that's usually a serious thing (laughs).

For mothers, disciplinary action often was guided by their perception of the child's understanding of the misbehavior and subsequent consequence. Christy, a mother of two

children with disabilities, mentioned that her methods of discipline changed from her previous plan of being strict as she had no consequence at times or gave her children more chances.

Guidance. Parents mentioned a variety of factors related to guidance how they feel they are able to promote their children's development and growth as individuals. All of the parents discussed two areas of guidance in parenting their young children with disabilities which are teaching and expressing care and concern to their children.

“I just want to make sure he's inundated with it”: Teaching. Fathers and mothers both mentioned the importance of repetition, following the children's interests, and limiting frustration while teaching their children. Fathers also discussed using everyday moments as teaching tools and making learning fun. Mothers also felt that it was important to constantly urge their children to go to the next level and would let the children try on their own to see if they were able to complete a task without assistance.

Parents also mentioned the influences of the children's disabilities on their methods of teaching. As previously discussed in greater detail in the Awareness and Intentionality section, the families recognized that teaching was more physical and more precise when interacting with their children with disabilities. It seemed important to make a bigger deal of everything they did, such as pointing out the sound of an airplane or labeling an item multiple times. They also found it necessary to learn new methods of communicating and interacting with their children. For instance, many of the parents were learning sign language as the result of their children's hearing loss. Parents, especially mothers, also revealed that getting their children appropriate and, often times, the best services aided in their children's learning.

Fathers mentioned that it was the children's communication was central to their children's learning and that it was necessary to modify based on the skills of their children.

Brandon: I think his learning, while I'm trying to learn much more about his condition and the things that I need to do as a parent, to be sympathetic to it, uh, but also communicating properly to him based on his needs... I just try to work on pronunciation and there's certain sounds softer sounds that he doesn't pick up as well. So while we communicate, he may get irritated with me, but I'll ask him to repeat certain sentences or certain words or certain sounds a number of times, until he tries to get it. I'll work with him on, um, I guess, positioning of his lips and tongue and mouth when he's trying to pronounce these. So, I know other people work with him, already, these other programs. But I just want to make sure that he, he's inundated with it. So he learns how to pronounce an /f/ or /ph/ or /th/ and softer sounds. So it's me getting face-to-face and, and constant repetition, trying to work on those sounds. And social skills, it's just getting him involved in the beginning.

Parents discussed the importance of spending more one-on-one time with their children with disabilities than they felt would be the case of their children without disabilities. It also was important to continue what they were learning at school, but in a more relaxed manner.

Mothers discussed the complexity of teaching their children with disabilities. Some mothers felt they were teaching their children skills that should come naturally whereas others felt they were teaching the same thing, but simply in different ways. It was important to adapt to teaching their children in a different way because they learn in a different way.

Georgia: It's teaching her how to listen, where a typical kid, they have that listening, it's just natural. You don't have to really sit there and enunciate things as crisp as I would with [focal child]. As far as, um, teaching things, it's just more precise. It's not as, um, it's more sit down, let's look at this book instead of just kinda walking around and, you

know, pointing things out...it's just closer contact, I guess, is what it would be. Just to have her ear, you know, right here next to my mouth as I'm talking to her. Um, whereas, you know, another child 'that's black, this is green'. You know, whatever, she's just, it's closer contact and more hands on.

Many mothers felt that they were learning more ways to play and interact with their children with disabilities. Irene expressed the importance of fixing the sensory issues before she could teach her son with autism.

“In every way”: Care and concern. Fathers and mothers expressed love through physical affection, spending time with the child, and play. Irene engaged in “snuggling and cuddling, and just normal like parent stuff”. Fathers also expressed care and concern through teaching their children and, for a few, it was while they also were limiting the frustration that the children feel. Some fathers mentioned the importance of being present and involved in their children's lives, while others felt their greatest method for expressing love was providing for their children through financial means. Mothers expressed that providing individual attention to their children, especially in the case of siblings, was an expression of their love for their children.

Christy: We do a lot of this [referring to a craft activity at the table during the interview], just like being together. And, um, I'm kind of a touchy parent (laughs). We're always, we're always tickling or wrestling or hugging or, you know, we have our cuddle time at night where we watch a movie together... I also do a lot, I try to do a lot of one-on-one stuff with them.

One mother even reported that discipline was a method of her expression of love.

Both fathers and mothers mentioned areas of their expression of care and concern as it related to their children's disabilities. Spending the time and energy researching the disabilities and seeking out specialized services was an expression of their care and concern.

Georgia: Our concern for her, we do everything in our power to get her everything out there that's available to her. Every, um, we go to speaking engagements at [a local center related to deafness] to learn more. We are online, researching things. Um, when we thought she was a candidate for the cochlear implant, we studied everything there was to know about it. So as far as our concern for her, it's, it's about as high as it could get (laughs). I mean, we just want the best that's available to her that we can get. But, other than that, she's just treated completely on, just a, you know, every level scale of how she would if she was not impaired with her hearing.

Also, in their interactions with their children, parents felt that it was important to treat their children the same as others without disabilities and love them regardless of the presence of their delays. On the other hand, fathers also mentioned the intentionality of their interactions in recognizing the children's disabilities and playing and teaching according to the children's abilities.

Alex: Just trying to, uh, effectively, you know, work with her. We're trying to teach her simple sign language like "no" and "yes" and "more" and "cup" and "food" and "eat", uh, but, I mean, just the barrier of just being able to figure out, you know "Does she want more of something?" "Is she done?" "Does she want anything?" or "What does she want in general?" or this and that. It's just been a challenge and just trying to figure her out. The amazing thing about kids is they'll figure out one way or another how to tell you what they want, whether she can talk or whether she can hear you.

Mothers discussed that it was important to be more expressive and really tune into the children to demonstrate their care and concern for the children.

Erica: We hug a lot (laughs) um, just you know, expression, you know, um, she's gonna to read facial expressions maybe more than lots of kids... I guess we've learned to use a lot of expression and stuff. So, she can understand what's going on, since she can't hear what's happening. So, yeah, there's a lot more of um (psst), I don't know, just other um, just uh, you know, touch and sight as much as we can cause she can't hear as much of what you're saying. Um, and just playing with her and spending time, you know, umm, take care of whatever she needs.

Mothers expressed love for their children through their involvement in organizations and therapy visits related to their children's disabilities.

Alexandra: In every way. I think, um, I'm [in a leadership position with an organization related to my child's disability]. You know we're trying to start up for children in families with hearing loss. Um, I think, showing your support for a child with disabilities is she don't ever miss an appointment or if her therapy for some reason gets cancelled or gets switched, to always try to see to it that she gets that day or that time in somehow, no matter what. I mean. My life revolves around my children.

There also was much focus on the constant communication with their therapists and teachers, asking multiple questions, and then following those recommendations.

Irene: I'm very much like protective, like super protective (laughs), so um, I'm always, you know, asking all of the caregivers and the therapist multiple questions, like what are we doing, why are we doing this, you know, how can we, how can we meet his needs better, how can we bring him out better... I really feel like I need to be an advocate for

him, and uh, going in to this, I mean, my husband and I knew nothing about autism, you know, at all, so then I had to do a lot of research and learn about it, and the different sort of ways to reach autistic kids and help bring them out.

Chapter V

Discussion

The present study adds to the body of literature on parenting young children with disabilities in a variety of ways. Previously, the available literature lacked a basic understanding provided by the population of interest as our understanding was based on quantitative measures originating from parents of children without disabilities. In the present study, I focused only on the population of interest and I allowed them to direct the focus of the interviews. This generated some similar experiences to what was previously available in the literature, but also provided novel, unique insight into parenting of young children with disabilities. In addition, previous research was based almost exclusively on mother data, whereas mothers and fathers were equally represented in the present study. Although they were similar at the broadest level, there were differences when examined more closely. Finally, there was a lack of theory for parenting young children with disabilities; therefore, a very preliminary theory was developed from the interviews and will be discussed following the responses to the research questions.

Answering the Research Questions

Research question one. The first research question in the present study is: what are the parenting styles, practices, and behaviors of parents of young children (0-5) with disabilities and what are the various influences on these? To best answer this question, it is necessary to first discuss the meaning-making process for the individual, then various external influences on parenting decisions, and conclude with the process of parenting. Overall, a parent not only made the decisions he or she would have made without the child's diagnosis, but also had to consider additional factors in relation to the disability. This was pervasive across psychological and external factors as well as parenting practices.

It was necessary for parents to engage in a meaning-making process with regard to their role as a parent, family member, and related to the child's diagnosis. The group of parents as a whole was highly involved and invested in the future of their children and the families generally functioned as a cohesive unit. This may be common among all types of families or this particular group of parents may be atypical in their level of cohesiveness. In an effort to best help their children, it may have been especially important for families to work together and provide unified care to their children with disabilities. This is evident, for instance, at both the individual and couple level in which parents of children with disabilities are at an increased risk of stress (Boyras & Sager, 2012; Gerstein, Crnic, Blacher, & Baker, 2009) and accordingly, they must insure that preventative steps are taken to maintain a family unit.

In addition to their perspectives on the functioning of their family, the parents needed to make decisions on how they were going to view and subsequently accommodate a child's disability. Many of the parents seemed to downplay the impact of the child's disability and generally maintained an optimistic attitude. Parents' positive appraisal of their experience of having a child with a disability is supported by the literature involving both mothers and fathers of children with disabilities (Boyras & Sager, 2012; Ekas, Lickenbrock, & Whitman, 2010; Hastings & Taunt, 2002; Trute, Benzies, Worthington, Reddon, & Moore, 2010). However, this also may be due, at least in part, to the age group that selected for the present study. All of the children had already received a diagnosis and families had already made the many adjustments that were necessary to acclimatize the family to their children's disability. Due to the young age of their children, they had not experienced many of the future challenges such as the legalities of the school system, adolescent hormones, or their children's placement and progress upon graduation. It may be that there is a bifurcation of the paths of parenting when the children are

somewhat older. More specifically, parents of children with mild diagnoses (e.g., hearing loss) may maintain their positive outlooks indefinitely, yet those with more complex diagnoses (e.g., ASD), who may be faced with a continuous barrage of challenges throughout life, need to adjust their viewpoints again to accommodate their lived experiences.

There also were multiple self-identified external influences on the process of parenting. Of particular importance for this group were the influences of both informal and formal social support. Many of the families discussed a lack of informal social support (i.e., family, friends) or failed to mention the presence of it beyond their spouses. It is worthy of note that informal social support is related to higher levels of optimism in families of children with ASD, yet the families in the present sample maintained their positive outlook even in the general absence of informal support (Ekas et al., 2010). The limited informal social support was related to a variety of circumstantial factors such as location due to employment or so their children could receive optimal services. Though, it also may be attributed to the uneasiness of leaving children with others due to a potential lack of others' understanding on how to best help their children's unique needs. Additionally, several of the families indicated they felt somewhat judged when their children were loud and/or misbehaved in public, which potentially may make them wary of reaching out to those in the community. A combination of all these factors may somewhat limit the informal social support network available to these families, but it is encouraging that they also mentioned their participation in support and play groups opened them up to relationships they may not have had otherwise.

Nearly every child is exposed to some type of formal social support, such as a pediatrician; however, children with disabilities often are interacting with many service providers and on a much more regular basis (i.e., weekly sessions) than children without disabilities.

Many of the parents indicated that they preferred to have service providers who were pleased with their job, but also specifically noted the importance of them having children of their own. It appeared that for parents, mothers in particular, delivery of the family's weekly goals was more acceptable from someone with personal experience as a parent. It is unclear if professionals were actually delivering the information in distinct ways based on their own family background or if the parents simply perceived a difference. Regardless, parents were more inclined to incorporate techniques for assisting their children if they felt goals were reasonable and consistent with their lived experiences. It is possibly for this reason that they identified the therapist's personal experience as a more valid understanding of their daily events. The formal service providers offered support in establishing goals and techniques, but also a level of accountability in parenting that is not true for parents of children without disabilities.

There also were differences in the perception of service providers based on the age of the child due to the alignment with the form of service delivery mandated for birth through two (Part C) and three to five (Part B; Individuals with Disabilities Education Improvement Act, 2004). Parents of children who received family-centered care often mentioned the supportiveness of their service providers, but families of children who received more educationally-based care discussed the disconnection from service providers. In each situation, both a parent and provider worked to facilitate the child's development, yet the level of unity among them changed based on the child's age. Family-centered service provision is related to positive child and family outcomes and provides support to parents in these early years (Davis & Gavidia-Payne, 2009; King, Kertoy, King, Law, Rosenbaum, & Hurley, 2003). As children age out of early intervention at three-years-old, parents are faced with increased responsibility for advocating for their children and decreased support from service providers. It is important that

families are provided with the necessary tools prior to this transition and have support from community agencies as their formal support system shifts. It remains to be seen if there are any long-term implications of the limited social support network for this group when their children enter the school system.

The families also discussed the process of parenting their young children with disabilities and this was related to expectations, structure, and guidance. There were three especially noteworthy findings related to the process of setting short-term goals for their children. Every parent mentioned that the current goals they had for their children were related to communication and/or building the child's confidence or self-esteem. This means that the presence of the child's disability overshadowed any other developmental goal as, not surprisingly, the area of child's delay was the focus of the family's efforts. Nearly every child had some form of language delay in addition to the primary delay and a few of the children had only recently started on the path to communication (i.e., cochlear implant or sign language). Confidence also was discussed by many of the parents and was related to a future concern for their children being at an increased risk for bullying due to their disability. It was necessary for them to designate this as a goal at this young age as a preventative measure potentially to empower their children. Although communication and building a child's self-esteem may be important for any parent to begin establishing early on, they may not be as predominant of a focus in parenting as it was for this particular group.

Parents also constantly struggled with setting short-term goals due to the lack of understanding of their child's actual abilities. Much of the time, the parents did not know if their child was choosing not to respond to their requests or if they were not capable of completing a task or responding to discipline. Many parents indicated they relied on the child to demonstrate

that he or she understood. This persistent ambiguity may lead to some uneasiness and potentially affect a parent's ability to be consistent in their parenting techniques. Additionally, all of these factors together mean that a parent must give some power to the child, which, in the future, may create difficulties in defiance. Also, many of the parents acknowledged they wanted their children to be "normal". This is consistent with previous research in which service providers encourage parents to treat their children the same as if they did not have disabilities or unique needs (Deatrick, Knafl, & Walsh, 1988). This may be a goal that remains constant throughout the child's development, but the manner in which they define what is normal and how to achieve it likely will change as the child grows older.

Discipline and teaching were highly interactive and necessitated almost constant additional effort from the parent. The parents often needed to be repetitive and physically at the child's level. This required additional time and energy throughout the day and, therefore, it is not surprising that many of the parents were fatigued by the end of the day and/or week. Within this group, parents mentioned they spanked their children or smacked their hands, yet timeout, redirection, or removal of reinforcement was the most common discipline techniques. This is contradictory to the findings of parents of children with hearing loss, in which parents reported that they were more likely to use physical discipline to insure their children understood they had misbehaved (Knutson et al., 2004). It may be that the group in the present sample is unique in their use of less restrictive discipline techniques and/or there is more variability in discipline of children with disabilities than was previously understood.

Parents also had greater opportunity to express their love for their children through participation in organizations or therapies related to their children's disabilities. This increased the demands on time and energy for the parents, but also allowed them an inimitable manner in

which they could demonstrate their care and concern for their children. This suggests that although parents of young children with disabilities are faced with unique challenges, they also have distinctive opportunities resulting from their child's disability.

A conditional matrix (graphic demonstration of findings) is included in Appendix J and is meant to serve as a visual guide. When a child with a disability is present, the components of individual meaning-making and external influences are included as a precursor to the actual process of parenting. They are not meant to be viewed independently, but as complementary and interactive influences on parenting beliefs and practices. The three process of parenting (i.e., expectations, structure, and guidance) are all simultaneously being considered and/or implemented by the parents and are in a constant state of reevaluation. These processes of parenting, in which parents must be more deliberate, are dynamic, reiterative, and affect each other. For instance, a parent who learns a new way to communicate with and teach his child, such as signing, then also may draw upon these same techniques in discipline. These parenting decisions, in turn, shape the individual meaning-making (e.g., constantly reassessing perception of disability and the impact on family) and external influences (e.g. interaction with early intervention versus school service providers) for the parents.

The entire process is affected by time, in that the past influences of the parent and future goals for the child will influence the decisions parents make for their children. Furthermore, as a child grows older their needs and abilities likely will change as well as the expectations and provision of services by professionals (i.e., early intervention to school system). Finally, parenting of young children with disabilities is influenced by the expanded nature of the needs of the children and the alterations in parenting this necessitates. This will be discussed in greater detail later (see development of preliminary theory section).

Research question two. The second research question in the present study is: what are the similarities and differences between mothers and fathers in parenting of young children with disabilities? Overall, mothers and fathers were more similar than different in their parenting of young children with disabilities, but there were a few important differences.

The majority of fathers worked full-time outside of the home whereas the majority of mothers stayed at home with their children. This appeared to have an effect on a father's perceived role within the family system, but also on his ability to communicate with early interventionists and therapists. Fathers mentioned that, when present, they were highly engaged in the decision-making process associated with their children and interacted with them regularly. Mothers independently reporting that fathers' engagement with the children verified this. This is in contrast to previous research concerning children without disabilities in which fathers were more likely than mothers to report higher levels of father involvement (Mikelson, 2008), yet it is supported by research on parents of young children with disabilities who report similar levels (Simmerman, Blacher, & Baker, 2001). This high level of involvement may be partially related to the trend of increasing father involvement in the United States (Pleck & Masciadrelli, 2004). However, it also may be that fathers in the present sample recognized the additional time and energy necessary to help a child with a disability and increased their involvement to match the needs. This awareness of need may be unique to fathers of children with disabilities because there is a notable change that, more or less, draws their attention.

Father involvement emerged throughout both father and mother interviews. Lamb and colleagues (1985) identified dimensions of father involvement that provide support for the present findings which were *engagement*, which incorporates both the physical presence of a father as well as their level of participation with the children, and *accessibility*, the general

opportunity for contact with the children. This was an accurate portrayal of fathers in the present sample given that their overall time with the children was limited, but they were actively involved when they were with them. *Responsibility*, or the manner in which fathers provide care to their children through areas such as financial provision or assistance in caretaking also was identified (Lamb Pleck, Charnov, & Levine, 1987). Many fathers expressed that their role was in provision and spoke at length about various ways they would provide support to their children, no matter the cost. Unfortunately, to be successful in one arena one must make sacrifices in others (Townsend, 2002). For example, if a father chooses to advance in his career to provide more for his family, this limits his time at home; however, if a father chooses to spend more time with his family, this limits his ability to provide for them. Fathers expressed some frustration by their limited ability to be with the children, but indicated that it was necessary, given their role of provision. Overall, it seems that fathers in the present sample were very interested in being active and involved in their children's lives, but were not always able to do so given the barrier of time.

Fathers especially were wary of the service providers and, at times, the actual diagnosis for their children. As a group, men are less likely than women to seek out medical and psychological services for themselves (Addis & Mahalik, 2003; Noone & Stephens, 2008) and it may be that fathers also would be less inclined than mothers to seek services for their children. It is plausible that they are less likely to put their trust in early intervention professionals due to their socialized gender role as a man (e.g., perceived as weak to need help) and as a father (e.g. that is the mother's job). This also may be related to the fact that they were rarely able to be present at important meetings (e.g., IEP) regarding their children's development. Their lack of knowledge about the process and the intricacies of their children's delays may have limited their

understanding and, therefore, trust of service providers. Furthermore, mothers often served as gatekeepers in relaying information from service providers to the fathers (McBride, Brown, Bost, Shin, Vaughn, & Korth, 2005). In this process, some information may have been limited and fathers may have felt distanced from the process overall.

It was necessary for them to not only be present, but it required that fathers be more effortful in their approach for engaging with their children in the constructive manner they desired. It may be especially important that fathers are more effectively included in the early intervention process given their distinctive style of interacting with children (Flippin & Crais, 2011; McBride & Mills, 1993). Their unique approach (e.g., play) in conjunction with the mother's style (e.g., caregiving, teaching) may provide a more diversified, yet comprehensive approach to aiding their children's development.

Development of a Preliminary Theory

Unlike the body of literature on parenting young children with disabilities, the present study is the first to provide a cohesive foundation of knowledge of parenting within this group. The themes that emerged are representative of the voices from all the parents and embody commonalities in their lived experiences. The psychological process of meaning-making and the external influences on parenting are indispensable in more comprehensively examining the process of parenting. However, for the purposes of the development of theory regarding parenting young children with disabilities, it is important to focus the attention on the actual beliefs and practices of parenting for this group. The development of a preliminary theory using the grounded theory approach is the inductive understanding of a phenomenon based on a group of individuals with similar experiences. This serves as a rather abstract, basic understanding of

their lived experiences, in need of further refinement in the development of a more comprehensive and testable theory.

The most notable finding for the present study that was pervasive across every aspect of parenting was the idea that parents are not necessarily altering their parenting, but rather are expanding it. When comparing their parenting to that of a child without a disability, the parents felt they had many of the same expectations (e.g., go to college), goals, and boundaries, used similar discipline techniques (e.g., timeout), and expressed their love and taught their children (e.g., using every day moments) in a comparable manner. However, parenting a child with a disability *also* required that they make certain accommodations in relation to the disability. For these families, they often needed to be physically near the child and at his or her level while being cognizant of their primary goals (i.e., language), making decisions on the child's actual abilities, and trying to incorporate techniques from therapists. It appeared that nearly every moment and action required some additional thought and modification to their parenting. Furthermore, parents were drawing from added input from others, personal experiences as a parent, and increased demands from the child and, therefore, must use additional energy, planning, and time. In order for their children to be comparable to other children's development, fathers and mothers needed to do and consider more and, thus, needed to be more deliberate in their approach to parenting.

The dynamic process of parenting young children with disabilities highlighted the additional demands on the parents that were not effectively captured based on previous theory and research. At the broadest level, parenting styles are the overall manner in which parents elect to aid in their children's development which encapsulates both demandingness (i.e., what a parent requires of the child) and responsiveness (i.e., how a parent responds to the needs of the

child). For families of young children with disabilities, one might also add a component of purposefulness that is indicative of the enhanced attention to choices these parents must make. The parents inadvertently revealed they demanded more of their children given that they wanted them to be similar to their peers, yet the children had some type of delay or difference in relation to their disability. Consequently, the parents needed to be more responsive given the needs of the children were greater than that of children without disabilities. However, it was important that they were proactive in identifying and responding to the children's needs, thus necessitating an intentional approach to parenting. In addition, there was an almost constant re-evaluation of their goals and strategies for best aiding a child's development. Given that this is only a preliminary understanding, future research should further explore the idea of intentionality to both broaden and deepen the understanding of the enhanced version of parenting that is possibly required when a child has a disability.

Parents often were unaware, however, of the multitude of changes they made with regard to their parenting. Parents regularly stated they parented the same regardless of the presence of their children's disability, but then they immediately describe a modification that they made in response to it. It appeared that for most, if not all, of the parents, the manner in which they chose to parent in relation to their children's disabilities was so embedded in their daily life that "to [them] it's normal" (Brandon). A preliminary understanding of parenting young children with disabilities was provided by the present sample, demonstrating an expanded model of parenting in which fathers and mothers make decisions for their children as well as their children's disability.

Comparison to previous literature. To further describe the additional components learned from the present study, it is important to compare the current findings to previous literature on parenting young children with disabilities.

Parenting styles. The current group of fathers and mothers described parenting styles that would be considered authoritative in that they described both high demandingness and high levels of responsiveness to their children's needs. This is in contrast to previous research on parenting young children with disabilities in which, when compared to parents of children without disabilities, parents of children with developmental delays reported higher levels of authoritative parenting, yet parents of children with autism, language delays, and mental retardation reported lower levels (Rutgers et al., 2007; Woolfson & Grant, 2006). It may be that the present group of parents is unique, yet this authoritative, intentional style of parenting was prevalent in the interviews with all twenty parents. Therefore, it appears that many families of young children with disabilities may be quite capable of parenting authoritatively, perhaps given the level of formal support they receive due to early intervention.

Expectations, discipline, and nurturance. In the previous literature, caregivers of children with mild delays reported higher, lower, and similar expectations to parents of children without disabilities (Carson et al., 2007; Keller & Fox, 2009; Tucker & Fox, 1995). These expectations were comparable to the short-term goals discussed in the present study, but generally were more focused on self-help tasks, compliance and educational skills (such as coloring; Fox, 1994). The current group of parents mentioned they felt their short-term goals were similar to what they would be if their children did not have disabilities, with few exceptions, and focused largely on development of language and self-esteem. Additionally, they highlighted many long-term expectations they had for their children with disabilities. For the

current sample, expectations centered on both present and future goals for children and entailed high levels of concern for the child's well-being as well as the need for normalcy in both parenting strategies and the child's developmental goals.

Mothers of children with developmental delays, speech-language delays and hearing impairments reported being more punitive in their discipline than parents of children without disabilities (Carson et al., 2007; Keller & Fox, 2009; Knutson et al., 2004). The current group of parents, on the other hand, discussed many methods of discipline that would be considered less restrictive (e.g., timeout, redirection) than what was previously discussed. As a group, they found methods for establishing and maintaining boundaries with their children, but suggested that it required more work than if their children did not have disabilities. It also demanded additional energy to establish and maintain boundaries for the children given their unique capabilities.

Previously, parents of children with language and developmental delays reported lower levels of nurturance than parents of children without disabilities (Carson et al., 2007; Keller & Fox, 2009). These related to factors such as engaging in activities with the children or physical acts of care (e.g., hugging). Parents in the present sample, on the other hand, felt they expressed the same amount of care and concern for their children with disabilities than they would if their children did not have disabilities. This was consistent across disability type and severity and involved the previous components of nurturance in addition to their expression of love in light of the child's disability. More specifically, fathers expressed many ways they cared for their children through finding optimal services and mothers discussed their role in advocacy and involvement in organizations and therapy services related to their children's diagnoses.

Parenting behaviors. Most of the parenting behaviors discussed in the literature review was so specific to a diagnosis or topic that it is difficult to draw comparisons with parenting behaviors in the present study. However, parents of children with high levels of concern and more severe diagnoses were more directive and less stimulative than parents of children with lower levels of concern and less severe diagnoses (Button et al., 2001; Roskam, 2005; Roskam & Schelstraet, 2007). The parents in the present study reflected on their high level of concern for their children, yet they discussed parenting behaviors that were very stimulative (e.g., engaging in play-based learning activities). Their concern appeared to be a perpetual part of their experience, but was attenuated by their ability to help their children in the present moment. This may be unique to this age group as great gains may be seen in early interventions that are not as pronounced as the children grow older.

Evaluation of the Study

Strengths. The present study was strengthened by the recruitment procedures that were utilized. Many parents indicated that they chose to participate given the recommendation of a service provider with which they were already familiar and trusted. Additionally, my presence at the targeted events paired with the personal introduction by these professionals seemed particularly fruitful in gaining participants for the present study. These gatekeepers of the community of disabilities provided me with support, but also a knowledge base about who was likely to participate. I asked a few families if they would have participated if they had only seen a flyer in a store, as an example, and they consistently indicated that they would not. Unfortunately, this also may have limited the variety of diagnoses, to some degree, as the majority of the participants who elected to participate were referred by two professionals working with highly specific populations (i.e., hearing loss and autism). Every effort was made

to target diverse populations with regard to recruitment sites (i.e., provision of a variety of therapeutic services), but there still was limited diversity in the sample. In future research, I would attempt to attend more events in support of the present population.

Fathers were not only included in the present study, but there were an equal number of mothers and fathers. A primary goal of the present study was to gain any perspective on fathers' perspectives on parenting their young children with disabilities, yet I was able to provide equivalent support for the findings. Several steps were taken to ensure at least some fathers would participate including the use of a targeted incentive, constant reminders to the recruitment team of the importance of their participation, and very specific language used throughout the process. For instance, on the recruitment flyer, fathers intentionally were placed first to demonstrate their importance in the process of parenting. Also, when possible and with a deliberate purpose, fathers were contacted separate from mothers to schedule their interviews. As previously mentioned, mothers regularly were the first contact based on their initiation of contact or on the information that was provided to me and it often took some effort to gain access to fathers separate from mothers. The inclusion of both mothers and fathers in the present study not only provided a diverse perspective, but also a potentially more accurate picture of the lived experiences of these children. Although most of the mothers stayed home with their children, fathers clearly are still present in their lives and work in conjunction with the mothers on the decision-making process of how to parent their children. In addition, the inclusion of couple data allowed me to further examine the manner in which this process occurred.

As part of the interview questions, every participant was asked their recommendations, if any, of how the study could be improved. In the majority of cases, no recommendations were provided and, at times, the parents indicated aspects that they particularly liked regarding the

study. Two primary strengths were mentioned most often including the location of the interview and incentives. Many parents indicated that they appreciated that the researchers gave them the option to meet on campus or at their homes, based on convenience and comfort. One can hope that this choice provided each participant a sense of empowerment in the research process. Parents also mentioned that they appreciated the cash incentive that was made available to them at the time of the interview. With that said, on a few occasions, the families tried to turn it down and many parents indicated that they would participate even without the incentive. Either during the interview or after, they mentioned that they would participate regardless because it was important to them to help future families that are in their same situation. This may be particularly unique to this population (e.g., Dolezal-Sams et al., 2009). In addition, the majority of parents I interviewed mentioned that I put them at ease and did not seem judgmental. Their openness was evident in that they did not only report the positive aspect of their experiences, but discussed aspects of parenting that may have been somewhat contentious (e.g., spanking) or was an area of concern (e.g., future worry with bullying).

Limitations. The present study was limited by the presence of children at the majority of the mother interviews. When scheduling the interviews, I mentioned that it would be *best*, but not required, that children were not present during the interview. However, due to various restrictions (e.g., time, money), it was not feasible for children to not be present during some of the interviews. Childcare was not provided during the present study given the financial limitations and liability associated with this incentive; however, it may be particularly important to include in any future interviews. Both the parents, primarily mothers, and I were distracted throughout the interview as the children required some form of attention. However, I am fairly

confident that my experience as an early interventionist, working in a similar capacity in families' homes, provided me with some experience in maintaining the fluidity of conversation.

The participants were homogenous with regard to race/ethnicity, educational background, marital status, and child diagnosis. This can be attributed, in part, to the homogeneity of the targeted area (race/ethnicity), some aspects innate to the design of the study (marital status, child diagnosis), selection bias, and chance. All participants were Caucasian with the exception of one family who was Asian. Although this family provided some diversity in perspective, the differences often were so unique to their family and culture that it did not help with the development of theory. All but one family was married, but this likely was due to the desire to have both fathers and mothers participate in the present study. Furthermore, single parents may be less likely to have the time and/or energy to participate in an hour-long interview. They likely would provide a unique perspective on the experiences of parenting young children with disabilities and this would be an area of future research. Also, the majority of the mothers were stay-at-home moms, generally related to the presence of their children's diagnoses, and it may be important to further explore differences related to both parent working outside of the home. The previous body of literature on parenting of young children with disabilities included many that also had behavior problems; however, parents in the present study *felt* that their children were generally not as problematic behaviorally as other similar children.

There also was limited variability in child diagnosis. Overall, parents mainly had children with one of two diagnoses, hearing loss or autism. This was related to the fact that the majority of parents who agreed to participate came from two professionals who happened to work with highly specific populations. In line with theoretical sampling, changes were made throughout the course of the study. When I recognized that we were only interviewing parents of

children with hearing loss, I contacted providers working with populations that are more diverse and those that were more severe, such as Autism Spectrum Disorders. The professionals who agreed to help with the recruitment process provided therapeutic services to a variety of children, but few additional families resulted from them. However, it is not surprising that the majority of the cases were mild diagnoses as they are more common and hearing loss was co-occurring with other delays.

An additional limitation was the need for further refinement when addressing fathers as parents. Although several steps were taken to encourage father participation and aid in the interview process, it could have been done even more directly. For instance, areas that may be more aligned with the role of the mother, such as teaching, were addressed quite directly, whereas areas that may be more aligned with the father role, such as playing or providing, only emerged throughout the interview process. In future research, it would be important to be more direct with areas of parenting that may be especially associated with fathering. Furthermore, the fathers who elected to participate in the present study may be more the exception than the rule. None of the fathers expressed hesitation about participating and was very open and willing to share about their experiences parenting their young children with disabilities. They were highly invested in their children's development and most were supportive of their spouses. Therefore, this collective group of fathers may represent the more "ideal" rather than the "typical" parent of a young child with a disability.

Reflections

Pregnancy and parenthood. One of the most consistent reflections I made throughout the process was concerning my pregnancy during the data collection process. At the time of the interviews, my pregnancy was visible and became the topic of much discussion initiated by both

fathers and mothers. Given the subject matter (parenting), parents would comment and then gesture to my expanding midsection. This seemed to indicate that I would have a similar experience or “well, you understand”. It is possible that this helped parents feel more at ease with me than if I was not visibly pregnant and it became more of a conversation about parenting than me simply asking questions of them. In other words, we had a common ground from which to start. As previously discussed, the parents were especially perceptive of service providers having their own children so it may have given me some credibility as a researcher.

Another aspect of the influence of pregnancy was related to the hiatus in the research process, from the end of October to the beginning of January, related to the birth of my daughter. In grounded theory, data analysis is concurrent with data collection and I was developing themes and refining my understanding throughout the process. The disruption in the work may have separated me from the data to a limited degree, but the documentation, reflections, and analysis that occurred throughout the process made me confident that the findings were in line with my original analysis. Furthermore, I believe the re-emersion in the data provided an even deeper and more detailed understanding of the phenomena of interest.

I elected to not conduct a bracketing interview prior to data collection, as I did not feel I had any major biases in relation to this topic. I believe that is accurate; however, near the end of writing of my findings, I found it necessary to document my feelings on parenthood as I recognized much of my feelings mirrored what I was learning from these families. I believe the following statement is the sum of my reflections: “Even while working on my dissertation, I still feel that being her parent is my biggest accomplishment--even though I’m not sure I’ve done anything yet but love her.”

Role as a researcher. My role as a researcher was to serve as a guide for a parent's personal understanding of their experiences. I previously worked as an early interventionist with families of children birth through two with disabilities in a home setting. It was my responsibility to provide the parents with support as well as techniques to encourage their children's development in the areas identified on their IFSP. As an early interventionist, I felt confident in my abilities to understand how to navigate the system and various strategies for promoting development within daily routines. However, I also acknowledged that I was unaware of the lived experiences of these families and the manner in which they made decisions on a daily, or even momentary, basis. As much as I enjoyed working with each child and family and was concerned for his or her development, I did not have to deal with daily hassles concerning care or the social stigma associated with a disability. I also was so focused on the short-term goals that I lacked an understanding of the burden of worry for their children in the long-term. I was cognizant of the limited understanding I had on the actual process of parenting within this group and the need for an understanding as a service provider. Accordingly, I felt that my role as a researcher was to provide voice to families of which little is known. The constructivist grounded theory approach seemed especially suited to the topic in that they parented in unique ways but were unaware of the changes they were making. Therefore, it was my role to work help draw out and tease apart some of these differences.

Special needs versus disabilities. The terminology used in the present study evolved over the course of the study. Upon review of a document "The Case Against Special Needs" (Snow, 2009) the argument was made that the term "disabilities" was more appropriate than "special needs" in addressing the present population. This terminology was reflected in my dissertation as well as documents used in recruitment. However, as the recruitment process

began, one of the members on my recruitment team contacted me and suggested that I change the flyer to say “special needs” as she felt this might be a barrier to parental participation. As a result, I changed the flyer back to “special needs”. As I reflected on this throughout the process, I decided to ask the families their perspective on the terminology used for the present study. I began an interview using special needs, but if they used the term disability, then I followed suit. Although generally, I simply referred to the child by his or her name. I also asked the families during either the individual interview, couple interview, or follow up document “to help this study, do you prefer the term special needs, disabilities, or some other terminology?”. From the individual interviews and follow-up documents, the majority of the parents indicated they preferred special needs, yet most mentioned that they did not have strong preferences. This is only a preliminary understanding and it is possible they were influenced by the terminology used on the flyers among many other factors.

Special needs. Many of the parents mentioned that they preferred the term special needs.

Irwin: Well, I suppose special need maybe sounds more positive, you know, than disability. It’s at least less negative (laughs). I mean, they both describe sort of an ‘other’-ness, right. Someone is different. They’re either less able or they have different needs, right? Special is just another word for different...I think there’s really no good label for something like that.

George: I guess, I, I prefer the term special needs. And the reasoning behind it is, I feel like it is a little bit less derogatory, and not even derogatory, but the, the disability means that to me, that you can’t do something. Where I think, you can do something; you just gotta find a special way of doing it. You, you need to have a different way of doing it. Um, and that’s that’s more based on with [focal child’s name]’s hearing loss, rather than

other complications because I do have friends that are disabled, they, they can't do it.

And at that, at that time it's okay to consider that, but with, with [focal child's name], I would consider it special needs. She needs that little bit of extra care, extra attention, um, just extra one-on-one.

Irene: I don't really like disability for autism because I don't think it's accurate because in my experience of autism, it's, I mean, he's a smart kid. He just, like, something's tweaked a little bit, you know? ...Special needs, I think, works pretty well 'cause he does have special needs. Not every kid needs to have its head squeezed (laughs) every five minutes...I don't get offended if someone says disabled cause, it's, it's you know, it's a very accepted term. I, I think special needs works better.

Other terminology. A couple of the parents mentioned that they did not care or discussed that they may use another term.

Irwin: Honestly, though, they can call it whatever they want if it gets us services.

Henrietta: Special needs seems to be the most politically correct thing that everybody uses, but honestly it kinda irritates me because years ago back in the early 90's I worked for, uh, adult disability. And that was right about the time that saying retarded was negative. But retarded, as a word, just means delayed, stopped, this is as far as they got. It shouldn't be a bad word because it does describe the situation...But it just kinda irritates me that that's been turned into a bad word because it really does describe it well, what's happened to that person. But now that use the words, delayed and special needs, and disabled and all that stuff is fine. But I won't call my child retarded in front of nobody because it's supposed to be soo bad, but technically that's a good word to

describe what's happened to them. If you just look it up in Webster's (laughs), you know. I don't know how that turned into a bad word.

Implications of terminology. There clearly were preferences on terminology that were not completely consistent across all families. From this process, I developed a deeper understanding the manner in which I, as a researcher and practitioner, address families is important and in continual need of consideration. It likely will constantly evolve and, consequently, I believe I am much more aware that the terminology used is weighted and specific to an individual. Although many of the families in the present sample indicated a preference for "special needs", their rationalizations varied. Just as parents of young children with disabilities are purposeful in their parenting, I must be in the manner in which I address them. I believe it is essential to develop a relationship that is supportive and respectful of the family and, within that context, terminology may not be as central of an issue.

Future Research

One area of future research would be the development, implementation, and analysis of a quantitative measure based on findings from the current study. There was much overlapping information between mothers and fathers, yet there were differences in their roles and perceptions. At this point it is not clear if the best approach is to create two separate measures for mothers and fathers or to create a single measure to assess both father and mother perceptions of parenting young children with disabilities. A pilot study of the measure and/or factor analysis of items would provide insight in the appropriateness of one method over another. In addition, although there were many similarities between parenting children within the first five years, there were distinct differences between birth to two and three to five. This was related to aspects such as participating in early intervention (0-2) and entering the school system (3-5) and factors

such as levels of professional support and parental requirements as well as child behaviors and level of independence. As a result, it is important to consider this in the development of a measure of parenting as various items may be more pertinent to one group or another. It may be that one section could be focused on items in which a parent responds based on his child's age.

It is necessary to expand the understanding to a much more diverse population with regard to parent role (e.g., adoptive parents, single parents), parent demographics (e.g., race, socioeconomic status), and child demographics (e.g., child diagnosis). In addition, a significant portion of the findings were considered typical for parents of children without disabilities based on report from parents in this study, an overview of the literature on parenting young children without disabilities, and an understanding developed from working with families for many years. Nevertheless, it would be important to substantiate the degree to which these parenting beliefs and practices are common and the potential influence of the disability on even these more characteristic behaviors. The inclusion of a comparison group of same-aged peers without disabilities and/or siblings would be an important step in refining our understanding of parenting young children with disabilities.

In the present study, I relied exclusively on parent report to develop an understanding of parenting young children with disabilities. A critical next step would be to verify the findings with observation of parent and child behavior within at least one naturalistic setting, such as the home. It may be informative to follow parents throughout a typical day of observing participation in therapy, the transition to the father coming home from work, and representative interactions that occur throughout the day.

Interviews also were conducted with both fathers and mothers together to confirm and revise findings from the individual interviews as well as develop an understanding of how

couples work together to parent their young children with disabilities. All couples agreed to participate in the couple interviews, but only five were completed due to time restrictions. The families that participated were highly cohesive in their approach to parenting, but they presented several methods for working together to raise their children. The analysis of these interviews will provide unique insight into the couple dynamics of the population and should be a next step in research on this topic. It also may be beneficial to perform a content analysis of the transcripts of both the individual and couple interviews to examine features of parenting and the degree to which they are represented, similar to the methodology used in Roskam and Schelstraete (2007). They examined control versus autonomy, yet it may be helpful for the present study to scrutinize the interviews for factors related to the degree of influence of the child's diagnosis.

Implications and Recommendations for Practice

The experiences of parenting a young child with disabilities are both similar and different from parenting a young child without disabilities. Therefore, it is important that practitioners are aware that their experiences are unique and service delivery should correspond with these differences. The families may not be aware of differences in their parenting, yet one must find areas of importance to them and tailor service provision to their individual needs. It is critical that practitioners are able to affirm a parent's positive outlook while balancing the needs of the child with a disability. This particular group of parents maintained an authoritative approach to parenting their young children with disabilities at the cost of the parent's time and energy. Therefore, it may be beneficial to hold them to the same standards that they are holding their children and not use the child's disability as an excuse. They may be expecting the same of themselves that they are of their children and practitioners must be aware and available to provide support as needed. It also may be useful to conduct therapy visits in a variety of places

as many of the parents discussed social stigma. This may consequently educate others in the community while empowering parents to maintain their parenting practices in public.

Fathers generally were not involved in weekly therapy visits or decisions related to a child's disability. This appeared to be due, in part, to work schedules and that many of the mothers were home all day and, therefore, had the role of maintaining services. Many of the fathers appeared to be involved when present and very invested in the child's well-being, so it is important that they are included in this process in some way. It may be helpful to provide an online and potentially interactive tool for displaying a child's goals and progress as well as suggested activities and techniques for helping him or her. A similar system is set up for documentation of services (i.e., Tennessee Early Intervention Data Systems) so it would simply be a manner of making it accessible to families and tailored to their needs. This would potentially limit the responsibility of the mother serving as a liaison between practitioners and fathers and help working families who only see their therapists on occasion. Many parents also suggested the helpfulness of interacting with other parents of children with similar disabilities and it may be advantageous to provide a central website for families to meet with others in similar situations as well as learn about events related to either specific or broad diagnoses. The playgroups appeared to be valued by both fathers and mothers and could be further highlighted within this population.

There also may be certain barriers to parental participation inherent to the structure of service provision and delivery. Fathers feel their role is to provide and some fathers mentioned the importance of early intervention is to provide the resources they need. However, if a father feels his main role is provision and he is not able to do so, this may limit his involvement in caring for his young child with disabilities. In other words, as important as it is to provide the

financial means to service provision, this may be inadvertently distancing a father from involvement in parenting as it relates to a child's disability. There may be additional ways in which we can highlight their role as a parent and what they feel is important to them as fathers.

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Appendix

Appendix A

Search Terms

Parent

parenting
parenting style
parent*
parenting practices
parenting behaviors
childrearing (1990s)

Child Age

preschool
toddler
infant

child*

children

Diagnosis

disability
disabilities
autism
Down syndrome
deafness
blindness
cerebral palsy
speech-language delay
speech impairment
physical disability
developmental delay
delay
disabilities
handicap (1990s)

Instrument

Child Rearing Practices Report
Parent Behavior Checklist
Parent-Child Relationship Inventory
Parenting Style/Parenting Behaviors
Baumrind
Maccoby/Martin

Permissive

Authoritarian
Authoritative
Neglectful
Spanking
Discipline
Expectations
Nurturance
Demandingness
Responsiveness

Other (inspired by Baumrind's constructs)

household chores
environment-enrichment
directive-structure
emotional dependency
infantile behavior
parenting views
views on parenting
firm enforcement
obedience
authority-respect
confidence as parent
independence
reasoning
verbal exchange
anger to child-harsh
gentle
individuality
punitive
unresponsive

Appendix B

Recruitment Flyer

You are invited to participate in a research project on

Parenting of Young Children with Special Needs

You are qualified to participate if:

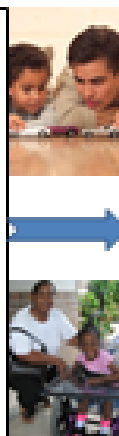
- +You have a child between 0 and 5 years of age with special needs
- +You are the biological father or mother of that child
- +You live in the East Tennessee region



****BOTH fathers and mothers are encouraged to participate!****

If you choose to participate in
the 1st portion of the study:

- +you will be interviewed individually
- +for between 1 and 2 hours
- +at a place that is convenient for you
- +you will be asked questions about
parenting your young child with
special needs
- +you will have the option of
participating in a second phase



If you also choose to participate
in the 2nd portion of the study:

- +you and your spouse will be
interviewed together
- +for between 1 and 2 hours
- +at a place that is convenient for you
- +you will be asked questions about
parenting your young child with
special needs as a couple
- +you must both participate in the
individual interviews first

As a thank you for your participation you will receive:

- +\$25 for an individual interview
- +\$50 for a couple interview

+Each individual will be entered in to a raffle
for a set of 2 tickets to 1 of 3 UT football games this fall!



For more information or to enroll in the study,
please contact Juli Sams at julisams@utk.edu or 865-974-5316.

Appendix C

Family Descriptions

Family One (Alex and Alexandra): The father was unemployed at the time of the study, but previously worked as a pastor and the mother was a student in special education. They had two boys and a girl who had a hearing loss and had a cochlear implant. She received her first cochlear implant approximately five months prior to the interview and was scheduled for her second one shortly after. The family was very active, valued family and mealtime, and felt religion was central to their lives.

Family Two (Brandon and Brandy): The father was employed as a salesman and traveled regularly throughout the month. He also was taking courses towards an advanced degree a couple nights a week. The mom stayed at home with their two boys. The older son had a hearing loss, wore hearing aids and attended a therapeutic preschool during the week.

Family Three (Chris and Christy): The father was employed as a professor and traveled regularly throughout the year. The mom had been an early interventionist, but found it necessary to stay home due to behaviors associated with her daughter's disability. They had a son with a hearing loss and a daughter with apraxia and anxiety disorder. The son attended a therapeutic preschool during the week while the daughter stayed home with her mom and attended therapies.

Family Four (Donald and Donna): The father was employed as a professor and traveled some throughout the year. The mom stayed at home with the children. They had a daughter and a son who did not have a fully developed ear. The family was from Asia and chose to stay in the United States so that their son could have better services than they felt he would have received in their country of origin.

Family Five (Eric and Erica): The father was employed as an programmer and worked long

shifts on four days during the week and then had three days off. They had two sons and a daughter. The daughter's eyelids had to be surgically repaired when she was born and she wore braces on her legs to help her with cruising. She had no hearing (i.e., no nerves present), but they only discovered this after several months of trying hearing aids and looking in to cochlear implants. She was beginning to sign with the help of an early interventionist and her mom. They suspected their daughter had a rare syndrome, but this was not confirmed. Their oldest son had a rare genetic disorder and he would be dependent on the caregiver for the rest of his life.

Family Six (Frank and Fran): The father was employed with the city and the mother was employed with the school system. Frank had a son from a previous marriage who lived with them on the weekends and together they had two daughters. The youngest daughter had congenital hypothyroidism that was discovered shortly after birth. She was on daily medicine and they were watching for potential delays as a result of the hypothyroidism. The focal child attended daycare during the week.

Family Seven (George and Georgia): The father was employed as a project manager and the mother stayed home with the children. They had twin girls, one of which had a hearing loss. They family valued being active (e.g., camping, hiking). They did not have many family or friends nearby. They did most tasks as a family unit when the father was present.

Family Eight (Henry and Henrietta): The father was unemployed at the time of the study and the mother was a nurse. They had a son with autism and he attended school during the week and the family moved to a different county so he could receive better services.

Family Nine (Irwin and Irene): The father was a doctoral student and professor and the mother stayed at home with the children. They had a son and an infant daughter. Their son had autism and was nonverbal. They did not have much extended family, but also discussed that their son's

services would be a major factor in determining where they lived upon Irwin's graduation.

Family Ten (Jack and Jaclyn): The father was employed as an engineer and the mother worked for a bank. They had a daughter and a son, who was diagnosed on with autism. He received his services through the school system.

Appendix D

Welcome Letter

July 15, 2012

Dear [participant name],

Thank you for your willingness to participate in the Parenting of Young Children with Disabilities Research Project! Your interview is scheduled for **[day of the week, date] at [time] and [place]**.

Enclosed is an Informed Consent Form explaining your rights as a participant. Please review this prior to our visit and sign and date the form if you choose to participate. You also may wait to sign the form until the day of the interview if you have any questions.

A brief demographic form also is enclosed. This is simply to provide us very basic information about you and your child with special needs. We encourage you to complete this prior to the visit. Please do not put any identifying information (i.e. your name, child's name, etc.) on this form.

Please feel free to contact me at julisams@utk.edu or 865-974-5316 if you have any questions.

Sincerely,

Juli M. Sams, MS
Child and Family Studies
University of Tennessee

Appendix E

Informed Consent Form

Parenting Young Children with Disabilities Phase I_Individual Interviews

INTRODUCTION

You are invited to participate in a dissertation research project regarding parenting of young children with disabilities. The purpose of the study is to learn about what choices mothers and fathers make in parenting their young children with disabilities.

INFORMATION ABOUT PARTICIPANTS' INVOLVEMENT IN THE STUDY

If you choose to participate in the study, you will participate in an individual interview at a time and location (your home or UT campus) that is convenient for you. The interview is expected to last between 1 to 2 hours. In the interview, you will be asked questions about parenting your child with disabilities. Your interview will be audiorecorded and transcribed by the interviewers involved in this study. You also will have the opportunity to record any additional thoughts or reflections, at your discretion, on an audiorecorder provided by the interviewers.

RISKS

We do not anticipate any risks associated with participation in the study. However, if you feel discomfort during the study, we can make a referral to a licensed, clinical psychologist.

BENEFITS

We do not expect any direct benefits from the study. General overall findings will be made available to you as well as local organizations, which may help inform service delivery. No individual parent responses will be shared with other organizations or families.

COMPENSATION

You will receive \$25 as a token of appreciation for participating and will be entered in to a raffle for one set (two tickets) to 1 of 3 University of Tennessee football games.

_____ Participant's initials

CONFIDENTIALITY

All information in the study records will be kept confidential. Any identifying information, audiorecordings, and transcripts will be stored securely on a password protected jumpdrive in locked filing cabinets. These will be made available only to persons conducting the study unless participants specifically give permission in writing to do otherwise. No reference will be made in oral or written reports which could link participants to the study.

CONTACT INFORMATION

If you have questions at any time about the study or the procedures, you may contact the researcher, Juli M. Sams, MS, at 1215 West Cumberland Avenue, JHB 115 or 865-974-5316 or her faculty advisor, Dr. Vey Nordquist, at 1215 West Cumberland Avenue, JHB 115 or 865-974-6269. If you have questions about your rights as a participant, contact the Office of Research Compliance Officer at (865) 974-3466.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. Your decision to participate or not participate in the study will in no way impact the services your child is receiving. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed.

CONSENT

I have read the above information. I have received a copy of this form.

I, _____, agree to participate in this study.

Signature _____ Date _____

Investigator's signature _____ Date _____

Appendix F

Demographic Form

Parenting of Young Children with Disabilities Research Project

Please fill out this brief demographic questionnaire to provide us background on you and your young child(ren) with disabilities. Please remember that you do **not** put any identifying information (your name, child's name, address or phone number) on this form.

Thinking of your child with disabilities under the age of 6--

I am the child's mother/father (circle one).

My child's date of birth is ____/____/____.

My child's gender is male/female (circle one).

My child's diagnosis/diagnoses is/are _____

My child is receiving the following services _____

If you have more than one child with disabilities, please fill this out for the second child--

I am the child's mother/father (circle one).

My child's date of birth is ____/____/____.

My child's gender is male/female (circle one).

My child's diagnosis/diagnoses is/are _____

My child is receiving the following services _____

If you have more than two children with disabilities, please fill this out for the third child--

I am the child's mother/father (circle one).

My child's date of birth is ____/____/____.

My child's gender is male/female (circle one).

My child's diagnosis/diagnoses is/are _____

My child is receiving the following services _____

[Please go to the next page]

Please circle the answer that fits best (or fill in, when necessary) when thinking of yourself (not your spouse). Remember, do not put identifying information on this form.

Parent Race/Ethnicity

African-American

Asian/Pacific-Islander

European-American

Hispanic/Latino(a)

Other _____

Parent Education Level

Did not complete high school

High school graduate/GED

Some college

Associate's degree/Technical

Bachelor's degree

Some graduate school

Master's degree

Doctoral degree

Parent Age (in years) _____

Employment Status

Full-time

Part-time

Unemployed

Please write your occupation (ex. lawyer, salesman, homemaker)

Years of Marriage _____

Siblings

Please list the other children living in the home that *do not have disabilities*:

Child 1- Gender: male/female

Date of Birth (DOB): ____/____/____

Child 2- Gender: male/female

Date of Birth (DOB): ____/____/____

Child 3- Gender: male/female

Date of Birth (DOB): ____/____/____

Child 4- Gender: male/female

Date of Birth (DOB): ____/____/____

Appendix G

Individual Interview Questions

Original finalized on 8-9-2011

*Updated on 8-18-2011

**Updated on 10-10-2011 (and moved to end of interview on 10-21-2011)

For all of the following questions, please think about your young, child with disabilities.

Remember to prompt further on—*

- Before/after diagnosis*
- Before/after intervention*
- IFSP in setting goals*
- IFSP in influencing parenting choices*
- Professional opinions on parenting*
- Public versus home*
- More appointments*
- Social skills/bullying**
- What does the term parenting mean to you?***
- Do you prefer the term special needs or disabilities? Why?***
- Why did you choose to participate in this study?***

Individual Interviews

Initial open-ended questions:

- 1) How do you feel you express your care and concern for your child?
- 2) How do you feel you support your child's learning?
- 3) As a parent, what are your expectations for your child?

- 4) How do you set boundaries for your child?
- 5) How do you identify limits and consequences for your child?
- 6) In what ways have you modified what you originally planned for your child?
- 7) What are some factors that you feel influence your parenting decisions?

Intermediate questions

- 8) What does a typical day look like for you and your child?
- 9) What are your broad goals when interacting with your child? What are your broad goals with him/her throughout the day?
- 10) In what ways does your parenting usually change throughout the day? Week? Location?
- 11) How do you feel your 'parenting' changed after the diagnosis of your child's special need? [If yes], how so?
- 12) Please describe a positive interaction with your child. A negative interaction.

Ending questions

- 13) What advice would you give another parent of a child with disabilities?
- 14) What struggles have you had in deciding when your child's dependence on you is appropriate?

Appendix H

Follow-up Questions

What does the term 'parenting' mean to you?

Why did you choose to participate in the study?

Do you prefer the term 'disabilities'? 'special needs'? another term? Why?

What role does play have in parenting your child(ren) with special needs?

What percentage (0-100%) of changes in your parenting do you attribute to your child's special needs?

Appendix I

Concepts to Families

- Parents discussed the awareness and intentionality in parenting their young children with special needs. In other words, it took more thought and action in each moment and planning than it would if their children did not have special needs.

- Parents struggled with understanding what their children were capable of and what their children were choosing not to do.

- Parents mentioned that they were concerned with the future prospect of their children being picked on or bullied.

- Parents revealed that they did not want themselves or their children to use the children's disability as an excuse.

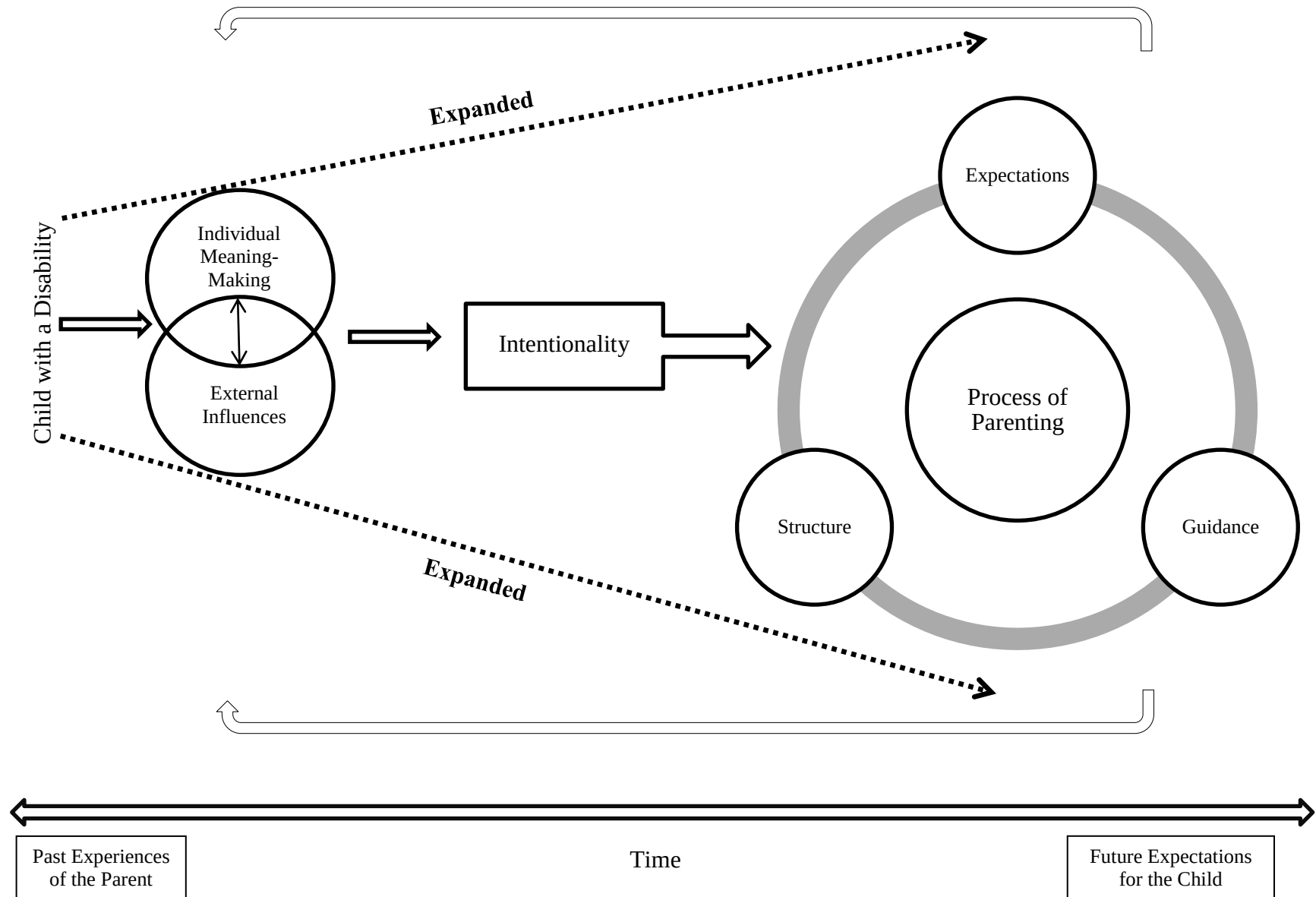
- Parents felt there were not a lot of available resources (ex. books) on parenting young children with special needs, but learned a lot from their spouses, early interventionists and/or therapists, and other parents of children with special needs.

- Parents discussed issues related to parenting in public due to behaviors associated with their children's diagnoses (ex. a child with a hearing loss being loud)

-
-
- Many parents felt they parented the same as if their children did not have special needs, but also described several differences in all aspects of parenting
 - *Expressing love*: advocacy, participating in organizations related to the disability, taking children to appointments
 - *Teaching*: face-to-face, focused on communication, teach concepts/skills that should come naturally, learn new ways to teach through intervention
 - *Discipline/Boundaries*: sometimes gave more leeway than children without disabilities, more physical in discipline (ex. run across room to stop behavior)
 - *Expectations/Goals*: determined somewhat by IFSP/IEP, modified based on children's abilities, gave up certainty that child would achieve milestones, wanted to children to catch up to peers, be normal

Appendix J

Conditional Matrix



List of Tables

Table A.1

Parent Demographic Information

Participant	Parent Age	Employment Status	Education (Highest Completed)	Years of Marriage
<i>Alex</i>	28	Unemployed	High School/GED	6
<i>Alexandra</i>	25	Student	Some College	
<i>Brandon</i>	32	Full-time	Master's	5
<i>Brandy</i>	32	Stay at home mom	Bachelor's	
<i>Chris</i>	34	Full-time	Master's	12
<i>Christy</i>	36	Stay at home mom	Bachelor's	
<i>Donald</i>	41	Full-time	Doctorate	6
<i>Donna</i>	36	Stay at home mom	Master's	
<i>Eric</i>	40	Full-time	Master's	13
<i>Erica</i>	37	Stay at home mom	Master's	
<i>Frank</i>	36	Full-time	Bachelor's	6
<i>Fran</i>	31	Full-time	Master's	
<i>George</i>	30	Full-time	Bachelor's	3
<i>Georgia</i>	37	Stay at home mom	Bachelor's	
<i>Henry</i>	45	Unemployed	High school/GED	6
<i>Henrietta</i>	40	Full-time	Associate's/Technical	
<i>Irwin</i>	28	Part-time	Bachelor's	6
<i>Irene</i>	28	Stay at home mom	Bachelor's	
<i>Jack</i>	41	Full-time	Bachelor's	12
<i>Jaclyn</i>	42	Full-time	Bachelor's	

Table A.2

Child Demographic Information

Family	Child Age (in mos.)	Child Gender	Race/Ethnicity	Siblings (gender, age in mos.)
<i>A</i>	17	Female	Caucasian	Male, 56; Male, 33
<i>B</i>	52	Male	Caucasian	Male, 27
<i>C</i>	58	Male	Caucasian	Female, 28
	28	Female	Caucasian	Male, 58
<i>D</i>	23	Male	Asian	Female, 42
<i>E</i>	24	Female	Caucasian	Male, 122; Male, 89
<i>F</i>	9	Female	Caucasian	Male, 122; Female, 46
<i>G</i>	19	Female	Caucasian	Female (twin), 19
<i>H</i>	67	Male	Caucasian	None
<i>I</i>	38	Male	Caucasian	Female, 6
<i>J</i>	64	Male	Caucasian	Female, 120

Table A.4

Interview Information

Participant	Interviewer	Transcriber	Length of Interview
<i>Alex</i>	Juli	Rhett/Juli	50:38
<i>Alexandra</i>	Juli	Juli	1:06:56
<i>Brandon</i>	Rhett	Juli	1:06:02
<i>Brandy</i>	Rhett	Juli	48:09
<i>Chris</i>	Juli	Juli	56:47
<i>Christy</i>	Juli	Juli	1:04:31
<i>Donald</i>	Juli	Juli	1:01:59
<i>Donna</i>	Juli	Juli	1:03:14
<i>Eric</i>	Rhett	Jessica	1:15:44
<i>Erica</i>	Juli	Juli	1:15:22
<i>Frank</i>	Juli	Jessica/Juli	53:14
<i>Fran</i>	Rhett	Juli	1:18:04
<i>George</i>	Juli	Jessica	49:10
<i>Georgia</i>	Juli	Juli	1:06:09
<i>Henry</i>	Rhett	Jessica	1:10:58
<i>Henrietta</i>	Juli	Jessica	1:20:51
<i>Irwin</i>	Rhett	Juli	1:31:31
<i>Irene</i>	Juli	Jessica	1:02:19
<i>Jack</i>	Rhett	Juli	32:47
<i>Jaclyn</i>	Rhett	Jessica	34:07
<i>Note:</i> Juli conducted all couple interviews.			

Table A.5			
<i>Comparison of Fathers and Mothers</i>			
	Same	Fathers	Mothers
<i>Individual Meaning-making</i>			
<i>Personal beliefs about family and parenting</i>	Value mealtimes, routines, staying active	- Perceived barrier of not at home due to work schedule - Role of provision	Life revolves around children
	Sacrifice	N/A	Stay home due to child's disability
<i>Personal beliefs about disability</i>			
-Perspective	N/A	N/A	N/A
	- Milder than others with similar disabilities - Changed how they viewed their children - Diagnostic process	- Did not see their children as having disabilities - Not convinced of diagnosis	Could always be worse
-Disability as an excuse	N/A	N/A	N/A
	- Not realistic or fair - Use to their advantage	Every child has some limitations	Self-fulfilling prophesy
-Same, but different	N/A	N/A	N/A
	- Speak louder - Be more physical - Professional influence	Not always successful in treating them the same	N/A
<i>External Influences on Adaptation</i>			

Table A.5			
<i>Comparison of Fathers and Mothers (cont.)</i>			
<i>Context</i>			
-Place	• Treat the same • Not always successful	• Caudle more in public than home • Relax at home (distractions)	• Utilized techniques at home
	• Children work hard in therapy (so rest at home) • Public perception • Children's behaviors associated with the disability	N/A	N/A
-Time	• More tired at end of the day/week • More likely to notice misbehavior and discipline	• Attributed fatigue to work	• Attributed fatigue to children
	N/A	N/A	• Attributed fatigue to therapies
<i>Social Support</i>			
-Informal	• Spouses, felt mothers did more caretaking than fathers • Felt fathers were involved • Childcare, churches	• Lack of time with children related to less time in childcare tasks	N/A
	• Online forums • Other parents of children with disabilities • Opened to new relationships	N/A	N/A

Table A.5			
<i>Comparison of Fathers and Mothers (cont.)</i>			
-Formal	N/A	N/A	N/A
	• Professionals (medical vs. early interventionists) • Varied level of trust, • Barriers to access • Teach activities • Want them to have experience	• Mixed perceptions (experts vs. guessing) • Enjoy what (they are doing) • Love their children	• Collaborative process • Better from therapists who have children of their own • Affect every aspect of parenting
<i>Other external influences</i>			
-Self-guided learning	• Trial and error • Other parents • Parenting books • Previous experience • Children's videos	• Learned from mothers	• Observed children, intuition
	• Resources were lacking (especially if diagnosis was rare)	• Online forums, each child is unique	N/A
-Various influences	• Their own parenting • Religion • Child characteristics (age, personality, gender birth order)	• Preference for parent	• Job or educational experience
	• Path to parenting (conceiving, pregnancy, labor/delivery)	N/A	N/A
<i>Process of Parenting</i>			

Table A.5			
<i>Comparison of Fathers and Mothers (cont.)</i>			
<i>Awareness/intentionality in parenting</i>	N/A	N/A	N/A
	Both felt they had to be more aware	- Somewhat less direct in their discussion than mothers - Spoke directly about drawing attention to sounds/daily skills	- Everything required extra attention-more articulate in speech - More precise in teaching, - Each moment required thought - Took more initiative - Purposefully push
<i>Expectations and goals</i>			
-Long-term expectations	- Remained the same regardless of disability - Wanted their children to be good, loving, independent, happy, do their best, succeed academically, guided by children's desires	- Be strong - Follow their own paths - Lead stable - Fulfilled lives	Have family of their own
	- Always changing process - Gave up certainty - Concern for future impact - Avoid self-fulfilling prophesy	N/A	Shifted, tried to not set too high
-Can't versus won't	N/A	N/A	N/A
	- Both struggled with this - Relied on child to demonstrate (difficult due to language delay) - Gave additional chances	- Wait for child to request/attempt - Discuss with therapists - Interact in ways confident children understood	- Compared to siblings - Child previously demonstrated they knew a rule

Table A.5			
<i>Comparison of Fathers and Mothers (cont.)</i>			
-Short-term goals	N/A	Preparing for school, independence, self-help tasks	Comfortable, happy
	- Learning - Confidence/self-esteem - Appropriate interactions - Language development - Be normal - Reduced role in school system	N/A	- Demonstrate abilities - Bigger accomplishments - Setting goals with TEIS/school - Too high or too low - IFSP/IEP pushed them to push their children in tasks they normally would not push - Collaborative process (0-2)
<i>Structure</i>			
-Boundaries	- Consistent on what was considered inappropriate: destructive to self, others, or property, concern for safety - Same as without disabilities	N/A	N/A
	Self-stimulatory behaviors (one couple only)	Social boundaries, hurting peer's feelings	N/A
-Discipline	- Discipline techniques: redirection, positive reinforcement, timeout, stern, remove reinforcement, spanking - Consistent, follow-through - Specific to misbehavior - More lenient with one child than another	- Get on child's level, - Repetition - Some explained, some just said no	- Consequences they knew they could keep - Effective

Table A.5			
<i>Comparison of Fathers and Mothers (cont.)</i>			
-Discipline (cont.)	• Sign and speak when discipline, be more expressive	N/A	• More physical (run across room to get attention) • Guided by child's understanding
<i>Guidance</i>			
-Teaching	• Repetition • Follow child's interests • Limiting frustration • Teach in everything	• Everyday moments as teaching • Fun • Child's communication	• Go to the next level • Allow children to try on their own
	• New methods of communication/interacting • Get child best/appropriate services • Teach differently • Teach more relaxed at home	N/A	• Teach skills that should come naturally • Teach in different ways • Learn more ways to play/interact
-Expressing care and concern	• Physical affection • Spending time with child • Play	• Teaching • Limiting frustration • Being present/involved • Providing	• Individual attention
	• Researching disability • Treating them the same • Loving them regardless of disabilities	• Teaching according to children's abilities	• Expressive • In tune with child • Involvement in organizations and/or therapy visits • Communication with therapist • Asking questions • Following recommendations

Vita

Juli Meagan (Dolezal) Sams completed her Bachelor's degree in 2004 from the department of Audiology and Speech Pathology at the University of Tennessee. She recognized her passion of the disabilities population as a whole and then pursued her Master's degree from the department of Child and Family Studies which she completed in 2006. She strongly desired to gain some experience prior to pursuing her PhD in an effort to better understand her interests and future goals. As a result, Juli took two and a half years off and worked in a variety of settings and it was during this time that she acknowledged a strong desire to help parents, especially those of young children with disabilities. In spring of 2009, she returned to UT to begin her doctoral program and, in spring of 2010, Juli completed the majority of her doctoral coursework and turned her attention to her dissertation work. She has a long-term goal of opening a parent resource center for families of children with disabilities in which services are provided not only to the child, but to the parent and siblings as well.