

**Families of Young Children with Developmental Disabilities:
A Model of the Parenting Process**

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Abstract

Parents of children with developmental disabilities (DD) experience a wide variety of conditions and influences that may affect the parenting process. Researchers have long recognized that child characteristics in particular influence parental behaviors and have demonstrated the reciprocal nature of the parent-child relationship. The main purpose of this study was to identify some of the primary mechanisms by which young children with DD influence their parents' behaviors. 10 couples (10 mothers, 10 fathers) raising young (birth to five years old) children with DD (e.g., hearing loss, autism, hypothyroidism) participated in the study. Following grounded theory methods, parents were interviewed using face-to-face audio-recorded semi-structured interviews that focused on their parenting behaviors and their experiences raising a child with DD. Parents described multiple categories related to the parenting process that highlighted the bidirectional influences between parents and children. The central categories that emerged from the analysis in relation to the overall parenting process were: *life history* (family of origin influences, other life experiences), *child effects* (characteristics of the disability, other child characteristics), *formal social support* (empowerment, homework, differentiating services), *informal social support* (family support, partner support, other parents), *worry and stress* (child's future, child's safety and wellbeing), and *parenting behaviors* (seeking normalcy, regulation, support). These categories are proposed to interrelate in a model illustrating the process by which parents and children with DD reciprocally influence one another. Limitations of this study are identified and implications of this model for future research and practice are discussed.

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Chapter 1

Introduction

Developmental disabilities (DD) are a varied collection of chronic disorders that affect everyday life experiences such as language, learning, mobility, self-help, and independent living (Centers for Disease Control and Prevention [CDC], 2012). DD are lifelong conditions that are caused by mental and/or physical deficiencies (CDC). In addition, researchers have found that from 2006-2008, one out of six children was diagnosed with DD, and current trends show that diagnoses of DD have been on a continual rise since 1997 (Boyle et al., 2011). As such, it is important that key components in the lives families of children with DD receive attention from scholars and practitioners. One such fundamental element in the lives of children with DD is the parent-child relationship. Aside from providing the basic necessities of life, parents of young children with and without DD act as socializing agents that promote autonomy and independence among their children (Baumrind, 1971). However, little is known concerning precisely what types of parenting styles and strategies are most common among parents of children with DD.

Children who have been diagnosed with developmental disabilities (DD) are often referred to as having “special needs”, which is a term that implies a level of attention, care, and treatment above and beyond what might be expected of raising a typically developing (TD) child. In most instances, these “special needs” are overseen and attended to by the parents. As a result, it is important that a better understanding of parenting is developed as it exists among families of young children with DD in an effort to avoid drawing uninformed conclusions and offering ineffective intervention recommendations when working with these families. Of particular interest are the parenting strategies used with children with DD during the early childhood years (i.e. birth to five years old) because this period of time has been shown

repeatedly to be a crucial developmental period in an individual's life (Landry, Smith, & Swank, 2003; Shonkoff & Phillips, 2000).

Parent-Child Relationships

Parent-child relationships are experienced universally across cultures and are often considered the foundational context for child socialization. As a result, the study of parenting and parent effects on children has become a mainstay of empirical research, particularly in the social sciences. A vast majority of research on parenting has focused on identifying how certain parenting strategies and behaviors, whether positive or negative, are associated with various child outcomes such as psychological well-being, behavior problems, prosocial behaviors, and academic achievement (e.g., Rinaldi & Howe, 2012). This unidirectional study of parent-child relationships has generated important understanding of the various ways parents influence child development. However, this approach does not address the various determinants of parents' behaviors.

Scholars have suggested that parenting behaviors are determined by a wide array of contextual factors (Belsky, 1984), and some have put particular emphasis on the importance of considering reciprocal nature of the influences between parents and children (Bell, 1968; Bell, 1979). The conceptualization of parent-child relationships as being bidirectional in their effects is an important perspective for parenting scholars to consider. Equally important for researchers who study parenting to consider is the theoretical perspective they will adhere to when studying parents' behaviors towards children.

Theoretically, parent child-relationships have been studied from a variety of perspectives. However, underlying the majority of these perspectives is the understanding that parents simultaneously attempt to control their children while also promoting their autonomy (Barber & Xia, in press). The two most influential theoretical understandings of parental support and parental control have come from two schools of thought. First is the *typological* approach,

which focuses on distinguishing distinct styles of parenting based on the aggregated levels of parental support and control demonstrated by parents. Researchers who utilize the typological approach often attempt to identify an optimal style of parenting by showing which style is positively associated with child well-being. The second approach is the *dimensional* approach, in which parental support and parental control are considered to be distinct aspects of parents' behaviors that have differing effects on children. Further, the dimensional approach differentiates between behavioral control and psychological control, which have divergent effects on children. Either of the two dominant theoretical approaches to parenting may be utilized when studying how children influence parenting practices.

Parenting Children with Developmental Disabilities

Despite the broad focus and diverse groups studied in the parenting literature, there exists a major oversight of the investigation of parenting among families that have young children with DD. Considering the unique experiences of families of young children with DD, this lapse in the literature is cause for concern. For example, researchers have discovered that these families are at risk for increased stress and poorer health (e.g. Oelofsen & Richardson, 2006; Smith, Oliver, & Innocenti, 2001), low-income (e.g. Parish & Cloud, 2006), and child behavior and emotional difficulties (e.g. Emerson & Einfeld, 2010; Hastings, 2003), all of which have been related to differing parenting expectations and behaviors in families of typically developing children (e.g., Bridgett et al., 2009; Lugo-Gil & Tamis-LeMonda, 2008; Lagacé-Séguin & d'Entremont, 2004). However, the extent to which parents of young children with DD differ in their parenting based on the same influences has not received near the amount of attention from researchers compared to the attention given to parents of typically developing children.

As evidenced by the relatively few studies available for review and their inconsistent findings, the parenting approaches of parents who have young children with DD are not well

understood. Moreover, there are a number of problems surrounding the existing studies of parenting young children with DD. One important oversight of studies on parenting children with DD has been the lack of clarity regarding the theoretical and conceptual understanding of parent-child relationships among this population. Though some have provided a brief overview using a *typological* approach (e.g. Woolfson & Grant, 2006), most have focused on measuring parenting practices (e.g. Keller & Fox, 2009) or parenting attitudes and behaviors (Osborne & Reed, 2009) that are not attached to any theoretical understanding of the parent-child relationship. Without reference to a theoretical framework, a thorough synthesis of the findings becomes a difficult task.

Some researchers have attempted to develop conceptual frameworks for understanding the experiences of families of young children with DD by employing qualitative and mixed methods. However, the lack of consensus among researchers has caused further schisms in understanding. For instance, one theory that has been developed is the theory of *compensatory parenting* in which parents of young children with DD attempt to compensate for a child's disability by providing treatment specific to the nature of the disability, as well as engaging in typical parenting behaviors (Miles & Holditch-Davis, 1995). Similarly, Johnson (2000) asserted a theory of *parental straddling* in which parents attempt to treat their young children with DD as normal as possible while simultaneously acknowledging their disabilities. Finally, more recently the theory of *expanded parenting* has been developed in which parents of children with DD broaden their parenting practices to accommodate the needs of their children (Sams, 2012). While these conceptualizations provide important sensitization to the topic, the lack of consensus in terminology and definition is confusing. Overall, the knowledge of the parenting approaches used in families that have young children with disabilities is incomplete.

The primary purpose of the present study is to provide some conceptual clarity to the understanding of parenting young children with DD. This purpose will be achieved through the

analysis of qualitative interviews that were conducted with mothers and fathers from the population of interest. These interviews will be analyzed for their content related to the broader literature on child effects and other determinants of parenting. As a result, researchers who study parent-child relationships among parents of young children with DD may benefit from a theoretical model that is grounded in the experiences of the population, but also fits within a broader and established literature.

Another key problem concerns how researchers have measured parenting. Although some scholars have been careful to develop culturally appropriate measures of parenting when conducting cross-cultural research among TD children (e.g., Barber, Xia, Olsen, McNeely, & Bose, 2012; McNeely & Barber, 2010), the same cannot be said of researchers who have studied parenting in families of children with DD. In the few studies that have been published, researchers have relied on parenting measures that were developed with parents of TD children (e.g. Carson, Carson, Klee, & Jackman-Brown, 2007; Woolfson & Grant, 2006). These measures may not accurately capture or reflect the experiences of parents who have young children with DD. Further, these measures may not address parenting behaviors that are unique to this population. Therefore, another purpose of the present study is to highlight some of the parenting behaviors that are unique to this population. The hope is that researchers may attempt to develop self-report, observational, and interview measures that more appropriately capture the experiences of this population.

Another problem within the literature is the lack of qualitative investigations of the parenting approaches used by parents of young children with DD. It is imperative that a qualitative, inductive approach is used so that the concepts relating to the overarching construct of parenting may emerge from the population of interest. By so doing, researchers and practitioners can more fully understand the nature of parenting among this population. For instance, parents of young children with DD may offer support to their young children with DD in

ways that have not previously been included in existing conceptualizations of parental responsiveness and support. For this reason, another purpose of this study is to utilize a qualitative, inductive approach to examine parenting of young children with DD by interviewing individual mothers and fathers about their parenting strategies. One of the strengths of using such an approach is the production of a rich data set that is grounded in the perspectives of the population of interest (Mills, Bonner, & Francis, 2006).

A final problem within the extant literature is that, despite arguments for including fathers in these types of investigations (Lewis & Lamb, 2003; Phares & Compas, 1992), the literature is nearly devoid of a father perspective on parenting of young children with DD. However, compared to mothers' parenting practices, fathers provide a distinctive set of parenting behaviors in samples of parents of children without disabilities (e.g., Casas, Weigel, Crick, Ostrov, Woods, Yeh, & Huddelston-Casas, 2006; Volling, Blandon, & Gorvine, 2006). Consequently, another purpose of the present study is to purposively include fathers' perspectives of parenting their young children with DD. Including fathers in a study of parenting adds credibility and trustworthiness to the data as well as the opportunity to compare mother and father perceptions of parenting practices. In addition, responses from fathers will provide vital information towards developing a conceptual understanding of the parenting process among both fathers and mothers of children with DD.

As previously noted, parents of young children with DD are among some of the least well understood and most infrequently studied populations in the parenting literature. While a very small number of quantitative studies suggest that these parents differ significantly in many ways from populations of parents who have typically developing children, most of these findings are based on the use of measures that were developed among families of typically developing children (e.g. Carson et al., 2007; Woolfson & Grant, 2006). The underlying question that these studies are not able to fully answer is the specific ways in which parents of young children with

DD differ in their parenting practices from parents of TD children. In other words, though it appears that parents are influenced by having a child with DD in ways that are distinct from the child effects experienced by parents of TD children, the mechanisms by which those effects operate are unclear.

The following literature review will further elucidate the current limitations described above and will be presented in three major sections. There will be an illustrative literature review of the broad literature regarding parent-child relationships that will be divided into two major sections: first, recent studies related to *typological* approach and the *dimensional* approach will be reviewed to illustrate the current state of research utilizing these approaches. Although other conceptual approaches to the study of parenting exist, these two have provided the theoretical foundations from which most other conceptualizations have emerged and have inspired a large base of empirical support. The second section of the illustrative review will focus on illustrating how researchers have studied the parenting process among this population, with specific attention to studies that have emphasized the reciprocal effects of having children with DD.

Following the illustrative reviews, a comprehensive review of the studies on parenting young children with DD will be presented. Given the primary interest in demonstrating how children with DD influence parenting behavior, the review will highlight important findings that demonstrate those effects.

Chapter 2

Literature Review

Parenting Typically Developing Children

Parenting scholars have suggested that parenting is best represented as a duality between freedom and control (Baumrind, 1978; Barber, Stolz, & Olsen, 2005; Rollins & Thomas, 1979). In other words, parenting in its very nature is a multidimensional construct consisting of attempts to promote autonomy while simultaneously exercising authority over children. As a result, researchers have attempted to investigate the various manifestations and degrees of control employed by parents over their children. Schaefer (1965) introduced a conceptualization of parenting based on parenting *dimensions*, which has been revisited and refined by other scholars (e.g. Barber, 1996). According to Barber (1996), specific parenting behaviors operate along three distinct parenting dimensions: *support*, *behavioral control*, and *psychological control*. Each of these dimensions have been shown to have unique, disaggregated effects on adolescent psychological functioning (Barber et al, 2005).

The *typological* conceptualization of parental control introduced by Baumrind, however, is based more on the assumption that parenting *styles* are an aggregate function of the demands placed on children by parents and the responsiveness of parents to their children's needs (Baumrind, 1971). In other words, parenting styles consist of the varying combinations of how parental authority and parental nurturance are expressed towards children. By aggregating patterns of parental authority with levels of parental warmth, specific categories, or styles, of parenting can be discerned.

Other variations in the conceptualization of parental control have largely been based on the dimensional approach, the typological approach, or some combination of the two (for a review, see Darling & Steinberg, 1993).

In measuring a construct as broad and diverse as parenting, various methodological approaches have been utilized. To some extent, each of these approaches reflect some conceptual understanding of the purpose and role of parents in the lives of their children and often highlight which parenting approaches are beneficial towards children and which are associated with harmful childhood outcomes. Both the dimensional and the typological frameworks are important conceptualizations of the basic components of the parent-child relationship and highlight beneficial and detrimental parenting strategies. The purpose of this section of the literature review is to provide an illustrative demonstration of how researchers have recently used both the typological and dimensional frameworks in their studies of parenting.

Parenting typologies. Baumrind's original conceptualization of how parents exercise control over their children focused on three distinct *types* of control, namely: authoritative, authoritarian, and permissive (Baumrind, 1966). According to this theoretical perspective, parenting typologies are characterized by the level of responsiveness combined with the level of demandingness displayed by parents during interactions with their children. The intersection of demands on one axis and responsiveness on the joining axis produced the three main parenting styles: *authoritative* parenting (high demands, high responsiveness), which is characterized by efforts to encourage children to conform while simultaneously maintaining a sense of self; *authoritarian* parenting (high demands, low responsiveness), which uses punitive disciplinary techniques in order to ensure that children will conform to parental expectations; and *permissive* parenting (low demands, high responsiveness), which is characterized by a low degree of parental authority and more child-directed childrearing (Baumrind, 1971). More recently, *neglectful* parenting (low demands, low responsiveness), has been introduced as a fourth parenting style, which includes absent and uninvolved parents (Maccoby & Martin, 1983).

Since the development of these four parenting styles, scholars have made several attempts to refine the typological approach and have introduced new terminologies that discriminate patterns of authority within the main parenting styles (e.g., Baumrind, Larzelere, & Owens, 2010), or have used alternative terminology such as *indulgent* rather than *permissive* parenting (e.g., Lamborn, Mounts, Steinberg, & Dornbusch, 1991) to describe parenting styles. However, the authoritative, authoritarian, permissive, and neglectful parenting styles reviewed previously are the terms most commonly associated with a typological approach. Generally speaking, scholars have regarded authoritative parenting as optimal, permissive and authoritarian parenting as having a mix of positive and negative effects on children, and neglectful parenting as detrimental to children (e.g., Baumrind, 1966; Lamborn et al.). However, some have argued that the effect of authoritarian parenting may not be consistent or relevant in other cultures (e.g. Chao, 2001; 1994).

Scholars have used a variety of methods to investigate how various parenting styles affect children. Originally, Baumrind (1971) used observation and interview methods to assess various patterns of parental control among 146 families of young, typically developing children. This approach allowed for a more objective assessment of parenting behaviors as they occur in a natural environment. Others have argued that measuring parenting from the child's perspective yields a more accurate depiction of how parenting affects children. For example, Lamborn and colleagues (1991) measured dimensions of parental restrictiveness and acceptance among approximately 4,100 adolescents to test Maccoby and Martin's (1983) classification of parenting styles. However, it has also been argued that using a child's perspective to examine parenting may only be advantageous among adolescent children and that preadolescent children may not provide accurate assessments of their parents' behavior (Robinson, Mandleco, Olsen, & Hart, 1995). Consequently, researchers have attempted to design parent self-report and partner-report questionnaires based on Baumrind's typological

conceptualization of parenting (e.g., Buri, 1991; Robinson et al., 1995). In all, there is no clear consensus of what methodological approaches are preferred for measuring Baumrind's parenting styles. The articles reviewed here were chosen based on their ability to illustrate the current state of research and the variety of methods employed in studies of parenting typologies among families with young, typically developing children.

In some recent studies of parenting styles, researchers have chosen to focus exclusively on measuring the effects of a single parenting style on children. As mentioned previously, this is especially true of assessments of whether the effects of authoritarian parenting are universal or dependent on cultural context. Chan (2010) investigated whether authoritarian parenting, children's negative emotionality, and negative coping styles had independent or joint effects on children's aggressive behavior at school. Teachers and parents of 185 (95 boys and 90 girls) children from Hong Kong between six and eight years old participated in the study.

Authoritarian parenting was measured using the authoritarian subscales from the short form of the Parental Behaviors Questionnaire (Russell, Hart, Robinson, & Olsen, 2003), which had been shown to be reliable and valid measure of Chinese parenting in previous studies (e. g., Chen & Luster, 2002). Chan reported an internal consistency of .79 for the authoritarian subscale in this study.

Through the use of structural equation modeling, Chan (2010) found that authoritarian parenting had a positive, indirect effect on child's aggressive behavior at school mediated by the child's negative coping strategies. In other words, an increase in authoritarian parenting predicted an increase child's negative coping, which then predicted an increase in aggressive behaviors. This type of mediation analysis allowed the author to explain why researchers had not previously found a direct effect of authoritarian parenting on child aggressive behavior among Chinese samples. The author interpreted these results through the lens of social learning theory, suggesting that children learn negative coping strategies and aggressive

behaviors from observing these behaviors from their authoritarian parents. Overall, this study demonstrates how some current studies of parenting that use a self-report measure focus on particular elements of parenting and the parent-child relationship rather than parenting in its entirety. Further, this study validates previous assumptions about the detrimental effects of authoritarian parenting on children across cultures (Nelson, Hart, Yang, Olsen, & Jin, 2006).

In other recent studies, researchers have developed sample-specific parenting typologies. Using self-report methods, McNamara, Selig, and Hawley (2010) investigated the links between self-reported maternal parenting behaviors and aggression, personality, and peer esteem of young children three to six years old. The purpose of the study was to use a typological approach to illustrate relations among parenting practices and child behaviors. However, the actual scale used to measure parenting styles (Hawley, 2003) had not previously been used in the typological literature. The sample consisted of 119 mothers of three to six year old children who completed an assortment of self-report measures concerning their child's behavior, child's personality, and peer acceptance. Mothers also responded to a number of items that focused on parental restrictiveness, nurturance, parental monitoring and autonomy support. Using exploratory factor analysis, the authors identified two parenting factors from a total of 14 items. The first was the firm autonomy support (FAS) factor ("I let him/her know his/her ideas are valuable"), which consisted of nine items and had a Chronbach's alpha of .82. All of the items loaded above .87, indicating a strong factor. The second factor, restrictive control (RC; "I give him/her a tough punishment when s/he does something wrong") included five items with an alpha of .75. Three of the items loaded above .92 and two loaded at .63. Factors were correlated at $r = .23$, showing independence between the factors. The authors grouped mothers based on their responses to parenting items using a *k*-means cluster analysis, which produced a three-group solution: a low FAS, high RC group ($n = 33$); a high FAS, low RC

group ($n = 40$); and a high FAS, high RC group ($n = 46$). The authors used these groups to determine how to define parenting typologies.

McNamara et al. (2010) found that children of mothers from the low firm autonomy support (FAS) and high restrictive control (RC) cluster were more aggressive, less pleasant, less hard-working, less out-going, and less well accepted by their peers than children of mothers from the other clusters. The authors suggested that their findings demonstrate the importance of parents using autonomy support in parenting young children, especially in buffering some of the negative effects of restrictive control. Further, the authors contended that their study illustrates the importance of including autonomy support as a fundamental domain of parenting, which the authors claim was overlooked in previous studies using the typological framework. This study exemplifies how recent studies utilizing a typological approach may use statistical analyses to develop typologies based on responses from their samples rather than relying on previous conceptualizations of parenting typologies.

Finally, Baumrind's recent work has involved the use of observational and interview methods in a longitudinal project investigating how patterns of parental authority during the preschool years affect children in the adolescent years (Baumrind et al., 2010). Rather than investigating the four traditional parenting typologies, the authors were interested in how parents of preschool aged children might utilize seven possible patterns of parental authority, ranging from *balanced-committed* styles (*authoritative*, *democratic*, and *directive*), a *good enough* style, and *imbalanced-uncommitted* styles (*disengaged*, *permissive*, and *authoritarian*). The sample consisted of 87 families that began the study when their children were in preschool as a part of a larger program of research. The researchers adhered to strict and rigorous methodological standards to ensure credibility of the data. Specifically, trained research associates spent an approximate total of 30 hours observing, interviewing and testing parents at several time points in multiple natural environments such as in the home, classroom, and playground, as well as

laboratory settings. Parents also completed project-designed measures: an 81-item mother and father preschool rating scales at Time 1, and a 174-item rating scales for parents of adolescent children at Time 3. The mean Time 1 Chronbach's alpha was .76 for mothers and .75 for fathers, and ranged from .60 to greater than .89 overall; at Time 3, inter-item reliabilities ranged from .48-.96 with a median of .86.

Directive, democratic, and authoritative patterns of parental authority that were exercised during the during preschool period (all variations of authoritative patterns of authority) were associated with competent and well-adjusted adolescent functioning when compared to adolescents whose parents were *authoritarian, permissive, or disengaged* during preschool. Among the most destructive parenting practices were verbal hostility, psychological control, physical punishment, and arbitrary discipline. These findings further validated the detrimental effects of authoritarian parenting and highlighted the value authoritative parenting. Furthermore, this study provides important insights into the variation that exists within each parenting typology, with particular attention to the authoritative parenting style. Overall, this study set a high standard for generating theoretical assumptions about how parental patterns of authority during the preschool years may affect children in their adolescent years. Furthermore, this study delved into the complexities in how parents exercise authority over their children and specified a more current description of parenting typologies.

Summary of typological studies. The studies reviewed here illustrate the advantage of using a typological approach in combining parental demandingness and responsiveness to categorize parenting strategies into independent parenting styles. Authoritative parenting and its parallel forms (e.g. firm autonomy support, directive parenting, democratic parenting, etc.) have been associated with improved psychological functioning among typically developing children and adolescents (Baumrind et al., 2010; McNamara et al., 2010). The consideration of authoritative parenting as the optimal parenting style has led scholars and practitioners to

emphasize one, overall message that parenting which consists of high expectations, high nurturance, and is supportive of the child's autonomy will lead to the best outcomes for offspring. On the other hand, parenting that lacks support and is overly restrictive, intrusive, punitive, and psychologically controlling has been shown to lead to internalizing and externalizing behaviors among children and adolescents (Barber et al., 2005; Chan, 2009; McNamara et al., 2010). The emphasis on these two main styles of parenting as examples of what is considered to be "good" parenting versus "bad" parenting exemplifies an interest among researchers and service providers to generate models for the general public to both mimic and avoid. In this way, the typological approach has a practical appeal that has led to its popularity among educators and other professionals.

Parenting dimensions. The dimensional conceptualization of parenting was introduced by Schaefer (1965a, 1965b) and consisted of three dimensions: (a) acceptance versus rejection, (b) psychological autonomy versus psychological control, and (c) firm control versus lax control. Through this approach, Schaefer focused on measuring how child outcomes were associated with distinct parenting behaviors. As mentioned previously, the main difference between the dimensional approach and the typological approach is that the dimensional approach seeks to address how distinct and disaggregated components of parenting predict specific child outcomes, whereas the typological approach addresses how aggregated dimensions such as warmth and parental authority affect the child socialization process. Further, the dimensional approach offered by Schaefer differs from the typological approach in the distinction that is made between the effects of *psychological* control from *behavioral* control on childhood functioning. Finally, Schaefer also introduced the Child Report of Parent Behavior Index (CRPBI), which employed a method of measuring parenting based on the child's report rather than through direct observation that was used by Baumrind (1966). The CRPBI was originally developed from Schaefer's (1965a; 1965b) cluster analysis of detailed lists of

parenting behaviors provided by psychologists. According to Barber et al. (2005), the CRPBI and its many subsequent versions has become one of the most popular measures of parenting behaviors available.

Since Schafer's work (1965a; 1965b), Barber (1996) and colleagues (2005) have revisited and refined the dimensions of parenting, labeling them as parental *support*, which includes accepting, nurturant behavior and is positively related to adolescent social initiative; parental *psychological control*, which includes intrusive and demeaning behavior and is linked to an increase in depression among adolescents; and parental *behavioral control*, which includes behavioral monitoring and regulation and is related to a decrease in adolescent antisocial behavior. While parental support is almost universally regarded as a beneficial quality of parenting, behavioral control is considered advantageous when it is reasonable and occurs in the absence of psychological control. The latter has been demonstrated to be deleterious for adolescents across cultures (Barber et al., 2005).

A recent study sought to establish the psychometric strength of the three-dimensional parenting framework by using a multitrait-multimethod analysis, which involves measuring multiple traits from several informants (Kuppens, Grietens, Onghena, & Michiels, 2009). More specifically, this approach provides the opportunity to test discriminant validity, convergent validity, and criterion validity. The sample consisted of 600 children (301 boys, 299 girls), 596 mothers, and 560 fathers living in Belgium. Each participant completed 24 items, with eight items measuring psychological control from the Psychological Control Scale – Youth Self Report (Barber, 1996), and eight items measuring parental support and eight items measuring behavioral control from the Ghent Parental Behavior Scale (Van Leeuwen & Vermulst, 2004). Participants also completed the Dutch Strengths and Difficulties Questionnaire (Van Widenfelt, Goedhart, Treffers, & Goodman, 2003) to provide an external criterion to measure against the measures of the parenting dimensions. Chronbach's alpha for all of the subscales from each

informant group showed acceptable internal consistency reliability at above .70, with the exception of child report on maternal psychological control ($\alpha = .66$). The authors used confirmatory factor analysis and correlated uniqueness models from the within-informant subscale scores to test their hypotheses.

Kuppens et al. (2009) found that in general, the psychometric properties of the three-dimensional framework were acceptable. More specifically, results from the confirmatory factor analyses and correlated uniqueness models consistently showed that mothers, fathers, and children reliably differentiated between parental support, parental behavioral control, and parental psychological control via responses to questionnaire items. Further, support and behavioral control were positively associated with child prosocial behavior, while psychological control was related to conduct problems and child internalizing problems. This study demonstrates important methods for validating the measurement of parenting dimensions from multiple perspectives. However, other more recent studies have focused on parsing out some of the variability in the construct of psychological control as well as establishing its cross-cultural relevance.

Soenens, Park, Vansteenkiste, and Mouratidis (2012) conceptualized psychological control as having two domain-specific manifestations: dependency-oriented psychological control (strives to make the child emotionally and psychologically dependent on the parent) and achievement-oriented psychological control (demanding exceptionally high amounts of achievement from their children). In their study, Soenens et al. sought to examine whether parental psychological control differentially mediated the relationship between adolescent depressive personality characteristics and depressive symptoms. The authors administered the Dependency-oriented (8 items) and Achievement-oriented (9 items) Psychological Control Scales (DAPCS; Soenens, Vansteenkiste, & Luyten, 2010) to 290 adolescents in Belgium and 321 adolescents in South Korea, as well as measures of depressive personality traits,

depressive symptoms, and other measures of parenting dimensions. Chronbach's alpha for the DAPCS ranged from .82 to .92 for both samples, indicating strong internal consistency reliability. In addition, the authors conducted confirmatory factor analyses of the DAPCS for both samples, substantiating the two-factor solution of the measure for both samples.

Results from the multi-group path analysis confirmed the hypotheses that the domain-specific expressions of psychological control (dependency-oriented and achievement-oriented) mediated the relationship between adolescent depressive personality characteristics and depressive symptoms (Soenens et al., 2012). Despite the evidence supporting two distinct forms of psychological control based on parental conditional regard, the authors emphasized the support of these findings across cultures, suggesting that the effects of psychological control are universally detrimental to adolescent psychological and emotional functioning.

Another recent dimensional study of parenting focused on enhancing the understanding and effects of psychological control on adolescent psychological functioning across cultures (Barber et al., 2012). The approach illustrated by Barber and colleagues demonstrates the importance of developing measures from qualitative data in order to be sensitive to the experiences of the population of interest. The authors interviewed 120 adolescents from five different cultures in groups of 6, where they were asked about ways in which their parents might not respect their individuality. Eight categories of responses emerged, which included: Ridiculing, Embarrassing in Public, Invalidating, Violation of Privacy, Guilting, Excessive Expectations, Comparing to Others, and Ignoring. From these eight categories, the authors generated eight new items to include as an additional component of an existing measure of psychological control. These items were then tested among 2,100 adolescents from the original five cultures from which they were generated, along with other measures of adolescent social and psychological functioning.

Through exploratory factor analysis, Barber and colleagues (2012) utilized traditional eigenvalue and scree criteria to identify new items that factored separately from the original measure of psychological control. Using confirmatory factor analyses, the authors demonstrated that the two scales that measured psychological control fit best when they were kept separate (CFI = .933, RMSEA = .020). Finally, through the use of several structural equation models, it was shown that the new scale, called Psychological Control – Disrespect, predicted youth depression and antisocial behavior better than the previous measure of psychological control. However, despite the study's large sample size and rigorous methods, the authors acknowledged the need for further validation of the distinction between the items that measured disrespect and those that measured a more global perspective of psychological control. Nevertheless, this study illustrated the possibility that among the more general dimensions of parenting, certain nuances might exist that operate in unique ways to explain aspects of adolescent functioning.

Summary of dimensional studies. The three-dimensional framework has been validated through rigorous methods across multiple cultures and contexts. In particular, recent studies have focused on refining psychological control, attempting to deconstruct its multiple domains and further elucidate its differential effects on offspring (Barber et al., 2012; Soenens et al., 2012). Indeed, the strengths of the dimensional approach to parenting has been its recognition of psychological control as crucial element in parental behavior directed toward children and the focus on measuring parental behaviors from the child's perspective.

Summary of illustrative review. It is important to acknowledge the conceptual overlap between the typological and dimensional approaches to studying parenting. For example, Baumrind acknowledged that the role of psychological control is a destructive component of parenting and has included measures of this construct in her recent studies (Baumrind et al., 2010). This overlap reflects a view illustrated by Steinberg, who over the years has refined

elements inherent to the *typological* study of parenting (e.g. Darling & Steinberg, 1993; Gray & Steinberg, 1999), but also has focused on advancing the work of the *dimensional* conceptualization of parenting (e.g. Silk, Morris, Kanaya, & Steinberg, 2003; Steinberg, 1990). Steinberg suggests that the two approaches that have guided the study of parenting are not mutually exclusive, but rather differ in the degree to which they emphasize how parental authority is conceptualized. Indeed, it is evident that each theoretical perspective complements the other and they are not necessarily at odds, but rather reflect specific methods and emphases to the study of the fundamental components of parenting, namely support and control (Locke & Prinz, 2002; Rollins & Thomas, 1979).

Child Effects

Ever since the important postulations by Bell (1968) regarding child effects on parental behaviors, a steady flow of research has been devoted to demonstrating the bidirectional effects between parents and children. The purpose of this section of the literature review is to illustrate some recent studies that have studied child effects that are informative to the issue of how children with developmental disabilities (DD) may affect their parents and their parents' behaviors.

In one study, researchers compared the mother-child interactions between three groups of mothers of 5 year-old children: typically developing children ($n = 142$), children with borderline intellectual functioning (IQ of 71-84; $n=29$), and children with developmental delays ($n=46$) (Fenning, Baker, Baker, & Crnic, 2007). In this study, researchers were specifically interested in how having a child with borderline intellectual functioning might negatively influence parenting behaviors. Analyses were based on naturalistic observations of parent-child interactions that were conducted in the home, in which observers evaluated mothers based on a set of six dimensions: positivity, negativity, sensitivity, intrusiveness, stimulation of cognition, and detachment. In addition, observers evaluated six types of child behaviors in order to account for

child effects: child positivity, negativity, liveliness/activity, sociability, sustained attention, and demandingness. The kappa coefficients for inter-rater reliability ranged from .59 to .64. Finally, mothers also completed the Child Behavior Checklist (Achenbach, 1991) to get the mothers' perceptions of child behavior.

Fenning et al. (2007) found that mothers of children with borderline intelligence were observed to be less positive, less sensitive, and displayed the least positive engagement than the other mothers in the study. Further, mothers of children with borderline intelligence perceived more externalizing symptoms than mothers of TD children, even though children with borderline intelligence were not observed to be more behaviorally problematic than the other children in the study. Despite the correlational nature of the data, the authors suggest that mothers of children with borderline intellectual functioning may perceive their children to be more difficult and problematic due to the characteristics of the child's delays. As a result, the authors imply that these children are at a greater risk for poorer parenting. Overall, this study demonstrates the value of utilizing both observations and parent self-reports when attempting to assess child effects. Fenning and colleagues corroborated previous studies that have used similar methods among similar populations to show how the quality of parenting is diminished when parenting a child with intellectual delays (Costigan, Floyd, Harter, & McClintock, 1997; Floyd, Harter, & Costigan, 2004; Floyd & Phillippe, 1993) In addition, this study is particularly informative to future studies of child effects among families of children with DD, given that borderline in this case is referring to borderline intellectual disability, which is a type of developmental disability.

Better suited for studying how children affect parents behaviors are studies that use longitudinal methods. A recent study used longitudinal methods to assess the bidirectionality between parenting and toddler externalizing behaviors across four time periods among 104 intact two-parent families and their toddler sons at 17, 23, 29 and 35 months of age (Verhoeven,

Junger, van Aken, Deković, & van Aken, 2010). The authors used self-report survey methods to obtain parent reports of a wide range of parenting behaviors related to support, lack of structure, positive discipline, psychological control, and physical punishment. Child externalizing behaviors were measured from mother reports. The authors tested non-recursive path models to test bidirectional models between parenting and child externalizing behaviors.

Verhoeven et al. (2010) did not find support for their bidirectional models because parenting behaviors were not predictive of child externalizing behaviors. However, the authors did find support for child effects in that boys' externalizing behaviors predicted decreases in parental support, decreases in structure, increases in the use of physical punishment, and increases in the use of psychological control at 23, 29, and 35 months of age. These effects were found to persist across time for both mothers and fathers. The authors suggest that as children get older, the frequency of their problematic behaviors may increase, which may influence parents to engage in less positive forms of parenting and use parenting tactics aimed at eliciting immediate responses from children. These results are similar to those of Fite, Colder, Lochman, and Wells (2006), who found that boys' externalizing behavior from 4th to 8th grade led to inconsistent discipline and a lack of parental monitoring. The study by Verhoeven et al. (2010) provides justification for the importance of studying how child behaviors influence parenting behaviors, particularly when examining child externalizing behaviors. However, because only boys were included in this study, it is unclear how the gender of the child may moderate these effects.

The study of child effects on parents also is useful when attempting to explore the inverse of well established relationships, such as the relationship between interparental conflict and child externalizing behaviors. Wymbs and Pelham (2010) conducted an experimental study comparing how children with attention-deficit/hyperactivity disorder (ADHD; $n = 51$) and without ADHD ($n = 39$) influence the quality of interparental communication. In the study, parents were

randomly assigned to interact with either a “disruptive” (i.e., oppositional, argumentative) or “typical” child confederate, who were trained to enact their respective scripts. Observers rated parents’ positive and negative interparental communication during the course of the interaction. In addition, parents completed a self-report of their communication following the interaction with the child. The authors conducted comparative analysis to detect significant differences between the test conditions and the parent types.

Wymbs and Pelham (2010) found that parents who interacted with the disruptive confederate children were observed and rated their communication with each other more negatively and less positively than parents who interacted with typical confederates. Further, parents of children with ADHD displayed greater negative interparental communication compared to parents of children without ADHD. The authors conclude that the reciprocal nature of the relationship between child characteristic and parental conflict are important for both researchers and clinicians to consider and in need of further validation. This conclusion is consistent with previous studies of families of children with ADHD, which have found that severity of disruptive child behavior is predictive of marital instability (Wymbs, Pelham, Molina, Gnagy, Wilson, & Greenhouse, 2008). Although Wymbs and Pelham (2010) did not investigate child effects on parenting *behaviors*, it demonstrates how experimental methods might be used to explore how children with developmental disabilities influence their parents. In addition, if disruptive children elevate negative communication between parents, then it is possible that children may indirectly influence parenting behaviors via parental distress.

This illustrative review of child effects studies demonstrated that there are a variety of methods of investigating the reciprocal nature of the parent-child relationship. In addition, Wymbs and Pelham (2010) demonstrated that children not only influence parental behaviors, but also influence other aspects of parents’ lives such as interparental communication. This is important to consider because it is likely that child effects do not operate according to a simple

bidirectional relationship between parents and children. Indeed, it is far more plausible that child effects fit into a more inclusive model of parenting determinants, such as the model proposed by Belsky (1984) in which parenting is thought to be influenced by a variety of contextual issues such as personal characteristics, marital relations, social networks, and work environment. Conceptualizing the effect of children with DD on parents' behaviors must be inclusive of these kinds of social conditions that also contribute to parenting practices.

Parenting Young Children with Developmental Disabilities

Parenting a child with developmental disabilities (DD) often requires additional time, effort, resources, and support. For example, parents of children with autism not only face a lack of social connection and behavioral outbursts from their child, but often spend considerable amounts of time and financial resources seeking treatments that sometimes offer questionable results (Bloch & Weinstein, 2010). Similarly, parents of young deaf children might have to make significant efforts to learn sign language in order to communicate with their child. These examples are illustrative of a host of issues faced by parents of young children with DD that play a role in the parent-child relationship. The purpose of this review is to provide a comprehensive presentation of the studies in which researchers have studied parenting behaviors among families of young children with DD.

Systematic literature review. The systematic review process involves a thorough and rigorous consideration of a specific topic. (Comprehensive review article) The value of conducting such a review is the reduction of bias that may result from the selectivity of an author in the review process (Littell, Corcoran, & Pillai, 2008). Indeed, the principal objective of a systematic review is to "...comprehensively locate and synthesize research that bears on a particular question, using organized, transparent, and replicable procedures at each step of the process" (Littell et al., 2008, p.1). As a result, a reader may be confident that the information available in a body of literature is being presented more accurately. For these reasons, the

literature on parenting young children with disabilities will be reviewed systematically based on all of the studies published since 1990 that include a sample of parents that have children with DD within the birth to five year range. Conducting a systematic review of the literature utilizing these criteria will be particularly informative for how parenting might be measured in future studies of families children with DD.

Eighteen articles were found by searching the keywords “parenting”, “parenting styles”, “disabilities”, and “young children” within databases such as PsychInfo, Web of Science, and Google Scholar. Each article is reviewed independently and organized by the method used by the authors to measure or otherwise assess parenting. Studies that used self-report measures (i.e. questionnaires) are presented first and are followed by those that utilized direct observation methods, interviews, and mixed methods. Following the review, key findings and trends among the existing studies will be highlighted and discussed.

Parent self-report studies. In nine of the eighteen studies, investigators relied exclusively on parental self-report measures. Among these, five instruments were used to measure specific parenting behaviors and practices that related to a broad range of parenting constructs such as discipline, responsiveness, and expectations. It is important to consider at this juncture that none of these studies attempted to develop or refine a self-report measure of parenting based on what parents had to say about their experiences raising a child with DD. Instead researchers relied on previously established measures of parenting that had not been subjected to rigorous psychometric evaluations nor included items meant to reflect the specific parenting experiences among this population.

Table 1. All tables and figures appear in the appendix. In order to more clearly illustrate the deficiencies in the literature on parenting young children with DD, Table 1 is provided which outlines key psychometric features of the studies under review. The authors and year of publication are provided in the first column, followed by the name of the scale used and the

reference to the study from which the scale originated. The next two columns provide a description of the sample included in the study, followed by a description of the method of measurement used in the scale. The remaining columns present information regarding the subscales and the number of items in those subscales, as well as information regarding internal consistency reliability, test-retest reliability, and validity assessments. It should be noted here that none of the nine studies using self-report scaling measures used any type of factor analysis to identify or confirm the structure of the scales that were used. For this reason, the table does not contain a column concerning factor analytic information.

Parent Behavior Checklist. The Parent Behavior Checklist (Fox, 1992), originally developed as the Parenting Inventory: Young Children (Fox & Bentley, 1992) is a 100-item questionnaire that assesses a parent's developmental expectations, disciplinary behaviors, and nurturing behaviors. The scale was originally developed and tested among a representative sample of 1,140 mothers of typically developing (TD) children and demonstrated sufficient reliability coefficients for the expectations ($\alpha = .97$), discipline ($\alpha = .91$), and nurturing ($\alpha = .81$) subscales. In addition, the test-retest reliabilities of each of the subscales were: expectations, .98; discipline, .87; and nurturing, .81. Overall, this parenting scale has been shown to reliably measure its respective subscales. However, the development of the PBC was not grounded in a broader conceptual framework of parenting such as the dimensional or typological frameworks. Instead, the authors claimed to have developed the items within a "developmental-behavioral conceptual framework" (p. 101), which the authors do not describe or explain. Four studies were found in which the PBC was used to measure parenting among parents of young children with developmental disabilities.

The Parent Behavior Checklist (PBC) (Fox, 1992) was first used among parents of children with developmental disorders by Tucker and Fox (1995). The purpose of their study was to explore the differences in parenting and child problem behaviors in families of children

with and without what the authors refer to as “mild handicapping conditions” (p. 29). The PBC and The Child Behavior Checklist (CBCL) (Achenbach, 1991) were completed by 125 mothers of children between the ages of three and five. Just over half ($n= 65$) of the children had 25% or more delays in language, vision, motor, and/or social development. Reliability coefficients were not reported by the authors for any of the PBC subscales, which makes it difficult to assess how reliable a measure it was among the parents (see Table 1). The authors found that mothers of children with mild delays reported lower developmental expectations of their children compared to mothers of typically developing children. However, mothers did not differ in their reported levels of discipline or nurturing. Though the findings from this study may not generalize to all parents of children with developmental disabilities (DD) due to the relatively small sample size, there is an important implication regarding child effects. It appears that parents of children with DD may expect less from their children than parents of TD children, which may in turn play a role in some of their behaviors towards their children.

Carson, Perry, Diefenderfer, and Klee (1999) conducted a longitudinal study of families of children with ($n=53$) and without ($n=11$) language delays and looked for differences in parenting behavior and family functioning. The authors used the PBC (Fox, 1992) to measure parenting behavior during a reassessment of 23 of the mothers when the children were five and six years old. The authors did not report the reliability coefficients for any of the subscales, which limits the credibility of their findings (see Table 1). Carson et al. found that compared to parents of TD children, mothers of children with language delays indicated that they used more discipline and were less inclined to nurture their children. However, it is important to note that these findings were generated from a very small sample of mothers, which present a problem regarding generalizability. However, the implication of this study is that parents of children with DD may be harsher and less nurturing towards their children.

More recently, Carson, Caron, Klee, and Jackman-Brown (2007) investigated parenting behaviors and child behavior problems among families of toddlers with and without language delays. The authors used the PBC (Fox, 1992) as their measure of parenting among 47 primary caregivers of children with ($n = 17$) and without ($n = 30$) speech and language delays. It was not specified how many of the primary caregivers were fathers and how many were mothers. In addition, the authors did not present the reliability or validity information related to any of the measures that were included in the study. Parents of toddlers with speech and language delays were significantly less nurturing and used more punitive methods of discipline compared to parents of typically developing children. However, as acknowledged by the authors, these findings must be interpreted with caution because the small and homogeneous sample limited the generalizability of the findings. Further, the authors neglected to provide vital internal consistency reliability information (see Table 1) about their use of the PBC in this study, which makes it difficult to draw conclusions about the advisability of using this instrument with parents of children who have speech and language delays. However, these findings echo the findings by Carson et al. (1999), and lend support to the consideration that having a child with DD influences parenting behaviors.

In the most recent article in which the PBC (Fox, 1992) was used, Keller and Fox (2009) sought to extend the findings from previous studies that had focused on the relationship between parenting practices and child behavior problems. Keller and Fox used 32-item version of the PBC along with Eyberg Child Behavior Inventory (ECBI) (Eyberg & Pincus, 1999) with 58 primary caregivers (85% biological mothers) of developmentally delayed toddlers between the ages of two and four. The authors did not provide reliability or validity information for any of the (see Table 1). They found that as parent expectations increased, the frequency and intensity of child problem behaviors also increased. Further, the authors found that an increase in parental expectations was associated with an increase in the use of verbal and corporal punishment and

a decrease in positive nurturing strategies. However, the characteristics of the sample (85% biological mothers, 67% not married, 56% unemployed) along with the small size of the sample limits the ability to generalize these findings beyond this study.

Child Rearing Practices Report. The Child Rearing Practices Report (CRPR) was originally developed by Block (1981) and consisted of 91 items measuring childrearing attitudes, behaviors, values, and goals. However, the original, 91-item version from Block was considered too long and cumbersome and yielded too many factors (28-33) to be considered a practical measure of parenting (Rickel & Biasatti, 1982). As a result, Rickel and Biasatti (1982) produced a 40-item version of the CRPR based on a two-factor solution with scales measuring restrictiveness and nurturance. The alpha coefficients for each of these scales were .82, showing good internal consistency of the two-factor scale. Further, Dekovic, Janssens, and Gerris (1991) noted that the CRPR was originally developed among American families, which limited its generalizability across cultures. Dekovic and colleagues (1991) were able to replicate the findings of Rickel and Biasatti using the 40-item version of the CRPR among a Dutch sample, producing alpha coefficients of .83 for the restrictiveness scale and .74 for the nurturance scale. However, Dekovic and colleagues also introduced a new, 29-item version of the CRPR containing scales measuring authoritarian and authoritative parenting. The internal consistencies were considered to be acceptable by the authors, with an alpha of .71 for the authoritarian scale and .65 for the authoritative scale.

The first study to use the Child Rearing Practices Report (CRPR) among families of children with developmental disabilities (DD) was conducted by Woolfson and Grant (2006). The purpose of their study was to compare parenting styles and stress among parents of children with DD and parents of typically developing (TD) children. The sample consisted of 53 parents of children with DD and 60 parents of TD children, with a total of 99 mothers and 12 fathers. The authors also sought to compare groups based on the age range of the child, so

there were 33 boys and girls between three to five years old and 20 boys and girls between nine to eleven years old with DD, and 55 boys and girls in the three to five range and 58 in the nine to eleven range that were TD. Woolfson and Grant used the 40-item version of the CRPR (Rickel & Biasatti, 1982) and produced good reliability coefficients for the restrictiveness ($\alpha = .89$) and nurturance ($\alpha = .80$) subscales among the parents of DD children (see Table 1). The authors used a method (Reitman & Gross, 1997) in which responses on the CRPR are classified as high or low using a median split. This method was used to categorize parents using a typological approach (Baumrind, 1966; Maccoby & Martin, 1983), and classified parents as authoritative, authoritarian, permissive, or neglectful. They found that parents of young pre-school age children with DD were more likely to report using an authoritative parenting style than parents of older children with DD. Further, parents of young children with DD were four times more likely to report using an authoritative parenting style when compared to parents of pre-school age TD children. Regarding stress, however, parents of children with DD reported higher levels of stress than parents of TD children regardless of parenting style. Overall, Woolfson and Grant's use of the CRPR yielded results that are helpful for understanding parenting among parents of children with DD. However, because the CRPR was not intended to be used among families of children with DD, the items contained in the CRPR may not fully capture their parenting experiences. In terms of child effects, Woolfson and Grant demonstrated that children with DD influence parents' levels of stress, which also may be related to their parenting behaviors.

Rutgers and colleagues (2007) conducted a study using the 29-item version of the CRPR (Dekovic et al., 1991) in conjunction with The Brief Attachment Screening Questionnaire (BASQ; Bakermans-Kranenburg, Willemsen-Swinkels, & Van IJzendoorn, 2003) among parents of children with autism spectrum disorders (ASD), mental retardation, and language delays. The purpose of their study was to compare attachment among young children with disabilities in

relation to various aspects of parenting, including parenting styles, to families of typically developing children. The sample consisted of 64 families of children with disabilities and 25 families of typically developing children, with a total sample of 89 families of children between 14 to 42 months old. Chronbach's alpha for the authoritative subscale of the CRPR was acceptable at .74; however, the authoritarian subscale produced an alpha of .53, which was not considered acceptable and was therefore excluded from the analysis (see Table 1). Parents of TD children were more likely to utilize an authoritative parenting style compared to parents of children with a disability. Further, there was no significant difference in parenting styles between children with ASD and the other types of disabilities. Finally, regardless of the disability, the authors found that parents who reported higher levels of self-efficacy were more likely to report authoritative parenting. However, these findings are based on a very small sample size and may not be representative of the parenting practices used by the general population of parents of children with DD. Further, it is evident that the measure of authoritarian parenting from the 29-item version of the CRPR was not reliable when used with families of children with disabilities.

Other Instruments. There are studies of parenting young children with DD that have used other parent self-report measures. For example, Little (2002) used the Conflict Tactics Scale-Parent Child Form (CTS-Parent Child Form; Straus, Hamby, Finkehor, Moore, & Runyan, 1998) in an investigation of the frequency and correlates of maternal psychological aggression and corporal punishment among mothers of children with Asperger's ($n = 308$) and nonverbal learning disorder ($n = 62$) or a combination of the two ($n = 41$) between the ages of four and seventeen. The CTS-Parent Child Form is a frequency rating scale consisting of items measuring how many times in the past 12 months parents have engaged in psychological aggression (shouting, name calling) and corporal punishment (hitting, spanking). Responses range from zero to 20 times or more on a 7-point Likert-type scale. Reliability for the

psychological aggression scale was .68, and corporal punishment was .58, indicating a moderate-to-weak relationship among items for both scales in this study (see Table 1). Parents of four year old children reported the highest levels of corporal punishment of all age groups, which declined over time. Increases in both parent age and child age were related to the more frequent use of both corporal punishment and psychological aggression. Disability status was not associated with either form of discipline. One drawback of the study was that it did not consider other aspects of the parenting such as expectations or responsiveness. However, it does provide insights into how often corporal punishment and psychological aggression are used by parents towards young children with DD. In addition, the findings related to the age of the child demonstrate that certain characteristics of children that are not related to their diagnosis influence parenting behavior.

Gau, Chiu, Soong, and Lee (2008) used the Chinese Parental Bonding Instrument in their comparison of the parenting styles, parental psychopathology, and child behavior characteristics involving 45 families of children with Down syndrome and 50 families of typically developing children between two to fifteen years old. Both mothers ($n = 93$) and fathers ($n = 87$) participated in the study. The Chinese Parental Bonding Instrument is a modified version of the Parental Bonding Instrument and consists of 25 items on a four-point, Likert-type scale ranging from very likely to very unlikely. Subscales in the Chinese Parental Bonding Instrument are care/affection (12 items), overprotection (7 items), and authoritarianism (6 items). The authors did not present any reliability or validity information for the Chinese Parental Bonding Instrument as it was used in this study (see Table 1).

Parents of children with Down syndrome were more overprotective and more authoritarian toward their children with Down syndrome compared to the siblings. Fathers of children with Down syndrome reported being more overprotective than fathers of TD children. There were no significant differences among mothers at the $p < .05$ level. These findings

provide unique implications for parents of children with DD in the inclusion of a scales measuring “overprotection”, which has not been considered to the same extent in other studies. Indeed, the implication of the study by Gau et al. (2008) in terms of child effects is that parents may see a need to be more attentive to children with DD than TD children.

Osborne and Reed (2010) used the Parent-Child Relationship Inventory (PCRI; Gerard, 1994) in their study of parenting behaviors and parental stress among 138 parents of children with autism spectrum disorders (ASD). The PCRI measures parenting behaviors rather than dimensions or styles of parenting, which reflects an interest in examining concrete parenting practices rather than broader domains of parenting. Indeed, the PCRI was designed and tested among a representative population in the U.S. and is used for clinical assessments aimed at discovering any problem areas in the parent-child relationship (see Gerard, 1994). The sample in this study included 130 male and 8 female children with autism between the ages of two and sixteen. However, it was unclear whether the mother or father responded to measures of parenting and stress. Of the seven subscales in the PCRI, the authors chose to focus on the subscales that measured involvement, communication, discipline, and autonomy granting behaviors. The authors did not report the reliability coefficient for each subscale; rather, they reported that the range of alphas was .76-.88. Parents and children were evaluated over a nine to ten month period in which the stability of the parenting behaviors was examined. The authors reported that the mean test-retest reliability score was .81 for all four subscales (see Table 1).

Osborne and Reed (2010) found that the parenting behaviors of parents of children with ASD were not problematic overall. The only subscale that stood out as a concern in the analysis was communication, which improved as the age groups of the children increased. Similarly, parents also reported decreased levels of stress among the older child age groups compared to younger children. In addition, the authors found that over the two time periods in which parents participated, parenting behaviors were consistent and did not change over time.

While some of these findings might be helpful and offer insights into the relationship between parents and children with DD, it is unclear whether these findings would generalize to all parents of children with DD, or even to all parents of children with ASD.

Observational studies. Some studies of parenting young children with developmental disabilities have used observational methods to examine parenting behaviors. This is similar to how Baumrind approached the study of parenting practices (e.g., Baumrind, 1971; Baumrind et al., 2010). Knutson, Johnson, and Sullivan (2004) were interested in studying the parental disciplinary choices of parents of children with ($n=79$) and without ($n=27$) hearing impairments. Mothers of children between the ages of two and twelve completed an analog parenting task, which involved viewing slide images of children engaging in both normative and deviant behavior. Mothers were then asked to indicate what form of discipline, if any, they would choose in response to the behavior depicted in the images. The authors were specifically interested in the use of physical discipline and how disciplinary techniques escalated in response to children's behaviors.

Knutson and colleagues (2004) found that, compared to parents of children without hearing impairments, parents of children with hearing impairments were more likely to report the use of physical discipline and to escalate their discipline techniques. The authors suggested that children with hearing impairments may be at increased risk for physical abuse from parents. Though these findings lend some insight into the overall interest in studying parenting of young children with DD, there are some major limitations to this study. First of all, the sample size was small and is not likely representative of all parents of children with hearing impairments, let alone to all parents of children with DD. In addition, the age range of the child spanned from toddlerhood to early adolescence, which makes it difficult to understand how the age of the child may have affected the mothers' choice of discipline. Finally, only mothers were studied and it is likely that fathers use different forms of discipline with their children than mothers. Nonetheless,

the implication of the results is that parents of children with hearing loss use forms of discipline that differ from those used by parents of TD children and that those differences result from characteristics of the child.

Other observational studies have relied on observing concrete behaviors of parents with their children in both home and laboratory settings. Lomax-Bream, Taylor, Landry, Barnes, Fletcher, and Swank (2007) were interested in studying the effects of parenting and motor skills on the development of 165 children with ($n=91$) and without ($n=74$) spina bifida between the ages of six months to three years. The authors used a variety of evaluations to assess the children's developmental skills, and a fifteen-minute videotaped play observation between mother and child in a laboratory setting was used to examine parenting. The authors used the term "parenting styles" to refer to observers' evaluations of parental warmth (e.g., praise, hugging), responsiveness to child's needs, and a mother's ability to sustain her child's attention during the interaction. Observed behaviors were rated on a behavioral rating scale, from which observers demonstrated inter-coder reliabilities of .87 for warmth, .63 for responsiveness, and .89 for maintaining attention.

Lomax-Bream and colleagues (2007) found that for both groups, higher scores on measures of cognitive, language, and physical development were associated with what the observers determined to be higher quality parenting. However, only for children with spina bifida was higher quality parenting related to the child's daily living skills. Lomax-Bream and colleagues made an important effort to study how parenting affects child outcomes among families of children with DD, which has often been neglected. Nevertheless, Lomax-Bream were able to demonstrate that warm, responsive, and engaging parenting practices among parents of children with spina bifida can lead to positive child outcomes such as an increase in daily living skills that is not seen in the general population of parents of TD children. It would be helpful to see these results replicated using a wider variety of methodological approaches and among

families of children with other types of DD. In addition, it would be important to test the inverse of the relationship shown here, where the daily living skills of children with DD may be predicting higher quality parenting.

While Lomax-Bream et al. (2007) focused on observing positive parenting behaviors, others have focused on observing the more negative components of parenting. Using a longitudinal design, Brown, McIntyre, Crnic, Baker, and Blacher (2011) sought to test whether early child risk factors would have an indirect effect on problematic child behavior through negative parenting among 260 families of pre-school aged children with ($n=103$) and without ($n=143$) developmental delays, and some ($n=14$) who straddled the cutoff for delay status. At 36 months, researchers measured child risk factors, and child problem behavior was measured at 60 months using home observations, laboratory tasks, and questionnaires filled out by parents. Maternal negative parenting was assessed as a mediating variable at 48 months by observers in home and laboratory settings using the Parent Child Interaction Rating Scale (PCIRS), which measured maternal intrusiveness and negative affect. The reliability for the PCIRS was .75, which demonstrates sufficient internal consistency as a measure of negative parenting.

Brown and colleagues (2011) found that, contrary to their hypotheses, child risk and negative parenting have an additive rather than indirect effect on child problem behaviors in that both operated as unique predictors of child problem behaviors. Furthermore, the most salient predictor of negative parenting was the delay status of the child, with parents of children with developmental delays demonstrating more negative parenting than parents of children without delays. This study is important for a number of reasons. First, it uses a longitudinal, observational approach to studying the effects of negative parents on children with developmental delays with a relatively large sample. This approach better demonstrated how child characteristics operate as both predictors and outcomes of parenting practices, which is evidence of the reciprocal nature of parent-child relationships. However, a major oversight of the

study was neglecting to include a broader measure of parenting that incorporates both positive and negative parenting behaviors. In addition, the authors demonstrated that having a child with a delay results in parenting behaviors that are observably distinct from the parenting practices of parents of children without delays. This gives further support of the need to generate measures of parenting that are specific to the experiences of parents of children with DD.

Interview studies. Some researchers have sought to investigate parenting children with developmental disabilities (DD) solely through the use of interviews. For example, Johnson (2000) used a grounded theory approach in an effort to capture mothers' perceptions of parenting children with disabilities. Johnson conducted telephone interviews focused on discipline, nurturance, teaching, and expectations with ten mothers of children with moderate physical disabilities between the ages of three to nine. Interviews were semi-structured such that mothers were given the opportunity to discuss their perceptions of parenting freely as they interpreted the questions of the interviewer.

Johnson (2000) proposed a theory of parental straddling, where parents of children with DD attempt to view their children as both normal as well as having special needs. According to Johnson's (2000) analysis of the interview data, some mothers reported high expectations of their children while others reported low expectations, yet only mothers who reported low expectations expressed any regret of their expectations towards their child. Johnson suggested that mother expectations were related to the need to normalize the child's development, which was connected to the perspectives of some of the mothers who mentioned that they attempted to view their children as separate from the disability. In other words, it was unclear how the disability influenced mothers' parenting strategies, especially given that some mothers sought to ignore their child's disability in making parenting decisions. Johnson also suggested that nurturance was indicative of validation and inherent worth of the child. In addition, mothers reported that discipline was specific to the child's needs, yet no information was provided as to

how they determined what the needs were for either the child or the discipline techniques. Though Johnson's study neglected to include the perspectives of fathers, it provides an important approach to studying parenting among parents of children with DD. Through qualitative interviews, Johnson was able to capture the voices of these parents and demonstrated that for some, disability shouldn't matter for how they parent. This is important to consider for future studies of parenting children with DD.

Most recently, Sams (2012) conducted a qualitative study of the parenting strategies used by parents of young children (birth to five years old) with developmental disabilities. In this study, 20 parents (10 mothers, 10 fathers) were interviewed in person and responded to a series of open-ended questions regarding their parenting behaviors. The author utilized grounded theory methods of data collection and analysis, from which the theory of expanded parenting emerged. According to the author, expanded parenting involves utilizing parenting behaviors that are frequent among parents of TD children, but then also expanding that approach to incorporate additional behaviors and considerations specific to the nature of the child's disability. The three primary themes described by the author related to this theory were individual meaning-making, external influences, and the process of parenting. Each of these themes illustrate the nuanced experiences of parents of young children with DD and are informative to the conceptualization of parenting among this population.

Other studies using interviews to study parenting practices among families of children with DD have followed interview protocols that allow for quantitative coding and analyses. For example, Roskam (2005) investigated the influence of a child's disability and mother's educational level on parents' beliefs and parenting behaviors. The researcher used interview protocols developed by Vandenplas-Holper (1996) with 102 mothers of children with mental delays (mild, $n = 18$; moderate, $n = 23$, severe, $n = 19$) sensory delays ($n = 19$), and developmental delays ($n = 23$) between the ages of three to six years old. During the interviews,

mothers were asked to provide specific examples of parenting behaviors they had recently used in terms of directive (i.e., teaching social norms and dependence), stimulating (i.e., encouraging development and autonomy), supportive (i.e., responding to child's needs), and maturation (i.e., developmentally appropriate) parenting practices. Mothers' responses were recorded on a Likert-type scale, and inter-rater agreement was .87.

Having a disability was related to differences in the combination of stimulating and directive behaviors (Roskam, 2005). More precisely, mothers of children with severe mental delays were more likely to bring up their use of directive behaviors, whereas mothers of children with sensory delays were more likely to mention utilizing stimulating behaviors. Additionally, parents with less education were more likely to report directive behaviors than those with more education. This study demonstrates how different types of DD may influence parenting behaviors in unique ways. Further, this study also shows how parent background characteristics are also important to consider when studying the parent child relationship.

More recently, Roskam and Schelstraet (2007) investigated childrearing behaviors related to controlling versus autonomy promoting practices among parents of young children with a variety of special needs. The sample consisted of 31 mothers of children between the ages of three and six with an assortment of special needs, ranging from 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 split based on severity. Mothers were interviewed according to an interview protocol (inspired by Honig & Caldwell, 1965) in which they described recent, specific examples of parenting and their language was analyzed for eight categories of behaviors which were rated for the level of autonomy and control. Responses were rated on a nine-point Likert-type scale. Responses were represented on a continuum with coerciveness on one end and inductiveness on the other. Some examples of categories of responses placed upon the continuum are explanations, directive, and managing strategy.

Roskam and Schelstraet (2007) found that the presence and severity of a disability was related to varying parenting behaviors. For instance, mothers of children with mental or multiple delays were more likely to report directive parenting behaviors and report providing less explanations to their children than parents of children with hearing impairments. The interview studies conducted by Roskam (2005) and Roskam and Schelstraet (2007) provide evidence that parents of children with DD not only parent differently from parents of TD children in their use of directive and stimulating parenting behaviors, but that parents of children with disabilities parent differently based on the type and severity of disability of the child, which is another important aspect of the parent-child relationship to consider when studying this population.

Mixed methods studies. Some researchers have used a variety of methods in studying the parenting strategies among parents of young children with DD. This approach reflects an interest in gaining multiple perspectives and insights into how parent-child relationships operate among this population. Lojkasek, Goldberg, Marcovitch, and MacGregor (1990) used self-report measures, observations, and interviews to assess factors associated with 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). Mothers and fathers completed questionnaires concerning child behaviors and parental attitudes, and the mothers participated with their children in an observed free-play task. The videotaped task lasted 7 minutes as a part of a longer observation and interview. Maternal responsiveness was observed with attention to positioning, facial expressions, vocal expressions, vocal appropriateness, and pleasure with child and was coded on a five-point rating scale 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. However, Lojskasek and colleagues demonstrated how

using a combination of methods to examine parent-child relationships can be valuable when studying families of children with DD.

Miles and Holditch-Davis (1995) chose to use a mixed-methods approach to investigate their hypothesis that parents of children with special needs use a unique type of parenting style that the authors refer to as compensatory parenting. The sample was made up of twenty-four mothers and three grandmothers of 30 children who were born premature and were three years old at the time of the study. The caregivers completed questionnaires examining their attitudes toward the child, level of vulnerability, and social strengths. In addition, the researchers used semi-structured interviews inquiring about the caregivers' experiences with the birth, hospitalization, transition to home, and parenting of their children. The authors used a constant comparative method of analysis to examine the interview transcripts. Two main themes emerged from the data in which mothers reported their children as being both normal and special. In addition, they emphasized the similarities of their children to typically developing peers, but also reported that they were more at-risk in some ways. As a result, mothers described feeling that they were less likely to set boundaries than they would if their children did not have special needs, in addition to being possibly more protective and stimulating in their interactions due to factors such as the child's past medical experiences and/or the loss of other children. The coining of the *compensatory* parenting style by Miles and Holditch-Davis, in which parents of children who were born premature must compensate for their children's special needs in their parenting, illustrates how mixed methods can be used to emphasize the similar yet distinct experiences of parents of children with DD.

Button, Pianta, and Marvin (2001) used self-report questionnaires, interviews and observations to examine the relationship between mother characteristics, parenting behaviors, and disability status among parents of young children with disabilities. The sample consisted of 112 mothers and fathers of children between one and four years of age with cerebral palsy

(n=58), epilepsy (n=19) or who were typically developing (n=35). The mother and child interacted during a videotaped problem-solving task in which the researchers examined behaviors including sensitivity, positive and negative affect, support (total, lack of, and situation specific), pressure to achieve, over involvement, and neglect. Behaviors were rated on seven-point rating scales following the observation and inter-rater 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, mothers who expressed concern with boundary issues were more likely to pressure their children and become over involved during the task.

Synthesis of findings from research on parenting young children with DD. It is evident that among the relatively few studies focused on the parenting practices parents of young children with DD, there is little consensus and, in some cases, even contradictory results. For example, in one study, parents of young children with DD were more likely to report using an authoritative parenting style than parents of TD children (Woolfson & Grant, 2006). In another study, however, parents of TD children were more likely to utilize an authoritative parenting style when compared to parents of children with DD (Rutgers et al. (2007). Notwithstanding these issues, it is important to review some of the overall findings and tentative conclusions reached based on the results generated by the investigators through various methodologies. In particular, these studies have key implications regarding how to conceive of the bidirectionality of the relationship between parents and their children with DD.

Self-report survey studies. Many of the studies using self-report surveys have been comparative in nature, contrasting parents of young children with DD to parents of young TD children. Of these comparative studies, most have used measures that address multiple components of parenting such expectations, discipline, and nurturing (Fox, 1992) or restrictiveness and nurturance (Rickel & Biasatti, 1982). As previously mentioned, results from

these studies have been inconsistent, with some reporting parents to be less nurturing and more punitive towards children with DD than parents of TD children (Carson et al., 1999; Carson et al., 2007), while others have found no significant difference on the same variables (Tucker and Fox, 1994). In other comparisons, fathers of children with DD have been found to be more overprotective than fathers of TD children, though there was no difference among mothers (Gau et al., 2008). Though these comparative studies are helpful attempts to understand how parents of children with DD are unique in their attempts to parent their children, the lack of agreement among the results is perplexing and highlights the need for deeper investigation and understanding.

Other studies using self-report methods have focused on highlighting correlations between parenting behaviors and other characteristics of parents of young children with DD. For instance, some have found that an increase in parental expectations of children with DD is associated with an increase in verbal and corporal punishment and a decrease in nurturing behaviors (Keller & Fox, 2009). Others have found that as both parents and children with DD get older, parents use more corporal punishment and psychological aggression (Little, 2002). This is somewhat contradictory to the finding in another study that as children with DD get older, there is a decrease in parental stress (Osborne & Reed, 2010). Overall, due to the lack of research, little is known about which parenting behaviors are related to different types of parental characteristics.

The self-report studies of parenting young children with DD are plagued with a number of issues. These issues are clearly observed in Table 1, which shows that most of these researchers have relied on small samples and have not provided sufficient information regarding the psychometric properties of the instruments used to measure parenting. As mentioned previously, there has not been a single study using self-report survey methods which has attempted to factor analyze the scales, which is problematic considering that the scales

were not originally developed to be used among parents of young children with DD. In addition, the parenting scales that have been used lack a grounding in either the typological or dimensional frameworks. Though some contain subscales with typological labels such as *authoritarian* and *authoritative* (Rutgers et al. 2007), overall these scales focus on parenting behaviors that are not connected to a broader understanding of how parent-child relationships operate.

Observational studies. Through direct observation, some researchers have attempted to further understand the specific parenting behaviors utilized by parents of children with DD. In one study focusing on parental disciplinary behaviors, the authors found that children with DD might be at a greater risk for physical abuse from their parents than TD children (Knutson et al, 2004). Others have focused on observing child outcomes in conjunction with parenting behaviors. Researchers who observed higher quality parenting also found higher scores on measures of cognitive, language, and physical development for children with DD as well as TD children (Lomax-Bream et al., 2007). On the other hand, others observed that negative parenting behaviors are associated with child problems and that negative parenting is more frequent among parents of children with DD (Brown et al., 2011). Overall, the links between the parenting quality and child outcomes are expected. What is more important is the disproportionate use of deleterious parenting strategies among parents of children with DD when compared to parents of TD children (Brown et al., 2011; Knutson et al., 2004). There is need for future studies to investigate the risk of physical abuse and other adverse parenting behaviors in larger, more inclusive samples of families of children with DD.

Interview studies. Researchers have used interviews to produce both qualitative and quantitative data on parenting young children with DD. A common feature in these studies is that parents of children with DD were not compared to parents of TD children. Rather, researchers focused on comparing parenting practices based on the type of DD of the children.

As a result, the findings reflect an interest in discovering the specific parenting behaviors utilized in relation to the type of disability of the child. For example, parents of children with mental delays reported using more directive parenting behaviors than parents of children with sensory delays (Roskam, 2005; Roskam & Schelstraet, 2007). In addition, mothers who attempted to see their child separate from the disability also reported having more normalized expectations of their children (Johnson, 2000). It is likely that in less severe cases, parents of children with DD are capable of maintaining expectations of their children that are consistent with those among TD children. Through interviews, researchers have demonstrated the importance of considering the type and severity of a child's disability when studying how children with DD influence parenting behaviors.

Mixed-method studies. Mixed-methods studies of parenting young children with DD have demonstrated that using a combination of several methods provides both breadth and depth to empirical investigation. For instance, researchers have introduced novel conceptualizations of the parenting styles used by parents of children with DD based on mixed-methods data (Miles & Holditch-Davis, 1995). Rather than attempting to categorize parents' based on existing frameworks, these researchers attempted to present a more sensitive understanding that better captured their experiences with parenting. Further, others have shown that mothers who were observed being less sensitive during interactions with their child with DD reported being more concerned about their child's future (Button et al., 2001). Through associating mothers' self-report responses with direct observations of parent-child interactions, these researchers showed how parental perceptions are connected to parenting behaviors. Through any combination of surveys, interviews, or observations, researchers have been better equipped to address issues of parenting children with DD from multiple angles.

Summary of systematic review. Through a systematic review of the literature on parenting young children with DD, it is evident that parenting behaviors are likely affected in

some way by the extra demands placed on the parents. Though several scholars have attempted to examine these differences, there is so little consensus and so many variations in how parenting has been studied that it is difficult to make any definitive assertions about the nature of parent-child relationships among this population. One of the biggest problems with these studies, however, is the lack of a conceptual framework for explaining the parenting behaviors of parents of children with DD. As a result, little can be said about the bidirectional relationship between child characteristics and parenting practices among this population. Only three studies (Johnson, 2000; Miles & Holditch-Davis, 1995; Sams, 2012) have attempted to understand experiences with parenting young children with DD through qualitative interviews, and none incorporate the broader literature on child effects. Moreover, two of those studies focused exclusively on mothers, which provides an incomplete perspective on parent-child relationships. Finally, despite the strong evidence of the reciprocal nature of the parent-child relationship presented by these studies, the authors neglected to incorporate any conceptual argument that their studies fit within the child effects literature.

The purpose of this study is to provide an in-depth analysis of the qualitative descriptions of the parenting strategies utilized by parents of young children with DD that illustrates the reciprocal nature of the parent-child relationship, as well as some of the broader conditions that also influence parenting behaviors. The hope in this regard is to bridge the gap between studies of parenting children with DD and the broader literature on parent-child relationships. Guiding this purpose are two primary research questions:

1. Do children with developmental disabilities present unique influences on parenting behaviors? If so, what are some of these unique effects?
2. What are some other determinants of parenting behaviors among parents of young children with DD?

In answering these questions, I present a secondary data analysis of interview data that was collected and has been previously analyzed (see Sams, 2012). This analysis contributes above and beyond what was presented previously by analyzing the data for specific content related to child effects and other determinants of parenting.

Chapter 3

Methods

Research Design

The research questions were addressed through the use of qualitative, open-ended interviews. Specifically, mothers and fathers of young children with DD were interviewed in-person and asked about their parenting strategies and practices by myself and another graduate student. All interviews were audio-recorded and transcribed word-for-word for qualitative analysis.

Qualitative study. There are two primary reasons a qualitative approach was used to explore the parenting process among this population. As noted previously, the existing literature is insufficient for understanding bidirectional nature of the relationship between parents and their children with DD. Moreover, few researchers have intentionally explored parent-child relationships among this population with the purpose of generating conceptualizations that are related to and consistent with the broader literature on parenting. As a result, analyzing qualitative data that were collected using grounded theory methods (GTM: described in detail below) presented an opportunity for theory construction that is not as readily available to other quantitative analyses.

A second reason for using a qualitative approach in exploring the effects of having children with DD on parenting behaviors was the desire to be sensitive to the experiences and behaviors that may be unique or otherwise specific to this population. By allowing parents to speak for themselves and describe their own parenting behaviors in concrete detail, the parenting behaviors of parents of young children with DD can be understood at a more specified level than what the analysis of quantitative instrumentation allows.

Ontological position. My position as the researcher is informed by many worldviews. From a subjective position, I acknowledge that reality is constructed by individuals based on

their experiences within their social and historical contexts (Daly, 2007). From this social constructivist worldview, I hope to gain a subjective understanding of the complexities surrounding parenting strategies used by parents of young children with DD.

I also hope to look for similarities and patterns among the reports from parents to generate themes and categories of responses that congruent with existing conceptualizations of the parent-child relationship. This approach reflects my post-positivist worldview, from which I will strive to look for objective interpretations of the interview data.

Grounded theory method. The data used in this analysis were collected using the grounded theory methods (GTM), a methodology which was originally developed by Glaser and Strauss (1967). This method calls for an atheoretical approach to research with the intent of developing theory for an area where existing theory is insufficient. However, Creswell (2007) acknowledged that in GTM, certain sensitizing concepts (Blumer, 1969) from existing theory provide important directions for where to look for meaningful categories among qualitative data. In the present analysis, I drew upon Baumrind's typological approach to parenting (Baumrind 1971, 1978), as well as the dimensional approach to parenting that has been refined by Barber and colleagues (Barber et al., 2005). Specific to parents of children with DD, I also draw on the concept of compensatory parenting (Miles & Holditch-Davis, 1995) the theory of parental straddling (Johnson, 2000), and the theory of expanded parenting (Sams, 2012). Each of these theoretical frameworks provide an important foundation to the present study in terms of the what to look for in parents' responses that may be important in answering the proposed research questions.

The use of GTM affects both the process of collecting and analyzing data. This is because in GTM, data are analyzed as they are collected, an approach known as the constant comparative method (Creswell, 2007). This study used open-ended responses from in-depth, one-on-one semi-structured interviews that were conducted with individual mothers and fathers

of young children with DD as the source of data for analysis. Data analysis included an open coding process conducted throughout the data collection process, followed by an analysis of content related to the primary research questions. The use of GTM in the data analysis process will be described in greater detail in the data analysis section below.

Participants

The present study employed a sampling approach known as theoretical sampling (Creswell, 2007). Theoretical sampling involved finding participants who represent the phenomenon I am interested in measuring. This sampling method is a matter of “sampling for ideas rather than sampling people.” (Daly, 2007, p. 104). It is an ongoing process that involves making decisions about where to go for missing pieces of information (Daly). In this case, any mother or father who has a child younger than 6 years old that had been diagnosed with a developmental disability that he or she is receiving services for qualified for the study. Initially, the sample was slightly more homogenous (i.e., parents of children with hearing loss) to ensure that the themes and categories that emerged were consistent with a narrow range of the overall population. Then, a more heterogeneous population (i.e., parents of children with DD other than hearing loss) was recruited to further establish the credibility of previous analyses (Creswell, 2007).

Participants were identified in partnership with local organizations serving young children with disabilities. Specifically, professionals at Little Tennessee Valley Educational Cooperative (LTVEC) and University of Tennessee (UT) Center on Deafness assisted in identifying and recruiting available families. Ms. Pam Potocik, Director of LTVEC Birth-to-Three Program provided support in recruitment at LTVEC, which serves approximately 45 to 50 families with young children (0-3) with developmental delays. Ms. Susie McCamy, MS, the Newborn Hearing Family Outreach Coordinator, assisted with recruitment at the UT Center on Deafness, which provides a hearing screening for newborns and other services to families with young children.

GTM generally calls for interviewing 20-60 individuals who have experienced the phenomenon of interest (Creswell, 2007). As such, we interviewed 20 individual parents (10 mothers, 10 fathers) about the parenting behaviors they use in relation to their child(ren) with DD. Demographic information for parents and their children is described in tables 2 and 3, respectively. To facilitate ease in identifying partnerships, mothers and fathers were given pseudonyms that were matched by the first letter of the name. For example, Amanda and Adam were a couple, as were Brittany and Ben, and so forth (see Table 2). The overall mean age for parents in this study was 34.95 years old ($SD = 5.57$), with an average age of 35.5 ($SD = 6.04$) for husbands and 34.4 ($SD = 5.32$) for mothers. All couples were married and had been married for an average of 7.5 years ($SD = 3.47$). Children ranged from 9 months old to 67 months old, with a mean age of 36.27 months ($SD = 20.6$), or about 3 years old.

Sampling ceased after 20 interviews were conducted because we determined that we had reached saturation in our responses from parents, which is the point at which interview responses no longer provided any distinct or novel information regarding parenting young children with DD (Creswell, 2007).

Procedures

Recruitment. Participants were recruited through the Little Tennessee Valley Educational Cooperative and UT Center on Deafness. Professionals in these institutions were given flyers to be distributed to potential families, with whom they discussed the project in greater detail. Potential participants were asked to contact the principal investigator via phone to discuss the study in greater detail, ask any questions they might have, and set up an interview time and location. In addition, professionals provided the principal investigator with contact information for interested families.

Interviews. Prior to data collection, I conducted a bracketing interview with the principal investigator in which I sought to increase my awareness of any personal biases and

preconceived expectations of the population. The purpose of the bracketing interview was to reduce my influence as the researcher on how participants responded to interview questions. Participants were given the option of being interviewed in their natural environments at home, or, if they wished to protect their privacy or if it was more convenient, on the campus of The University of Tennessee Jessie Harris Building. The aim was to maximize the comfort level of the participants so that they might focus on their responses rather than distractions in the environment. Participants determined which location they preferred during the initial phone calls.

Prior to beginning the interview, participants reviewed and completed an Informed Consent form and were also be given the opportunity to ask questions about the study. In addition, they were be given the option of completing a follow-up couple interview after individual interviews had been completed with both the mother and the father. Following the issue of written consent, the audio-recorded interview began and lasted between 30 to 75 minutes. Once the interview was over, the participants were asked if they had any additional information to provide or questions about the study. At this point, the audio-recording was stopped and the interview finished.

Immediately following an interview and in a private location, the interviewer recorded her/his thoughts regarding the interview and his or her reaction to it, as well as possible codes and other information pertaining to the study. This process is known as reflective memoing (Daly, 2007). The interviews were then transcribed word-for-word and analyzed following GTM coding guidelines. In addition, interview questions were modified slightly throughout the data collection process as per the constant comparative method of data analysis used in GTM in which data is analyzed while it is still being collected (Creswell, 2007). As themes and patterns began to emerge from the data, some interview questions were added, deleted, and reworded to produce more salient responses.

Secondary couple interviews were conducted with a smaller sample of couples (5

couples, 10 individual parents) once mother and father interviews were completed. These interviews took place after transcriptions from the individual interviews had been completed so that the interviewer might identify questions for the couple based on their individual responses. In addition, a few general questions were asked of all couples who chose to participate in this phase of the study. As with the individual interviews, couples had the option of determining day, time, and location of the interview.

Interview questions. A predetermined list of general interview questions was asked of all parents that addressed the overall construct of parenting. However, the interviews were guided in part by what participants identified as important elements of their experience parenting a young child with DD. Interview questions were developed through a review of the parenting literature, previous experience working with the population as a service provider, analyzing content from available scales on parenting, and consultation with an experienced qualitative researcher. As recommended by Charmaz (2002; 2006), the interview began with broad, open-ended queries and concluded with more specific questions. Each question was expanded through prompts seeking for clarification and elaboration (e.g., “What do you mean when you say. . .?”)

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 special needs?
- 14) What struggles have you had in deciding when your child's dependence on you is appropriate?

Couple Interviews

Beginning Questions

- 1) What surprised you about the findings from your spouse's interview?

Intermediate Questions

- 2) What differences would you describe in your parenting and (the other parent's) parenting? What similarities?
- 3) How do you make decisions with your spouse regarding your parenting of [the focal child]?

Ending Questions

- 4) What advice would you give another couple for parenting a child with special needs?

These questions were altered slightly throughout the data collection process as we constantly compared emergent themes and codes. The persisting goal was to use questions that are sensitive to and relevant to the population under study.

Compensation. Participants received \$25 for participating in the individual interview. In addition, couples that selected to participate in the secondary couple interview were given an additional \$25 each (or, \$50 for the couple) for their participation. Overall, each family was eligible for up to \$100 for participating in the present study. Participants were provided compensation prior to the interview and signed a written receipt. As a further compensation and in a direct effort to recruit sufficient fathers into the study, participants' names were entered into a drawing for one of three sets of two tickets to a University of Tennessee football game.

Data Analysis

Qualitative data software. All interviews will be analyzed using Atlas.ti, a computer assisted qualitative data analysis (CAQDAS) software package that assists the researcher with coding and organizing textual data. The use of CAQDAS is common in grounded theory method (GTM; Creswell, 2007) and facilitates ease with organizing codes into a sensible framework.

Qualitative data analysis. GTM uses one of the most common forms of qualitative data analysis and coding: *open*, *axial*, and *selective* coding. This method, developed by Strauss and Corbin (1998), is popular in qualitative research due to its straightforward and logical technique. As per the constant comparative method, interviews were analyzed as soon as they were transcribed. During this phase, analysis consisted of *open coding*, which involved a careful line-by-line reading of each transcript, from which we identified salient themes and categories. Interviewing and open coding continued until a point of saturation had been reached, which is the stage at which no new themes emerged from the data. The next phase involved identifying categories among the themes that emerged from the open coding process that appeared illustrate the central phenomenon expressed by participants. This is the classification phase of data analysis, or, axial coding.

In *axial coding*, I reviewed the original transcripts again to see how each of the identified categories related to and explained how children with DD influence the parenting process. This

also involved identifying causes, contexts, intervening conditions, and consequences that relate to the central phenomenon of parenting young children with DD.

Finally, in the *selective coding* phase, I interpreted the data further by interrelating the categories into a set of proposed relationships between categories. The final result of the entire data analysis process involved constructing a conditional matrix, or, a visual model that emerged illustrating the process of reciprocal influences between parents and children with DD.

It is important to note that data analysis in GTM does not occur in a necessary sequence, but is a process of identifying and refining codes and categories into a sensible framework (LaRossa, 2005). This means that data may be coded using each of the three analytical techniques delineated by Strauss and Corbin (1998) at any stage in the analytic process. In general, however, analysis typically begins with open coding and is finalized with selective coding.

Credibility and Trustworthiness

Transcription. In order to ensure that interviews were transcribed accurately and to correct any mistakes, a second transcriber listened to the original interview while analyzing the transcript. When the second transcriber noticed any inconsistencies in the audio and the typed transcript, he or she made the necessary changes. The second transcriber then immediately saved a new copy of the transcript to be used in subsequent stages of analysis.

Credibility. As mentioned previously, both interviewers conducted bracketing interviews to sensitize themselves to personal biases and expectations prior to conducting any research interviews. In addition, mothers and fathers were interviewed by both primary investigators (one male, one female) in order to ensure that four possible interview scenarios might occur (i.e., male interviewing a mother, male interviewing a father, female interviewing a mother, and female interviewing a father). The aim in this regard was to increase the diversity in interview setting in the case that parents may respond differently depending on their own gender and the

gender of the interviewer. Finally, the subsample of parents who chose to participate in the couple interviews phase of the project provided the opportunity to conduct “member checking” (Creswell, 2007), a method in qualitative research that involves following up with participants to clarify that the themes generated through open coding accurately reflect participants’ methods of parenting young children with DD. Overall, we sought to increase the credibility and trustworthiness of our findings through multiple checkpoints along the research process.

Trustworthiness. The primary aim of this study is to analyze parents’ responses for content related to the broader literature on parent-child relationships. Thus, it was expected that many of these parents would use several parenting strategies that are common among parents of young typically developing children. As a result, the focus of this analysis was on relating parents’ responses to previously established and validated constructs related to the parenting process. Furthermore, because an initial analysis of the data used in this study has already been completed, it will provide an important backdrop for informing the purposeful analysis presented here. In all, several efforts were made to ensure the trustworthiness of the analysis process by attempting to ground the analysis not only in the data itself, but in previous analyses that were informative to the present study.

Chapter 4

Results

Major Categories and Themes

After engaging in open coding with the co-principal investigator, transcripts were selectively coded for content related to child effects and other determinants of parenting. During this coding process, certain categories of responses emerged consisting of themes illustrated by parent responses. These categories are interrelated in a conceptual model illustrating the reciprocal process of influences between parents and children with developmental disabilities (DD; see Figure 1). This model attempts to illustrate some of the complexities surrounding the parent-child relationship and how certain aspects of that relationship may be mediated by factors outside the parent-child dyad. In addition, a condensed version of the results is presented in Table 4, which provides the labels of the major categories, sub-categories, themes, and quotations from parents who were interviewed for this study. The major categories in the model are *life history*, *child effects related to the disability*, *child effects related to other child characteristics*, *formal social support*, *informal social support*, *worry and stress*, and *parenting behaviors*. *Life history* emerged as a major facet in the lives of parents of children with DD that had a direct influence on their parenting behaviors. In addition, life history also has a logical relationship with the characteristics of the child, both those related to the disability and those that are typical of all children. *Characteristics of the disability* have a direct relationship with parenting behaviors, but also are associated with the various kinds of informal and formal social supports received. *Other child characteristics* share the same relationships as the characteristics of the disability, but affect parenting behaviors and the types of support received in differential ways. *Worry and stress* is another central category that may explain some of the effects of children with DD on parenting behaviors. Finally, although *parenting behaviors* appears to be an outcome variable, it is important to note the bidirectional relationships between

parenting behaviors and the other aspects of the model. The results will be presented by giving examples from parents of the types of responses that fit into each overarching category and how they relate to other categories in the model.

Life history. When parents were asked about what they felt influenced their parenting decisions, many spoke of experiences related to life experiences in their past. The major themes that emerged with the category of life history were *family of origin* influences and *other life experiences*.

Family of origin. When asked about influences on their parenting, many participants spoke how experiences in their family of origin helped shape their current parenting behaviors. For instance, Curtis, who has a 2 year-old daughter with apraxia and anxiety disorder as well as a 4 year-old son with hearing loss, spoke of how he treated his children differently because of his experiences in his family of origin:

I think [focal male], overall, I think I'm a lot harder on [focal male]. What I mean by that is, is 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. So I'm a lot, 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. Um, so, um, that's from opening the door for mom or [focal female]. Just, you know, little stuff. With [focal female] I'm more relaxed. Um, I don't know what it is, but, you know, uh *because I never had any brothers or sisters. So I never had a sister in the house, so I'm not familiar with it. So I think it's maybe just having a little girl, I might be more relaxed with it* [emphasis added].

Curtis attributed his differential treatment between his son and his daughter to his previous experience in life of not having any siblings and not being accustomed to having a girl around. This shows how experiences in the family of origin, particularly regarding family structure, play a role in how parents behave towards their own children.

Ben, the father of a 4 year-old boy with moderate hearing loss, also brought up the influence of his family of origin on his parenting decisions. Specifically, Ben spoke about how he felt like his parents provided an example for him that he tried to follow:

I would definitely say the relationship that I had with my parents. . . Um, and while I didn't always see eye to eye with my parents growing up, that, that stability has helped me out a lot and it's provided a sense of confidence in me that while they may not have all the answers, they do know, at least, what it takes to get from zero years of marriage to 35 so they have experience in, um, parenting, in marriage, more than I do. And 35 years of marriage versus my 5 years of marriage or my 4 years of parenting now. It's something that if I'm facing a situation that I'm unsure of, that I can go ask them for advice. And I rely on them heavily.

Ben's comment illustrates that he trusted his parents and was aware that they helped shape the person he had become as an adult. Because of the relationship he had with them, Ben considered his parents as important influences on his parenting.

Other life experiences. Parents also noted other experiences in their lives that influenced their approach to parenting young children with DD. For example, several parents brought up their desire to instill morals and values in their children that were often from a religious perspective. For example, when asked about what influences his parenting decisions, Adam, the father of a 17 month-old daughter with profound hearing loss, mentioned, "I'm also a pastor of a church, uh, you know and I hold to-to, my kids to a moral biblical standard and, you know, just following after what I feel is right in that area." Adam illustrates how religious experiences and beliefs play a background role in how parents decide to raise children.

Though several parents talked about their religious beliefs and wanting to instill moral values in their children, parents in this study also talked about lessons they had learned in life

that they wanted to make sure their children could benefit from. For example, Amanda, whose 17 month-old daughter has profound hearing loss, explained:

I've always had to work for what I've got. I worked and bought my own car and I appreciate stuff a lot more than he does. And I take care of stuff versus he's [her husband] not careless, careless, but you know what I mean. I mean, if something happens, it's no biggie, like it is to me. You know what I mean? So, you know, the same kind of concept that, you know, if she gets by with more, then she's going to act worse.

Amanda's life experiences demonstrate the development of her values of self-reliance and taking care of her possessions. These values then influenced her parenting philosophy that she should not let her daughter get away with more than her other children because, according to Amanda, permissiveness could lead to behavior problems.

Other parents talked about how their background in terms of education and work experience played a role in their parenting decisions. One example is Christina, the mother of a 4-year old son with hearing loss and a 2 year-old daughter with apraxia, anxiety disorder, and sensory integration dysfunctions. Christina said the following about her background:

My major is psychology but I've only ever worked in special ed (laughs). I started out in preschool special ed and then I did [early intervention] so I was in preschool for 6 years and then [early intervention] for 8 years. So I don't think I ever done, I guess, just knowing what worked with other kids.

While Christina's background in working with children with DD was by no means normative in this study, it highlights the importance of considering how previous experiences in life shape parenting behaviors.

Child effects. Several child effects were observed in the interview data. However, there was a clear distinction between effects that were primarily due to the nature of the child's disability, and effects that were related to other characteristics of the child that would be

expected among parents of typically developing children. For these reasons, results reflecting *effects related to the disability* and *effects related to other child characteristics* will be presented in two separate sub-categories of child effects.

Effects related to the disability. Parents explained how certain parenting behaviors were directly and indirectly affected by the nature of their child's disability. The themes that fit into this category are *type and severity of disability*, *discovery and uncertainty*, and *increased demands*.

Type and severity of disability. Parents in this study were aware of how the type and severity of a child's disability affect parents in different ways. Overall, parents expressed that children with more mild forms of DD that also function at typical cognitive and social levels could be parented much like TD children, whereas children with more severe DD that had cognitive or social impairments would require a somewhat different approach. Edmond, whose daughter was deaf and had impaired vision, spoke to these differential effects when asked about what advice he would give to another parent of a child with special needs:

There's a huge difference between a physical special need like deafness and a, uh, mental special need, as would be the case with. . . people with Down syndrome, things like that. And I think, um, that it is the, um, special needs that are of the mental or social nature, as in the case of autism, for instance, that really would require a lot of, um, advice or, um, empathy, whatever the case may be, um, for parents. So, um, so you know that's, uh, for, for something like deafness, you know, I, I would think in terms of, in helping another parent, I'd encourage them, you know, to start learning sign language.

In another example, Greg, the father of a 19 month-old daughter with moderate hearing loss, explained how his perspective towards children that have more severe DD had changed after his experience with his daughter:

More than anything realizing other people that are out there that have more severe um, disabilities that they're, they're dealing with, and they, the achievements they've made. And now, you know, to me it just seems, I know it's hearing, but it seems, somewhat minor, it seems like you can get over it. Um, my grandfather didn't have hearing, so we're used to uh, him lip reading and doing different things about it, so I think, just the overall picture just made me more comfortable knowing that it wasn't that big of a deal.

Greg perceived his daughter's hearing loss as some that was not "that big of a deal" and something that she would become capable of managing on her own. His perspective was that compared to children with other more severe handicaps, his daughter's disability was "somewhat minor."

In another example, Amanda, the mother of a 17 month-old girl with profound hearing loss, explained how making decisions about how to parent a child with DD depends on the type and severity of the disability:

It would depend on the disability, too. I mean, you know what I mean, if you had a child who was severely disabled then you're not going to, you know what I mean? You can't, like, you couldn't put me in a survey with someone who had a child who really didn't understand that there was rules and, you know what I mean? Does that make sense, like a child who wasn't really fully capable of understanding that, that something's right and wrong. Then, of course, you're just, I mean, I don't know what you would do. But apparently you would, you obviously would do something different.

Amanda provides the specific example that parents of children with DD that are not "fully capable of understanding" right from wrong face an obstacle that other parents of children with DD may not face in the same way. In all, it was clear that parents in this study had an understanding that not all childhood disabilities affect parents in the same ways.

Discovery and uncertainty. Several parents described experiences illustrating moments of discovery and uncertainty that were directly related to their child's disability. For many, parents often did not know whether to attribute certain characteristics of their child to the disability, or whether those characteristics were part of the child's temperament. Christina, who has a 2-year old daughter with apraxia, anxiety disorder, and sensory integration dysfunctions, mentioned:

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 sometimes if it's she's stubbed up (i.e., being stubborn) and 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.

Christina described that she felt uncertain whether to attribute certain characteristics of her daughter to her disabilities, or whether they had more to do with her daughter's personality and temperament. As a result, Christina felt that it was more challenging to know how hard she could "push" her daughter and when it would be appropriate to try to be more responsive.

Many parents also illustrated the theme of discovery and uncertainty when describing the diagnosis process. In this sense, the theme of discovery and uncertainty is a time sensitive effect that is experienced to the greatest degree after a child is first diagnosed, followed by a steady decline. Isaac, whose 3 year-old son was diagnosed with pervasive developmental disorder – not otherwise specified (PDD-NOS; a diagnosis that falls on the autism spectrum), described his experience with the diagnosis process by saying the following:

It took us a long time to, to come to terms with the diagnosis and I guess for my wife and I, it really didn't take that long, um, I don't know, I just, I feel like we got positive about it

really fast. I think partly *because we had a long time of not knowing* [emphasis added] and so having a label actually made it easier. Um, you know, ‘oh, now you can get services, now, you know now we can start researching what we need to do to sort of, you know, to help him get past those delays.’ Um, and so *I feel like the uncertainty was worse, way worse than the diagnosis* [emphasis added].

In Isaac’s case, he and his wife were not immediately aware that their son had a developmental disability. Isaac explained that the diagnosis came after a year of feel uncertain about certain characteristics of his son and that this period of uncertainty was “way worse” than actually receiving the diagnosis.

Increased demands. Most parents spoke of how having a young child with DD required extra demands of several things, such as time, energy, and resources. For example, Faye, whose 10 month-old daughter was diagnosed with congenital hypothyroidism, spoke of these increased demands when comparing her experiences between raising a child with DD and a TD child. She said:

We definitely didn’t have all these specialists appointments. You know (laughs)? Like so much of our life has been, you know, on the road, going to appointments and especially just, you know, those first few months. It was like, I felt like I was just constantly in a waiting room, constantly in an elevator, you know (laughs) it was just very surreal.

For Faye, having a child with DD has meant an increased demand on her schedule in order to ensure that her daughter receives the services she requires.

Amanda’s experience with her 17 month-old daughter with profound hearing loss sounded fairly similar to Faye’s. Amanda said:

My life revolves around my children. [Focal child] more sometimes because it has to, but...(I: Can you describe a little more about what you mean by that? That your life revolves around your children especially her?) Well, just cause she has so many

appointments that we have to tend to. And work with her and, I mean, you know, like I've been working with her at home, to taking her to her appointments.

Amanda was aware that because of her daughter's hearing loss, she spent more time making sure that her needs were met than she did for her other TD children. This involved both taking her child with DD to appointments as well as spending extra time working with her at home.

Effects related to other child characteristics. Parents also spoke about other characteristics of their children with DD that influence their parenting practices that are unrelated to the child's diagnosis. In this category, the major themes are *gender*, *age*, and *personality and temperament*.

Age. Regardless of the type or severity of disability, many parents acknowledged that certain effects of the child on their parenting behavior were related to their child's chronological age. One specific example is that younger children required less attention in terms of boundaries and consequences. When asked about how she identified consequences for her ten month-old daughter, Faye replied "Um, like with disciplinary consequences? I guess, (laughs) she's still, still a little bit young for that." Due to her daughter's young age, Faye had not yet attempted to identify consequences for her child with DD.

In contrast, some parents felt that as their child with DD got older, the easier it was to distinguish characteristics of the child that were associated with the child's disability. For example, Jessica, whose 5 year-old son was diagnosed with autism, gave the following explanation when she was asked about the extent to which she felt her interactions with her son were influenced by his age compared to his diagnosis:

You know, and I have some friends close to his age, you know, and I can see the differences, so I, I think a good majority of it is due to autism. (I: So, has that changed a little bit over time as he's gotten older?) Yeah, 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 at his age that's pretty normal. But I think, as he gets older, that difference might be more pronounced [emphasis added].

Jessica explained that when her son was younger, it was harder to pick up on features that distinguished him from other children. As her son got older, however, those differences became more “pronounced”.

Still, other parents were quick to attribute characteristics of their child's behavior to the child's age rather than anything related to the disability. For example, Brittany did not find it striking that her 4 year old son with profound hearing loss was so active. She explained:

He's very rambunctious toddler. So he's always hitting his brother or picking on him or touching him or. So, as far as discipline, *but I would expect that from any kid his age. I don't notice any different behavior that has, that's any different from his hearing loss. It's related more to his age* (laughs) [emphasis added]. If that make sense.

Brittany was clear to that she did not believe that her son's “rambunctiousness” was a feature of him being a toddler and not having a hearing loss.

Gender. Parents also attributed aspects of their child's behavior to the gender of their child, which then affected certain aspects of their parenting. For example, Denise, whose 2 year-old son wore hearing aids for his hearing loss, claimed that she treated her son the same as her TD daughter, but then elaborated by saying “But the thing is, he's boy, he's really active, so he's more trouble maker. So (laughs) he's, um, I always say, I mean, he's, he makes me more angry than his sister.” In fact, several parents described their boys with DD as active and as trouble makers. For example, though Brittany ascribed part of her son's “rambunctious” behavior to his being so young, she also attributed it in part to him being a boy. For example, when describing the relationship between her 4 year-old son with hearing loss and her TD 2 year-old son, Brittany said, “He fights with his brother like crazy (laughs). Um, just two typical boys. Um, but one with a hearing loss.”

Some parents of girls with DD in this study attributed their daughters' characteristics to common girl stereotypes, such as being a drama queen or having a lot of attitude. When talking about how she parents her 17 month-old daughter with hearing loss differently than her two older sons, Amanda provided an interesting perspective that included age, temperament, *and* gender:

She obviously don't get in as much trouble as the boys because they're 4 and 2 so they get in to more and, just with her, it's attitude. I'll say, I call it a girl fit. She pitches a lot of girl fits that the boys didn't pitch (laughs) so I didn't have to deal with that so, so I mean that's new too. It's just the difference between a girl and a boy. It's just a *big* [emphasis added] difference.

Despite the inclusiveness of Amanda's perspective in how other child characteristics influence her parenting decisions, because she emphasized her daughter's gender, it was included in this section. Overall, however, Amanda's point provides a look at how some parents of young children with DD explain much of the differences in their parenting to characteristics of their child, such as gender, that are not related to their child's disability.

Personality and temperament. Parents attributed certain aspects of how they treated their child to their child's personality and temperament instead of to the child's disability. This was especially true among parents who also had typically developing children in the household. For example, Greg, whose 19 month-old daughter with hearing loss had a TD twin, explained that the types of boundaries he used with his daughters differed because of their personalities. Greg claimed:

You could tell their personalities and they're just becoming more and more evident. I think [focal child's name] is just stubborn and hardheaded and very, I guess just um, she keeps trying over and over and over again on certain things. And [sibling's name] is just more relaxed, she just goes with the flow. If [focal child's name] wants something then

she usually give it to her, and, but on the other hand, [focal child's name] can be so sweet too, and she'll help out with [sibling's name]. So, they both have opposite personalities, but they're a lot of traits that are in common."

From Greg's perspective, his daughter with hearing loss was more stubborn than the twin sister. Greg even characterized their personalities as "opposite", but never attributed their differences in behavior and temperament to their physical differences in hearing capacity. As a result, when Greg spoke about how he might treat his daughters differently, he focused on how their personality differences shaped his behavior rather than their differences in ability to hear.

Other parents were more uncertain whether certain characteristics of their child were due to the child's disability or the child's personality. One example is from Ben, the father of a 4 year-old boy with moderate hearing loss:

I don't know if it's necessarily because of his hearing loss, but it's more because of his personality. He seems to want a little bit more structure and explanation about what's going to happen. 'Now, in an hour, in 3 hours, in 4 hours,' so with [focal male] we try to explain what the plan is for the day. If the, if the day is 'we're going to this store to get groceries and we have to go pay for our tags and then we're going to the park for an hour and kick a soccer ball and then go home and give you a bath and put on your pajamas.' It might sound a little bit regimented, but he likes to know what the routine is.

Although Ben was uncertain about the degree to which his son's preference for following a schedule were due to his hearing loss or his personality, the lack of clarity demonstrates that child characteristics such as temperament persist as important elements to the child effects process among parents of young children with DD.

Formal social support. In this sample, all parents had some degree of knowledge of the formal supports and services their child was receiving, whether it was from pediatricians, therapists, early interventionists, or other service providers. Invariably, parents' described how

their behaviors toward their children were influenced at some level by the services their children and families receive. The major themes parents described related to this category are *empowerment, differentiating services, and homework.*

Empowerment. Many parents spoke about the role of professionals in providing guidance and direction that had an empowering effect. Gloria, whose 19 month-old daughter wore hearing aids for moderate hearing loss in both ears, mentioned multiple ways she had felt supported through the early intervention system:

Yes, they're very supportive. Um, we meet with her case manager probably, officially, probably 4 times a year, I think it is. About every 3 months, we do her IFSP. Every 6 months and then like half way in between, we review it just to make sure, um, last, 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. We've talked about, um, the daycare at (the local school for the deaf) and getting her incorporated in that and, um, it just, for the transition, when she's 3, and for when she transitions out of (the early intervention system), they're just, they're so helpful. We do a playgroup with them and her caseworker is at most of those. *And they're just a very, very supportive group of people and it really, it gave us a huge, uh, I don't even know, like a stepping point, like where to start when we found out 'cause . . . we just kind of didn't know. And they contacted us and got the ball rolling* [emphasis added] and it was just, ah, I want to say 2 months old. Right around 2 months. So they've been very supportive and any idea that I have, they're open to, any idea they have, I'm open to. So we work well together and it's, it's been a great fit and just a great source of support for my husband and I both.

Gloria described the various ways the early intervention system had provided guidance and direction during the period after diagnosis and throughout the process of getting treatment for

her daughter. According to Gloria, those who provided formal support to her family provided a “stepping point” that was empowering for the entire family.

Jessica, the mother of a 5 year-old son with autism, was asked about the degree to which she felt like professionals and service providers influenced her parenting decisions. Her response illustrates how formal social supports and services affect the entire family and not just the focal child:

I mean, they’ve completely influenced it (i.e., her parenting decisions), you know, because we wouldn’t know how to deal with it, you know, with a child with special needs, otherwise, you know. Raising [sibling’s name]’s been completely different because we hadn’t had those particular challenges. So, they’ve given us, you know, they’ve probably given us therapy (laughs) as much as [focal child’s name].

According to Jessica, raising her 10 year-old daughter was a “completely different” experience than raising her son with autism. Jessica’s response reflects that feeling that the services her son received provided support and empowerment for the whole family.

Differentiating Services. Though some sources of formal support were empowering, parents also identified sources of formal support that were less helpful. Parents in this study often differentiated between the types of services that they preferred versus those that they felt were not as beneficial. Overwhelmingly, parents seemed to prefer services that took place in the home in a natural environment compared to types of formal support that occur in classes or therapists’ offices. For example, John, whose 5 year-old son was diagnosed with autism, clearly felt that he learned more from in-home services than he did from parenting classes he had attended:

The thing about the training classes, parenting classes - they help you kind of understand what’s going on, but to try to apply it, I think is a little bit more of a challenge. I think we’ve had much more benefit, greater benefit from one of our ABA [applied

behavior analysis] therapist that comes to the house. And she actually works with us and actually applies common steps that we, we've benefited a lot more from that. We could intellectually understand what they're talking about when we go to these classes, but to try to actually apply it is an area we've struggled with.

In John's case, receiving family-centered services provided a much greater practical benefit than attending a class or a workshop. In addition, John's statement alludes to the sense of teamwork and camaraderie that is developed between families and family-centered service providers.

Other parents in the study pointed out how different sources of formal support provided services that affected their lives in different ways. For example, Brittany, the mother of a 4 year-old son with hearing loss, explained the various ways the early interventionist and the university center for deafness helped her son and her family in different areas:

Well, his preschool. The, applying for that. I wouldn't have known about many of those things if it wasn't for him having a, um, his early interventionist that came to the house and she helped us get prepared to get him into, um, school, and get him evaluated. So, a lot of that I wouldn't have known how to do without them. Um . . . and it, and it helped him a lot. But I feel like he had more help, as far as language and development or anything with [the university] than he did with the early interventionist.

Brittany illustrates how the early interventionist was helpful with getting their family prepared to get her son into school and get him evaluated. However, when it came to language development, Brittany explained that the university center for deafness had been more helpful than the early interventionist. Brittany's statement demonstrates the kinds of distinctions that exist when assessing how the types and delivery methods of formal supports and services influence families in different ways.

Homework. When discussing the formal supports and services that their child received, many parents spoke of how service providers gave them specific assignments to work on at home. Harold, the father of a 5 year-old boy with autism, said about his son's school that "They send stuff home with him all the time, uh, you know, for us to work on. For me to work with him." Harold went on to describe that he was glad that the school as interested in helping his son progress, which made him eager to complete the tasks recommended by his son's teachers. Similarly, Ben, whose 4 year old son had moderate hearing loss, explained how the services his son received influenced his parenting choices:

I guess from the plans that we received, whether it was from the [the early intervention system] or if it's from [the university's center for deafness], it's mostly reading material or, um, sentence structure or, uh, writing that they've asked us to work with him at home, um, there 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.

Ben described his experience as feeling like he was a "student all over again", which illustrates how parents of children with DD perceive their experience receiving assignments via their child's clinicians and service providers.

In another example, Forrest, whose ten month-old daughter was diagnosed with congenital hypothyroidism, also spoke about the work assigned by his child's service providers:

Just like having all these extra duties that we have. And all the extra, um, there's a lot of extra work that goes with, I mean. We get a packet, like every time they do some therapies, we get a packet of what we should be, um, working with her on.

Forrest went on to describe in detail the kinds of assignments he and his wife had received regarding his child's physical development, such as having his daughter sit up, roll over, or lay on her stomach. Though Forrest and other parents did not necessarily express any discontent

with having to complete tasks assigned by their child's service providers, some parents expressed that the homework was a burden. For example, Denise, the mother of a two year-old boy with moderate hearing loss, talked about the difficulty she has incorporating all the goals and assignments set by her son's service providers and in his service plan:

I kind of forget everything (laughs). And then I was really stressed because I should do this, this, this. Following this, their orders, because they're giving me two places, different order and then the other orders from other places. Like we had an eye doc surgery. And then he need some ointment for that and then he need to do this, he need to do that. Many orders from them, so I'm kind of burned out.

Although Denise also expressed that her son's service providers were helpful in many ways, she also felt that she was given too many tasks to remember and was feeling "burned out" by all of the "orders" she was being given. Though this type of response was infrequent in the present study, it adds a dimension to the element of homework experienced by parents of young child with DD.

Informal social support. Parents of young children with DD in this study also described receiving additional support from informal sources such as family members, neighbors, church members, and online communities. Although parents were less conscious of how informal social supports influenced their parenting, I include it in the model on the strong evidence from previous research suggesting the importance of informal social support for parents of young children with DD (e.g. Davis & Gavidia-Payne, 2009; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Some themes from this category are *help from family members*, *partner support*, and *support from other parents*.

Help from family members. Parents in this study who lived near extended family members spoke about how their kinship networks were an important source of informal social support. In addition, parents who had other children that were typically developing occasionally

mentioned how helpful the TD children were with their siblings with DD. For example, Jessica, the mother of a 10 year-old TD daughter and a 5 year-old son with autism, described the help she receives from family members when talking about the challenge of raising a child with autism:

I think that it's challenging, and you think about your child's well-being so much that you need to think about your own well-being also, which probably goes without saying, um, that I think having breaks, I mean, me and [husband's name] are lucky that we have our mothers that can give us breaks, you know, and even [sibling's name]. I mean, I didn't really mention his sister, but she is wonderful with him. Um, you know, and just her, sometimes he'll play with her in her room for 20 minutes, and that's helpful.

Jessica described how her family members, including her own children, provided moments of respite that were important to her own well-being.

In another example, Faye, the mother of a nine month-old girl that was born without a thyroid gland, spoke about how she relied on her mother to help take her daughter to appointments: "My mom just retired last year and she takes her to, you know, some of the appointments she has to go to." Other times throughout the interview with Faye, she referred to times when her mother had taken her daughter to see the doctor or therapist. It was apparent that Faye and her husband benefited from having a family member living close by that could provide such instrumental assistance. Having a break from rushing to appointments and entertaining a child with DD allows parents focus more on themselves and their other children.

Partner support. When describing informal sources of social support, parents from this study talked about how helpful their partners were in sharing the load in carrying for a child with DD. For example, Ben traveled a lot for work and could not always be as involved with his son with hearing loss as his wife. Ben said:

Since I am at work during the week and I rely a lot on what my wife says, what [focal male] did, and his behavior. If he was good, um, in terms of interacting with his little brother or helping around the house or whatever it may be. Um, if I get home after dinner and we start to play and he's still in good spirits and I find out that he's had a, I guess a good report card from mom, so to speak. . . I don't get to spend as much time with him as my wife, who stays at home with our children.

Ben emphasized that he relies on his wife to take care of their child with DD during days he is at work and that he also relies on her for reports on his son's behavior so that he can know how to treat his child with DD when he gets home from work. Parents' dependence on one another is part of the broader process of raising and parenting children with DD.

Support from other parents. Many parents described receiving extra social support from other parents who have children with DD, as well as other parents in general. For example, Harold said, "I'll tell you, the classes haven't helped me as much as talking with other parents of other autistic children, [which] has helped me more than anything." Compared to the support he had received from parenting classes, Harold clearly felt that he had gained more from the support he had received from other parents. Specifically, Harold later indicated that talking to other parents of children with autism helped him "to try to know what's coming down the road." In other words, other parents supported Harold by giving him advice related to what he might be able to expect from having a child with autism.

Other parents in this study mentioned how they received help from other parents via the internet. For example, Faye described some of her email exchanges with another mother of a child with congenital hypothyroidism:

There's not many babies with, born without a thyroid gland. It's very rare. Or so, you know, I mean 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? Um, I

did have a friend who had, who knew someone in Denver. Like their kid had the same experience. We did, like connect on email with them and just compare notes. . . we just talked about medicine, administering the medicine and, I think, was her daughter, I think about 2 there, just give her the pill and tell her to like chew it up or swallow it, so she didn't have to grind it up any more.

Faye described her desire to share her experience with someone who had been through it before. She was looking for someone she could “compare notes” and relate to. Given the rare nature of her daughter's condition, Faye could only receive this kind of informal social support through email.

Worry and stress. Although parents were not asked about how having a child with DD affects their experiences of *worry and stress*, many parents voluntarily spoke to this category of responses when answering other questions. The themes that emerged related to the worry and stress category were *child's future* and *child's safety and wellbeing*.

Child's future. Worry and stress came up frequently as parents discussed their concern for their child's future. Many parents seemed uncertain about what the future would hold for their children with DD. For example, when discussing potential barriers his daughter would face due to her hearing loss, Adam said:

That was what we feared was, you know, is from what research - having an idea of what was probably going to be wrong with her before we had the deafness test - that was the fear that we had had that deaf children graduate at, what was it? Was it a second grade reading level? Um, you know, and the social skills, they would be learned without people learning sign language and such, so, we really worried that she would never be given the same opportunities in life that [Child's Name] and [Child's Name] would be given because they were able to go to regular school, because they were able to get a normal education and be able to learn at a capacity that normal kids can. So, long term

we were worried about having, being able to have a normal, you know, given a chance at life. You know, going to college, just being able to pursue whatever she wanted to pursue without that barrier there.

Adam's narrative provides two key examples of how parents of children with DD experience worry and stress related to their child's future. First, he mentioned the fear that his daughter with hearing loss might not have the same capacity for learning as his other children. This led to Adam's next concern that his daughter might not have the same opportunities in life as his TD children because of her hearing loss. These two concerns of child capacity and child opportunities created worry and stress about the future of his child with DD.

Doug, the father of a boy with hearing loss, illustrated his concern for his son's future by providing the following statement:

Now, I worrying about how he develop, grow up. And, uh, how and what kind of job can he find like or finding and how he can pl-, uh, play with, uh, his friends. When he grow up and I'm curious about. And worry, also worry about, he should go, if he should go to the deaf schools or should go to the normal school. And, if he go to the normal school, how can he play with everybody and play with friends. Just I worry about that now.

Doug was concerned about whether his son would be capable of finding a job and his son's ability to play with friends because of his hearing loss. Further, Doug faced concerns about what kind of education would be best for his son. This narrative demonstrates the kinds of issues parents of young children with DD face when making decisions that could ultimately play a role in their child's future. Along the same lines, Amanda discussed the worry and stress she experienced in deciding whether to have her daughter with hearing loss undergo a major surgery for a cochlear implant, a device that amplifies hearing capability. Amanda said:

When you're a parent, you kind of 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, and they, you know 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 to be, you know what I mean, I mean, I either have to make a choice for her or make it and that means that she is, that she's probably not going to be happy with that choice, you know what I mean? Cause she may learn to hear but speech is really not going to be an option so, and then you do a cochlear [implant], which is major surgery and you worry about having a child who's healthy, but not hearing, so to say.

Amanda was well aware that her decisions regarding her daughter's opportunity to receive a cochlear implant would play a significant role in her daughter's future. These kinds of decisions influence the stress parents of young children with DD experience related to their child's future.

Child's safety and wellbeing. Parents also mentioned their experiences with worry and stress when describing their concern for their *child's safety and wellbeing*. This theme illustrates the perspective of some parents that their children with DD are more vulnerable and susceptible to being victimized or harmed in some way. For example, Ben said the following about him and his wife's perceptions of their son with hearing loss:

I don't know if it was because he was our first child or because he had a hearing loss, but we were extremely protective and extremely nervous of everything. If it was a speck of dirt we saw flying through the air or if it was a car honking their horn, we were extremely nervous that anything could hinder his hearing or hurt him or make him sick, and we just looked at him as extremely fragile.

Ben went on to explain that he and his wife eventually felt less worried and stressed about their son's safety and wellbeing, but their original experiences of anxiety and concern related to their

son's safety and wellbeing is something that other parents of children with DD experience as well.

For example, Isaac provides an in-depth look at why parents of children with certain types of DD may experience increased worry and stress related to the wellbeing of their child. Speaking in reference to his son with PDD-NOS, Isaac says:

When he's sick, that's very hard. Uh, we know to consider that kind of a negative time 'cause he's upset and he can't tell us what's wrong. Um, so a lot of times he'll get sick. You know. Sometimes we think 'oh, it's nothing' and 'don't take him to the doctor'. Then it becomes something. Um, he had croup and we didn't even know until we finally took him to the doctor and they're like 'oh, he needs to go to the hospital for a breathing treatment'. I mean, it was serious and we had no idea because he's just sort of under-responsive to things like that. You know, he just sounded like he had a little cough and then, um, *apparently most kids get, um, really upset and, there's a lot of pain and they cry and you know something's really wrong with them and he wasn't that way, so that's a very scary time as a parent* [emphasis added]. You think that things aren't wrong, but something is serious and you can't tell . . . there's a lot of worry that something might happen to him that we wouldn't be aware of. Or that he could wander off someday and we wouldn't even, we wouldn't (laughs), you know, what would we do then, you know? Um, so, yeah, so there's, you know, we worry a fair bit about him, uh, just cause we know that he really *can't* take care of himself. Uh, and he can't tell us of something is wrong, so that's, *there's always a constant worry on my mind, you know, with him spending so much time away from home that something could happen and we wouldn't know about it* [emphasis added].

Though this is a long and involved passage, it provides a rich description of the reasons parents of young children with DD experience stress related to their child's safety and wellbeing. For

example, Isaac mentions that the primary reason for his worry and stress is that his son with PDD-NOS is not very expressive and “under-responsive” to potential health risks, which limits his ability to know exactly when something might be a problem and when everything is fine.

Parenting behaviors. The parenting behaviors described by parents fit into two sub-categories common in the parenting literature: *regulation* and *support*. Because the focus of this analysis is to demonstrate how children with DD influence parenting behaviors, the major themes in these sub-categories focus on illustrating those effects. However, a preeminent theme emerged as a category of responses that transcended the differentiation of regulatory and supportive parent behaviors. In other words, *seeking normalcy* was an aspect of parenting behaviors described by parents that fit into both sub-categories that emerged.

Seeking normalcy. Nearly every single parent that was interviewed used the term “normal” or any of its derivatives (i.e., normality, normally) at least once in their descriptions of their expectations, goals, and parenting behaviors. Due to the salience of this theme and its fit with both regulatory and supportive behaviors, seeking normalcy is considered as a distinct feature of parenting behaviors among parents of children with DD. Faye illustrated this concept of seeking normalcy when she spoke of how she planned to help her daughter pursue her hopes and dreams:

I guess just, you know, treat her like any of our other kids and just, um, and try to make her feel normal. I just, you know, again, I just don't want her to, you know, even if she has cognitive delays or physical problems, you know, she'll, she's a little physically delayed now. Um, some things she's right on track and some things, like crawling, she's definitely a few months behind. So, but, um, you know, I just want her to, 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.

Faye demonstrated that seeking normalcy is a proactive component of parenting a child with DD that involves “pushing” her child and not subscribing to any preconceived labels about her disability.

While Faye illustrated her desire for her daughter to have a “normal” life, some parents also emphasized their efforts to treat their child with DD in the same manner they treat their other TD children. This idea of “sameness” in parenting behavior fits with the category of seeking normalcy because it relates to the overall notion that many parents of children with DD attempt to foster development among their child(ren) that closely resembles the development of TD children. For example, Greg explained the following when describing how he expresses his care and concern:

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. Um, but other than that, we, you know, she gets in trouble, she gets rewarded, she plays, she’s happy. We’ve got to be a lot more physical, in her face, look at me type of deal when you’re dealing with her. Um, but even with the hearing loss, she has hearing aids, so she can still hear us, and we don’t let her get away with anything that we wouldn’t let the other one.”

Greg’s emphasis on treating his daughters the same, despite some minor alterations to account for the one daughter’s hearing loss, reflects back to the category of seeking normalcy in that whether he is disciplining or expressing affection, his goal is to treat his daughter with hearing loss “no different” than his TD daughter.

Similar to Greg’s experience, Adam also spoke of his desire to avoid giving his 17 month-old daughter an advantage in life because of her hearing loss. When asked about what advice he would give to a parent of a child with DD, Adam said:

The best advice I would give - treat them fairly. I mean, if they, if they have kids, I would just always say, you know, 'Don't give them an advantage, um, over your other kids.' Try to treat them as fair as you could. The other ones, if they don't have kids, um, you know, you always spoil your first one no matter what. But, you know, *just try to be as normal as a parenting style as you can with them and not give them an advantage, I would say* [emphasis added].

Adam's desire to use a normal parenting style with his daughter reflects an interest in helping his daughter learn to play by the same rules as children who are TD. Adam's quote illustrates parents' desire to treat their children with DD as normal as possible and providing little, if any, special treatment.

Support. Parents described various ways in which their methods of showing support were influenced by having a child or children with DD. The themes that emerged related to parental support were *affection and nurturance*, *progress with disability*, and *acquiring knowledge and skills*.

Affection and nurturance. Parents were aware of how their child's disability affected their capacity for demonstrating affection and nurturance. When asked how she shows care and concern for her daughter with deafness and vision impairment, Edith explained:

We are always hugging each other, so as soon as I see her I look surprised, you know, happy and surprised, and, and uh, I talk, you know, 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, I don't know, just other, you know, touch and sight as much as we can cause she can't hear as much of what you're saying* [emphasis added].

Edith demonstrated that having a child with DD involves taking certain aspects of the child's functioning into consideration. Despite efforts to treat her daughter in normative ways, Edith

acknowledged that her daughter was incapable of receiving any type of verbal affection and praise. As a result, Edith spent more time showing affection and love through physical and visual cues.

Other parents spoke of an increased intentionality in showing affection and support of their child with DD. Though it could be considered normative for all parents to be supportive and attempt to instill confidence in their children, parents from this study felt an increased need to demonstrate their affection and nurturance toward their children with DD in an effort to instill confidence in their child. For example, when discussing how other people might view her son with autism, Harriet said

I just don't want people staring at him, and I don't want him to have a low self-esteem.

And I, I try to build him up as much as possible, you know, 'you're so beautiful, you're so smart, you're so sweet. Um, good job this, good job that, [focal child's name] can do this, yeah!'

Similar to Harriet's response was Brittany's, who has a 4 year-old son with profound hearing loss:

When he's at home, he gets tons of love. I mean, he gets a lot of support at home, emotionally. A lot of emotional support. I think that's helped him a lot. Especially with all of his therapy from birth. I think has been the big, the key to his. But we try to give him a lot of emotional support at home so he has a little bit more confidence when he goes to school.

In terms of affection and support, parents indicated two primary ways that having a child with DD influences their supportive behaviors. First, that some conditions dictate the types of behaviors parents can utilize to show affection. For children with hearing loss, parents may use more visual and physical indicators of affection and less verbal indicators. Second, parents of children with DD use many forms of positive reinforcement and display affection in ways that are

common in many households, but also appear to be used intentionally among some parents who have children with DD.

Progress with disability. Another prominent theme that emerged from parents' descriptions of their supportive behaviors had to do with their intentionality in attempting to help their child make progress in areas that were specifically related to the nature of their child's disability. For example, Gloria explained that the way she has shown concern her daughter involves the following:

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 (the local school for the deaf) 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.

In Gloria's case, supporting her child involves helping her child get all the resources she needs to make progress related to her hearing loss. Ben, the father of a 4 year-old boy with moderate hearing loss, also mentioned his efforts to make sure his sons gets all treatment he qualifies for related to the son's disability:

I just want to, to make sure that what I do to work with him, or what I can do as a parent to get him involved with things that will help, *I want to make sure that I as a parent and my wife as a parent are exposing to every resource and avenue that's available to him, if it can be of benefit in his, um, interpersonal skills or in his speech ability or, something that will help build confidence in him* [emphasis added] so that when, later on in life, he's facing difficult situations with friends, people at school, whatever, because it's, it's inevitable, it will happen, I want to make sure he's got enough self-assurance to know

'hey, I'm okay, just because this person's picking on me because of hearing aids or whatever, it doesn't mean I'm worthless to society'.

For Ben, showing support of his son with hearing loss meant getting his son involved in any treatments and interventions that were available. Ben and Gloria both demonstrate that parents of children with DD show their support when they attempt to help their children make progress in areas related to their disability.

Another example of how parents wanted their children to make progress with their disability is from Isabel, who specifically mentioned that her primary goal was to keep her son happy. However, due to her son's deficits in his ability to relate to others in social situations, Isabel also spoke about another goal:

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 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 sort of re-train the way he acts with people, so he can have close friendships and things like that.

Isabel mentioned that she wants her son to be able to connect to others in socially normative ways. However, because of his disability, Isabel is aware that this effort will require intentional training on how to act with people that will allow her son to have close relationships with others. For Isabel, supporting children with DD involves helping them make progress.

Acquiring knowledge and skills. Parents we interviewed consistently mentioned how supporting and caring for their child(ren) with DD involved acquiring knowledge and skills that they previously did not have. They spoke of learning about their child's disability and learning specific skills they would need for interacting with their child. For example, most parents of

children that were deaf or had hearing loss in this study talked about learning at least some amount of sign language, especially right after they first learned of their child's diagnosis.

Other parents discussed the efforts they went through to learn the skills they needed to provide treatment and intervention for their child. Isabel spoke in detail about having to learn how to teach her 3 year-old son with an autism spectrum disorder (PDD-NOS) how to learn:

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. . . I think, the best thing that I can do in that arena, is be well informed myself because um, I mean, you can't, can't expect him to, to learn skills at like a typical child because there's a very like specific pattern to teach autistic kids how to learn. It's like, you know, short drill, reward, short drill, reward, short drill reward, so um, I had to learn how to do that.

Isabel specifically mentioned learning about autism and learning about how to use behavioral intervention techniques when she was asked about how she shows her care and concern and supports her son's learning. Harriet also spoke about her efforts to acquire the skills she needed to care for her son with autism. She specifically mentioned the difficulty she had keeping her son in his car seat while driving:

Me and (the child's therapist) are still working on that. She's trying to teach me more positive reinforcement type things to do for him. Rather than waiting till he's done made himself unsafe, and for instance, she said, 'praise him every few minutes, good job staying in your car seat.' You know, that kind of thing that I wasn't doing before. I was just driving thinking, 'he's supposed to stay in his car seat, kids stay in their car seat!' . . . I still have a lot to learn.

Harriet had to learn alternative ways of encouraging her son to remain in his car seat from her son's therapist because it was a scenario where her expectations for her child's behaviors (i.e.,

that he stay in his car seat while driving) did not match the reality of her experience. Indeed, though it depends largely on the type and severity of the child's disability, parents of young children with DD are put into a scenario in which they must acquire some kind of new knowledge and learn new skills for interacting with and supporting their children.

Regulation. Parents in this study described various behaviors related to the discipline, monitoring, and control they exercise over their children. In order to incorporate each of these behaviors into one sub-category, I introduce the term *regulation* as a descriptor of the types of behaviors parents engage in to enforce boundaries with their young children with DD. In the sub-category of regulation, parents' responses illustrated themes related to *discipline, public vs. private, and vigilance*.

Discipline. Parents were asked about how they identify boundaries and consequences for their child(ren) with DD. Invariably, parents used the term discipline when describing this process and the strategies they used. While many parents described using disciplinary tactics that would be found in many homes of children in the birth to five age range such as timeouts, spanking, taking away desired objects, and telling children "no", parents in this study spoke about the added difficulty in disciplining their child due to the nature of their child's disability. For example, Isaac said:

Discipline has been a problem; setting boundaries has been difficult since we can't, since he's not very expressive, we can't tell whether he understands why something is being taken away. Cause it's dangerous or that it's just not his to play with or break and, you know, it would have to be replaced and that would be expensive and, et cetera. So there's a lot of, you know, levels where we're not sure where he's taking away from it.

Isaac demonstrates that the use of discipline with a child with DD can be difficult and unpredictable depending on the nature of the child's disability.

Like Isaac, Ben also spoke about how having a child with DD affects the disciplinary strategies that he is able to use with his 4 year-old son with moderate hearing loss. Comparing his son with hearing loss to his TD son, Ben said:

Even though [focal male] does wear hearing aids, I make an effort that if I want to really communicate something with him, like if he's done something wrong and we want to teach him about safety, like why you shouldn't climb on a 20-foot ladder when no one is looking. Um, with [focal male], 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 fingers) '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.

Ben further illustrates the predicament introduced by Isaac in which parents who wish to use effective methods of discipline with their children with DD must consider the cognitive and communicative abilities of the individual child. Otherwise the purpose of the disciplinary action may not be clear.

Public vs. private. When parents were asked whether their parenting behaviors differed in public settings (e.g., the park, the grocery store, the library, a restaurant, etc.) versus private setting (e.g., at home), nearly all parents described how being in public vs. private affected their efforts to regulate their child's behavior. For example, Harriet, the mother of a five year-old boy with autism, answered in this fashion:

Yeah, I try to be more firm in the store because I don't want him to throw some kind of tantrum that looks like, I may be abusing my child, or something, like something bad in that kind of way, and, and most people don't understand autism, or, or disabilities.

Harriet's response highlights the effort parents make to avoid public tantrums due to the perception that "most people" don't understand children with DD. In Harriet's case, she claims to use more firm tactics while in public to keep her child under control.

Similar to Harriet's experience, John spontaneously brought up how his regulatory practices differed depending on whether they were in public or in a private location. When asked about the types of consequences he uses with his 5 year-old son with autism, John said:

It depends on the situation and the environment that we're in. If we're out in public we can't, well, we might employ a different strategy than at home, just because we're trying to, uh, keep the situation from devolving too much in a public environment. So try to, might try to [avoid problems] in public than we would at home or, or might, uh, you know, try a different strategy that we don't usually use in the home environment.

Both John and Harriet described how the types of consequences and discipline they used with their children depended on whether they were at home or whether they are in a public setting. In both cases, parents spoke about using different strategies in public than at home in an effort to avoid tantrums or other behaviors that might draw unwanted attention to themselves or their child.

Another important perspective comes from Adam, the father of a 17 month-old girl with profound hear loss. Adam also has two older sons who are typically developing, and in the following excerpt he discusses how his regulatory behaviors differ in public depending on the child:

Well, the one thing about [Focal Child's Name] is that she is really loud. And, I guess, again people don't understand why she's loud. She don't know she's being loud. You know, with her we're more apt when we're out to take her, uh, maybe out of the environment to calm her down. Whereas with the boys I, you know, may just, kind of, I may just say "Hey! Calm down, we're in public" You know, "I'll take you to the car" or "I'll

take you to the bathroom”. You know, with her, you know, we just may take her out of the environment for just a few minutes so we can get her to calm down before we bring her back in.

Adam provides a perspective in how the strategy of regulating the behaviors of a child with DD in public is different than compared to a TD child. Whether parents of children with DD are more or less strict in public is not clear. However, it is clear that parents of young children with DD use differing regulatory behaviors that are more appropriate to managing the specific child.

Vigilance. When parents were asked about how they set boundaries with their children with DD, many described a heightened sense of awareness and attentiveness to the child’s schedule. I use the term *vigilance* following a response to this question about boundaries given by Forrest, whose daughter was born without a thyroid gland: “The main thing for her is just uh, is for us to kind of, you know being doing the work that the therapy is kind of asking us to do, and trying to stay *vigilant* [emphasis added]”. Though vigilance is clearly related to the protective anxiety parents illustrated in the theme of *child’s safety and wellbeing*, it is important to distinguish the experience of stress and the parent behaviors that are related to that stress. In this case, vigilant parenting behaviors include those related to monitoring child behaviors.

Isaac demonstrated how vigilance fits in the sub-category of parental regulation. When asked about the boundaries and consequences he uses with his son with PDD-NOS, Isaac said:

But we just try to be consistent with boundaries that we have set and just try to be vigilant and make sure that we can get to him right away if he starts to do something that we don’t want him to do.

Parents’ descriptions of keeping an extra watchful eye on their children with DD shows the types of effects of children with DD on parental regulatory behaviors.

Chapter 5

Discussion

The current study explored the various ways in which parenting behaviors are influenced by young children with developmental disabilities (DD). According to the child effects literature, the parent-child relationship is conceptualized as a bidirectional relationship in which as parents influence child development and behavior, parent behaviors are influenced by characteristics of the child (Bell, 1968; Bell, 1979). In the present study, I analyzed interview data to investigate the reciprocal nature of the parent-child relationship among this population. Though a previous analysis of this interview data was completed exploring the overall experience of parenting children with DD (see Sams, 2012), the present analysis contributes beyond this previous analysis by incorporating the important perspective posed by the child effects literature. No prior study has employed a qualitative design to explore how parents' behaviors are influenced by the presence of a child with DD. In addition, this analysis contributes a conceptual model of how the parenting process operates among parents of children with DD that includes constructs that are familiar to the overall literature on families of children with DD (see Figure 1). The proposed linkages in this model provide important theoretical value to future studies of parenting young children with DD.

Categories and Themes

The categories illustrated in Figure 1 reflect broad, overarching constructs that were relevant in some way to each of the parents that were interviewed. These categories consist of a broad array of major themes discussed by parents and, in some cases, sub-categories that provide further clarity to the main categories.

Life history. The first category of responses emerged primarily from parents' responses to questions about what they felt influenced their parenting decisions. Parents often spoke about experiences in their lives prior to having children. For this reason, this category of

responses was named *life history*. The category illustrates that parents of children with DD are unique individuals that have a history of important life experience that contribute to the behaviors they engage in with their children. Although Sams (2012) considered the role of “past experiences of the parent” in her conditional matrix (p. 180), she provides no evidence from the analysis of parents’ responses related to this component of the model. It was apparent, however, that parents gave considerable weight to their life history in terms of its effects on their parenting behaviors.

The themes that emerged related to life history were *family of origin* and *other life experiences*. *Family of origin* emerged as parents described how their experiences with how they were raised by their own parents and their relationships with their siblings served to influence their goals and behaviors when parenting their own children. This theme fits with evidence from studies showing direct transmission of parenting styles across generations among families of TD children (e.g., Kerr, Capaldi, Pears, & Owen, 2009). *Other life experiences* is a broad theme that incorporates and previous life experience not related to the family of origin that may affect parenting behaviors among parents of children with DD. At first, the name for this theme was *education and work experience*, which resulted from a few parents describing how they felt their experiences in school and in their careers may have influenced their parenting decisions. However, there was limited support for this theme, which resulted in the use of a more broad and inclusive label for this theme that represents any life history experiences that occurred outside of the family of origin that affects parenting behaviors. Overall, parents in this study were aware of the various ways that their experiences in life prior to having children influenced the parenting decisions. Though parents’ emphasized their experiences in their family of origin, many pointed out other experiences in their lives that also were important.

Child effects. The second primary category of responses, *child effects*, was the focus of this analysis. Specifically, *child effects* represents a broad array of responses in which parents discussed the various ways that certain characteristics of their child with DD affected their parenting behaviors. Two sub-categories emerged differentiating the types of child effects experienced by parents of children with DD: *characteristics of disability* and *other child characteristics*. The sub-category of *characteristics of disability* was reflected by parents' descriptions of the various ways which having a child with DD affects their parenting decisions. The first theme related to this sub-category is *type and severity of disability*. Parents were very clear that the effects of having a child with DD depended on the nature of child's disability. Parents primarily spoke of two types of disabilities – those that affect cognitive functioning and those that affect physical functioning. The perspective of parents in this study was that children who have a more physical handicap such as hearing loss do not affect parenting behaviors to the same extent that having a child with cognitive impairments might. In addition, parents also differentiated by the severity of a diagnosis. For example, hearing loss ranged from mild, for which children wore hearing aids and could still hear to a degree, to complete deafness in which children could not hear at all. In turn, parents described that the more severe a diagnosis was resulted in larger effects on the parents. Although type and severity might be considered as separate types of child effects related to a child's disability, it was too difficult to disentangle the two based on parents' responses from this study. For example, when comparing their own child's disability to other *types* of disabilities (e.g., hearing loss to autism), parents used the words "severe" and "type" conjointly, expressing that autism is a more *severe type* of disability than hearing loss.

Another theme that emerged in the sub-category *characteristics of disability* was *increased demands*. Although most parents experience increased demands when raising a child between birth and 5 years old, the nature of the demands of children with DD goes beyond

what parents of typically developing (TD) children encounter. Most often, parents spoke about having to constantly be on the road going from one appointment to the next making sure their child receives all the services her or she qualified for. Parents acknowledged that they spent more time focused on their child(ren) with DD because of the demand for providing and facilitating treatment and intervention related to the child's diagnosis. Parents' awareness of the increased demands of their child(ren) with DD was especially apparent when parents had already raised older, TD children.

The final theme in this sub-category emerged as parents described their experiences of *discovery and uncertainty* while raising a young child with DD. Though it is plausible that most parents of young children experience some uncertainty and must adapt to the characteristic of their child, parents of children with DD spoke about the specific ways that having a child with DD heightened the intensity of their experiences. Specifically, parents illustrated the theme of discovery and uncertainty when discussing the diagnosis process and when they first learned about their child's disability. However, parents of older children with DD also described the uncertainty of how to treat their child in some situations and were still discovering the best methods for parenting their child. Overall, it appears that having a child with DD is related to encountering more heightened and more frequent experiences of discovery and uncertainty in determining the needs, capabilities, and parenting practices to use with their child.

The second sub-category of *child effects* illustrated by parents' responses from this study had to do with *other child characteristics*. This sub-category contains themes related to characteristics of the child that were not directly related to the nature of the child's disability. However, these *other child characteristics* such as *age, gender, and personality and temperament* were important elements to the larger question of how parents perceive the effects of their child(ren) with DD on their parent behaviors. Parents in this study often attributed aspects of their child's behaviors to these other characteristics. For example, boys

were perceived as rambunctious and trouble makers and girls were considered to be drama queens. Younger children were perceived to be more similar to TD children, but older children were seen as more different. Finally, some parents attributed the demands of their child to the child's personality and temperament rather than to the nature of the child's disability. Overall, the characteristics of children with DD that parents perceived to be unrelated to the nature of the disability were still relevant in shaping parental behavior.

Worry and stress. Though the emphasis of this analysis is on how children with DD influence parenting practices, it was clear that *worry and stress* exemplified another important category of responses in this study. Previous scholars have conceptualized entire models of stress among families of children with DD (see Perry, 2004). Here, stress is considered as an added variable that helps explain the overall process of parenting young children with DD. The two primary themes that emerged as parents discussed their experiences with stress and raising a child with DD were *child's future* and *child's safety and wellbeing*. Stress related to the child's safety and wellbeing was an experience in which parents described their elevated levels of stress, discouragement, and worry when facing issues related to their child's physical, emotional, and mental health. Though there is ample evidence that parents of children with DD encounter heightened levels of stress overall, parents in this study consistently described the added anxiety of feeling that their child with DD was more vulnerable than TD children.

The second theme that emerged related to worry and stress, *concern for the child's future*, illustrates that parents of young children with DD worry about what the future will be like for their child. Though some parents in this study - particularly those with children with mild diagnoses - were less concerned about their child's future, one area that many parents discussed in relation to this theme had to do with their child's future social life. Indeed, parents expressed the fear that their child might be bullied or excluded because of his or her disability. Many parents seemed to cope with this stress by attempting to let go of any expectations for

their child's future and instead focused on the goal of keeping their child happy. Indeed, because the children in this study were so young, parents often did not know what life could be like for their child once they became adults and whether they would be capable of functioning independently.

Social Support. Parents in this study described two categories of support that influenced their parenting behaviors: support from professionals and service providers, known as *formal social support*, and support from family, friends, and members of the community, known as *informal social support*. These categories of support are commonly referred to in the literature on families of children with DD and were clearly important to parents in this study. Furthermore, although the previous analysis of this data demonstrated that parents in this study spoke of formal and informal social support (Sams, 2012), these supports were not considered in their connection to an overall model of the reciprocal relationship between parents and children with DD.

Formal Social Support. In the category of *formal social support*, parents spoke about the role of their child's doctors, therapists, teachers, early interventionists, and other service providers in relation to their parenting practices. The three primary themes that emerged reflecting this category were *empowerment*, *homework*, and *differentiating services*. The theme of *empowerment* captures parents' descriptions of feeling strengthened and supported in ways beyond what they could achieve through personal efforts. Indeed, parents felt grateful and appreciative of the services their children received and often described these services as indispensable to their child's development, as well as to their parenting efforts. More specifically, parents felt that the formal social support they received after the diagnosis gave them important direction and guidance for how to manage the transition into becoming a parent of a child with DD.

Another theme related to the formal social support received by families of children with DD was *homework*, which encompassed the responses of parents who spoke about the many different assignments and tasks they were given directly from professionals and also through their child's IFSP or IEP. It is important to note that parents did not necessarily resent the added homework they were assigned. On the contrary, many parents often felt grateful to have extra guidance and direction from professionals for how to support their child's progress. Parents most often spoke about homework when asked about how professionals and service plans affect their parenting practices. It was apparent that parents did not necessarily feel that these formal social supports did not fundamentally affect their parenting styles, but rather gave them added guidance on ways to interact with and foster positive development in their child.

The final theme, *differentiating services*, emerged as parents spoke specifically about the various services their child received. Overwhelmingly, parents preferred services that they received in their home, such as early intervention for children in the birth to three age range. Parents valued the relationships they developed with their child's early interventionist and the approach of involving the whole family in the child's treatment. The use of these kinds of family-centered practices have been found to foster positive child and family outcomes (Davis & Gavidia-Payne, 2009; King, Kertoy, King, Law, Rosenbaum, & Hurley, 2003), findings echoed by the parents in this study. Conversely, several parents seemed indifferent and, occasionally, frustrated with services from professionals that involve traveling to and from an office and sitting in waiting rooms. Indeed, parents were particularly critical at times of pediatricians and other medical professionals for their insensitivity in diagnosing and providing checkups for their children. This finding is consistent with studies showing the stressful nature of the diagnostic process, particularly when it comes to ASD (Braiden, Bothwell, & Duffy, 2010; Moh & Magiati, 2012; Siklos & Kerns, 2007). In addition, this particular finding highlights the value the design

and analysis of the present study, which allows the voices of parents of children with DD to be represented, which show preferences for certain formal supports over others.

Informal Social Support. The category of responses from parents that describe the value of family, friends, and social networks for providing support fit into the category of *informal social support*. Within this category, parents from the present study illustrated the themes of *help from family*, *partner support*, and *other parents*. The inclusion of informal social support and the related themes also is supported by a strong base in the literature on stress in families of children with DD. These studies have repeatedly shown that having a steady foundation of informal social support is associated with reducing negative outcomes such as depression and caregiver burden while also increasing positive outcomes such as sense of confidence and accomplishment (Davis & Gavidia-Payne, 2009; Ekas, Lickenbrock, & Whitman, 2010; Weiss, 2002).

Parents who lived near extended family members and/or their child(ren)'s grandparents were able to benefit from support that fit into the theme of *help from family*. In addition, some parents also spoke about how helpful it was when their other children would help to entertain or otherwise assist in caring for siblings with DD. Overall, it seems that family members can provide respite as well as instrumental help such as caretaking and taking children to appointments. *Partner support* is another type of informal social support that parents spoke of as an important source of support in raising a child with DD. This finding corroborates with previous studies that have demonstrated the importance of partner support in this population (Kersh et al., 2006). In the families where the mother was able to stay at home with the child(ren) (6 out of 10), fathers were particularly reliant on their wives to be aware of their child(ren)'s needs and to keep track of the therapeutic schedule and goals for their child with DD. On the other hand, several mothers expressed their appreciation and gratitude for having a spouse that was willing to be involved in the treatment process and caretaking responsibilities.

Finally, some parents spoke about the support they felt that they received from other parents who have children with DD. Parents who were able to get advice and “compare notes” with other parents experienced the value of having a social network beyond their relationships with service providers and family members. Conversely, those who did not have such a network described feelings of isolation and exclusion and experienced a general lack of informal social support.

Overall, parents from this study seemed to benefit when they felt that they had added support from an informal network of family, friends, and other acquaintances. These benefits include increases in moments of respite, receiving advice and recommendations related to childrearing, a sense of camaraderie and teamwork, and the general benefits of having someone to talk to and share experiences with. Data from this study support the proposition that the perceived availability of informal social support among parents of children with DD is directly related to their feelings of stress and their ability to provide quality care for their children.

Parenting behaviors. Similar to the general conceptualizations of parenting, this study found that parents of children with DD engage in parenting behaviors that are similar in type to the types of parents of TD children. Specifically, the sub-categories of *support* and *regulation* emerged as the major organizers of the behaviors parents described using with their children. However, one theme emerged that transcended either of these sub-categories: *seeking normalcy*. This theme consisted of the descriptions by parents of their efforts to try to treat their children with DD as normal as possible and try to avoid giving their children special treatment because of a diagnosis. Overall, *seeking normalcy* seems to characterize parents’ wishes that their children be included with other children and to not be marginalized or viewed as “less-than”. Whether parents’ were disciplining or showing their support, participants from this study overwhelmingly endorsed this theme that children with DD needed to be treated as equals to TD children. This finding replicates what has been suggested in previous studies (Johnson, 2000;

Miles & Holditch-Davis, 1995; Sams, 2012) regarding how parents treat their children with DD in intentionally normative ways.

Parental Support. The analysis presented regarding the sub-category of *parental support* is representative of the responses of parents who were interviewed in the present study and are not meant to encompass every possible means by which parents care for their young children with DD. Rather, the analysis highlights the uniqueness of the supportive behaviors used by this population. For instance, though *affection and nurturance* would most likely be considered a theme relevant in any conceptualization of parental support, many parents in this study discussed how the methods they used to show affection and the purpose of their nurturing behavior were often influenced by the characteristics of their child's disability. Similarly, when discussing how they support their children with DD, many parents described their attempts to make sure their child gets all the services he or she qualified for so that that the child could make *progress with the disability*. For parents of young children with DD, helping their child receive services and make progress with those services is part of the daily and weekly experience of showing parental support. Though parents of TD children may want their children to make progress related to physical and cognitive developmental milestones, parents of young children with DD focus on goals and milestones that suited to the specific capabilities of each child with DD.

Finally, another important theme demonstrating the unique ways in which parents of young children with DD show support for their children was *acquiring knowledge and skills*. Though many parents may read books or attend classes to learn how to best care for their young children, parents from this study showed that having a child with DD means having to go above and beyond what is required of parents of TD children. Parents of children with DD not only spend time learning about their child's diagnosis and learning and implementing all appropriate methods of intervention and therapy, but they also must learn to navigate the

system that has been put in place to support children with disabilities. Eventually, many parents of children with DD end up becoming actively involved in support networks and, in some cases, become self-described advocates not only for their own child, but for all children with DD.

Parental regulation. Like the analysis of responses related to parental support, themes illustrating the sub-category of *parental regulation* are not expected to encapsulate a comprehensive view of the parental regulatory behaviors used by parents of young children with DD. The themes presented in the results related to this sub-category focus on the regulatory behaviors that are distinctive to the focal population. *Discipline* is one of the broadest components of parental regulation and has been studied in a variety of fields with a wide range of populations. This study has shown that although the disciplinary behaviors used by parents of young children with DD do not fundamentally differ from the discipline used by other parents, parents often face challenges and must be more sensitive to their child's disability when attempting to take disciplinary action. This finding has important implications for how researchers conceptualize and operationalize their study of parental discipline among this population.

Two other themes from the results of the analysis related to parental regulation were *public vs. private* and *vigilance*. Again, although most parents of young children would likely encounter experiences that are related to these themes, the experiences of parents of young children with DD illustrate that having a child with DD influences the nature of these themes. With *public vs. private*, parents of children with DD face added barriers in considering how to regulate their child's behavior due to the perception that the general public does not understand what it's like parenting a child with DD. Like most parents, parents of children with DD want to avoid anything that might send their children into a tantrum or meltdown. However, parents in this study that had TD children as well as children with DD provided important contrast when describing some of the specific ways being in public affects their parental regulatory behaviors

differently depending on the child. Further, although it is logical that *public vs. private* may also be a theme related to parental support, parents from this study only addressed this issue while talking about their regulatory behaviors. Similarly, when talking about boundaries and consequences, many parents spoke of an added need for *vigilance* while parenting a child with DD. Though most parents of young children attempt to monitor their children and keep them safe, some parents of young children with DD face added obstacles in keeping an eye on their children that seem to make them more vigilant of their child's behavior.

Overall, parents of young children with DD encounter additional barriers and conditions that affect the way they attempt to regulate their child's behavior. However, it should be emphasized that in general, it seems that these parents attempt to use regulatory strategies that are the same or very similar to strategies used with TD children. Thus, it appears that parents of children with DD do not fundamentally transform their approach to regulating their child just because of the nature of the child's disability, but rather find themselves having to make extra considerations based on their child's needs and capabilities.

Parenting Process Model

The categories and themes which emerged from the qualitative interview data fit together into a conceptual model of how the parenting process among parents of children with DD (see Figure 1). This model emerged as I sought to answer the second research question about the broader determinants of parenting among this specific population. The model that I present shows some similarities to Belsky's (1984) process model of the determinants of parenting, which adds credibility to the present model in that it provides conceptual justification for the inclusion of both proximal and distal factors that influence parenting in families of children with DD.

This model is important for illustrating the complexities of the parent-child relationships among this population. Researchers who intend to study the parenting styles of parents of

children with DD can benefit from taking these complexities into consideration when forming hypotheses, designing their studies, and selecting their methods of measurement. Indeed, as evidenced by limitations of the literature on parenting children with DD and the lack of a parenting framework, this model can provide a key foundation to future studies. The purpose of this section is to identify some of the primary additions of this model to the broader literature on parenting children with DD.

The first important contribution of this model is the consideration of the life history of the parent. Whether researchers are looking for parent effects or child effects in their study, parenting behaviors have a foundation in the experiences and context surrounding each individual parent. Thus, it is important that researchers attempt to assess the influence of parents' life history on their parenting decisions so that important variation may be accounted for. One important note about the linkages of life history to other areas of the model is that the data from the present study did not support any conclusions regarding the influence of life history on formal and informal social support. For this reason, these relationships have been depicted using dotted lines, suggesting that although it is likely that life history variables are related to families' engagement with formal and informal social supports in some way, these relationships are only assumed and not supported by the data.

A second contribution of this model is the split conceptualization of child effects that applies specifically to families of young children with DD. Indeed, though children with DD present added considerations to parenting and family experiences, children with DD are not defined by their disabilities. These children have personalities and likes and dislikes and often function in ways that are far more similar to their TD peers and siblings than they are different. Thus, it is imperative that researchers attempt to measure both types of child effects so as not to marginalize an already vulnerable population. However, it is equally important that

researchers attempt to measure the unique effects of having a child with DD on parenting behaviors.

The third contribution of this framework for understanding the parent-child relationships among families of children with DD is the inclusion of informal and formal supports to the parenting process. Although previous models of *stress* have been developed that incorporate these types of support (e.g., Perry, 2004), few researchers, if any, have attempted to investigate how receiving support from outside the family – or a lack thereof – may influence parenting practices among this population. This framework shows that some effects of having a child with DD may influence parenting indirectly through the supports these families receive. For example, the very involvement of parents with early interventionists and other service providers is determined by the characteristics of their child's disability. As a result, any parenting behaviors that are influenced by these service providers may be seen as an indirect effect of having a child with DD. Future studies could provide important verification of these types of indirect child effects.

A fourth contribution of this model is the connection between family stress and parenting behaviors. Though this model is not a stress model and though the focus of the present study was not on stress, based on parents' responses and previous literature (e.g., Woolfson & Grant, 2006), it became clear that stress likely plays an important role in explaining the parenting behaviors of parents of young children with DD. Conceptually, there is likely a reciprocal connection (as illustrated in the model) between parental distress and perceived parenting behaviors, where parents who feel more distressed are likely to feel less competent and may behave more harshly towards their children with DD. The finding that parents of children with DD are harsher or more authoritarian towards their children is supported by some studies (e.g., Gau et al., 2008). However, future research must be done to verify such connections using measures that are sensitive to the experiences of this population.

The final contribution of the model and overall purpose of this analysis is the proposition that parents' behaviors are influenced by having a child with DD. Though these influences are similar in many ways to the child effects experienced by parents of typical children, this analysis has demonstrated that children with DD impact parenting behaviors in ways above and beyond what parents of TD children encounter. As a result, it is imperative that researchers studying the parenting process among parents of children with DD consider the findings of the present study so that they may develop measures that more fully capture the various influences that parents experience. Furthermore, this study also demonstrated that there is another element to the parenting behaviors of this population that needs to be addressed: seeking normalcy. This added self-awareness of intentional efforts to create a "normal" environment and the desire to avoid giving special treatment to a child with DD is a unique finding of this study overall and echoes the theme of "same, but different" explored by the previous analysis of this data (Sams, 2012). Thus, it appears that while using traditional measures of parenting among this population may provide some insights into general parenting behaviors, there are many behaviors and conditions that are left untapped by using such an approach. As a result, the hope of this analysis is to provoke researchers to consider the relevant themes and categories demonstrated in the present study when planning and conducting their studies.

Limitations

There are several limitations in the present study. The first limitation concerns the size and representativeness of the sample. Only ten couples were interviewed in the present study, which limits the range of possible responses that were received and the types of themes that emerged from those responses. More importantly, there was a limited range of types of DD present in the study; the majority of the couples had a child with hearing loss ($n = 6$), while others had a child with an autism spectrum disorder ($n = 3$), and there was one couple that had a child with congenital hypothyroidism. The makeup of this sample is hardly representative of

the variety of developmental disabilities that many other families encounter. As a result, it is unknown what added perspectives parents of young children with DD such as Down syndrome, intellectual disabilities, cerebral palsy, or blindness may have brought to the study.

An additional limitation of the current study concerns the method of data analysis. Although initial open coding was conducted between myself and the principal investigator, the final analysis presented in the present study was conducted individually, which limits the credibility and trustworthiness of the data. Indeed, with only one perspective of how the present data support a model of the parenting process for parents of children with DD, it is unclear what kinds of bias were introduced to the analysis process.

A final limitation of the present study is that there is no comparative analysis of mothers and fathers responses. This is due primarily to two reasons. First, there were not any glaring differences between how mothers and fathers responded to the interview questions. Out of 10 couples, six followed the traditional divisions in which the father worked full-time while the mother stayed at home full-time with the children. This is a slim majority and did not justify a separate analysis. The second reason mothers and fathers responses were not analyzed comparatively is that the main purpose of the analysis focused on discovering themes and patterns that applied to both mothers *and* fathers of children with DD. In other words, the goal was to analyze parenting behaviors in broad, inclusive terms rather than looking for gender-specific parenting styles. However, despite these justifications, the lack of comparison between mothers and fathers limits the usefulness of the findings.

Implications

There are many implications regarding both research and practice suggested which can be gleaned from the present study. Several of the implications regarding future research have been identified in the section describing the major contributions of the proposed model of the parenting process among parents of children with DD (see Figure 1). Overall, it is not likely that

researchers could test the proposed model in its entirety in a single study. Rather, part of the value of this model is the opportunity for researchers to select from it the propositions that stand out as being particularly novel and provocative, such as the implication that formal supports and services play a key role in explaining the bidirectional effects between parents and children with DD. Or, researchers may take interest in the split conceptualization of child effects that is unique among this population and study how these distinct effects play differing roles in the parenting process. In sum, the present study and the proposed model of the parenting process among families of young children with DD provide several starting points for scholars interested in this population.

In terms of practice, this study contributes important findings and theoretical propositions that inform how educators, practitioners, and service providers approach their efforts with families of children with DD. In particular, this study highlights the importance of formal supports and services to the parent-child relationship. It is important to recognize that parents of young children with DD value different types of services for different reasons. In turn, practitioners can attempt to focus in on where they are doing the most good while also attempting to pay attention to areas that need improvement.

Another practical implication comes from the finding that parents seemed to prefer services that were family-centered and took place in the home. Not only did this approach seem to be more effective for teaching parents and families, but also seemed to be less stressful for parents who felt run down by their busy schedules that involved sitting in waiting rooms and running from one appointment to the next on a regular basis. Indeed, this study provides validation to the family-centered model of service delivery among this population.

Finally, clinicians and practitioners need to be more sensitive to the worry, stress, and uncertainty faced by families of children with DD. In particular, clinicians need to be aware that their methods of delivering the child's diagnosis to parents should be empathetic and

understanding rather than cold and detached. This is sensitive information that needs to be treated as such. In addition, service providers need to be respectful of parents' wishes and desires regarding the childrearing process. Families of children with DD are far more susceptible to the influence of outsider support and influence than the general population. As a result, professionals need to be careful not to take advantage of their position of influence.

Conclusion

Scholars have noted that parenting involves an apparent paradox where parents attempt to simultaneously control and regulate child behavior while also promoting autonomy and independence. This study not only supports that this same paradox is true among parents of young children with DD, but introduces a different paradox experienced by these parents that is altogether unique. Indeed, though parents of children with DD emphasized that their efforts to parent using methods that were the same or similar to parenting TD children, parents from this study described a wide range of behaviors in the domains of parental regulation and parental support that are not characteristic of the parenting behaviors used by parents of TD children. This unique paradox exhibited by parents of children with DD previously has been explained by developing theories such as *compensatory parenting*, *parental straddling*, and *expanded parenting*.

Though these theories provide an important perspective to how parent-child relationships among families of children with DD differ from the general population, few efforts have been made to integrate the valuable existing perspective offered by the child effects literature. This study has depicted the broader processes by which children influence parents' behaviors and vice versa. However scholars attempt to study parenting among this population in the future, it will be important that they give greater consideration of these contextual process.

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Appendices

Appendix A: Tables

Table 1. Summary of Scales Used to Measure Parenting Among Parents of Young Children with DD

Study	Scale Used (Original Author[s])	Sample	Measurement Method	Sub-Scales (# of items)	Internal Consistency Reliability*	Test-Retest Reliability	Validity Assessment
1. Tucker and Fox (1995)	Parent Behavior Checklist (Fox, 1992)	125 mothers of children with developmental delays	Performance and Attitudes ("almost always/always" to "almost never/never" on a 4-point scale)	1. Expectations (50) 2. Discipline (30) 3. Nurturing (20)	N.R.	N.R.	N.R.
2. Carson et al. (1999)	Parent Behavior Checklist (Fox, 1992)	23 mothers of children with (n = 9) and without (n = 14) language delays	Performance and Attitudes ("almost always/always" to "almost never/never" on a 4-point scale)	1. Expectations (50) 2. Discipline (30) 3. Nurturing (20)	N.R.	N.R.	N.R.
3. Carson et al. (2007)	Parent Behavior Checklist (Fox, 1992)	47 primary caregivers of children with (n = 17) and without (n = 30) speech and language delays	Performance and Attitudes ("almost always/always" to "almost never/never" on a 4-point scale)	1. Expectations (50) 2. Discipline (30) 3. Nurturing (20)	N.R.	N.R.	N.R.
4. Keller and Fox (2009)	Parent Behavior Checklist (Fox, 1992 [32 item version])	58 Primary caregivers (85% mothers) of children with DD.	Performance and Attitudes ("almost always/always" to "almost never/never" on a 4-point scale)	1. Expectations (N.R.) 2. Discipline (N.R.) 3. Nurturing (N.R.)	N.R.	N.R.	N.R.
5. Woolfson and Grant (2006)	Child Rearing Practices Report (Rickel & Biasatti, 1982)	53 parents of children with DD and 60 parents of TD children (99 mothers and 12 fathers)	Performance and Attitudes ("not-at-all descriptive of me" "highly descriptive of me" on a 6-point Likert type scale)	1. Restrictiveness (22) 2. Nurturance (18)	1. alpha = .89 2. alpha = .80	N.R.	N.R.

Table 1. Continued

Study	Scale Used (Original Author[s])	Sample	Measurement Method	Sub-Scales (# of items)	Internal Consistency Reliability*	Test-Retest Reliability	Validity Assessment
6. Rutgers et al. (2007)	Child Rearing Practices Report (Deković et al. 1991; 29)	89 parents (64 families of children with autism [n = 41], mental retardation [n = 12], or language delayed [n = 11], and 25 families of TD children)	Performance and Attitudes (“not-at- all descriptive of me” “highly descriptive of me” on a 6-point Likert type scale)	1. Authoritative (16) 2. Authoritarian (13; excluded from analysis)	1. alpha = .74 2. alpha = .53	N.R.	N.R.
7. Little (2002)	Conflict Tactics Scale – Parent Child Form (Straus et al., 1998)	411 mothers of children with Asperger’s (n = 308) and nonverbal learning disorder (n = 62) or a combination of the two (n = 41)	Performance in the past 12 months (7 response categories ranging from “never” to “more than 20 times”)	1. Aggression (5) 2. Corporal Punishment (5)	1. alpha = .68 2. alpha = .58	N.R.	Discriminant
8. Gau et al. (2008)	Chinese Parental Bonding Instrument (Gau et al., 2006)	95 families (45 Down syndrome, 50 TD)	Performance and Attitudes (“very likely” to “very unlikely” on a 4- point Likert type scale)	1. Care/affection (12) 2. Overprotection (7) 3. Authoritarianism (6)	N.R.	N.R.	N.R.
9. Osborne & Reed (2010)	Parent-Child Relationship Inventory (Gerard, 1994)	138 parents (130 male, 8 female) of children with autism	Performance and Attitudes (“strongly agree” to “strongly disagree” on a 4- point Likert type scale)	1. Involvement (14) 2. Communication (9) 3. Autonomy (10) 4. Limit Setting (12)	Ranged from .76 (<i>Involvement</i>) to .88 (<i>Limit Setting</i>)	1. .81 2. .81 3. .81 4. .81	Social Desirability

* Internal Consistency Reliability Using Chronbach’s Alpha. N.R. = Not Reported. DD = Developmental Disabilities. TD = Typically Developi

Table 2. Parent Demographic Information

Participant	Parent Age	Years of Marriage	Education Completed	Employment Status
Amanda	25	6	Some college	Student
Adam	28		High school/GED	Unemployed
Brittany	32	5	Bachelor's	Stay at home mom
Ben	32		Master's	Full-time
Christina	36	12	Bachelor's	Stay at home mom
Curtis	34		Master's	Full-time
Denise	36	6	Master's	Stay at home mom
Doug	41		Doctorate	Full-time
Edith	37	13	Master's	Stay at home mom
Edmond	40		Master's	Full-time
Faye	31	6	Master's	Full-time
Forrest	36		Bachelor's	Full-time
Gloria	37	3	Bachelor's	Stay at home mom
Greg	30		Bachelor's	Full-time
Harriet	40	6	Associate's/Technical	Full-time
Harold	45		High school/GED	Unemployed
Isabel	28	6	Bachelor's	Stay at home mom
Isaac	28		Bachelor's	Part-time/Student
Jessica	42	12	Bachelor's	Full-time
John	41		Bachelor's	Full-time

Mean (SD) 34.95 (5.57) 7.5 (3.47)

Table 3. Child Demographic Information

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

M(SD) 36.27 (20.60)

Table 4. Results: Categories, Themes, and Quotations

Main Category	Sub-Categories	Main Themes	Examples
Life History		Family of Origin	"I never had any brothers or sisters. So I never had a sister in the house, so I'm not familiar with it. So I think it's maybe just having a little girl, I might be more relaxed with it." – Curtis "I would definitely say the relationship that I had with my parents. . . Um, and while I didn't always see eye to eye with my parents growing up, that stability has helped me out a lot and it's provided a sense of confidence in me. . . It's something that if I'm facing a situation that I'm unsure of, that I can go ask them for advice. And I rely on them heavily." - Ben
		Other Life Experience	"I'm also a pastor of a church, uh, you know and I hold to-to, my kids to a moral biblical standard and, you know, just following after what I feel is right in that area." - Adam "My major is psychology but I've only ever worked in special ed (laughs). I started out in preschool special ed and then I did (early intervention); so I was in preschool for 6 years and then (early intervention) for 8 years. So I don't think I ever done, I guess, just knowing what worked with other kids." - Christina
		Type and Severity of Disability	"There's a huge difference between a physical special need like deafness and a, uh, mental special need, as would be the case with. . . people with Down syndrome." - Edmond "People that are out there that have more severe um, disabilities that they're, they're dealing with, and they, the achievements they've made. And now, you know, to me it just seems, I know it's hearing, but it seems, somewhat minor, it seems like you can get over it." - Greg
		Increased Demands	"We definitely didn't have all these specialists appointments. You know (laughs)? Like so much of our life has been, you know, on the road, going to appointments and especially just, you know, those first few months. It was like, I felt like I was just constantly in a waiting room, constantly in an elevator, you know (laughs) it was just very surreal." - Faye "My life revolves around my children. [Focal child] more sometimes because it has to. . . 'cause she has so many appointments that we have to tend to. And work with her and, I mean, you know, like I've been working with her at home, to taking her to her appointments." - Amanda
Child Effects	Characteristics of Disability	Discovery and Uncertainty	"We had a long time of not knowing and so having a label actually made it easier. . . so I feel like the uncertainty was worse, way worse than the diagnosis." - Isaac "It's hard to distinguish sometimes between what she can't do and what she's just not willing to try. . . 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." - Christina
	Other Child Characteristics	Age	"You know, and I have some friends close to his age, you know, and I can see the differences . . . previously it's been harder for me to see that well, that at his age that's pretty normal. But I think, as he gets older, that difference might be more pronounced." - Jessica

Table 4. Continued

Main Category	Sub-Categories	Main Themes	Examples
Child Effects (Continued)	Other Child Characteristics (continued)	Age (continued)	"He's a very rambunctious toddler. So he's always hitting his brother or picking on him or touching him or. So, as far as discipline, but I would expect that from and kid his age. I don't notice any different behavior that has, that's any different from his hearing loss. It's related more to his age." - Brittany
		Gender	"But the thing is, he's boy, he's really active, so he's more trouble maker. So (laughs) he's, um, I always say, I mean, he's, he makes me more angry than his sister." - Denise
			"She pitches a lot of girl fits. That the boys didn't pitch (laughs) so I didn't have to deal with that so, so I mean that's new too. It's just the difference between a girl and a boy. It's just a BIG difference." - Amanda
		Personality and Temperament	"I think [focal child's name] is just stubborn and hardheaded and very, I guess just um, she keeps trying over and over and over again on certain things. And [sibling's name] is just more relaxed, she just goes with the flow. . . So, they both have opposite personalities." - Greg "I don't know if it's necessarily because of his hearing loss, but it's more because of his personality. He seems to want a little bit more structure and explanation about what's going to happen." - Ben
Worry and Stress		Child's Future	"Now, I worrying about how he develop, grow up. And, uh, how and what kind of job can he find like or finding and how he can pl-, uh, play with, uh, his friends. When he grow up and I'm curious about. And worry, also worry about, he should go, if he should go to the deaf schools or should go to the normal school. And, if he go to the normal school, how can he play with everybody and play with friends. Just I worry about that now." - Doug
			"Long term we were worried about having, being able to have a normal, you know, given a chance at life. You know, going to college, just being able to pursue whatever she wanted to pursue without that barrier there." - Adam
		Child's Safety and Wellbeing	"He can't tell us of something is wrong, so that's, there's always a constant worry on my mind, you know, with him spending so much time away from home that something could happen and we wouldn't know about it." - Isaac "We were extremely protective and extremely nervous of everything. If it was a speck of dirt we saw flying through the air or if it was a car honking their horn, we were extremely nervous that anything could hinder his hearing or hurt him or make him sick, and we just looked at him as extremely fragile." - Ben
Formal Social Support		Empowerment	"And they're just a very, very supportive group of people and it really, it gave us a huge, uh, I don't even know, like a stepping point, like where to start when we found out 'cause . . . we just kind of didn't know. And they contacted us and got the ball rolling." - Gloria

Table 4. Continued

Main Category	Sub-Categories	Main Themes	Examples
Formal Social Support (continued)		Empowerment (continued)	"Raising [sibling's name]'s been completely different because we hadn't had those particular challenges. So, they've [i.e., professionals and service providers] given us, you know, they've probably given us therapy (laughs) as much as [focal child's name]." - Jessica
		Homework	"There's a lot of extra work. . . We get a packet, like every time they do some therapies, we get a packet of what we should be, um, working with her on." - Forrest "I feel like I'm the student all over again so I just follow instructions and do what they (i.e., the service providers) 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.
		Differentiating Services	"The thing about the training classes, parenting classes - they help you kind of understand what's going on, but to try to apply it, I think is a little bit more of a challenge. I think we've had much more benefit, greater benefit from one of our ABA [applied behavior analysis] therapist that comes to the house. And she actually works with us and actually apply common steps that we, we've benefited a lot more from that. We could intellectually understand what they're talking about when we go to these classes, but to try to actually apply it is an area we've struggled with." - John
			"Well, his preschool. The, applying for that. I wouldn't have known about many of those things if it wasn't for him having a, um, his early interventionist that came to the house and she helped us get prepared to get him into, um, school, and get him evaluated. So, a lot of that I wouldn't have known how to do without them. Um . . . and it, and it helped him a lot. But I feel like he had more help, as far as language and development or anything with (the university) than he did with the early interventionist." - Brittany
Informal Social Support		Help from Family	"Me and [husband's name] are lucky that we have our mothers that can give us breaks, you know, and even [sibling's name]. I mean, I didn't really mention his sister, but she is wonderful with him. Um, you know, and just her, sometimes he'll play with her in her room for 20 minutes, and that's, helpful." - Jessica
			"My mom just retired last year and she takes her to, you know, some of the appointments she has to go to, or sometimes I take off work." - Faye
		Partner Support	"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." - Ben
			"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." - Gloria
		Other Parents	"Talking with other parents of other autistic children has helped me more than anything." - Harold

Table 4. Continued

Main Category	Sub-Categories	Main Themes	Examples
Informal Social Support (continued)		Other Parents (continued)	"There's not many babies with, born without a thyroid gland. It's very rare. Or so, you know, I mean 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? Um, I did have a friend who had, who knew someone in Denver. Like their kid had the same experience. We did, like connect on email with them and just compare notes." - Faye
Parenting Behaviors		Seeking Normalcy	"So, but, um, you know, I just want her to, 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." - Faye
			"Try to treat them as fair as you could. . . But, you know, just try to be as normal as a parenting style as you can with them and not give them an advantage, I would say." - Adam
	Support	Affection and Nurturance	"I guess we've learned to use a lot of expression and stuff. So, she can understand wants going on, since she can't hear what's happening. So, yeah, there's a lot more of, I don't know, just other, you know, touch and sight as much as we can cause she can't hear as much of what you're saying" - Edith
			"When he's at home, he gets tons of love. I mean, he gets a lot of support at home, emotionally. A lot of emotional support. I think that's helped him a lot. Especially with all of his therapy from birth. I think has been the big, the key to his. But we try to give him a lot of emotional support at home so he has a little bit more confidence when he goes to school." - Brittany
		Progress with Disability	"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 (the local school for the deaf) to learn more. We are online, researching things. . . I mean, we just want the best that's available to her that we can get." - Gloria
			"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 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 sort of re-train the way he acts with people, so he can have close friendships and things like that." - Isabel
		Acquiring Knowledge and Skills	"Me and (the child's therapist) are still working on that. She's trying to teach me more, positive reinforcement type things to do for him. Rather than waiting till he's done made himself unsafe, and for instance, she said, 'praise him every few minutes, good job staying in your car seat.' You know, that kind of thing that I wasn't doing before. I was just driving thinking, 'he's supposed to stay in his car seat, kids stay in their car seat!' . . . I still have a lot to learn." - Harriet

Table 4. Continued

Main Category	Sub-Categories	Main Themes	Examples
Parenting Behaviors (continued)	Support (continued)	Acquiring Knowledge and Skills (continued)	"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. . . I mean, you can't, can't expect him to, to learn skills at like a typical child because there's a very like specific pattern to teach autistic kids how to learn. . . so um, I had to learn how to do that." - Isabel
	Regulation	Discipline	"Discipline has been a problem; setting boundaries has been difficult since we can't, since he's not very expressive, we can't tell whether he understands why something is being taken away." – Isaac "Even though [focal male] does wear hearing aids, I make an effort that if I want to really communicate something with him, like if he's done something wrong and we want to teach him about safety, like why you shouldn't climb on a 20-foot ladder when no one is looking. Um, with [focal male], 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." - Ben
			"I try to be more firm in the store because I don't want him to throw some kind of tantrum that looks like I may be abusing my child or something." - Harriet "It depends on the situation and the environment that we're in. If we're out in public we can't, well, we might employ a different strategy than at home, just because we're trying to, uh, keep the situation from devolving too much in a public environment." - John
		Vigilance	"But we just try to be consistent with boundaries that we have set and just try to be vigilant and make sure that we can get to him right away if he starts to do something that we don't want him to do." - Isaac "The main thing for her is just uh, is for us to kind of, you know being doing the work that the therapy is kind of asking us to do, and trying to stay vigilant" - Forrest

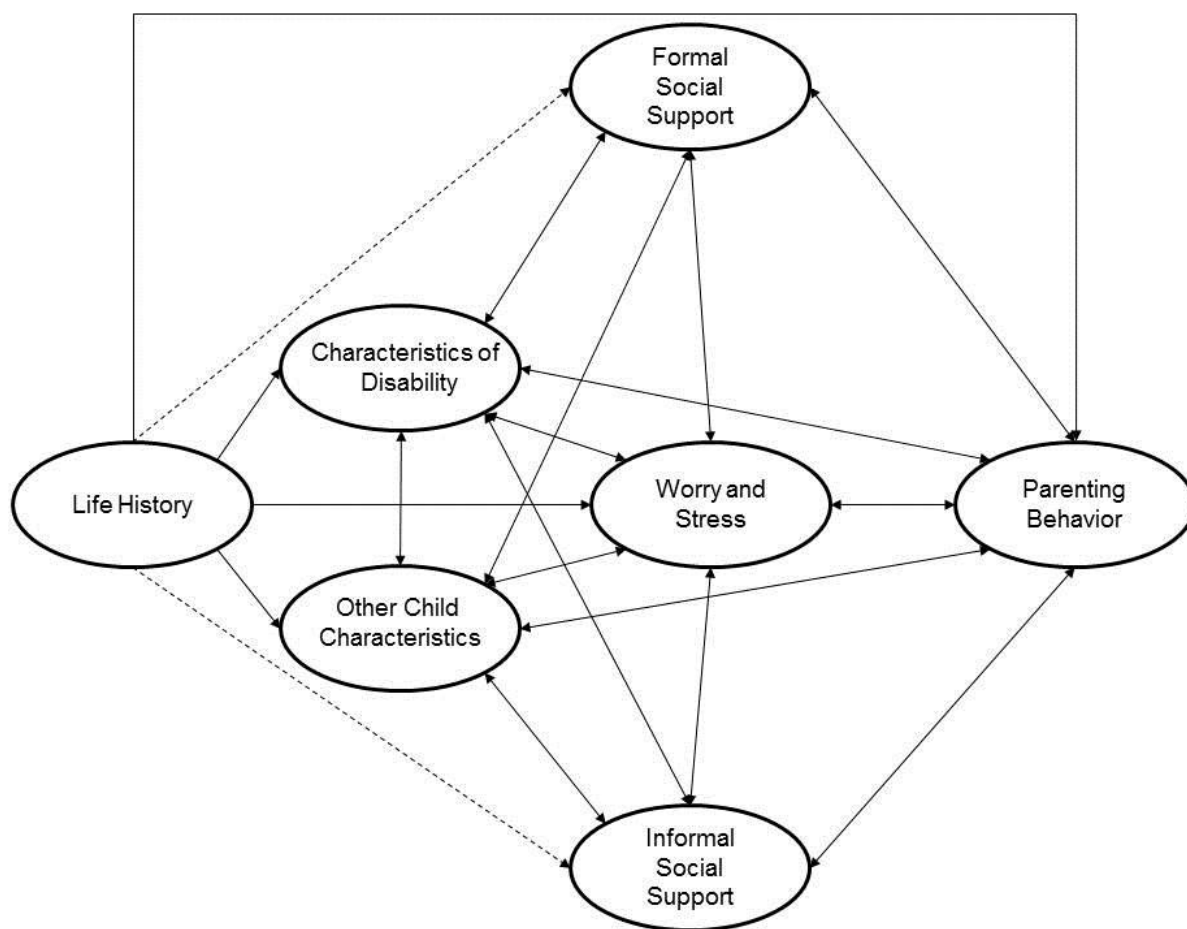
Appendix B: Figures

Figure 1. A Model of the Parenting Process for Parents of Young Children with DD

Vita

Prior to receiving a Bachelor of Science degree in Marriage, Family, and Human Development from Brigham Young University in 2010, Rhett Billen worked as an instructional aide using applied behavior analysis (ABA) among young children with autism spectrum disorders (ASD) in severely disabled children (SDC) preschools in California. This hand-on experience working with young children with disabilities sparked Rhett's interest in family dynamics and processes among this population. While pursuing his undergraduate education, Rhett furthered this experience and developed his interest in research by participating in an internship working in an orphanage and children's hospital in Romania. While in Romania, Rhett completed a case study of the reinforcement preferences of children with ASD in Romanian institutionalized care. In addition, Rhett also worked as a mentor at a residential treatment center in Orem, UT, which involved building positive relationships with adolescent males who struggled with a variety of internalizing and externalizing behaviors, as well as other disabilities. This experience helped him understand the clinical approaches that are used to treat adolescents and their families. In the Fall of 2010, Rhett enrolled as a Master's student in the department of Child and Family Studies at the University of Tennessee, Knoxville. As a graduate student, Rhett has had the opportunity to work with several faculty and other graduate students that has strengthened his knowledge and commitment to studying family processes and dynamics. After completing his Master's degree, Rhett plans to continue his work at the University of Tennessee as a doctoral student in Child and Family Studies.