Impact of Children with Developmental Disabilities and Behavior Problems on Parenting Stress

THESIS

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The current study sought to further characterize the predictive relationship between child behavior problems and parenting stress in the developmental disability population. Previous studies on parenting stress have explored risk factors for increased parenting stress, but few have examined the role of child characteristics, such as diagnosis, or used complex estimation procedures to characterize the relationship. Structural equation modeling was implemented to conduct analyses on the moderating effects of child age and developmental disability diagnoses as moderators of the behavior problems – parenting stress relationship. A structural model representation of parenting stress was confirmed using four factors: personal, financial, health insurance, and service provider stressors. This model confirmed a significant predictive relationship between behavior problems and parenting stress. Early childhood was found to significantly predict parenting stress above and beyond middle and late childhood. A diagnosis of autism spectrum disorder and intellectual disability were also significantly more likely to contribute to parenting stress compared to other developmental disability diagnoses, such as developmental delay. These findings support the literature on risk factors for parenting stress in the developmental disability population. Strengths of the study include the use of weighted data and stratified sampling to yield estimates that are representative of the developmental disability population. Limitations and recommendations for further
explorations of the behavior problems – parenting stress relationship using longitudinal SEM modeling are discussed.
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Chapter 1: Introduction

Problem behaviors commonly displayed by children with developmental disabilities include aggression, tantrums, non-compliance and hyperactivity (Keller & Fox, 2009), and are frequently characterized as interfering with learning, academic performance, family cohesion, parent well-being, and family members’ physical health (Eisenhower, Baker, & Blacher, 2009; Mitchell & Hauser-Cram, 2009). As of 2008, the estimated prevalence of developmental disabilities, including autism spectrum disorders (ASDs), intellectual disability, cerebral palsy, and other developmental disabilities or delays, was 6.08% in the United States (Boyle et al., 2011), an estimate has become unstable due to the increased prevalence of ASDs (Baio, 2012). This is significant in that children with developmental disabilities are at increased risk for emotional and behavioral problems compared to their typically developing peers (Lach et al., 2009). More specifically, children with developmental delays are 3 to 4 times more likely to display clinically significant levels of behavior problems than children without delays (Baker et al., 2002). Children with developmental disabilities have greater risks for negative life outcomes than typically developing children and this prognosis is further exacerbated by problem behaviors. The parenting stress (i.e.: stress specific to the responsibilities associated with caring for the mental, physical, and emotional needs of one’s child) and health of caregivers for children with developmental disabilities and co-
occurring behavior problems has received a substantial amount of attention (Osborne & Reed, 2009; Blacher & McIntyre, 2006; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Eisenhower et al., 2009; Osborne, et al., 2008b), due to the increased recognition of the importance of maximizing parental health to enable parents in providing appropriate care for a child with a disability, as well as the negative impacts behavior problems can have on parenting stress.

**Impact of behavior problems on parenting stress**

Child behavior problems have been associated with the use of ineffective discipline strategies, conflicts with and complaints from schools, social embarrassment, and sibling conflicts (Suárez & Baker, 1997). Such problems have additive effects on parenting stress (Webster-Stratton, 1990), though any one such factor can negatively impact the family’s quality of life (Davis & Gavidia-Payne, 2009). A positive family quality of life is attained when the needs of all family members are met, when its members enjoy spending time with one another, and are able to independently participate in activities of importance to each individual (Park et al., 2003).

According to Donenberg and Baker (1993), mothers of children with externalizing behavior problems experience negative impacts in several areas of family life (social, marital, and sibling relationships; finances) and report negative attitudes toward parenting (Suárez & Baker, 1997). Lach et al. (2009) studied the differences in health (psychological and physical) and psychosocial functioning (including marital satisfaction, social support, and family functioning) across caregivers whose child had a
neurodevelopmental disorder only, externalizing problem behaviors only, both, or neither conditions (ie.: neither a neurodevelopmental disability nor externalizing problem behaviors), using a longitudinal sample from the Canadian National Longitudinal Study of Children and Youth (NLSCY). Results showed a significant negative effect of having a child with both neurological and externalizing problem behaviors on the physical and psychological health of caregivers, with these parents being most likely to report at least one chronic health condition, limitations in at least one domain of daily living skills, and suffering from physiological consequences such as asthma, arthritis, back problems, and/or migraines. Authors concluded that the effects of having a child with a neurodevelopmental disorder and behavior problems are additive, with these parents being 2.1 times more likely to report having a chronic health condition than parents in the neither condition (Lach et al., 2009). Beyond parenting stress, parents of children with disabilities are at increased risk for depression and other mental health concerns compared to parents of children with neither neurological nor externalizing behavior problems (Olsson & Hwang, 2001; Singer, 2006; Emerson, 2003), displaying greater negative affect (Blacher & Baker, 2007), endorsing more frequent negative life events, and experiencing feelings of incompetence and social isolation (Embergts, Gimbrel du Bois & Graef, 2010).

Parental relationships, on the other hand, are subject to mixed effects from child behavior problems. Parents report lower relationship satisfaction, yet do not differ from parents of typically developing children in degree of spousal support, respect for one’s partner, and commitment (Brobst, Clopton, & Hendrick, 2009; Seltzer et al., 2001). No
differences in martial satisfaction have been found between parents with and without a child with a developmental disability and behavior problems (Lach et al., 2009). However, mothers of children with ASD report less support from their spouses as severity of behavior problems increase (Brobst, Clopton & Hendrick, 2009), suggesting that the resilience held by many parents caring for a child with a developmental disability is impaired by the addition of behavior problems. A limitation of these findings is that the sample was overrepresented in highly educated Caucasian parents with above-average incomes (Brobst, Clopton, & Hendrick, 2009).

**Impact of parenting stress on the child**

In addition to the negative effects the problem behaviors of children with developmental disabilities have on parents, it has become increasingly recognized that parenting stress negatively affects child development. Indeed, it continues to be debated whether parenting stress precedes child behavior problems, or whether child behavior problems precede parenting stress (Osborne & Reed, 2009). Lecavalier, Leone, and Wiltz (2006) measured behavior problems of young children (mean age = 9.0 years) with autism spectrum disorders (ASDs) over a one-year period, finding that behavior problems and parenting stress exacerbate one another increasingly over time. Though evidence for the relationship between child behavior problems and subsequent parenting stress is mixed, there is a great deal of evidence to support that initial parenting stress affects subsequent child behavior problems (Osborne & Reed, 2009). For example, parenting stress is associated with more authoritarian and neglectful parenting styles, which in turn
has been found to be a risk factor for negative child developmental outcomes (Belsky, Woodworth, & Crnic, 1996; Conger, Patterson, & Ge, 1995; Deater-Deckard & Scarr, 1996; Rothbaum & Weisz, 1994). It has consequently become accepted that parenting stress and child problem behaviors exist in a transactional relationship, with each exacerbating the other (Neece, Green, & Baker, 2012; Baker et al., 2003; Sameroff et al., 1998).

Parenting stress and perceptions of problem behaviors have been associated with decreased family quality of life (Baker et al., 2003; Hastings, 2002; Lecavalier et al., 2006; Davis & Gavidia-Payne, 2009). Fathers’ involvement in child care has been found to decrease as behavior problems escalate (Bristol, Gallagher, & Schopler, 1988), and parent resources available to the child wear thin as more time and energy is spent on maintaining the child’s well-being (Seltzer et al., 2001). Performing a meta-analysis on the effects of children with disabilities on families, Risdal and Singer (2004) found that parents of children with developmental disabilities are 6% more likely to file for divorce than parents of typically developing children. This is just one example of how the child’s support system is more likely to be reduced and can therefore heighten parent and child stress. Family circumstances that are exacerbated by stress also impact the child. Such circumstances can include difficulties in maintaining parent employment, exacerbated preexisting stressors in the family, reduced sense of spirituality and participation in religious activities, and decreased involvement in social support groups and activities (Brobst, Clopton & Hendrick, 2009).
Neece et al. (2012) explored the transactional relationship between parenting stress and child behavior problems using cross-lagged panel analyses, hypothesizing that parenting stress would lead to higher rates of behavior problems over time. Comparing self-report measures of stress from parents and behavioral observations of typically developing versus developmentally delayed children aged 3 to 9 years taken once per year, a covariation was found between parenting stress and behavior problems, as well as a decrease in child behavior problems with age. Initial parenting stress was significantly higher in the developmental delay group, although there were no significant group differences in rates of stress decline over time. It was concluded that both parenting stress and behavior problems act as an antecedent and consequence to child behavior problems to each other over time. Parenting stress interestingly only showed a decrease over time for parents of typically developing children, suggesting greater stability in the stressors experienced by parents of children with developmental delays. Authors called for research to investigate potential mediators and moderators of the parenting stress – behavior problem relationship, in order to identify both protective and risk factors that may contribute to this relationship over time.

**Impact of child age on parenting stress**

Adopting a lifespan perspective in studying the behavior problem – parenting stress relationship in children with developmental disabilities is important as these parents are faced with numerous challenges across the each stages of the child’s life. These challenges include the disappointments related to the original diagnosis,
advocating for appropriate supports, transitioning the child into adulthood and greater independence, and navigating the healthcare and educational systems (Chen & Tang, 1997; Floyd et al., 1996). The predictive relationship between child behavior problems and parenting stress has been suggested to be the most prominent in early childhood (Neece et al., 2012). Osborne and Reed (2009) found a strong positive relationship between ASD severity and parenting stress in children 2.6 to 4.0 years old. As the child ages, however, child behavior problems become the best predictors of parenting stress over and above ASD severity, especially externalizing and disruptive behaviors (Osborne & Reed, 2009; see also Donenberg & Baker, 1993; Dumas et al., 1991; Floyd & Gallagher, 1997). Assuming a broader perspective, a longitudinal study following families of children with developmental delays from infancy through age 10 years found that by child age 10, parents were four times more likely to report clinically-significant levels of stress than parents of typically developing children (Baker et al., 2003).

The learning rate of young children with ASD has been shown to be less favorable when mothers experience high parenting stress (Robbins, Dunlap, & Plienis, 1991; Lecavalier et al., 2006). Concerning children enrolled in early intervention programs, successful outcomes are negatively correlated with parenting stress (Osborne & Reed, 2009), which suggests that the educational gains made by an early intervention program can be counteracted by parent difficulties in managing caretaking demands. Other studies (eg. Lecavalier et al., 2006), using a wider age range (3 – 18 years) found a main association between parenting stress and child behavior problems, but perhaps would have found differences in effect had the sample been stratified into age groups.
It could be anticipated that parents are resilient to the additional stressor of caring for a child with a disability during early childhood, as parents already anticipate being entirely responsible for the child’s well-being (Estes et al., 2009). For example, when Sarimski (2010) compared the parenting stress of mothers of boys with fragile x syndrome in early, middle, and late childhood, increased levels of maternal stress were found in the middle-childhood cohort. Approximately 85% of mothers reported very high levels of parenting stress, with temperament and atypical behaviors being the main contributors. Though generalizability of these results is limited due to data having been collected from predominantly affluent families using unvalidated German translations of stress measures, this study supports the idea that aging contributes to greater parenting stress. Sarimski’s (2010) findings, for example, may be attributable to the new barriers to service access within the school system that many parents face as their child enters middle childhood and consequently the school system.

The parent-child relationship has been studied extensively in middle and late childhood with a focus on the relational factors, but few studies have considered the role of parenting stress in the relationship. Research on problem behaviors of adolescents with developmental disabilities is especially limited. Osborne and Reed (2009) found that severity of behavior problems in children with developmental disabilities reduces over time, suggesting that parents of young children experience higher levels of parenting stress when behavioral problems are more prominent, and that parenting stress decreased as either these problem behaviors reduce with age, or, alternatively, parents develop more efficient behavior management strategies.
Parents of older children with developmental disabilities and behavior problems appear to experience differences in stress across cultures. In collectivist and heavily family-oriented cultures, in which the norms are for parents to continue to provide for their children intensively into adulthood, the stress of having to continue to provide for a child with a disability may be no higher than that of parents of typically-developing children (Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005). Latina mothers report more positive impacts of having a child with a disability and/or mental health problems than Caucasian mothers (Blacher, Baker, & MacLean, 2007). Highly religious parents may also be more likely to positively interpret experiences of continuing to provide for an older child with a disability, which may alleviate some parenting stress (Blacher et al., 2007).

While there have been several studies to-date presenting evidence on the effect of behavior problems on parenting stress across the lifespan, some discrepancies remain. Further exploration is needed to determine overall effects of having an older child with a developmental disability and behavioral problems on parenting stress.

*Impact of diagnosis on parenting stress*

The contrasting behavioral phenotypes associated with specific developmental disorders suggest that varying levels of stress are experienced across parents of children with differing diagnoses and problem behaviors. Research exploring this idea has yielded mixed results. For example, Davis and Gavidia-Payne (2009) explored the relationship between disability severity (using the 24-item Child/Behavior Needs subscale of the
Parenting Hassles Scale; Gavidia-Payne, Matthews, Hudson, Richdale, & Nankervis, 2003) and family quality of life, finding no significant association. In contrast, another study found that over 40% of children with mild intellectual disability have been found to demonstrate serious behavior and emotional problems (Embregts, Gimbrel du Bois & Graef, 2010). A meta-analysis of the family literature found inconclusive results regarding the functioning of families containing children with various neurodevelopmental disorders (ie.: cerebral palsy, epilepsy, and developmental delay), some studies indicating that such families experience difficulties no more challenging than families of typically developing children (Lach et al.,2009).

In contrast, there is a growing body of evidence suggesting that diagnosis does impact the severity of parenting stress. Elevated levels of parenting stress have been associated with neurogenetic disorders, specifically Prader-Willi syndrome, Cri-du-chat syndrome, and Smith-Magenis syndrome (Hodapp, Fidler, & Smith, 1998; Hodapp, Wijma, & Masino, 1997; Sarimski, 1997), most likely due to an interaction effect of developmental delay and the comorbid medical conditions linked with these syndromes. Eisenhower et al. (2009) found that type of disability accounted for maternal stress above and beyond behavior problem severity and child cognitive level. Mothers of children with an ASD diagnosis reported more parenting stress than mothers of children with undifferentiated developmental delays, Down syndrome and cerebral palsy in early childhood (3, 4, or 5 years old), regardless of behavior problem type (based on subscales\(^1\) of the Child Behavior Checklist 1 ½ to 5 years; Achenbach & Rescorla, 2000), or

\(^1\) Externalizing behaviors, Internalizing behaviors, Aggression, Anxious/depressed, Attention problems, Emotionally reactive, Sleep problems, Somatic complaints, Withdrawn

Numerous studies have found that parents of children with ASD experience higher levels of distress than parents of children with other disabilities (Blacher & McIntyre, 2006; Bouma & Schweitzer, 1990; Dunn et al., 2001; Estes et al., 2009; Eisenhower et al., 2005; Koegel, Schreibman, Loos, Dirlich-Wilhelm, & Dunlap, 1992; Osborne & Reed, 2009; Perry, Sarlo-McGarvey & Factor; 1992; see Pisula, 2003 for a review). For example, Abbeduto et al. (2004), comparing the experiences of parents with children with ASDs, Fragile X syndrome, cerebral palsy, and Down syndrome, noted that mothers of children with ASDs demonstrated the lowest levels of psychological well-being and coping. Estes et al. (2009), studying the impact of child diagnosis, problem behavior, and daily living skills on maternal stress, found that mothers of children with ASDs reported higher parenting stress than mothers of children with developmental delays, and that children with ASDs demonstrated lower daily living skills and higher rates of problem behaviors than their age-matched comparison group of children with developmental delays. No support was found, however, for the contribution of poorer adaptive skills to increased parenting stress, a finding that corroborates previous studies (Beck et al., 2004; Lecavalier et al., 2006) but also contradict others (Fitzgerald et al., 2002; Tomanik et al., 2001).

Some studies, on the other hand, have failed to find support for disability type impacting parenting stress. According to Blacher and McIntyre (2006), type of disability (considering intellectual disability, cerebral palsy, Down syndrome, and ASDs) did not
contribute to severity of maternal stress or depression after having controlled for
differences in behavior problems (looking at internalizing, externalizing, and antisocial
behaviors as measured on the *Scales of Independent Behavior – Revised Problem
Behavior Scale*; Bruininks et al., 1996) in late childhood and early adulthood. Several
additional studies have found a positive correlation between parenting stress and child
behavior problems after partialling out stress associated with symptoms associated with
an ASD diagnosis (Baxter, Cummins, & Yioltis, 2000; Hodapp, Fidler, & Smith, 1998;
Stores, Stores, Fellows, & Buckley, 1998). Donenberg and Baker (1993) noted similar
levels of stress in parents of children with externalizing behaviors versus ASDs,
suggesting that children with ASDs demonstrating problem behaviors outside of their
behavioral phenotype contribute to even greater parenting stress. Studying the positive
impacts of disability on families, Blacher and Baker (2006) inferred that child behavior
problems account for more variability in parenting stress than type of disability, based on
their findings that positive impact is significantly negatively related to child behavior
problems. These findings are supported by previous literature (Baker et al., 2003;
McIntyre et al., 2002).

**Impact of family finances and service supports on parenting stress**

Limitations in family resources, supports, and finances contribute significantly to
parenting stress, especially in parents of children with developmental disabilities and
problem behaviors. Receiving professional support for the child’s problem behaviors and
disability has been found to be one of the strongest predictors of family quality of life;
social support for the parents also acts as a strong predictor (Davis & Gavidia-Payne, 2009). Higher family income enables the family to provide more appropriate treatments for the child, as well as specialized schooling and aids, and parents with higher incomes have consistently reported higher satisfaction with life (Davis & Gavidia-Payne, 2009; Wang et al., 2004). When taking support from extended family and professional support into consideration, the predictor variable of family income is rendered insignificant, highlighting the importance of social support in protecting against parenting stress (Davis & Gavidia-Payne, 2009; Suárez & Baker 1997; Webster-Stratton, 1990). These findings suggest that, with reduced financial and social resources, behavior problems and parenting stress will worsen as the child ages, although no differences in challenging behaviors have been found between children of different income levels (Mitchell & Hauser-Cram, 2009). The availability of a greater number of financial and support resources to parents most likely has a direct effect on amount of parenting stress experienced, as exemplified by studies finding that families who have successfully adapted to parenting stressors and tend to view their child as primarily a positive contribution to their family quality of life (Glidden in press; King et al., 2006). Only 22.7% of children with developmental and behavioral needs who are limited to services through government welfare programs have access to intervention services (Stahmer & Carter, 2005). Little research has explored the outcomes in late childhood for these children and families.
In consideration of recent evidence of the relationship that exists between behavior problems in children with developmental disabilities and parenting stress (Neece et al., 2012), this project aims to further characterize and clarify this relationship with an emphasis on the moderating effects of child characteristics. The following research questions are being explored:

- **Primary hypothesis:** Age moderates the behavior-stress relationship, with late childhood (12 to 17 years) contributing to greater parenting stress.

- **Related Hypotheses:**
  - Diagnosis moderates the behavior-stress relationship, with an ASD diagnosis contributing to higher parenting stress than other developmental disability diagnoses (specifically intellectual disability and developmental delay).
  - Families of children with developmental disabilities and co-occurring behavior problems are receiving inadequate amounts of family-focused services to address the child’s behavior.
Chapter 2: Methods

Procedure

Data was drawn from the *National Survey of Children with Special Healthcare Needs* (Maternal and Child Health Bureau in collaboration with the National Center for Health Statistics, 2009), a health core indicator survey conducted through a randomized telephone dialing system, the States and Local Area Integrated Telephone Survey (SLAITS) system, under contract with the National Opinion Research Center at the University of Chicago (NORC). This survey gathered a nationally representative sample of children, ages 0 to 17, with special health care needs. The Data Resource Center for Child and Adolescent Health, a national initiative funded by the Child and Adolescent Health Measurement Initiative of the Oregon Health and Science University, maintained responsibility of data collection and analysis. A total of 372,698 households were surveyed for the presence of a child with a special healthcare need within the home. Of these 40,242 landline and cell telephone interviews were conducted of households containing one or more children with special health care needs across all 50 states. Cell phone weights created by the Data Resource Center were applied to the sample to ensure accurate representation of those contacted by cell phone.

Data collection occurred between January 2009 and March 2010. The finalized dataset has been released for free public use and analysis on the Data Resource Center
website (http://www.childhealthdata.org/). Authors submitted a request to use the data set to the Data Resource Center for Child and Adolescent Health, which was granted in October, 2011.

**Measures**

*2009 – 2010 National Survey of Children with Special Healthcare Needs*  
(Maternal and Child Health Bureau in collaboration with the National Center for Health Statistics, 2009): The primary goal of this survey was to create a source of detailed information on the rate of children with special healthcare needs within each state and in the United States as a whole, as well as to characterize the demographic characteristics of these children, the health and support service needs of their families, and their access to and satisfaction with care. This project was funded by the Maternal and Child Health Bureau, a subsection of the U.S. Department of Health and Human Services, Health Resources and Services Administration.

**Eligibility**

Each child within the household aged birth to 17 years was screened for a special healthcare need. A child was determined to have a special healthcare need if parents endorsed at least one of the items on the CSHCN Screener (See Appendix A). A special healthcare need was identified based on McPherson et al.’s (1998) definition: “Children with special health care needs are those who have... a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” Once a child with a special
healthcare need was identified, the primary care provider of the child was requested to participate in an approximately 25 minute long survey on the child’s health and health care. If the responder indicated that more than one child with a special healthcare need lived in the home, one child was randomly selected as the subject of the interview.

Sample

The 2009 – 2010 NS-CSHCN dataset contains records for 40,242 children with special healthcare needs between the ages of birth and 17 years. For the purpose of this analysis, the total subsample of children indicated as having a developmental disability in the 2009 – 2010 sample (n = 10,390) will be used. Developmental disability diagnoses probed for during the interview were: autism spectrum disorders (ASD), intellectual disability, developmental delay, Down syndrome, and cerebral palsy. Since the subsample of children who were endorsed as having Down syndrome and cerebral palsy were 1.1% and 1.6%, respectively, Down Syndrome and cerebral palsy were not included as diagnoses when testing moderation effects, but were included for full sample analyses.

Model Description and Development

A review of the developmental disabilities literature was performed to identify commonly supported predictors of parenting stress in this population, using the Worldcat@OSU article search engine to search for peer-reviewed journal articles published between 2002 and 2012 containing key terms “predictors,” “parenting stress,” “behavior problems,” and “developmental disabilities” or “developmental delays”. This
search yielded 338 results, 15 articles of which were relevant to the current topic. Articles were reviewed for parent and child predictors of parenting stress in parents of children with developmental disabilities. A table of relevant articles can be found in Appendix A. From this literature review, common trends in predictors of overall parenting stress were identified: informal parent social supports (such as friends and relatives), formal social supports (child service providers), and financial stressors. Severity of child behavior problems was consistently found to be predictive of parenting stress, while child level of disability (based on IQ score and functional limitations) were not predictive. As a result the hypothesized model of parenting stress (See Figure 1) is composed of four sources of stress: personal stressors, financial stressors, health insurance stressors, and service provider stressors.

In order to address the current study’s third hypothesis, that families of children with developmental disabilities and co-occurring behavior problems are receiving inadequate amounts of family-focused services to address the child’s behavior, the roles of health insurance and service provider stressors will be compared across structural models. Limited information was found in the literature on the role that insurance stressors play on parenting stress, but it is anticipated that insurance limitations represent a large source of parenting stress in the developmental disability population due to the limitations in long-term supports that are typically available. The role of health insurance and service provider stressors will be explored using the structural and measurement models to determine adequacy of supports being provided to children with developmental disabilities.
Figure 1 represents the relationship between behavior problems displayed by children with developmental disabilities and parenting stress. Items from the NS-CSHCN that pertained to the four constructs of parenting stress were included in the model as observed variables loading on its respective construct (See Appendix C for these items and further information on the response options). The following points are explanations of each of the four latent constructs and their respective observed variables:

(1) “Personal stressors” refers to the negative impact anticipated on personal factors associated with caring for a child with a developmental disability and co-occurring behavior problems. It is measured based on the endorsement of the following four questions from the NS-CSHCN: (a) whether the parent has needed mental health services in the past due to the stress of having to care for a child with developmental disabilities and behavior problems, (b) whether the parent was unable to access all the mental health services needed over the past year, (c) the number of hours spent at home providing care for a child with developmental disabilities and behavior problems, (d) the number of hours personally coordinating health care services for child with developmental disabilities and behavior problems, and (e) the parents subjective dissatisfaction with the quality of social support, both formal and informal, received over the past year.

(2) “Financial Stressors” refer to the financial limitations resulting from caring for a child with a developmental disability and co-occurring behavior problems. This construct is measured based on the endorsement of five specific questions from the NS-CSHCN: (a) the amount of out-of-pocket expenses paid for the child’s
Figure 1: Hypothesized model
mental and behavioral health services, (b) whether the family has endured financial problems due to having a child with developmental disabilities and behavior problems, (c) whether another relative in the home has had to work fewer hours in order to care for a child with developmental disabilities and behavior problems, (d) whether the responding parent has stopped working in order to provide care for child with developmental disabilities and behavior problems, and (e) whether a family member was unable to change employment positions in order to maintain health care for the child to access behavioral health services.

(3) “Insurance Stressors” refer to limitations in access to mental and behavioral healthcare as a result of health insurance limitations. This item is indicated by insufficient access to mental healthcare due to: (a) there being no providers for child’s insurance, (b) problems with the child’s health plan, (c) the parents’ subjective opinion on the unreasonableness of uncovered health care costs in the past year, and (d) whether the child had any unmet prescription medication needs as a result of health insurance limitations.

(4) “Provider Stressors” refers to a limited access to mental and behavioral healthcare services as a result of service provider limitations. The construct is intended to measure severity of parent stress due to insufficient supports from mental and behavior support and treatment services received from healthcare professionals, whether in a healthcare or school setting. Stressor severity will be indicated by: (a) high out-of-pocket costs for care, (b) lack of local services or transportation to
services, (c) dissatisfaction with the provider, (d) the provider not knowing how to
treat the child’s symptoms, (d) the healthcare provider not having appointments
available, (e) the family not knowing where to seek mental or behavioral health
services, (f) the absence of mental or behavioral health services at the child’s
school, and (g) the child not receiving a referral for treatment.

Behavior problems are represented as a latent variable loading upon three
manifest variables: (a) a doctor of health care provider ever having confirmed that the
child has behavior problems, (b) the child currently displaying behavior or conduct
problems, and (c) the severity of current behavior problems, rated mild, moderate, or
severe.

In addition to exploring the predictive relationship between child behavior
problems and parenting stress, the influence of several moderating factors will be
explored. Specifically, the moderating effect of type of developmental disability (ie.:
developmental delay, intellectual disability, ASD) and child age, specified as early (0 to 6
years), middle (7 to 11 years), and late (12 to 17 years) will be tested. It is anticipated that
an ASD diagnosis will have a stronger moderating effect on the predictive relationship
between child behavior problems and parenting stress than a developmental delay or
intellectual disability diagnosis. In other words, it is anticipated that parenting stress will
be higher in families in which the child demonstrates behavior problems and has an ASD
diagnosis than in families in which the child has an intellectual disability or a
developmental delay in addition to behavior problems. Late childhood is predicted to
strengthen the behavior problems predicting parenting stress relationship. As the child
ages, gains in the child’s strength, as well as independence, will make it more difficult for parents to manage problem behavior, which in turn can contribute to more significant levels of parenting stress.

**Data Analysis Strategy**

The data analysis procedure was to (a) weight the dataset, (b) perform sample descriptive analyses, (c) test the measurement and structural model, (d) modify the model, and (e) conduct multigroup comparisons to test moderating effects. SPSS Version 19.0 (IBM Corp., 2010) was used to analyze participant demographic information and run a missing data analysis. All structural models were tested and modified using structural equation modeling, using AMOS 19.0, a SPSS add-on software package. Structural equation modeling (SEM) was used to test the relationship between child behavior problems and parenting stress and the moderating hypotheses, using maximum likelihood (ML) and general least squares (GLS) estimation procedures. ML and GLS estimations were used as they both have been found to yield highly similar estimates in large samples, though GLS provides a more robust approach to model estimation and was therefore used to explore moderating effects. SEM was chosen as the approach because this procedure allows researchers to evaluate how closely a hypothesized model fits an actual data set while examining the strength and significance of the relationships between different theoretical constructs.

In order to produce model estimates that would be representative of the population as a whole, normalized weighting was applied to all entries in the dataset.
Since the NS-CSHCN collected data based on the participants’ willingness to complete a phone interview, it is highly likely that the dataset was subject to disproportionate sampling and oversampling (Thomas & Heck, 2001). The dataset included weights intended to represent the population of non-institutionalized children with special healthcare needs aged 0 to 17-years-old nationally in each of the 50 states and the District of Columbia (The Child and Adolescent Health Measurement Initiative, 2012). Since stratified sampling as was used in this dataset, normalized weights, also known as relative weights, are recommended to ensure that oversampling was accommodated. Previous studies have found that raw weights can unduly influence estimates that are sensitive to sample size such as test statistics (Hahs-Vaughn & Lenox, 2006; Thomas & Heck, 2001), that normalized estimates generate likelihood-ratio chi-square statistics closer to results of the population, and that fit indices, including root mean square error of approximation (RMSEA), show more precise values in large sample sizes (Hahs-Vaughn & Lenox, 2006).

The ML and GLS procedures make the following assumptions regarding a dataset: (1) the sample observations are independently distributed, (2) the measured variables have a multivariate normal distribution, (3) the hypothesized model is approximately correct, (4) a sample covariance matrix is being analyzed, and (5) it has a large sample size in order to appropriately measure the asymptotic properties of parameter, standard error, and model-fit estimates (Tabachnick & Fidell, 2012). In testing the assumptions of the ML procedure, all assumptions were met with the exception that variables were found to demonstrate skew and kurtosis. Since the dataset does not have a
multivariate normal distribution, Bayesian estimates were calculated in addition to ML estimates to verify that the ML estimates being calculated are not underestimated (Byrne, 2010). Estimates provided by Bayesian analyses were identical to the ML estimates, and consequently only ML estimates are reported. For testing moderator effects in the structural model, GLS estimators are reported. As previously stated, GLS estimates have been found to yield almost identical estimates to the ML method using a more robust estimation procedure, which was necessary for the AMOS software to complete moderation testing.

Criteria used to test the measurement and structural model are squared multiple correlations ($R^2$) to explain the relative contribution of each latent variable onto each other and regression estimates ($\beta$) to measure the contribution of each measured variable onto its respective latent variable. Multiple fit indices are reported for each model to evaluate the degree to which the models exhibit an appropriate fit for the data. The chi-square statistic ($\chi^2$), its relative degree of freedom, and its $p$-value are reported, as is traditional in the SEM literature; however, it is important to note that $\chi^2$ tends to be substantial when the model is large, which increases the likelihood of Type-I error with large datasets (Jöreskog & Sörbom, 1993). Model fit will therefore be determined using additional fit indices that were selected based on recommendations by Bentler and Hu (1999), Browne and Cudeck (1989), and Hooper, Coughlan, and Mullen (2008). Comparative fit index (CFI) and root mean square error of approximation (RMSEA) will be the primary fit indices used in this analysis because they control for sample size (Hu and Bentler, 1999). CFI values greater than .95 indicate very good fit, although a CFI of
.90 also indicates the model is a good fit to the data (Hu and Bentler, 1999). When the RMSEA value is less than .06, the hypothesized model is said to have an adequate fit for the data (Hu and Bentler, 1999), although others say less than .05 is more appropriate measure of good fit (Browne & Cudeck, 1993).

The moderating relationships were conceptualized as identifying how the effect of a quantitative variable, namely, behavior problems, differ across levels of the independent variables, child age and diagnosis—a conceptualization based largely off Baron and Kenny’s (1986) seminal paper on the topic (Hopwood, 2007). However, Baron and Kenny’s (1986) traditional approach to moderation is not recommended for evaluation of multiple moderators and outcomes in structural equation modeling, because recent studies have found that their approach can lead to inflated Type II error rates (Hopwood, 2007; Tabachnick & Fidell, 2012). For this reason, a Monte Carlo bootstrap approach was chosen. This approach determines the accuracy of sample estimates and is suggested to provide more accurate results than ML estimation alone, especially when the sample exhibits a non-normal distribution (Byrne, 2010). Specifically, the Monto Carlo bootstrap approach produces bias-corrected confidence intervals for the estimates using 500 pseudo-cases that are generated from the sample correlation matrix. If the confidence intervals of each level of the moderator are found to be significantly different (i.e.: they do not overlap), it is said that there is a significant difference between levels of the moderator (Tabachnick & Fidell, 2012).
Chapter 3: Results

Descriptive Statistics and Correlations

A prevalence of 9.23% of the total sample was reported as having a special health care need \((n = 40,242; 59.3\% \text{ male})\). Of the special health care needs sample, 10,390 (25.82%) children had a specific developmental disability diagnosis. Of children with a developmental disability, many children were endorsed as having one or more diagnoses (43.9%), resulting in the following prevalence rates: ASD = 38.7%, intellectual disability = 24.0%, developmental delay = 85.6%, Down syndrome = 4.3%, and cerebral palsy = 7.2%. The early childhood subsample (0 – 6 years) was characterized as having a lower prevalence of overall special health care needs (20.8%) than middle (7 -11 years, 38.7%) or late childhood (12 – 17 years, 40.5%), and no significant differences were found in prevalence of special health care needs by socioeconomic status (See Table 1). Of children with a developmental disability, 58.7% were reported to have ever had difficulties with behavior problems, such as acting out, bullying, or fighting. Of the developmental disability sample, 23.8% were reported as demonstrating behavior problems at the time of the survey, 27.6% of which were reported to have severe behavior problems. See Table 2 for prevalence of behavior problems by diagnostic group. Correlations between measured variables included in the model are weak but significant (See Table 3).
<table>
<thead>
<tr>
<th>Child Characteristic</th>
<th>Autism (%)</th>
<th>DD (%)</th>
<th>ID (%)</th>
<th>CP (%)</th>
<th>DS (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early (0 to 6 years)</td>
<td>880(21.87)</td>
<td>1944(21.86)</td>
<td>412(16.54)</td>
<td>203(27.28)</td>
<td>157(35.04)</td>
<td>1916(18.44)</td>
</tr>
<tr>
<td>Middle (7 to 11 years)</td>
<td>1563(38.85)</td>
<td>3273(36.80)</td>
<td>819(32.88)</td>
<td>249(33.47)</td>
<td>129(28.79)</td>
<td>4383(22.60)</td>
</tr>
<tr>
<td>Late (12 to 17 years)</td>
<td>1580(39.27)</td>
<td>3677(41.34)</td>
<td>1260(50.58)</td>
<td>292(39.25)</td>
<td>162(36.16)</td>
<td>4091(39.37)</td>
</tr>
<tr>
<td><strong>Sex (male)</strong></td>
<td>3175(79.00)</td>
<td>5981(67.35)</td>
<td>1548(62.17)</td>
<td>431(57.93)</td>
<td>246(54.91)</td>
<td>7125(68.58)</td>
</tr>
<tr>
<td><strong>Hispanic ethnicity</strong></td>
<td>452(11.38)</td>
<td>1074(12.22)</td>
<td>328(13.33)</td>
<td>86(11.72)</td>
<td>61(13.80)</td>
<td>131(1.26)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White only</td>
<td>3054(75.39)</td>
<td>6535(73.21)</td>
<td>1782(71.19)</td>
<td>546(73.68)</td>
<td>345(77.18)</td>
<td>7776(74.84)</td>
</tr>
<tr>
<td>Black only</td>
<td>350(8.64)</td>
<td>918(10.28)</td>
<td>290(11.59)</td>
<td>89(12.01)</td>
<td>42(9.40)</td>
<td>1066(10.26)</td>
</tr>
<tr>
<td>Other</td>
<td>647(15.97)</td>
<td>1473(16.50)</td>
<td>431(17.22)</td>
<td>106(14.30)</td>
<td>60(13.42)</td>
<td>1548(14.90)</td>
</tr>
<tr>
<td><strong>Need or use prescription medications</strong></td>
<td>2440(60.74)</td>
<td>5684(63.97)</td>
<td>1618(65.06)</td>
<td>468(62.99)</td>
<td>234(52.35)</td>
<td>6662(64.12)</td>
</tr>
</tbody>
</table>
### Behavior problems

<table>
<thead>
<tr>
<th></th>
<th>1331(33.08)</th>
<th>2453(27.58)</th>
<th>768(30.83)</th>
<th>84(11.29)</th>
<th>53(11.83)</th>
<th>2853(27.50)</th>
</tr>
</thead>
</table>

### Highest parent education

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Less than high school</th>
<th>High school graduate</th>
<th>More than high school</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>206(5.19)</td>
<td>591(6.74)</td>
<td>201(8.19)</td>
</tr>
<tr>
<td></td>
<td>549(13.84)</td>
<td>1543(17.61)</td>
<td>422(17.20)</td>
</tr>
<tr>
<td></td>
<td>3212(80.97)</td>
<td>6629(75.65)</td>
<td>1831(74.61)</td>
</tr>
</tbody>
</table>

### Household Poverty Level (% below FPL)

<table>
<thead>
<tr>
<th>Poverty Level</th>
<th>740(18.4)</th>
<th>1995(22.43)</th>
<th>596(23.92)</th>
<th>157(21.1)</th>
<th>86(19.2)</th>
<th>2058(19.81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 100</td>
<td>863(21.45)</td>
<td>1946(21.87)</td>
<td>539(21.64)</td>
<td>155(20.83)</td>
<td>100(22.32)</td>
<td>2064(19.87)</td>
</tr>
<tr>
<td>100 - 200</td>
<td>669(16.63)</td>
<td>1544(17.36)</td>
<td>417(16.74)</td>
<td>145(19.49)</td>
<td>71(15.85)</td>
<td>1643(15.81)</td>
</tr>
<tr>
<td>200 - 300</td>
<td>559(13.90)</td>
<td>1174(13.20)</td>
<td>318(12.77)</td>
<td>110(14.78)</td>
<td>67(14.96)</td>
<td>1280(12.32)</td>
</tr>
<tr>
<td>300 - 400</td>
<td>1192(29.63)</td>
<td>2235(25.13)</td>
<td>621(24.93)</td>
<td>177(23.79)</td>
<td>124(27.68)</td>
<td>2391(23.01)</td>
</tr>
<tr>
<td>Above 400</td>
<td>4023(100)</td>
<td>8894(100)</td>
<td>2491(100)</td>
<td>744(100)</td>
<td>448(100)</td>
<td>29(100)</td>
</tr>
<tr>
<td>Total</td>
<td>4023(100)</td>
<td>8894(100)</td>
<td>2491(100)</td>
<td>744(100)</td>
<td>448(100)</td>
<td>29(100)</td>
</tr>
</tbody>
</table>
Table 2: Prevalence of behavior problems across disability groups and total sample

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Doctor endorsed Behavior problems</th>
<th>Current Behavior problems</th>
<th>Mild(%)</th>
<th>Moderate(%)</th>
<th>Severe(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1394 (45.86)</td>
<td>1237 (46.77)</td>
<td>1326 (32.96)</td>
<td>1419 (35.27)</td>
<td>1278 (31.77)</td>
</tr>
<tr>
<td>No</td>
<td>1646 (54.14)</td>
<td>1408 (53.23)</td>
<td>2970 (46.64)</td>
<td>1996 (31.34)</td>
<td>1402 (22.02)</td>
</tr>
<tr>
<td>ID</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>882 (29.01)</td>
<td>804 (30.40)</td>
<td>985 (39.54)</td>
<td>800 (32.12)</td>
<td>706 (28.34)</td>
</tr>
<tr>
<td>No</td>
<td>2158 (70.99)</td>
<td>1841 (69.60)</td>
<td>3311 (41.91)</td>
<td>2615 (33.10)</td>
<td>1974 (24.99)</td>
</tr>
<tr>
<td>DD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2649 (87.17)</td>
<td>2318 (87.64)</td>
<td>3649 (23.60)</td>
<td>2919 (18.88)</td>
<td>8895 (57.52)</td>
</tr>
<tr>
<td>No</td>
<td>390 (12.83)</td>
<td>327 (12.36)</td>
<td>647 (43.25)</td>
<td>496 (33.16)</td>
<td>353 (23.60)</td>
</tr>
<tr>
<td>Total</td>
<td>2853 (27.5)</td>
<td>2472 (23.8)</td>
<td>673 (27.2)</td>
<td>1113 (45.2)</td>
<td>683 (27.6)</td>
</tr>
</tbody>
</table>

Severity percentages represent percentage of sample that endorsed having current behavior problems.

ASD = Autism spectrum disorder; ID = Intellectual disability; DD = Developmental delay.
Table 3: Correlations between observed variables

|     | 1.   | 2.   | 3.   | 4.   | 5.   | 6.   | 7.   | 8.   | 9.   | 10.  | 11.  | 12.  | 13.  | 14.  | 15.  | 16.  | 17.  | 18.  | 19.  |
|-----|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|
| 1.  | 1.00 |      |      |      |      |      |      |      |      |      |      |      |      |      |      |      |      |      |
| 2.  | .91  | 1.00 |      |      |      |      |      |      |      |      |      |      |      |      |      |      |      |      |
| 3.  | .84  | .92  | 1.00 |      |      |      |      |      |      |      |      |      |      |      |      |      |      |      |
| 4.  | .25  | .25  | .27  | 1.00 |      |      |      |      |      |      |      |      |      |      |      |      |      |      |
| 5.  | .12  | .13  | .15  | .54  | 1.00 |      |      |      |      |      |      |      |      |      |      |      |      |      |
| 6.  | .02  | .04  | .06  | .08  | .09  | 1.00 |      |      |      |      |      |      |      |      |      |      |      |      |
| 7.  | .09  | .08  | .10  | .17  | .23  | .11  | 1.00 |      |      |      |      |      |      |      |      |      |      |      |
| 8.  | .02  | .01  | .02  | .10  | .09  | .11  | .12  | 1.00 |      |      |      |      |      |      |      |      |      |      |
| 9.  | .08  | .08  | .09  | .13  | .12  | .19  | .16  | .25  | 1.00 |      |      |      |      |      |      |      |      |      |
| 10. | .08  | .08  | .10  | .11  | .12  | .32  | .12  | .16  | .27  | 1.00 |      |      |      |      |      |      |      |      |
| 11. | .09  | .09  | .12  | .21  | .23  | .25  | .23  | .27  | .32  | .28  | 1.00 |      |      |      |      |      |      |      |
| 12. | .05  | .04  | .05  | .12  | .17  | .03  | .05  | .04  | .05  | .03  | .09  | 1.00 |      |      |      |      |      |      |
| 13. | .03  | .04  | .03  | .07  | .11  | .05  | .08  | -.01 | .08  | .06  | .05  | .32  | 1.0  |      |      |      |      |      |
| 14. | .05  | .06  | .08  | .12  | .17  | .03  | .15  | .06  | .08  | .05  | .14  | .11  | .08  | 1.00 |      |      |      |      |
| 15. | .09  | .08  | .08  | .10  | .16  | .03  | .12  | .04  | .09  | .04  | .09  | .13  | .20  | .04  | 1.00 |      |      |      |
| 16. | .04  | .04  | .06  | .04  | .08  | .02  | .08  | .06  | .02  | .06  | .09  | .09  | -.003 | .09  | 1.00 |      |      |      |
| 17. | .05  | .05  | .07  | .11  | .15  | .05  | .10  | .02  | .02  | .02  | .05  | .19  | .14  | .10  | .19  | .08  | 1.00 |      |
| 18. | .01  | .02  | .03  | .07  | .12  | .01  | .11  | .05  | .06  | .01  | .04  | .20  | .24  | .10  | .23  | .08  | .20  | 1.00 |
| 19. | .07  | .08  | .08  | .16  | .28  | .02  | .15  | .09  | .07  | .04  | .14  | .18  | .23  | .25  | .20  | .08  | .17  | .16  | 1.00 |

$r \geq .03, p < .01$ (two-tailed)
$r = .01 - .029, p < .05$ (two-tailed)
Table 4: Variable names for itemized row in correlation matrix

<table>
<thead>
<tr>
<th>Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Doctor confirmed behavior problems</td>
</tr>
<tr>
<td>2. Currently behavior problems</td>
</tr>
<tr>
<td>3. Severity of current behavior problems</td>
</tr>
<tr>
<td>4. Parent needed mental health treatment related to caring for child</td>
</tr>
<tr>
<td>5. Parent did not receive needed mental health treatment</td>
</tr>
<tr>
<td>6. Number of hours providing care</td>
</tr>
<tr>
<td>7. Parent social support dissatisfaction</td>
</tr>
<tr>
<td>8. Another family member avoided a job change</td>
</tr>
<tr>
<td>9. Another family member was working less to help with child’s health problems</td>
</tr>
<tr>
<td>10. Parent stopped working due to provide greater care for child</td>
</tr>
<tr>
<td>11. Family financial problems due to child’s health problems</td>
</tr>
<tr>
<td>12. No mental health treatment for child due to insurance plan problems</td>
</tr>
<tr>
<td>13. No mental health treatment for child due to no provider for insurance</td>
</tr>
<tr>
<td>14. Unmet prescription medication needs for child</td>
</tr>
<tr>
<td>15. No mental health treatment for child due to there being no local providers</td>
</tr>
<tr>
<td>16. No mental health treatment for child due to provider not knowing how to treat</td>
</tr>
<tr>
<td>17. No mental health treatment for child due to no convenient appointment times</td>
</tr>
<tr>
<td>18. No mental health treatment for child due to not knowing where to get treatment</td>
</tr>
<tr>
<td>19. No mental health treatment for child due to treatment being too expensive</td>
</tr>
</tbody>
</table>

Measurement Model Testing

An important step in the analysis of a full latent variable model before continuing on to test the structural model is to verify whether the measurement model fits the sample data. Before looking at the fit indicators of the full model, model specification and fit was calculated for each of the subclusters of the hypothesized model. Based on initial model analyses, modifications to the model were made based on recommendations from Tabachnick and Fidell (2012) and Byrne (2010). Adjustments to the model are warranted in the event of Heywood cases, in which negative variances or non-positive definite correlation matrices are observed, as well as inappropriate standard errors of estimates,
insignificant critical ratios of estimates, statistically significant discrepancies in residual values (greater than $\pm 2.58$), and large modification indices associated with each fixed parameter (Tabachnick & Fidell, 2012). See Table 5 for fit statistics of each of the first-order models at initial and after adjusted finalized testing.

**Table 5: Goodness-of-fit statistics for latent variable structures**

<table>
<thead>
<tr>
<th></th>
<th>Goodness-of-Fit Index</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$\chi^2$</td>
</tr>
<tr>
<td><strong>Personal Stressors</strong></td>
<td></td>
</tr>
<tr>
<td>Initial model</td>
<td>2024.51</td>
</tr>
<tr>
<td>Final model</td>
<td>178.81</td>
</tr>
<tr>
<td><strong>Financial Stressors</strong></td>
<td></td>
</tr>
<tr>
<td>Initial model</td>
<td>626.42</td>
</tr>
<tr>
<td>Final model</td>
<td>37.52</td>
</tr>
<tr>
<td><strong>Insurance Stressors</strong></td>
<td></td>
</tr>
<tr>
<td>Initial model</td>
<td>219.66</td>
</tr>
<tr>
<td>Final model</td>
<td>29.61</td>
</tr>
<tr>
<td><strong>Provider Stressors</strong></td>
<td></td>
</tr>
<tr>
<td>Initial model</td>
<td>974.36</td>
</tr>
<tr>
<td>Final model</td>
<td>11.66</td>
</tr>
<tr>
<td><strong>Behavior Problems</strong></td>
<td></td>
</tr>
<tr>
<td>Initial model</td>
<td>225.73</td>
</tr>
<tr>
<td>Final model</td>
<td>7.672</td>
</tr>
</tbody>
</table>

For the second-order model of Parenting Stress, model parsimony was explored by comparing the fit of nested submodels compared to the full model’s fit (See Table 6). Combining the first order model representing the four parent stressors into a second-order measurement model of “Parenting Stress,” fit indices were found to show good fit and remained consistent with the fit estimates of the first-order models.
Table 6: Fit estimates for second-order “Parenting Stress” and first-order models

<table>
<thead>
<tr>
<th>Model</th>
<th>$\chi^2$</th>
<th>df</th>
<th>$p$</th>
<th>RMSEA</th>
<th>RMSEA 90% CI</th>
<th>CFI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Stressors</td>
<td>178.81</td>
<td>4</td>
<td>.001</td>
<td>.065</td>
<td>.057 -.073</td>
<td>.97</td>
</tr>
<tr>
<td>Financial Stressors</td>
<td>37.52</td>
<td>2</td>
<td>.001</td>
<td>.041</td>
<td>.030 -.052</td>
<td>.99</td>
</tr>
<tr>
<td>Insurance Stressors</td>
<td>29.61</td>
<td>2</td>
<td>.001</td>
<td>.036</td>
<td>.026 -.049</td>
<td>.98</td>
</tr>
<tr>
<td>Provider Stressors</td>
<td>11.66</td>
<td>5</td>
<td>.040</td>
<td>.011</td>
<td>.002 -.020</td>
<td>.99</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>4036.20</td>
<td>147</td>
<td>.001</td>
<td>.050</td>
<td>.049 -.052</td>
<td>.93</td>
</tr>
</tbody>
</table>

Two instances of Heywood cases were observed, which presented difficulties in successfully estimating the model. Specifically, the covariance matrix of latent factors was not positive definite, showing a correlation larger than one for the residual terms for “Provider Stressors” and the error term for one observed variable on the Behavior Problems latent construct, “Currently behavior problems”. These findings imply a high multicollinearity between these factors. To account for this, the variances of these residual terms were constrained to a non-negative number, close enough to zero so as to not affect results, specifically to 0.001. Two covariances were added between an observed variable in the Personal Stressors construct, “Number of hours providing care” and two observed variables on the Financial Stressors construct, “Family member working less” and “Parent stopped working.” Since it can be anticipated that if the parent has had to leave employment to provide full-time care to their child, number of hours providing care for the child will increase and that likely other family members will also have to provide assistance in providing care, rendering these covariances logical additions to the model.
**Structural Model Testing**

The final structural model contained the following variables: (1) observed endogenous variables (all measured variables for Behavior problems, Personal stressors, Financial stressors, Insurance Stressors, and Service provider stressors), (2) latent endogenous variables (Behavior Problems, Parenting Stress, Personal stressors, Financial stressors, Insurance stressors, Service provider stressors), and (3) unobserved exogenous variables (error terms, latent factor residual terms). Latent variables refer to values represented by ellipses in the model that are assumed to contribute to values measured by the observed variables. Observed variables, represented by rectangles in the model, serve as indicators of the underlying latent variable construct which they are presumed to represent. Endogenous variables represent the dependent variables in the diagram that are predicted by other variables in the model, whereas exogenous variables are equivalent to the independent variables (Byrne, 2010). Standardized regression coefficients were used to represent the independent contributions of each observed variable to the prediction of its respective latent variable.

In performing exploratory data analyses in SEM, an inflated risk for Type I error arises from post-hoc modifications and re-specification of a model (Tabachnick & Fidell, 2012). In order to account for inflated Type 1 error, narrower cut-points were used to identify good fit within the model, and regression coefficients significant at only the .05 level were interpreted with caution. Multiple squared correlations ($R^2$) were assessed to test the hypothesis and explain the relative contribution of Behavior Problems onto Parenting Stress and the loading of Parenting Stress onto first-order stressor predictors.
This value can also be conceptualized as the coefficient of determination, or the proportion of variability in the statistic that is accounted for by the model. For the Behavior Problem predicting Parenting Stress full model, the exact fit test indicator suggested that the structural model fit the sample data ($\chi^2 = 4036.20$, $df = 147$, $p < .001$) once the final model had been established. Goodness-of-fit indexes ($CFI = .93$, $RMSEA = .050$) also indicated that the structural model fit the sample data. Consistent with the hypothesized model, Parenting stress is properly explained as a second-order model with four first-order factors: Personal stressors ($R^2 = .57$), Financial stressors ($R^2 = .40$), Insurance stressors ($R^2 = .78$), and Service provider stressors ($R^2 = .94$). Behavior Problems as a latent factor is properly explained by the variance associated with a doctor of health care provider ever having confirmed that the child has behavior problems (“Ever behavior problems”; $\beta = .91$) and severity of current behavior problems (“Behavior severity”; $\beta = .92$). Since the error of “Current behavior problems” demonstrated initial negative variance and was therefore constrained to .001, its regression coefficient could not be estimated ($\beta = 1.00$). Overall, behavior problems were found to contribute to parenting stress ($R^2 = .20$).
Figure 2: Final Model; $\chi^2 = 4036.20$ (147), $p < .001$, CFI = .93, RMSEA = .050 (90% Confidence Interval = .049 - .052)
**Multigroup Analyses of Age**

These analyses tested whether age moderated the relationships in the model using early childhood ($n = 1,916$), middle childhood ($n = 4,383$), and late childhood ($n = 4,091$) as moderating variables. Bias corrected confidence intervals were created using a Monte-Carlo bootstrap approach with 500 resamples. The structural model was consistent with the original measurement model. Results showed that early childhood significantly moderated behavior problems predicting parenting stress, while no significant differences were found between middle and childhood in moderating effects. Late childhood was an insignificant predictor or parenting stress. Overall, severity of parenting stress appeared to be highest when behavior problems were moderated by early age ($R^2 = .44$). The late childhood group experienced substantially lower levels of stress (See Table 7).

**Table 7: Standardized regression estimates for moderation of levels of age**

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Dependent Variable</th>
<th>$R^2(\beta)$</th>
<th>SE</th>
<th>90% CI</th>
<th>$p &lt; .01$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Early Childhood</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>0.438</td>
<td>.097</td>
<td>.39 - .52</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>(.659)</td>
<td>.575</td>
<td>.507 - 2.71</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>(.472)</td>
<td>.095</td>
<td>.107 - .553</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Insurance Stressors</td>
<td>(.295)</td>
<td>.088</td>
<td>.010 - .406</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>(.271)</td>
<td>.053</td>
<td>.200 - .336</td>
<td>**</td>
</tr>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>.062</td>
<td>.029</td>
<td>.019 - .116</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>(.409)</td>
<td>.039</td>
<td>.335 - .466</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>(.207)</td>
<td>.045</td>
<td>.130 - .280</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Insurance Stressors</td>
<td>(.645)</td>
<td>.042</td>
<td>.571 - .715</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>(.664)</td>
<td>.011</td>
<td>.647 - .685</td>
<td>**</td>
</tr>
</tbody>
</table>

SE = bootstrap estimate of standard error; *significant at $p < .05$ (two-tailed)  
** significant at $p < .01$ (two-tailed)  

Continued
Table 7: Standardized regression estimates for moderation of levels of age

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Dependent Variable</th>
<th>$R^2$ ($\beta$)</th>
<th>SE</th>
<th>90% CI</th>
<th>$p &lt; .01$</th>
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<tbody>
<tr>
<td><strong>Late Childhood</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>.043</td>
<td>.028</td>
<td>-.003 - .09</td>
<td></td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>(.249)</td>
<td>.039</td>
<td>.190 - .312</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>(.151)</td>
<td>.043</td>
<td>.078 - .221</td>
<td>**</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Insurance Stressors</td>
<td>(.002)</td>
<td>.024</td>
<td>.000 - .012</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>(.783)</td>
<td>.007</td>
<td>.773 - .796</td>
<td>**</td>
</tr>
</tbody>
</table>

SE = bootstrap estimate of standard error; *significant at $p < .05$ (two-tailed)  
** significant at $p < .01$ (two-tailed)

**Multigroup Analyses of Diagnosis**

The moderating effect of child diagnosis was explored within the context of the behavior problems – parenting stress relationship. Since a high percentage of children were reported to have multiple developmental disabilities, analyses were run comparing model fit statistics and regression estimates between children with an ASD ($n = 4,023$) versus no ASD ($n = 6,367$), children with intellectual disability ($n = 2,491$) versus no intellectual disability ($n = 7,899$), and children with developmental delay ($n = 8,894$) versus no developmental delay ($n = 1,496$). Moderation was tested using the same procedure as with the age group analyses, using GLS estimations and bias-corrected confidence intervals from a Monte-Carlo bootstrap approach with 500 resamples. Results showed that diagnoses of ASD and intellectual disability were not significantly different in moderating the prediction of parenting stress from child behavior problems. Significant differences were found between having an ASD diagnosis versus non-ASD developmental disability diagnosis including developmental delay, and having an intellectual disability diagnosis versus non-intellectual disability diagnosis on the...
prediction of parenting stress. This suggests that behavior problems of children with a diagnosis of either ASD or intellectual disability were more likely to predict parenting stress than behavior problems of children with developmental disability diagnoses other than ASD or intellectual disability. This finding is supported by insignificant differences in the predictive strength between a diagnosis of developmental delay and not having a diagnosis of developmental delay in moderating parenting stress. These findings suggest that a diagnosis of an ASD or intellectual disability in combination with behavior problems contributes to parenting stress above and beyond the diagnoses of undifferentiated developmental delay (See Table 7).

Table 8: Standardized regression estimates for moderation of diagnoses

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Dependent Variable</th>
<th>$R^2$ ($\beta$)</th>
<th>SE</th>
<th>90% CI</th>
<th>$p &lt; .01$</th>
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<tbody>
<tr>
<td><strong>ASD</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>.252 (.526)</td>
<td>.002</td>
<td>.003</td>
<td>.208 - .311 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>(.452)</td>
<td>.004</td>
<td>.003</td>
<td>.391 - .52 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>(.443)</td>
<td>.003</td>
<td>.003</td>
<td>.368 - .526 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Insurance Stressors</td>
<td>(.242)</td>
<td>.003</td>
<td>.003</td>
<td>.193 - .291 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>(.479)</td>
<td>.004</td>
<td>.004</td>
<td>.417 - .53 *</td>
</tr>
<tr>
<td><strong>No ASD</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>.083 (.266)</td>
<td>.003</td>
<td>.003</td>
<td>.056 - .112 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>(.326)</td>
<td>.004</td>
<td>.004</td>
<td>.298 - .35 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>(.229)</td>
<td>.002</td>
<td>.002</td>
<td>.193 - .271 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Insurance Stressors</td>
<td>(.732)</td>
<td>.004</td>
<td>.004</td>
<td>.705 - .758 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>(.806)</td>
<td>.004</td>
<td>.004</td>
<td>.796 - .815 *</td>
</tr>
<tr>
<td><strong>Intellectual Disability</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>.244 (.349)</td>
<td>.007</td>
<td>.007</td>
<td>.174 - .302 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>(.349)</td>
<td>.004</td>
<td>.004</td>
<td>.269 - .431 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>(.344)</td>
<td>.005</td>
<td>.005</td>
<td>.235 - .442 *</td>
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<tr>
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<td>Insurance Stressors</td>
<td>(.512)</td>
<td>.005</td>
<td>.005</td>
<td>.429 - .577 *</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>(.503)</td>
<td>.003</td>
<td>.003</td>
<td>.444 - .557 *</td>
</tr>
</tbody>
</table>

SE = bootstrap estimate of standard error; *significant at $p < .05$ (two-tailed)
** significant at $p < .01$ (two-tailed)
### Table 7: Standardized regression estimates for moderation of diagnoses

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Dependent Variable</th>
<th>$R^2(\beta)$</th>
<th>SE</th>
<th>90% CI</th>
<th>$p &lt; .01$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No Intellectual Disability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>.035</td>
<td>.05</td>
<td>.005 - .062</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>(.315)</td>
<td>.003</td>
<td>.288 - .345</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>(.205)</td>
<td>.003</td>
<td>.166 - .243</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Insurance Stressors</td>
<td>(.683)</td>
<td>.005</td>
<td>.657 - .706</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>(.761)</td>
<td>.004</td>
<td>.748 - .772</td>
<td>*</td>
</tr>
<tr>
<td><strong>Developmental Delay</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>.179</td>
<td>.004</td>
<td>.151 - .205</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>(.411)</td>
<td>.002</td>
<td>.379 - .446</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>(.326)</td>
<td>.002</td>
<td>.29 - .371</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Insurance Stressors</td>
<td>(.454)</td>
<td>.004</td>
<td>.422 - .484</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>(.729)</td>
<td>.005</td>
<td>.71 - .745</td>
<td>*</td>
</tr>
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<td><strong>No Developmental Delay</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>Parenting Stress</td>
<td>.151</td>
<td>.004</td>
<td>.087 - .217</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Personal Stressors</td>
<td>.226</td>
<td>.004</td>
<td>.16 - .298</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Financial Stressors</td>
<td>.22</td>
<td>.003</td>
<td>.124 - .327</td>
<td>*</td>
</tr>
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<td>Insurance Stressors</td>
<td>.749</td>
<td>.004</td>
<td>.707 - .783</td>
<td>*</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Provider Stressors</td>
<td>.682</td>
<td>.003</td>
<td>.649 - .712</td>
<td>*</td>
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</tbody>
</table>

SE = bootstrap estimate of standard error; *significant at $p < .05$ (two-tailed)
** significant at $p < .01$ (two-tailed)
Chapter 4: Discussion

This study contributes to our understanding of the nature of how behavior problems across different ages and diagnostic groups contribute to parenting stress in the developmental disability population. While structural equation modeling has been used within the separate developmental disabilities and parenting stress literatures (e.g.: Östberg & Hagekull, 2000; McManus et al., 2011), there is a paucity of studies using structural equation modeling to determine the effects of child characteristics on the relationship between developmental disabilities, co-occurring behavior problems and parenting stress. These findings support the literature, indicating that behavior problems in children with diagnoses of ASD and intellectual disability lead to significant parenting stress, above and beyond other developmental disability diagnoses such as developmental delay. Financial, insurance, and service provider stressors across almost all diagnostic and age groups were significant factors in the behavior problem – parenting stress relationship. Significant differences in contribution of health insurance and service provider stressors to parenting stress reflect the recent trends in an autism spectrum disorder diagnosis being afforded a greater range and coverage for mental and behavioral health services.

The first goal of this study was to explore the moderating effects of child characteristics on the predictive relationship between behavior problem and parenting
stress among children with developmental disabilities. A secondary goal was to test a hypothesized model of the relationship between child behavior problems and parenting stress that is representative of the developmental disability population as a whole using a nationally-representative health core indicators dataset and weighted analyses procedures. It was anticipated that parenting stress in children with developmental disabilities and behavior problems could be predicted by parent personal stressors, family financial stressors, and the child’s limited access to mental health services through two forms of care limitations: health insurance barriers and service provider barriers. A measurement and structural model were tested to confirm these hypothesized relationships. The measurement model showed good fit to the weighted sample data, showing that each of these factors adequately measured parenting stress in the developmental disability population.

Behavior problems significantly predicted parenting stress in the full sample. Stressors resulting from service provider limitations followed by insurance limitations were especially powerful contributors to parenting stress. The presence of behavior problems in children with developmental disabilities emphasizes the importance of ongoing access to behavioral supports, in order for the child to attain highest possible life outcomes and to protect family well-being. Access to behavioral supports was conceptualized in this model as either availability of mental health treatment (such as psychotherapy or behavioral interventions) or psychopharmacological treatment. Limited access to these treatment options was related to greater stressors stemming from health
insurance and provider limitations, which in turn contributed to greater parenting stress when the child demonstrates behavior problems.

Personal stressors also significantly contributed to parenting stress. Much of the literature suggests that limited free time, complexity of care giving activities, and perceived social support are significant contributors to parenting stress (Antshel & Joseph, 2006; Johnston et al., 2003; Majnemer et al., 2012; Plant & Sanders, 2007; Smith et al., 2007). Parent need for mental health treatment related to caring for the child’s needs and not receiving all needed mental health treatment were strong contributors to the personal stressors model, supporting the notion that parents of children with developmental disabilities and behavior problems are indeed at increased risk for parenting stress.

While financial stressors showed the lowest contribution to parenting stress, they were still significant in contributing to overall parenting stress. Factors relating to caring for a child with complex needs, such as a developmental disability and co-occurring behavior problems relate to difficulties affording care for the child, maintaining full-time employment, and pursuing occupational advancements as a result of the high degree of stress that results from parenting this population of children.

Effect of Age

We were interested in exploring parenting stress in late childhood because the gains made in physical strength and independence associated with the transition into adulthood may confer an increased negative impact of behavior problems on parenting
stress. For children who continue to have significant behavior problems in adolescence, we anticipated that parenting stress would increase further. We were also interested in looking at parenting stress in late childhood because this age group has received minimal attention in the literature, primarily due to the belief that, as children age, behavior problems decrease due to advancements made in coping skills (Baker et al., 2002, 2003; Hill, Degnan, Calkins, & Keane, 2006; Olson, Sameroff, Lunkenheimer, & Kerr, 2009).

Contrary to our expectations, early childhood, and not middle or late childhood, significantly moderated the prediction of parenting stress from child behavior problems in the developmental disability population. There were no significant differences in moderating effects found across middle or late childhood in predicting parenting stress. Vulnerabilities for parenting stress associated with early childhood include coping with the child’s diagnosis, implementing new strategies for supporting the child’s development, and navigating a new service system (Neece et al., 2012). This age group is especially at risk because children in early development often lack the emotional self-regulation skills to manage their own behaviors, resulting in a greater likelihood for behavior problems. It has been suggested that behavior problems decrease entering middle childhood partially because the increased structure offered in a school setting reduces opportunities for behavior problems to arise (Neece et al., 2012), which is consistent with the current results of lower parenting stress in middle childhood. Parenting stress stemming from behavior problems declines further as the child enters adolescence, suggesting that interventions should continue to focus not only on the child’s early developmental gains but also the parent’s early coping and resilience, as is
supported by previous literature (Mitchell & Hauser-Cram, 2009; Donenberg & Baker, 1993).

**Effect of Developmental Disability Diagnosis**

Diagnosis was investigated to determine whether a specific disability acted as a moderator to the behavior problems – parenting stress relationship. The specific diagnoses of autism spectrum disorders (ASD), intellectual disability, and developmental delay were compared. Analyses showed that having a diagnosis of ASD and behavior problems was significantly more predictive of parenting stress than a developmental disability diagnosis other than ASD or a diagnosis of developmental delay. Each of the four sources of parenting stress (personal, financial, health insurance, and service provider stressors) acted as significant parent stressors when ASD moderated the behavior problem – parenting stress relationship. This finding is consistent with the literature that has previously suggested that ASDs have a stronger influence on parenting stress than other developmental disabilities, such as developmental delay.

**Effect of Intellectual Disability Diagnosis**

Similarly, a diagnosis of intellectual disability in combination with behavior problems was significantly more predictive of parenting stress than not having an intellectual disability. There were, however, no significant differences between the diagnoses of ASD and intellectual disability in predicting parenting stress, suggesting that parents of children with these diagnoses experience similar levels of stress. The finding
of an intellectual disability diagnosis being predictive of parenting stress, however, is inconsistent with studies that have found severity of behavior problems predicted parenting stress regardless of level of cognitive functioning based on IQ scores (Blacher & McIntyre, 2006; Bouma & Schweitzer, 1990; Dunn et al., 2001; Estes et al., 2009; Eisenhower et al., 2005; Wulffaert, Scholte, & Van Berckelaer-Onnes, 2010).

It was anticipated that intellectual disability would show greater moderation than a diagnosis of developmental delay in predicting parenting stress; however, results showed that the moderation of intellectual disability was not significantly different from developmental delay in predicting parenting stress from child behavior problems. This finding was surprising, as developmental delay was anticipated to contribute to less parenting stress since it may reflect milder forms of impairment, such as speech or motor delay, which are typically not as impairing as a cognitive delay. One explanation is that the stress associated with parenting children with developmental delays can be multifaceted in that parents must cope with both the challenges of caring for the child’s disability as well as the ambiguity surrounding the etiology and prognosis of the child’s delays. Consequently one can anticipate that these parents are especially prone to parenting stress because their child lacks a clear diagnosis, and must therefore also be considered along with parents of children with ASD or intellectual disability as being at risk negative life outcomes.

**Impact of Support Services**

Significant differences were found in the effect of behavior problems and diagnosis type on parenting stress stemming from insurance and service provider
limitations. Concerning insurance limitations, stress was found to be higher for parents of children with a diagnosis other than ASD than for all other groups (ASD, intellectual disability, a diagnosis other than intellectual disability, developmental delay, and a diagnosis other than developmental delay). This finding is most likely reflective of the increased rate of mental health services covered for children with an ASD diagnosis, especially autistic disorder. With the growing scientific and media attention on ASDs, health insurance companies have increased their awareness and service coverage for children with a diagnosis of autistic disorder. In fact, parents often seek out an autism diagnosis for their child because access to services appears to be more readily available for this population compared to milder forms of ASD or other developmental disabilities. These findings suggest that for parents of children with ASD, limitations in supports from a health insurance plan appear to have the weakest impact on families in comparison to other groups.

A similar pattern was found across stress stemming from service provider limitations. A diagnosis of developmental delay was more predictive of parenting stress associated with service provider limitations. Many service providers, especially those with limited funding such as the public school system, provide fewer services to children with a diagnosis of developmental delay than to children with a more pervasive disability, such as an ASD. Examples of differences in services include providing a 504 plan over an individualized education plan (IEP), as 504 plans provide fewer services and supports within the school than an IEP and are typically allocated to children with less pervasive disabilities.
Strengths and Limitations

The primary strength of this study relates to the use of a large nationally-representative sample of children with developmental disabilities, as it has historically been difficult to perform research with large samples of individuals with developmental disabilities. The method of using sample weights suggests that the findings on parenting stress from this study are representative of the developmental disability population as a whole. The size of the current sample also provides greater confidence in our findings.

A secondary strength was the use of structural equation modeling to estimate the relationship between behavior problems and parenting stress as well as the moderating effects of diagnosis and age. Structural equation modeling has several advantages: 1) it allows for the measurement and testing of complex relationships between observed and latent variables, 2) it enables the estimation of relationships between factors free of measurement error as the error has been estimated and removed from the model, with only common variance remaining, and 3) well-fitting models can be used in future research to model relationships within additional populations (Tabachnick & Fidell, 2012). This study was able to identify a well-fitting model to represent the nature of parenting stress within the developmental disability population.

Several limitations should be considered when interpreting study findings. The use of a pre-existing dataset meant we lacked control over survey item wording and administration. Consequently, more precise measures of behavior problems were not possible. An interesting component of the model would have been to create a larger structural representation of behavior problems using observed variables from a behavior
assessment tool, such as the Aberrant Behavior Checklist (Aman, Singh, Stewart, & Field, 1985), Nisonger Child Behavior Rating Form (Aman et al., 1996), or Child Behavior Checklist (Achenbach & Rescorla, 2000). Future research on behavior problems should explore this relationship in order to assess how different severity and types of behavior problems, such as physical aggression, self-injurious behavior, or noncompliance, contribute to greater parenting stress.

A second limitation was the use of cross-sectional sampling. Future research would benefit from using longitudinal designs in analyzing the behavior problems – parenting stress relationship within the context of structural equation modeling. Using longitudinal data would enable the exploration of the bidirectional relationship between parenting stress and behavior problems, and could advance our understanding of how the two constructs predict one another over time. Looking at potential moderators and mediators of this transactional relationship would be especially useful in being able to identify characteristics that can protect parent well-being and in turn promote the child’s developmental outcomes.

**Conclusion**

This study was successful in further characterizing the behavior problem – parenting stress relationship within the developmental disability population. Previous studies (eg.: Neece et al., 2012) have called for the exploration of moderators and mediators of this relationship to further characterize risk and protective factors for parenting stress. Results confirmed that parenting stress associated with caring for a child
with developmental disabilities and behavior problems is most prominent in early childhood. This highlights the importance of ongoing early intervention services being provided to families of children with developmental disabilities. Results suggested that, while having an autism spectrum disorder in combination with behavior problems predicts increased parenting stress, parents of children with a diagnosis of an autism spectrum disorder appear to have some degree of a buffer against negative outcomes through increased access to services for their child through health insurance and service providers. A diagnosis of intellectual disability in combination with behavior problems was also found to contribute to significantly higher parenting stress. This illustrates the importance of providing early intervention services not only to children with autism spectrum disorders, but also to children with early signs of cognitive delays. Future research should continue to explore this relationship using structural equation modeling with longitudinal data to confirm the transactional nature of the behavior problem – parenting stress relationship and to further our understanding of the impact of developmental disabilities on the family.
References


Appendix A: Child with Special Healthcare Needs Screener
1. Does your child have a need for prescription medicine because of ANY medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer
   (1) YES    (0) NO    (6) DON’T KNOW    (7) REFUSED

2. Does your child have a need for medical care, mental health or educational services because of ANY medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer?
   (1) YES    (0) NO    (6) DON’T KNOW    (7) REFUSED

3. Does your child have a limitation in abilities because of ANY medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer?
   (1) YES    (0) NO    (6) DON’T KNOW    (7) REFUSED

4. Does your child have a need for special therapy because of ANY medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer?
   (1) YES    (0) NO    (6) DON’T KNOW    (7) REFUSED

5. Does your child have an emotional, developmental or behavioral problem lasted or is it expected to last 12 months or longer (OR a condition, need, or problem that lasts for short periods but is expected to keep coming back for 12 months or longer?)
   (1) YES    (0) NO    (6) DON’T KNOW    (7) REFUSED

*Note:* The presence of a special healthcare need was determined based on the endorsement of any one of the above items.
Appendix B: Parenting Stress Literature
<table>
<thead>
<tr>
<th>Authors</th>
<th>Sample</th>
<th>Parenting Stress Predictors</th>
</tr>
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<tbody>
<tr>
<td>Antshel &amp; Joseph, 2006</td>
<td>8 - 11 year old children with reading disorders (n = 31), nonverbal learning disorders (n = 21), and typically developing control group (n = 23), and their mothers</td>
<td>X X X</td>
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<tr>
<td>Baker, Blacher, Crnic, &amp; Edelbrock, 2002</td>
<td>Parents of 3-year-old children with behavior problems, with or out developmental delays (n = 225)</td>
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<tr>
<td>Boyd, 2002</td>
<td>Literature review on the relationship between lack of social support and stress in mothers of children with autism</td>
<td>X X</td>
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<tr>
<td>Bromley, Hare, Davison, &amp; Emerson, 2004</td>
<td>Mothers of children with ASD and behavior problems (n = 68)</td>
<td>X X</td>
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<tr>
<td>Eisenhower, Baker, &amp; Blacher, 2009</td>
<td>218 children aged 3, 4, and 5 years with and without developmental delays (n = 218)</td>
<td>X</td>
</tr>
<tr>
<td>Embregts, du Bois, &amp; Graef, 2010</td>
<td>Parent and teacher reports for children attending special education programs (n = 45)</td>
<td>X X</td>
</tr>
<tr>
<td>Authors</td>
<td>Sample</td>
<td>Parent Mental Health</td>
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<tr>
<td>Emerson, 2004</td>
<td>Meta-analysis; children with developmental disabilities</td>
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<tr>
<td>Huaqing &amp; Kaiser, 2003</td>
<td>Meta-analysis; behavior problems in children from low-income families</td>
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<tr>
<td>Hassall, Rose, &amp; McDonald, 2005</td>
<td>Mothers of children with ID (n = 46)</td>
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<tr>
<td>Johnston et al, 2003</td>
<td>Mothers with a child affected by Fragile-X syndrome (n = 75)</td>
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<tr>
<td>Spratt, Saylor, &amp; Macias, 2007</td>
<td>Children with behavior and developmental problems, LD/ADHD, neural tube defects, or intraventricular hemorrhage</td>
<td></td>
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<tr>
<td>Majnemer et al., 2012</td>
<td>Parents of school-aged children with Cerebral palsy (n = 95)</td>
<td></td>
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<tr>
<td>McGill, Papachristoforou, &amp; Cooper, 2006</td>
<td>Family carers of children with developmental disabilities and challenging behavior (n = 66)</td>
<td></td>
</tr>
<tr>
<td>Authors</td>
<td>Sample</td>
<td>Parenting Stress Predictors</td>
</tr>
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<td>---------------------------------------------------------------------------------------------</td>
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<tr>
<td>Smith, Oliver, Innocenti, 2001</td>
<td>880 families of children with developmental disabilities (n = 880)</td>
<td>Parent Mental Health X Informal Social Supports X Formal Social Supports X Financial Resources X Severity of Child disability X Difficulty of care giving tasks</td>
</tr>
<tr>
<td>Wulffaert, Scholte, Van Berckelaer-Onnes, 2010</td>
<td>Mothers of children with Angelman or PW syndrome (n = 24)</td>
<td></td>
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</tbody>
</table>
Appendix C: NS-CSHCN Items included in Model
Behavior Problem Items

1. [C3Q33] (READ IF NECESSARY: Compared to other [CSHCN_AGE]-year-old children, would you say [he/she] experiences a lot, a little, or no difficulty...) With behavior problems, such as acting-out, fighting, bullying, or arguing?

   (1) A LOT OF DIFFICULTY   (2) A LITTLE DIFFICULTY   (3) NO DIFFICULTY   (6) DON’T KNOW   (7) REFUSED

2. [K2Q34A] (READ IF NECESSARY: Has a doctor or other health care provider ever told you that [S.C.] had…) Behavioral or conduct problems, such as oppositional defiant disorder or conduct disorder?

   (1) YES   (0) NO   (6) DON’T KNOW   (7) REFUSED

HELP SCREEN: Oppositional defiant disorder is an ongoing pattern of defiant and hostile behavior that interferes with a child’s life and daily activities.

3. [K2Q34B] [IF K2Q34A IS NOT “1,” THEN SKIP TO K2Q35B] Does [S.C.] currently have behavioral or conduct problems?

   (1) YES   (0) NO [SKIP TO K2Q35B]   (6) DON’T KNOW [SKIP TO K2Q35B]   (7) REFUSED [SKIP TO K2Q35B]

4. [K2Q34C] Would you describe [his/her] behavioral or conduct problems as mild, moderate, or severe?

   (1) MILD   (2) MODERATE   (3) SEVERE   (6) DON’T KNOW   (7) REFUSED

Developmental Disability Diagnosis Items

1. [K2Q35A] (READ IF NECESSARY: Has a doctor or other health care provider ever told you that [S.C.] had…) Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder?
HELP SCREEN (K2Q35A): Children with autism have delays in language, communication, and social skills. Children with Asperger’s disorder have impaired social skills but do not have speech or language delays. They often have an intense interest in a single subject or topic. Children with pervasive developmental disorder have severe and persistent delays in language, communication, and social skills.

2. [K2Q36A] (READ IF NECESSARY: Has a doctor or other health care provider ever told you that [S.C.] had…) Any developmental delay that affects [his/her] ability to learn?

(1) YES (0) NO (6) DON’T KNOW (7) REFUSED

HELP SCREEN (K2Q36A): A child with a developmental delay does not achieve certain skills as quickly other children of the same age. A developmental delay is a major delay in motor, language, social, or thinking skills.

3. [K2Q37A] (READ IF NECESSARY: Has a doctor or other health care provider ever told you that [S.C.] had…) Intellectual disability or mental retardation?

(1) YES (0) NO (6) DON’T KNOW (7) REFUSED

HELP SCREEN [K2Q37A]: Children with intellectual disabilities or mental retardation learn and develop more slowly than a typical child.

Access to Mental Health Services Items

1. [C4Q05_6] (READ AS NECESSARY: [During the past 12 months/ Since [his/her] birth,], was there any time when [S.C.] needed…) Mental health care or counseling?

(1) YES (0) NO [SKIP TO C4Q05_7] (6) DK [SKIP TO C4Q05_7] (7) REFUSED [SKIP TO C4Q05_7]

2. [C4Q05_6A] Did [S.C.] receive all the mental health care or counseling that [he/she] needed?

(1) YES [SKIP TO C4Q05_7] (0) NO (6) DK [SKIP TO C4Q05_7] (7) REFUSED [SKIP TO C4Q05_7]

3. [C4Q05_6B] Why did [S.C.] not get all the mental health care or counseling [he/she] needed?

(1) COST WAS TOO MUCH
(2) NO INSURANCE
(3) HEALTH PLAN PROBLEM
(4) CAN’T FIND PROVIDER WHO ACCEPTS CHILD’S INSURANCE
(5) NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS
(6) NOT CONVENIENT TIMES/COULD NOT GET APPOINTMENT
(7) PROVIDER DID NOT KNOW HOW TO TREAT OR PROVIDE CARE
(8) DISSATISFACTION WITH PROVIDER
(9) DID NOT KNOW WHERE TO GO FOR TREATMENT
(10) CHILD REFUSED TO GO
(11) TREATMENT IS ONGOING
(13) NO REFERRAL
(14) LACK OF RESOURCES AT SCHOOL
(15) DID NOT GO TO APPT/NEGLECTED APPT/FORGOT APPT
(16) OTHER
(77) DON’T KNOW
(99) REFUSED

4. [C8Q01_C] Does [S.C.’s] health insurance allow (him/her) to see the health care providers [he/she] needs? Would you say never, sometimes, usually, or always?

(1) NEVER (3) USUALLY (2) SOMETIMES (4) ALWAYS
(6) DON’T KNOW (7) REFUSED

Personal Stressors Items

1. [C4Q06_3] (During the past 12 months/ Since [his/her] birth, was there any time when you or other family members needed…) Mental health care or counseling related to [S.C.’s] medical, behavioral, or other health conditions?

(1) YES (0) NO (6) DK (7) REFUSED

2. [C4Q06_3A] Did you or your family receive all the mental health care counseling that was needed?

(1) YES (0) NO (6) DK (7) REFUSED

3. [C5Q12] Does anyone help you arrange or coordinate [S.C.’s] care among the different doctors or services that [he/she] uses? READ IF NECESSARY: By “arrange or coordinate,” I mean: Is there anyone who helps you make sure that [S.C.] gets all the health care and services [he/she] needs, that health care providers share information, and that these services fit together and are paid for in a way that works for you? READ IF NECESSARY: Anyone means anyone.

(1) YES (0) NO [SKIP TO C5Q17] (6) DON’T KNOW [SKIP TO C5Q17]
(7) REFUSED [SKIP TO C5Q17]

4. [C5Q13] Does a doctor or someone in a doctor’s office provide this help arranging or coordinating [S.C.]’s care?

(1) YES [SKIP TO C5Q15]  (0) NO [SKIP TO C5Q16]  (6) DON’T KNOW [SKIP TO C5Q16]  (7) REFUSED [SKIP TO C5Q16]

5. [C5Q15] Is there anyone else who helps arrange or coordinate [S.C.]’s care?

(1) YES  (0) NO [SKIP TO C5Q17]  (6) DON’T KNOW [SKIP TO C5Q17]  (7) REFUSED [SKIP TO C5Q17]

6. [C5Q16] IF C5Q13=01 THEN DISPLAY: Is this person a parent, guardian, other family member, friend, nurse, therapist, social worker, hospital discharge planner, case manager, or someone else?

7. IF C5Q13=0,6,7 THEN DISPLAY: Who does provide help arranging or coordinating [S.C.]’s care? A parent, guardian, other family member, friend, nurse, therapist, social worker, hospital discharge planner, case manager, or someone else? [MARK ALL THAT APPLY]

(1) PARENT  (2) GUARDIAN  (3) OTHER FAMILY MEMBER
(4) FRIEND  (5) NURSE  (6) THERAPIST
(7) SOCIAL WORKER  (8) HOSPITAL DISCHARGE PLANNER
(9) CASE MANAGER  (10) SOMEONE AT CHILD’S SCHOOL
(11) SOMEONE ELSE  (7) DON’T KNOW (99) REFUSED

8. [C5Q10] Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [S.C.]’s doctors and other health care providers?

(1) VERY SATISFIED  (2) SOMEWHAT SATISFIED
(3) SOMEWHAT DISSATISFIED  (4) VERY DISSATISFIED
(5) NO COMMUNICATION NEEDED OR WANTED  (6) DON’T KNOW
(7) REFUSED

Financial Stressors Items

1. [C8Q01_B] Are the costs not covered by [S.C.]’s health insurance reasonable? Would you say never, sometimes, usually, or always?

(1) NEVER  (2) SOMETIMES  (3) USUALLY  (4) ALWAYS
2. [C9Q01] The next question is about the amount of money paid [during the past 12 months/ Since [his/her] birth] for [S.C.’s] medical care. Please do not include health insurance premiums or costs that were or will be reimbursed by insurance or another source. But do include out-of-pocket payments for all types of health-related needs such as co-payments, dental or vision care, medications, special foods, adaptive clothing, durable equipment, home modifications, and any kind of therapy. (During the past 12 months/ Since [his/her] birth), would you say that the family paid more than $500, $250-$500, less than $250, or nothing for [S.C.’s] medical care?

   (1) MORE THAN $500   (2) $250-$500   (3) LESS THAN $250
   (4) NOTHING, $0       (6) DON’T KNOW   (7) REFUSED

3. [C9Q01_A] [During the past 12 months/ Since [his/her] birth], would you say that the family paid more than $5000, $1000 to $5000, or less than $1000 for [S.C.’s] medical care?

   (1) MORE THAN $5000   (2) $1000-$5000   (3) LESS THAN $1000
   (6) DON’T KNOW        (7) REFUSED

4. [C9Q05] Have [S.C.’s] health conditions caused financial problems for your family?

   (1) YES   (0) NO   (6) DON’T KNOW   (7) REFUSED

5. [C9Q10] Have you or other family members stopped working because of [S.C.’s] health conditions?

   (1) YES   (0) NO   (6) DON’T KNOW   (7) REFUSED

6. [C9Q06] [IF C9Q10 = 1, THEN READ: Not including the family members who stopped working...] Have you or other family members cut down on the hours you work because of [S.C.’s] health conditions?

   (1) YES   (0) NO   (6) DON’T KNOW   (7) REFUSED

7. [C9Q11] Have you or other family members avoided changing jobs because of concerns about maintaining health insurance for [S.C.]?

   (1) YES   (0) NO   (6) DON’T KNOW   (7) REFUSED
Family Financial Income Questions

1. [C11Q01] What was the total combined income of your household in \textit{[FILL LAST CALENDAR YEAR]}, including income from all sources such as wages, salaries, unemployment payments, public assistance, Social Security or retirement benefits, help from relatives and so forth? Can you tell me that amount before taxes?

   \textit{RECORD INCOME} $___________________ \ (96) DON’T KNOW \ (97) REFUSED

2. [C11Q01 _ DON’T: \textit{Asked only if respondent endorsed “Don’t Know” for C11Q01}] You may not be able to give us an exact figure for your total combined household income, but was \textit{KNOW} your total household income during \textit{[FILL LAST CALENDAR YEAR]} more or less than $20,000.

   (1) MORE THAN $20,000 \ (2) $20,000 \ (3) LESS THAN $20,000 \ (6) DON’T KNOW
   (7) REFUSED

3. [C11Q01_ REFUSED: \textit{Ask only if respondent endorsed “Refused” for item C11Q01}] Income is important in analyzing the health care information we collect. For example, this information helps us to learn whether persons in one group use these medical services more or less than those in another group. Now you may not be able to give us an exact figure for your total combined household income, but was your total household income during \textit{[FILL LAST CALENDAR YEAR]} more or less than $20,000?

   (1) MORE THAN $20,000 \ (2) $20,000 \ (3) LESS THAN $20,000 \ (6) DON’T KNOW \ (7) REFUSED

4. [W9Q03] Was the total combined household income more or less than $10,000?

   (1) MORE THAN $10,000 \ (2) $10,000 \ (3) LESS THAN $10,000 \ (6) DON’T KNOW
   (7) REFUSED

5. [W9Q04] Was it more than $7,500?

   (1) YES \ (2) NO \ (6) DON’T KNOW \ (7) REFUSED

6. [W9Q05] Was it more than $15,000?

   (1) YES \ (0) NO
7. [W9Q05A] Was it more than $17,500?
   (1) YES [SKIP TO W9Q12]  (0) NO [SKIP TO W9Q12]
   (6) DON’T KNOW [SKIP TO C11Q12]  (7) REFUSED [SKIP TO C11Q12]

8. [W9Q05B] Was it more than $12,500?
   (1) YES [SKIP TO W9Q12]  (0) NO [SKIP TO W9Q12]
   (6) DON’T KNOW [SKIP TO C11Q12]  (7) REFUSED [SKIP TO C11Q12]

9. [W9Q06] (READ IF NECESSARY: Was the total combined household income) more or less than $40,000?
   (1) MORE THAN $40,000 [SKIP TO W9Q06A]  (2) $40,000 [SKIP TO C11Q12]
   (3) LESS THAN $40,000 [SKIP TO W9Q07]  (6) DON’T KNOW [SKIP TO C11Q12]
   (7) REFUSED [SKIP TO C11Q12]

10. [W9Q06A] (READ IF NECESSARY: Was the total combined household income) more or less than $60,000?
    (1) MORE THAN $60,000 [SKIP TO W9Q08]  (2) $60,000 [SKIP TO C11Q12]
     (3) LESS THAN $60,000 [SKIP TO W9Q06B]  (6) DON’T KNOW [SKIP TO C11Q12]
     (7) REFUSED [SKIP TO C11Q12]

11. [W9Q06B] (READ IF NECESSARY: Was the total combined household income) more or less than $50,000?
    (1) MORE THAN $50,000 [SKIP TO W9Q12]  (2) $50,000 [SKIP TO C11Q12]
     (3) LESS THAN $50,000 [SKIP TO W9Q06C]  (6) DON’T KNOW [SKIP TO C11Q12]
     (7) REFUSED [SKIP TO C11Q12]

    (1) YES  (0) NO  (6) DON’T KNOW  (7) REFUSED

13. [C11Q13] Is this for a disability [he/she] has?
    (1) YES  (0) NO  (6) DON’T KNOW  (7) REFUSED
14. [C11Q11] At any time during the past 12 months, even for one month, did anyone in this household receive any cash assistance from a state or county welfare program, such as [*FILL STATE NAME*]?

(1) YES (0) NO (6) DON’T KNOW (7) REFUSED