



## AN ABSTRACT OF THE THESIS OF

Meghann L. Fenn for the degree of Master of Science in Human Development and Family Studies presented on April 13, 2016.

Title: Does Disability Severity Matter? The Daily Lives of Parent Caregivers of Children with Developmental Disabilities

Abstract approved:

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Individuals with disabilities and their parents, even within specific disability diagnoses, have diverse life experiences and trajectories. The current study focuses on parents of individuals with developmental disabilities. Developmental disabilities (DD) are a diverse group of severe chronic conditions evident at birth or acquired during childhood that affect major life activities such as language, mobility, learning, self-help, and independent living; and include conditions such as Down syndrome, attention deficit hyperactive disorder (ADHD), autism spectrum disorders, and general developmental delays.

This study builds on previous literature concerning stress, caregiving, and disability by examining the daily lives, experiences, and wellbeing of parents of children with DD. The majority of health and wellbeing research being done in this area focuses on overall or global wellbeing. Comparatively little research has examined the daily lives, experiences, and wellbeing of these parents, who exist within extremely fluid contexts that change daily. Furthermore, this study also aims to

build on previous research by considering the severity of the child's disability, in order to further contextualize and understand the complex levels of influence within these parents' daily lives.

Using data from the second wave of the National Study of Daily Experiences (NSDE), the daily diary project of the National Survey of Midlife in the United States (MIDUS), this study examined these topics further by answering three specific research questions; First, to what extent does the association between daily stressors and same-day positive and negative affect differ for parents of children with and without DD? Second, to what extent does the association between daily positive events and same-day positive and negative affect differ for parents of children with and without DD? And lastly, are these associations further moderated by the severity of the child's disability?

A total of 82 participants (Mean Age = 57.4; 59% female, 96% non-Hispanic White, 79% married, Mean Education = 14 years) were identified as parents of children with DD. A sample of 82 individuals who were parents of typically developing children were identified and matched as a comparison group based on: parent gender, parent age, number of children in the household, child age, whether the target child lives with the parent, parent marital status, and parent educational attainment. Participants completed 8 nightly telephone interviews, which included assessments of their daily stressors and positive events, as well as positive and negative affect.

Results from the current study found that the daily lives of individuals with disabilities and their parents are diverse and complex. Compared to their matched

counterparts, parents of children with DD experienced significantly greater increases in negative affect associated with the experience of daily stressors. In contrast, parents of children with DD exhibited comparable increases in daily positive affect associated with the daily positive experiences. With respect to severity of disability, the longevity of the child's disability diagnosis, the number of comorbid disability diagnoses, and the number of comorbid mental health diagnoses, did selectively moderate daily experience-wellbeing associations, but not in a symmetric fashion across indicators.

Taken together, the daily experiences and daily wellbeing of parents caring for a child with a disability cannot be understood and defined merely by knowing their child's disability status. Parents of children with DD may be vulnerable because of the chronic stress context of caring for a child with a disability, and they show more reactive patterns of daily wellbeing when experiencing daily stressors, however, they also show resiliency in their daily wellbeing when experiencing daily positive events. The current study attempted to better contextualize and understand the daily lives of caregiving parents by moving beyond a binary definition of disability (yes/no a disability is present), and findings suggest that severity of disability is a complex phenomenon in need of continued empirical investigation.

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Does Disability Severity Matter? The Daily Lives of Parent Caregivers of Children  
with Developmental Disabilities

by  
Meghann L. Fenn

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I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

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Meghann L. Fenn, Author

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## Does Disability Severity Matter? The Daily Lives of Parent Caregivers of Children with Developmental Disabilities

### Chapter 1. Introduction

In the United States in 2006-2008, one out of every six children were reported as having a developmental disability (Boyle et al., 2011). Developmental disabilities are a diverse group of severe chronic conditions evident at birth or acquired during childhood that affect major life activities such as language, mobility, learning, self-help, and independent living (Boyle et al., 2011). Developmental disabilities include conditions such as Down syndrome, attention deficit hyperactive disorder (ADHD), autism spectrum disorders, and general developmental delays. For the purposes of this study, the focus will be on the parents of individuals who are growing, developing, and **aging with** disabilities (i.e., developmental disabilities), and will not include parents of children **aging into** disabilities. Given the wide age range of children in the current study (3 – 63 years old), this distinction is important because aging into a disability is more common the older an individual becomes (Kyle, 2012). From herein, unless otherwise specified, discussions of “disability” will refer specifically to individuals with “developmental disabilities”.

Parents are strongly impacted by the developmental disabilities of their children, due to the upset in expectations for their child and the additional roles they must assume (Richman, Belmont, Kim, Slavin, & Hayner, 2009). Children with disabilities often require additional time and care with respect to activities such as bathing, dressing, eating (i.e., Activities of Daily Living or ADLs), and in engaging in their school and community (i.e., Instrumental Activities of Daily Living or IADLs) (Vitaliano, Zhang, & Scanlan, 2003; Satorius et al., 2005). As a result, parents often take on additional roles such as nurse, caretaker, and advocate, resulting in increased stress due to the additional and sometimes conflicting roles they undertake in the home

(e.g., mother, wife, caretaker) (Satorius, Leff, Lopez-Ibor, Maj, & Okasha, 2005) and the workplace. The additional stress and decrease in mental and physical health experienced by parents is known as caregiving burden, and is a byproduct of the relational process in which these parents provide continuing care for their child with a disability. Caregiving is a significant source of parental stress. Compared to parents of typically developing children, the parental stress of parents of children with disabilities is greater and lasts longer as they continue to care for their child with a disability into adulthood (Richman et al., 2009; Satorius et al., 2005).

Individuals with disabilities and their parents have diverse life experiences and trajectories. Disability frequently is defined dichotomously in research (yes/no disability is present), which does not explain or account for the diversity in severity or type of disability, and for the wide array of influences it may have on the lives of the individual and their parents (Weedon, Wilson, Jones, & Bilder, 2015). In order to better contextualize disability as a complex context that affects the lives of all involved, further specification and measurement precision beyond the binary (yes/no) is needed (Weedon et al., 2015). In the past, individuals with developmental disabilities have often had severely diminished life expectancies when compared to their peers (Kyle, 2012). Children with developmental disabilities may have more than one type of disability, and have significantly higher rates of concurrent medical conditions such as epilepsy, asthma, gastro-intestinal difficulties, and recurrent ear infections, contributing to higher needs for health care (Schieve et al., 2012).

Parents of children with disabilities experience many sources of stress, including financial burden, time demands, physical care demands, behavioral monitoring, and provision of healthcare to address their children's changing needs as they grow and develop (Kreider &

Pepper, 2007; Satorius et al., 2005). These additional stressors can affect the overall health and wellbeing of parents (Hammen, 2005; Horwitz, Briggs-Gowan, Storfer-Isser, & Carter, 2007). On average, parents of children with disabilities report more chronic and daily stressors, and worse overall mental and physical wellbeing, compared to parents of typically developing children (Kreider & Pepper, 2007; Satorius et al., 2005; Hammen, 2005). Beyond affecting their overall health, previous research has also shown impacts of caregiving on the daily wellbeing of parents of children with disabilities (Barker et al., 2010; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999; Miller et al., 2002; Seltzer et al., 2009), whereby caregiving parents are more emotionally reactive to additional daily stressors (i.e., stressors other than those associated with caregiving) compared to parents of typically developing children (Barker et al., 2010; Seltzer et al., 2009). Understanding daily wellbeing in the context of caregiving and disability is important and meaningful for scientific inquiry. The lives of these parents are complex and fluid in ways such that the ebb and flow of daily experiences and demands could have considerable effect on their daily wellbeing (Miller et al., 2002; Seltzer et al., 2009; Kanner, Coyne, Schafer, & Lazarus, 1980). Disability in the context of the parent-child relationship (i.e., having and caring for a child with a disability) is a significant source of stress for parents. Understanding the daily lives of parents of children with disabilities will help contextualize and elucidate the experiential factors, such as daily uplifts and hassles, stressors and positive experiences (Almeida et al., 2005; Kanner et al., 1980) impacting their daily wellbeing.

Stress as a concept carries a negative connotation colloquially, and research often reinforces that stereotype by only focusing on individual's negative experiences. Many studies are now considering the impact of both positive and negative events and experiences on

wellbeing (Zautra, Reich, Davis, Potter, & Nicolson, 2000; Lazarus, 1980; Lazarus & Cohen, 1977). Whereas considerable research has shown negative or stressful experiences to compromise wellbeing (Almeida, Piazza, Stawski & Klein, 2010), positive experiences serve as a protective factor that shields individuals from negative wellbeing outcomes and promote positive wellbeing (Pressman & Cohen, 2005; Pressman et al., 2009). A wide range of positive and negative experiences have been shown to have significant effects on daily and overall wellbeing, including interpersonal experiences, experiences in the home or at work, and experiences that occur in an individual's social network (Almeida, Wethington, & Kessler, 2002; Seltzer et al., 2009; Nicolson, 2000; Pressman & Cohen, 2005; Pressman et al., 2009). Including a wide variety of experiences and experiential contexts is more holistic, and better captures the strengths and vulnerabilities revealed through an individual's daily experiences (Almeida, Wethington, & Kessler, 2002). By examining the impacts of both daily stressful and positive events, studies can highlight both the vulnerability and the resiliency of parents of children with developmental disabilities compared to parents of typically developing children. Similar to stress, the diagnosis of disability is often viewed as a negative life event for the individual and their parent, and is considered a risk factor that compromises overall wellbeing. In addition to the well documented negative wellbeing effects of caring for a child with a disability, parents show resiliency that directly relates to their experiences of daily positive events, which promote daily positive wellbeing, as well as protect against daily negative wellbeing (Hammen, 2005; Horwitz, Briggs-Gowan, Storfer-Isser, & Carter, 2007; Kreider & Pepper, 2007; Satorius et al., 2005).

## **Aims**

This study builds on previous stress, caregiving, and disability literatures by examining the effect of daily life experiences on the wellbeing of parents of children with disabilities. The majority of wellbeing research done in this area focuses on overall or global wellbeing outcomes. Comparatively less research has considered the extremely fluid contexts in these parents' daily lives, and examined their effect on parental daily wellbeing. In addition, rather than approaching this exclusively from a deficit perspective, this study will examine both positive and negative daily experiences and their impacts on daily positive and negative affect, gold standard measures of daily emotional wellbeing.

The current study examines the daily life of parents of individuals with disabilities by utilizing a daily diary approach. This study design allows researchers to assess within-person change over time through the collection of frequent reports from each individual (Almeida et al., 2005; Bolger, Davis, & Rafaeli, 2003). This method allows researchers to rule out external influences that are stable over time, and allows for more focus to be placed on the individuals' experiences within daily life and their effect on same-day outcomes. Within this framework, this examination of time-varying associations between experiences (e.g., daily stressors and positive events) and wellbeing is used to reflect emotional reactivity (Almeida et al., 2005; Bolger et al., 2003). Such an approach allows for more direct examination of parents' daily experience and wellbeing, whether daily experiences impact daily wellbeing, and differences associated with living within the context of disability. Additionally, this approach is consistent the daily stress process model (Almeida, 2005), considering the context of disability and disability severity as resilience/vulnerability factors for understanding daily life.



Not all individuals will be as reactive to additional daily stressors, with some reporting drastic decreases in daily wellbeing, and others reporting gradual decreases (Almeida et al., 2005). But, despite these individual differences, individuals who are exposed to chronic stress contexts, such as caring for a child with a disability, are at a greater risk for exhibiting maladaptive daily wellbeing patterns (i.e., caring for a child with a disability is viewed as a source of vulnerability). Parents exposed to chronic stress are more likely to show increased sensitivity and reactivity to each additional stressor, meaning that their daily wellbeing will change more (i.e., higher negative affect, and lower positive affect) with every stressor experienced (Almeida et al., 2005; Barker et al., 2010; Seltzer et al., 2009). In contrast, resiliency, which occurs when an individual shows adaptive wellbeing patterns when experiencing daily events, is expected to occur even among parents caring for an individual with a disability (Almeida et al., 2005; Singer, 2006; Vitaliano et al., 2013). Despite the child's disability status, which serves as a source of chronic stress and vulnerability in the parent's lives, parents are expected to show both risk and resiliency in their patterns of daily experiences and affect.

A central goal of daily experiences research is to identify resilience and vulnerability factors which moderate the impact of daily experiences on wellbeing (Almeida et al., 2005). In the context of the current study, disability severity is examined as a moderator of the impact of emotional reactivity to daily experiences. Disability severity has mostly been used to determine access to federal services (e.g., K-12 schooling and continuing support services) and possible areas for healthcare intervention, but few empirical studies of parental wellbeing consider disability severity (Weedon et al., 2015).

This study seeks to examine these topics by answering three specific research questions. First, to what extent does the association between daily stressors and same-day wellbeing (i.e., positive and negative affect) differs for parents of children with and without disabilities? Second, to what extent does the association between daily positive events and same-day wellbeing (i.e., daily positive and negative affect) differ for parents of children with and without disabilities? And lastly, are these associations further moderated by the severity of the child's disability?

## Chapter 2. Literature Review

### **Life Course Theory**

This study draws influence from two life course principles in order to explore the experiences of parents caring for individuals who are aging with disabilities. Although experiences vary between parents, there are broad themes that can be used to illustrate the life course principles of historical time and linked lives.

#### *Historical Time*

The life course of individuals is embedded in historical time, affected by social change, and bound to cohorts. Cohorts represent groups of individuals who share commonalities, including similar birth years and timing of historical events within the lifespan (Elder, Shanahan, & Jennings, 2015). Because the lives of individuals with disabilities and their families are strongly institutionalized (i.e., shaped and guided by social systems), key policy and social changes reviewed mark salient points in historical time that create cohort divides. Therefore, parents caring for individuals with disabilities living before and after these points would likely have distinctly different life trajectories, opportunities, and choices (Mannheim, 1928).

In 1964, the U.S. passed the Civil Right Act protecting individuals from discrimination based on race, religion, sex, and national origin. This law did not protect individuals from discrimination based on disability status, however. In 1965, the Voting Rights Act provided legal protections for the voting rights of minorities across the nation, and included protections for individuals with disabilities. In 1975, the Education for all Handicapped Children act was passed, which guaranteed a free public education for all children with disabilities, and forbade schools from turning children away based solely on disability status. In 1990 this act was renamed the

Individuals with Disabilities Education Act (IDEA), at which point many changes were made to fully desegregate children with disabilities, who were still being sent to separate or “special” schools. In 1990, the Americans with Disabilities Act (ADA) was passed, which extended the protections allotted in the 1964 Civil Rights Act to include adults with disabilities. IDEA was recently amended in 2004, which added components to more fully include children with disabilities in classrooms alongside their non-disabled peers.

Each piece of policy, social, or historical change that has been outlined creates cohort divides within the population of individuals with disabilities. Many of these cohort markers line up with what we would consider to be cohorts or generations within the general population (e.g., baby boomers, generation X, generation Y, millennials, etc.). But, there may be unique experiences that would be felt by parents of individuals with disabilities dependent on their child’s birth year, disability onset, and the state of policy or social climate (Mannheim, 1928; Mayer, 2004; Ryder, 1965; Schieve et al., 2012).

In addition to experiential differences, individuals from different cohorts have different life expectancies. Individuals with disabilities have always had significantly lower life expectancies when compared to their non-disabled peers (Kyle, 2012). However, older cohorts (e.g., those that reached school age before IDEA and ADA passed in 1990) had severely diminished life expectancies, and were often not expected to live beyond 40 years of age. Although there are still major inequalities present within populations with disabilities, cohorts since the passage of IDEA and ADA have life expectancies that are closer to that of their non-disabled counterparts than ever before (Schieve et al., 2012). This has created a gap in the literature. With fewer individuals with disabilities of previous generations living into adulthood,

limited research examines parents of individuals with disabilities beyond childhood. The current study attempts to fill in gaps in knowledge concerning the daily lives of parents caring for children with disabilities from early childhood through adulthood.

The caregiving demands and the burden it places on parents will differ based on whether the parent is providing care for an adult child or a child under the age of 18, due to the varied governmental supports and legislations enacted to mitigate the burden of providing care for an individual with a disability (e.g., families of children versus adults with disabilities qualify for different governmental provisions such as in-home care, education, assistive technologies, and financial support) (Kyle, 2012; Barker et al., 2010; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999; Satorius et al., 2005). Differences in caregiving demands, differences in external and governmental supports afforded, and its effect on parent's daily wellbeing, are all contingent on not only the child's age, but their cohort. Currently all children with a disability are afforded a free public education under IDEA, but older cohorts were not guaranteed the opportunity to attend school. That is, the experiences of a parent caring for a 5-year-old with Down syndrome now would be different than the experiences of a parent caring for a 5-year-old with Down syndrome prior to 1990 when IDEA passed. As previously discussed, the life course theory asserts that cohort effects, and their influence on the daily experiences and daily wellbeing of parent caregivers, is an important consideration in research (Mannheim, 1928; Mayer, 2004; Ryder, 1965; Schieve et al., 2012). Age alone does not fully control or account for cohort differences, but is often the best approximation that can be made (Mayer, 2004; Elder et al., 2015).

*Linked Lives*

As stated in Elder, Shanahan, and Jennings (2015), no person exists within a vacuum, and the experiences of individuals are shaped by the lives of those around them. In addition, the life of an individual touches and affects others' lives. This process is bidirectional and always changing as people and relationships change over time. The most evident connection and example of linked lives is that of family (Elder, Shanahan, & Jennings, 2015). For individuals with disabilities, family is a strong link that will typically last a lifetime (Kyle, 2012). Many individuals who are aging with disabilities may continue to live with their family well into adulthood. Individuals with developmental disabilities may never become fully independent, and the effects of this linkage will be stronger compared to the link between parents and typically developing children (Kyle, 2012). In addition, relationships between individuals with disabilities and their main caregivers (often their parents) are more interdependent and the trajectory of their lives move in tandem, especially in cases where disability severity affects performance of ADLs (Vitaliano et al., 2003; Satorius et al., 2005). For this reason, disability status has been considered to be an important contextual factor when studying parents and children at any age or stage.

When a child is born, all parents go through an adjustment period in order to align their lives to better support that child, and the family is redirected toward a different trajectory (Kyle, 2012). Parents will interact with and move through society in ways that they never would have before (Kreider & Pepper, 2007; Richman et al., 2009). For example, there are many programs and services that are only offered to individuals with disabilities and their families, and by

having a child with a disability, these parents' lives now address accessing services or participating in these programs.

Parents of individuals with disabilities often serve as an advocate for their child. In addition to navigating the complex social systems put in place, they are called upon to educate and advocate in schools and the community at large on behalf of their child (Richman et al., 2009). In the United States a great deal of responsibility and burden is placed on the parents of individuals with disabilities, leaving them in a state of discontinuity, and at an increased risk for negative wellbeing outcomes (Richman et al., 2009; Satorius et al., 2005; Vitaliano et al., 2003).

Parent's daily wellbeing is expected to be influenced by the child's disability status and the severity of that disability. These effects are expected due to the close interconnectedness (i.e., lined lives) seen between parents and children with a disability (Kyle, 2012), and the increased caregiving demands experienced by parents in these contexts (Vitaliano et al., 2003; Satorius et al., 2005). Among parents of children with a disability, those with more severe disabilities are expected to show even worse wellbeing outcomes (e.g., higher negative affect and lower positive affect). Despite the wealth of literature that paints disability as a solely negative context in the lives of parent caregivers, the relationship between the parent, child, and context is complex (Jennings, 2015), and parents of children with a disability, no matter how severe, are expected to show resiliency (i.e., show marked increases in positive daily wellbeing and decreases in negative daily wellbeing) when experiencing daily positive events (Kyle, 2012).

Although life course research traditionally looks at change over long periods of time, from a more comprehensive birth through death perspective and across life transitions, daily experiences and daily wellbeing are meaningful when looked at using a life course lens. There

are clear ties between daily experiences and diverse chronic contexts, and both affect an individual's wellbeing (Almeida, Neupert, Banks & Serido, 2005; Miller et al., 2002; Seltzer et al., 2009). By measuring and examining daily experiences researchers are able to make suppositions about an individual's wellbeing more accurately than if major life events were considered alone (Kanner et al., 1981). Furthermore, examining daily experiences and wellbeing transpiring within a chronic context provides unique insight into how daily life is shaped by being embedded in a particular context (e.g., disability). The current study aims to do this by examining the daily lives, experiences, and wellbeing of parents caring for a child with a disability.

### **Daily Stress and Wellbeing Among Parent Caregivers**

The chronic stress levels of parents of children with any disability is much greater than that of the greater population, with subgroups such as parents of children on the autism spectrum reporting even higher levels of chronic stress and poorer wellbeing compared to parents of children with other types of disabilities (Abbeduto et al., 2004; Blacher, & McIntyre, 2006; Eisenhower et al., 2005). Chronic stress is defined as recurring stressors that create radiating effects and is understood to moderate daily stressors (day-to-day negative events). This relationship is evident across studies of parents with stressful caregiving experiences, and has been demonstrated among parents of children with specific disorders such as autism spectrum disorders (Miller et al., 2002; Seltzer et al., 2009). Both Seltzer et al. (2009) and Miller et al. (2002) found that caregivers with higher levels of chronic stress, on average, tend to report higher numbers of daily stressors. These findings also suggest that parents of children with a disability are not only exposed to or experience more stressors, but are also more reactive to



stress (e.g., for each additional stressor they show markedly worse wellbeing) when compared to parents of typically developing children (Miller et al., 2002; Seltzer et al., 2009).

The differing levels of both chronic and daily stressors, as well as heightened stressor reactivity, experienced by parents of children with disabilities is significant and meaningful. Stress is a multifaceted entity that penetrates many aspects of an individual's life affecting both their psychological and physical health (Hammen, 2005; Horwitz, Briggs-Gowan, Storfer-Isser, & Carter, 2007). Research has extensively examined the psychological impact of parenting a child with disabilities, especially in terms of perceived burden (Satorius, Leff, Lopez-Ibor, Maj, & Okasha, 2005). Increasingly, research has focused on the physiological impact of parenting a child with a disability (Barker, Greenberg, Seltzer, & Almeida, 2011). Stress associated with caregiving also takes a toll on physical health (Vitaliano, Zhang, & Scanlan, 2003). The hormone cortisol is a biomarker of hypothalamus-pituitary-adrenal (HPA) axis activation that plays an important role in mediating the effects of stress on physical health (Sapolsky, Krey, & McEwen, 1986). Over time, repeated or chronic stress exposure can lead to persistent low levels of cortisol, which indicates repetitive and/or constant activation of the HPA axis or stress response system (Miller, Chen, & Zhou, 2007).

Non-normative cortisol patterns are linked to chronic stress, including chronic caregiving stress seen in parents of individuals with disabilities (Barker, Greenberg, Seltzer, & Almeida, 2011). Among parents of children with a disability, cortisol declined less on days when parents spent more time with that child (Seltzer et al., 2009). These heightened levels of stress create a disparity, where parents of children with disabilities are more susceptible to exhibiting non-normative cortisol patterns, such as a slower return to normal cortisol levels after the HPA axis

has been activated. Increased HPA reactivity and non-normative cortisol patterns can manifest as a detriment to both physical and emotional health, with increased rates of mental health disorders, and increased reports of physical ailments (Vitaliano, Zhang, & Scanlan, 2003). Increased stress can also disrupt traditional nocturnal HPA activation and neurochemical patterns, which results in a decreased number of hours slept, lower quality of sleep (individuals are prevented from entering the rejuvenating REM stage of sleep), and thus posing further detriments to overall wellbeing (Barker et al., 2011; Miller, Chen, & Zhao, 2007).

The physical, emotional, and psychological demands experienced by parent caregivers of children with disabilities continues as their child enters adulthood (>18 years old). Roughly 75% of children with disabilities will continue to live with their parents into adulthood, and of those that do leave the home, most will need continuing financial, emotional, and physical supports (Kreider & Pepper, 2007; Satorius et al., 2005). Providing these supports adds extra burden on parents, who as these children are entering adulthood, are themselves making the transition to middle and late adulthood (Satorius et al., 2005). This continued level of dependence well into adulthood continues to pose a threat to the emotional and physical wellbeing of the parents of these adult children with disabilities, who report more daily stressors when compared to parents of typically developing adults (Barker et al., 2010; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999).

### **Daily Positive Experiences**

Compared to daily stressors, daily positive experiences have been studied considerably less often, and less is known about the experience of daily positive events in the lives of parent

caregivers for individuals with disabilities. There is a modest literature base concerning the broader benefits of studying daily positive events.

Positive experiences are understood to serve as a protective factor that shield individuals from negative wellbeing outcomes, and they serve as a promotive factor that strengthens and fosters positive wellbeing, therefore making them an important area for empirical study (Pressman & Cohen, 2005; Pressman et al., 2009). In addition, positive and negative experiences are not mutually exclusive. An individual may report both negative and positive experiences at work, home, and interpersonally (Kanner et al., 1981). Studies that only capture daily negative experiences (e.g., stressors), are missing a large and important part of the story in those individual's daily lives. By assessing an individual's daily positive experiences and daily wellbeing, studies are able to not only discuss daily risks and vulnerability (e.g., reactivity to daily stressors), but also their daily resiliency (Hammen 2005; Horwitz, Briggs-Gowan, Storfer-Isser, & Carter, 2007; Kreider & Pepper, 2007; Satorius et al., 2005). Just as an individual's day is made up of both negative and positive experiences, an individual's wellbeing is a balance of both positive and negative (Gersten et al., 1974). By considering wellbeing promoting factors, daily positive events, and wellbeing hindering factors, daily negative events, studies are able to more accurately map the effects of daily experiences on daily wellbeing (Kanner et al., 1981; Gersten et al., 1974).

Despite the fact that disability is generally viewed as a negative context, parents of children with disabilities are still expected to experience daily positive events, and are expected to show resilient patterns of daily wellbeing through comparable reactivity to those daily positive events (Singer, 2006; Vitaliano et al., 2013).

## **Disability Severity**

Although numerous studies have shown that parents of individuals with disabilities have poorer overall wellbeing (Hammen, 2005; Horwitz et al., 2007; Barker, Breenberg, Seltzer, & Almeida, 2011; Miller, Chen, & Zhao, 2007), less is known about how severity of the child's disability affects parental wellbeing. When parents of individuals with disabilities are compared with parents whose children do not have disabilities, they report increased chronic and daily stress levels and suffer many of the negative health outcomes that can be related to stress (e.g., poorer physical health and increased incidence of mental health conditions) (Barker et al., 2011; Miller et al., 2007; Vitaliano, Zhang, & Scanlan, 2003). These effects are often attributed to the close interdependent ties (i.e., linked lives) that parents from this population form with their children (e.g., additional supports and caregiving in childhood that continues as the child enters adulthood) (Richman et al., 2009; Satorius et al., 2005; Vitaliano et al., 2003). Compromised mental and physical wellbeing outcomes have been observed in parents of children across a range of ages, from parents of young children with disabilities as well as in aging parents of adults with disabilities, with higher levels of negative wellbeing outcomes relating to the extent and duration of caregiving responsibilities (Hammen, 2005; Horwitz et al., 2007; Barker et al., 2011; Miller et al., 2007; Seltzer et al., 2012).

Disability is often not contextualized in a way that fully captures the intricacies of the influence it has on parent caregivers. Previous research has typically focused on a specific disability diagnosis (e.g., autism, Down syndrome), such as in the Miller et al. (2002) and Seltzer et al. (2009) studies, or has treated disability status as a binary (yes/no) variable, such as in the Barker et al. (2007) and the Satorius et al. (2005) studies. The current study seeks to further

contextualize these caregiving parents' lives by considering the severity of their child's disability and how severity may differentiate the daily experiences and wellbeing of parents of children with disabilities.

The focus of analysis in the current study is the parents' daily experiences and their daily emotional wellbeing (i.e., positive and negative affect) moderated by the child's disability status and its severity. The severity of that child's disability is therefore framed using linked lives, and is defined as the level of caregiving provision a parent is expected to exert in order to care for said child. Previous research has supported the inclusion and consideration of comorbid mental health conditions, comorbid disability diagnoses, and longevity of the child's disability diagnosis which have been shown to require additional care, and will be considered in the current study (Tarleton & Porter, 2012; Richman et al., 2009; Kyle 2012; Gameren-Oosterom et al., 2011; Rao & Beidel, 2009; Schieve et al., 2012).

### **Comorbid Mental Health Conditions**

The number of co-morbid disorders a child is diagnosed with has been shown to be positively correlated with increased chronic stress among parent caregivers (Richman et al., 2009). The co-morbid disorders include many physical disorders which are more common in children with a disability (Tarleton & Porter, 2012). For example, children with Down syndrome have some of the highest rates of co-morbid diagnoses such as congenital heart defects, ear infections, and early onset Alzheimer's disease (Davis, 2008).

Comorbid mental health disorders, such as depression and anxiety, are more common among individuals with disabilities, and are even more common among individuals who also have comorbid physical conditions (i.e., the presence of any comorbid disorder leads to a higher

likelihood of developing additional comorbid disorders) (Tarleton & Porter, 2012; Richman et al., 2009; Kyle, 2012).

The transition to parenthood can be stressful in itself. This transition is compounded by the stress of adjusting to having a child with a disability, and further compounded by having a child with serious physical, medical, emotional, or psychological conditions as well. On average, an increase in parental stress is associated with poorer child outcomes in all domains of development, which creates a cyclical relationship between parental stress and child outcomes (Gameren-Oosterom, 2011). Disabilities can affect many aspects of a family's life, and as the child grows older these effects can worsen or lessen depending on the severity of the disability, the severity of the co-morbid disorders, and the level of external support the family receives (Gameren-Oosterom et al., 2011; Rao & Beidel, 2009; Schieve et al., 2012).

### **Comorbid Disability Diagnoses**

Children diagnosed with multiple (i.e., comorbid) disabilities have worse overall wellbeing outcomes when compared to their non-disabled peers including shortened life expectancy and higher incidence of comorbid physical and mental conditions (e.g., heart disease, diabetes, obesity, and other chronic illnesses) (Schieve et al., 2012). By their nature, children with multiple diagnoses require additional time, and often more extensive care, due to the ways in which the disabilities manifest and interact (e.g., limited functionality in multiple domains requires parents to provide care for bathing, dressing, bathroom, etc.).

Parents of children with multiple disabilities have an overall higher rate of negative wellbeing outcomes compared to parents of children with one disability diagnosis (Hinojosa, Hinojosa, Fernandez-Baca, & Thompson, 2012). These rates are partially attributed to the

heightened level of interdependence between parents and their children with disabilities, which is greater than seen in most parent-child dyads (Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaïdan, 2013; Singer, 2006). Due to the increased risk to the child's wellbeing, children diagnosed with multiple disabilities are often considered to have a more "severe" clinical diagnosis. However, this distinction is not often used in empirical studies, and instead, often determines access to additional classroom supports in schools, or a need for early healthcare intervention by practitioners (Weedon et al., 2015).

### **Longevity of Disability diagnosis**

The current study also considers longevity of the child's disability diagnosis in years, which has been shown to be a significant indicator of caregiving burden in previous studies (Barker et al., 2011; Schieve et al., 2012; Seltzer et al., 2009; Singer 2006, Vitaliano et al., 2013). Previous studies found that providing care for a child with a disability is a significant source of chronic parental stress (Almeida et al., 2005; Singer, 2006; Vitaliano et al., 2013). Moreover, the longevity of the caregiving context created a compounding effect, whereby the effects of chronic stress were exacerbated over time (Floyd & Gallagher, 1997).

The current study furthers the discussion of disability and its effect on the daily wellbeing of parent caregivers by considering the severity of the child's disability. In alignment with the literature reviewed above, the current study uses number of comorbid mental health conditions and number of comorbid disability diagnoses (i.e., number of additional disability diagnoses above and beyond the primary developmental disability) as indicators of disability severity. In general, individuals with comorbid disability diagnoses, or those that have comorbid mental

health diagnoses, are expected to have a lower life expectancy, poorer quality of life, and therefore are considered to have a more severe prognosis (Weedon et al., 2015).

### **Current Study**

In sum, the current study builds from previous literature and uses an extant data set to examine three specific research questions.

1. To what extent does the association between daily stressors and same-day positive and negative affect differ for parents of children with and without disabilities?

Parents of children with developmental disabilities are expected to exhibit more reactive patterns when experiencing daily stressors. For parents of children with a disability each additional daily stressor was expected to result in a steeper decrease in daily positive affect and steeper increase in daily negative affect.

2. To what extent does the association between daily positive events and same-day positive and negative affect differ for parents of children with and without disabilities?

Parents of children with a developmental disability have shown resilience in past studies, and therefore it is expected they will reap similar benefits from experiences of daily positive events. Each additional daily positive event were expected to show comparable increases in daily positive affect and decreases in daily negative affect when compared to the parents of typically developing children.

3. And lastly, are these associations further moderated by the severity of the child's disability?



In reference to the third and final question, despite the fact that severity has not been used in this way, each aspect used to define severity has been shown to affect the lives of individuals with disabilities and their parents, and therefore it is expected that parents whose child has a more severe disability will show further exacerbated effects. Each additional stressor for parents of individuals with more severe disability diagnoses will be associated with even steeper declines in positive affect and increases in negative affect.

### Chapter 3. Materials and Methods

#### Participants

The data for the current study comes from the National Study of Daily Experiences (NSDE II), which is the daily diary project of the National Survey of Midlife in the United States (MIDUS II). The original MIDUS project, or MIDUS I ( $N = 7,108$ ), started in 1994, and was made up of a nationally representative sample of adults ranging in age from 25 to 74 (Brim, Ryff, & Kessler, 2004). The second wave of the study, or MIDUS II ( $N = 6,151$ ), started in 2003, at which point all participants were asked if any of their children had a developmental or mental health condition. Information concerning specific diagnosis was also gathered. Of those involved in MIDUS II 10.5% ( $n = 646$ ) reported having a child who had a developmental or mental health condition. Of those; 46.3% ( $n = 299$ ) reported having a child with a developmental condition, 42.7% ( $n = 276$ ) reported having a child with a mental health problem, and 11% ( $n = 71$ ) reported having a child with another type of neurological disability.

Of the 299 parents that reported having a child with a developmental condition, 82 participated in both the MIDUS II and NSDE II, and were selected as the focus for the current study. The child's parent provided disability diagnosis. Reported diagnoses included attention deficit hyperactivity disorder (15.9%), bipolar disorder (12.2%), schizophrenia (9.8%), depression (7.3%), Down syndrome (6.1%), and others (48.7%). In families where there was more than one child with a disability, the oldest child was designated as the focus for the current study, and all diary questions were posed in regard to the parent's relationship with that child.

A matched comparison group of equal size is also included in the analysis. The comparison group ( $n = 82$ ) was also selected using participants in the NSDE II (See Figure 1). In

order to qualify, participants needed to be a parent of a typically developing child (i.e., no disability or chronic health diagnosis indicated), and could not serve as a caregiver for another family member during the time of the study. Parents in the comparison group were matched to parents in the target group based on: parent gender, parent age, number of children in the household, child age, whether the target child lives with the parent, parent marital status, and parent educational attainment, which have all been shown to influence measures of daily experiences and affect (see Almeida et al., 2005).

As shown in Table 1, the target and comparison groups are highly similar. They show similarities in parental age, gender, race, marital status, employment status, years of education, income, and number of children. For both groups, the average age of the target child (oldest child) was 29, with 60% of the target children being sons in both groups. Statistical tests, t-tests for continuous variables and chi-square tests for categorical variables, were run. With the exception of household income, the final groups were equivalent in all areas. To adjust for differences in income, it was included as a covariate in the models.

## **Procedure**

Participants in the NSDE ( $n = 806$ ) completed eight consecutive nightly telephone interviews, which included questions about their daily experiences. The current study will focus on questions concerning number of daily stressors, number of daily positive events, and daily measures of positive and negative affect (Almeida et al., 2002).

## **Measures**

All measures were included in nightly telephone interviews for eight consecutive days, and all questions were posed asking about experiences “in the last 24 hours”.

### *Daily Stressors*

Daily stressors were assessed through the Daily Inventory of Stressful Events (Almeida et al., 2002). The inventory consists of questions asking whether certain types of events had occurred in the past 24 hours (e.g., arguments, avoided arguments, work stressors, home stressors; See Appendix 1). An individual's experience for each type of stressor was coded as a 1 or 0 (1 = *yes, this type of stressor was experienced*; 0 = *no*), and stressors were summed to determine the total number of stressors per day (see Table 2).

### *Daily Positive Events*

Similar to stressful events, parents reported positive events that occurred in the previous 24 hours (e.g., a particularly positive interaction with somebody, a positive interaction at work/volunteering/home, a positive event that occurred for a close friend or relative, or anything else that was particularly positive; See Appendix 1). The positive events were summed to determine number of positive events per day (see Table 2).

### *Daily Affect*

The negative affect scale (14 items based on PANAS; See Appendix 2) measured daily negative emotional wellbeing (e.g., How much of the time today did you feel angry?) (Watson et al., 1988). The positive affect scale (13 items; See Appendix 2) measured daily positive emotional wellbeing (e.g., How much of the time today did you feel satisfied?) (Watson et al., 1988). Each day, participants indicated how frequently they felt each emotion over the past 24 hours on a 5-point Likert-type scale from *none of the time* to *all of the time*. The averages of all items were calculated daily to determine their daily scores on positive and negative affect, respectively (see Table 2).

### *Disability Severity*

Disability severity was assessed using three variables: number of comorbid disability diagnoses (0-2), number of comorbid mental health conditions (0-2), and longevity of the child's disability diagnosis in years (0-55 years) (see Table 2). All three measures were collected as part of the MIDUS II, and were contingency questions asked after parents identified their child's primary disability. Comorbid conditions were collected as a parent identified count (i.e., no specific diagnoses were identified), and longevity of disability diagnosis is the age at which the child was first diagnosed with the primary disability subtracted from their current age.

### **Analyses**

All data were analyzed in Stata 13 (Stata Corp., 2013) using multilevel models with time-varying predictors to adequately account for the dependent and nested structure of the data (days nested within individuals; Hoffman & Stawski, 2009). In relation to the first research question, a parent's daily affect (either positive or negative), on day  $d$  for individual  $i$ , was modeled as a function of the number of daily stressors that individual experienced on the same day, and the child's disability status (1 = *yes*; 0 = *no*).

$$Daily\ Affect_{di} = b_{0i} + b_{1i}(Number\ of\ Daily\ Stressors_{di}) + e_{di} \quad (1)$$

$$b_{0i} = \beta_{00} + \beta_{01}(Child's\ Disability\ Status_i) + \beta_{02}(Parent's\ Stressor\ Mean_i) \quad (2)$$

$$b_{1i} = \beta_{10} + \beta_{11}(Child's\ Disability\ Status_i) \quad (3)$$

The above equations are an example of how the first research question was modeled. Equation 1 models level 1 effects, and equations 2 and 3 are modeling level 2 effects. In the first equation,  $b_{0i}$  represents the mean affect for an individual on a day when no stressors are reported, and  $b_{1i}$  represents the change in affect with each additional daily stressor (i.e.,

emotional reactivity). In the second equation,  $\beta_{00}$  represents the average level of affect for parents of typically developing children on non-stressor days, and  $\beta_{01}$  represents the difference in affect on non-stressor days between parents of children with and without a disability. In the third equation,  $\beta_{10}$  represents the sample average effect for number of stressors, and  $\beta_{11}$  allows emotional reactivity to vary as a function of the child's disability status. This model was estimated separately with negative and positive daily affect as outcomes. In addition, the second research question was modeled in the same way, exchanging number daily stressors for daily positive events. Models measuring daily positive events also considered daily positive and negative affect as outcomes.

The third and final research question examined only parents of individuals with disabilities, and used each of the three measures of disability severity.

$$\text{Daily Affect}_{di} = b_{0i} + b_{1i}(\text{Number of Daily Stressors}_{di}) + e_{di} \quad (4)$$

$$b_{0i} = \beta_{00} + \beta_{01}(\text{Disability Severity}_i) + \beta_{02}(\text{Parent's Stressor Mean}_i) \quad (5)$$

$$\square_{1i} = \beta_{10} + \beta_{11}(\text{Disability Severity}_i) \quad (6)$$

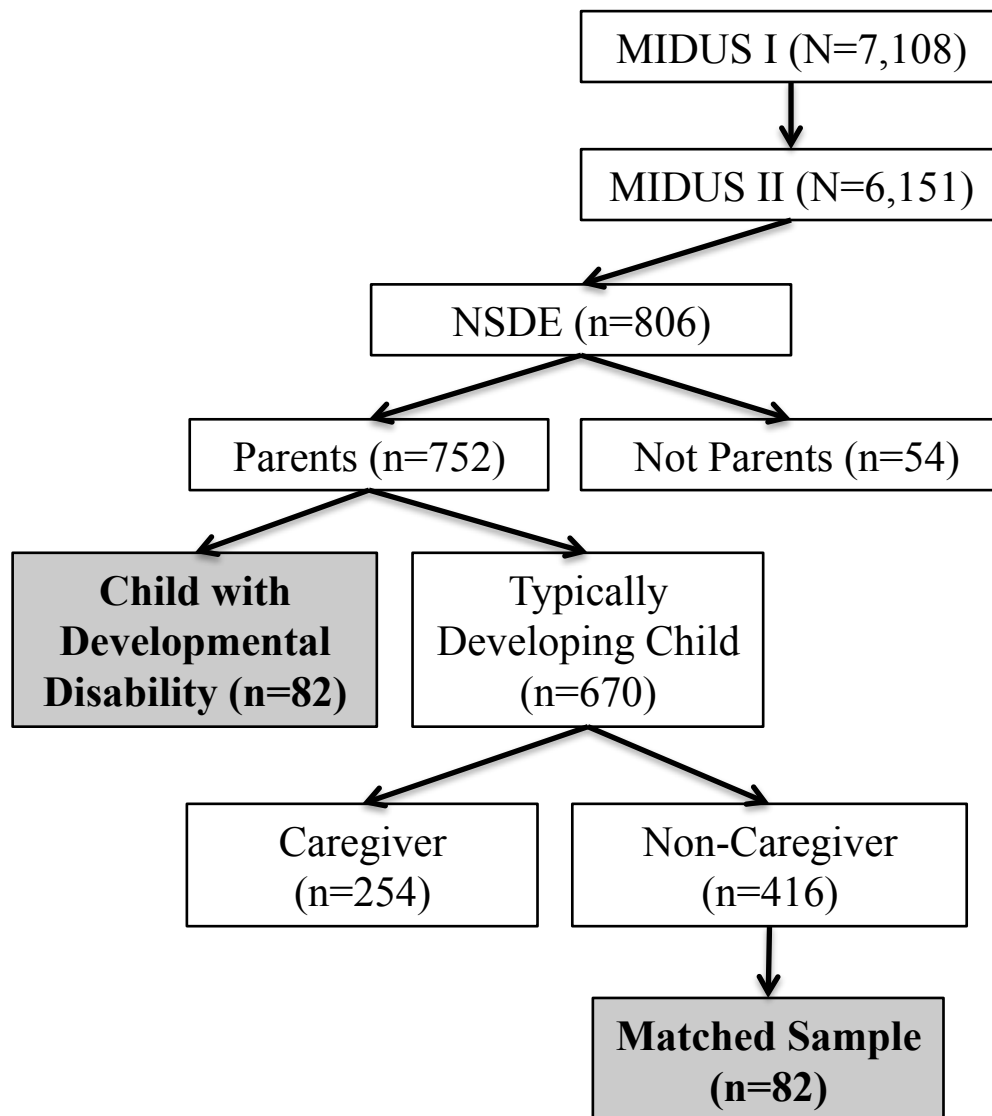
The above equations are an example of how the third research question was modeled. Equation 4 models level 1 effects, and equations 5 and 6 are modeling level 2 effects. In the fourth equation,  $b_{0i}$  represents the mean affect for all parents of children with a disability on a day when no stressors are reported, and  $b_{1i}$  represents the change in affect seen with each additional daily stressor (i.e., emotional reactivity). In the fifth equation,  $\beta_{00}$  represents the average level of affect for parents of children with a less severe disability on non-stressor days, and  $\beta_{01}$  represents the difference in affect on non-stressor days for parents of children with more versus less severe disabilities. In the third equation,  $\beta_{10}$  represents the sample average effect of

stressors, and  $\beta_{11}$  allows emotional reactivity to vary as a function of the severity of the child's disability.

To test disability severity, we estimated 4 models at each step outlined below, predicting the associations between daily positive (negative) events and daily positive (negative) affect. First, individual models were run with all factors of severity separately (i.e., models of daily positive (negative) daily experiences predicting daily positive (negative) affect were run separately to test longevity of disability diagnosis, comorbid disability diagnoses, and comorbid mental health diagnoses as moderators) Second, all models were re-estimated and included covariates of parent's marital status, education, age, gender, number of children in the household, child age, and whether the child lives with their parent or independently. Third, pooled analyses were run with all severity factors simultaneously in the 4 models. Finally, the 4 pooled models were rerun with all covariates included. The covariates are controlled for by the matched sampling in analyses of research question 1 and 2, but have been shown to impact daily experiences and daily wellbeing in previous studies, so are being statistically accounted for when modeling research question 3 (see Almeida et al., 2005).

Figure 1

*Target and matched sample selection criteria*



*Note.* Non-Caregivers ( $n = 416$ ) were compared to and matched with the target sample (parents of adult children with developmental disabilities) based on parent gender, parent age, number of children in the household, child age, whether the target child lives with the parent, parent marital status, and parent educational attainment in order to select the 82 participants in the final matched sample.



Table 1

*Descriptive statistics for parents of children with disabilities and a matched comparison Sample of parents of typically developing children*

Variables	Parents of children with disabilities	Comparison group
<b>Parent's Characteristics</b>		
Age	57.4 years ( $SD = 13$ )	57.4 years ( $SD = 13.1$ )
Female	59%	59%
Non-Hispanic white	96 %	97%
Married	79%	84%
Employed	57%	61%
Years of education	14.4 years ( $SD = 2.65$ )	14.5 years ( $SD = 2.35$ )
Total household income	\$74,400 ( $SD = \$49,800$ )	\$78,300 ( $SD = \$50,100$ )
Number of children	3.29 ( $SD=1.91$ )	3.21 ( $SD = 1.26$ )
<b>Child's Characteristics</b>		
Age	29.3 years ( $SD = 13.4$ )	29.9 years ( $SD = 13.4$ )
Female	40%	40%
Living with parents	41%	32%

*Note.* Statistical tests, t-tests for continuous variables, chi-square tests for categorical variables were run, and with the exception of household income, target and comparison groups are equitable ( $n = 82$  for both groups).

Table 2

*Descriptive statistics for daily experiences, daily wellbeing, and variables used to define disability severity*

Variables	Mean	SD	Range	
<b>Daily Experiences and Wellbeing (n = 164)</b>				
Negative affect	.170	.258	0	2.357
Positive affect	2.677	.791	.308	4
Positive events	1.058 events	.628	0	4
Stressors	.614 stressors	.522	0	3.714
<b>Disability Severity (n = 82)</b>				
Longevity of disability diagnosis	18.479 years	13.574	0	55
Number of comorbid disability diagnoses	1.8 diagnoses	.4	0	2
Number of comorbid mental health conditions	1.429 conditions	.496	0	2

*Note.* Positive affect and negative affect are the average scores on affect for an individual across all 8 days. Positive events and stressors are the average number of each that an individual reported across all 8 days. SD indicates standard deviation of a given mean estimate.

## Chapter 4. Results

Results directly relating to the study hypotheses from all models will be reported. To see results pertaining to model covariates, see corresponding tables for all models herein (Table 3 – Table 8). Models pertaining to research questions 1 and 2 compared parents of children with and without a developmental disability ( $n = 164$ ), and models pertaining to research question 3 were tested examining only parents of children with a disability ( $n = 82$ ).

### **Research Question 1: Effects of Daily Stressors and Child Disability Status on Daily Negative and Positive Affect**

To address research question 1, a multilevel model was run to predict associations between number of daily stressors and daily negative affect moderated by the child's disability status (see top portion of Table 3). In the model, each additional stressor an individual reported was significantly associated with a .094 increase in negative affect ( $p < .001$ ). Negative affect is higher on days when parents report more stressors, and negative affect is higher for parents who report more stressors on average. The child's disability status was non-significantly related to the effect of stressors on daily negative affect ( $p = .660$ ), but the disability by number of stressors interaction was marginally significant ( $p = .057$ ). Among parents who had a child with a disability, each additional stressor was on average associated with a .029 increase in negative affect when compared to parents of a typically developing child (see top left of Figure 2).

An analogous model was run to predict associations between number of daily stressors and daily positive affect moderated by the child's disability status (see top portion of Table 4). In the model, each additional stressor an individual reported was significantly associated with a .065 decrease in positive affect ( $p < .01$ ). Positive affect is lower on days when parents report

more stressors, and positive affect is lower for parents who report more stressors on average. The binary indicator of child's disability status and the disability by stressor interaction were both non-significant with  $p$ 's equal to .268 and .285, respectively. Having a child with a disability was non-significantly associated with a .115 decrease in positive affect, and among parents who had a child with a disability, each additional stressor was on average associated with a .035 decrease in positive affect when compared to parents of a typically developing child (see top right of Figure 2).

### **Research Question 2: Effects of Daily Positive Experiences and Child Disability Status on Daily Negative and Positive Affect**

A multilevel model was estimated to assess the associations between number of daily positive events and daily negative affect moderated by the child's disability status (see bottom portion of Table 3). All the relationships were non-significant. In the model, each additional positive event was associated with a non-significant .008 decrease in negative affect. Having a child with a disability was associated with higher negative affect, but this difference was not significant, .031 ( $p = .292$ ). Furthermore, the disability status by positive event interaction was not significant, .022 ( $p = .144$ ) (see bottom right of Figure 2).

An analogous model was run to assess the associations between number of daily positive events and daily positive affect moderated by the child's disability status (see bottom portion of Table 4). In the model, each additional positive event was significantly associated with a .062 increase in positive affect ( $p < .01$ ). On days when parents reported a positive event they saw increases in positive affect, but parents who reported more positive events on average had similar daily positive affect compared to other parents. The child's disability status and the disability by

positive event interaction (see bottom left of Figure 2) were non-significant, and were both associated with an average decrease in positive affect by .197 ( $p = .075$ ) and .024 ( $p = .412$ ), respectively.

### **Research Question 3: Effect of Daily Experiences and Disability Severity on Daily Negative and Positive Affect**

To test disability severity, there were 4 models estimated at each step outlined below, predicting the associations between daily positive (negative) events and daily positive (negative) affect. First, individual models were run with all factors of severity separately (i.e., models of daily positive (negative) daily experiences predicting daily positive (negative) affect were run separately to test longevity of disability diagnosis, comorbid disability diagnoses, and comorbid mental health diagnoses as moderators). Second, all models were re-estimated and included covariates (i.e., parent's marital status, education, age, gender, number of children in the household, child age, and whether the child lives with their parent or independently). Third, pooled analyses were run with all severity factors simultaneously in the 4 models. Finally, the 4 pooled models were rerun with all covariates included. There were no differences between the pooled and individual models run, so the 4 pooled analyses with covariates were used to answer research question 3.

First, a multilevel model was run to predict associations between number of daily stressors and daily negative affect moderated by the severity factors (see Table 5). In the model, each additional stressor an individual reported was significantly associated with a .215 increase in negative affect ( $p < .05$ ). Negative affect was higher on days that parents reported more stressors, but parents with higher mean stressors had similar daily negative affect compared to

other parents. The longevity of the child's disability status was significant ( $p < .01$ ), but the longevity by stressor interaction was not ( $p = .344$ ). A 1-year increase in longevity of diagnosis was associated with a .023 decrease in negative affect on average. Similarly, the number of comorbid mental health diagnoses was significant ( $p < .05$ ), but did not significantly interact with number of stressors to predict daily negative affect ( $p = .715$ ). On average, each additional comorbid mental health diagnosis was associated with a daily negative affect increase of .226. In contrast, the main effect of number of comorbid disability diagnoses and interaction with number of stressors was not significant ( $p$ 's  $> .15$ ).

Second, models to predict associations between number of daily positive events and daily negative affect moderated by the severity factors (see Table 6) indicated that each additional positive event an individual reported was significantly associated with a .394 decrease in negative affect ( $p < .001$ ). Daily negative affect was lower on days when parents reported positive events, and parents that had more mean positive events tended to report lower negative affect. The longevity of the child's disability status was significant ( $p < .01$ ), but the longevity by positive event interaction was not ( $p = .443$ ). A 1-year increase in longevity of diagnosis was associated with a .024 decrease in daily negative affect. The number of comorbid disability diagnoses was not significant ( $p = .110$ ), but the interaction with number of positive events was ( $p < .001$ ). For each additional disability diagnosis, a parent was less reactive to daily positive events and their daily negative affect decreased by .168 on average (see Figure 3). The number of comorbid mental health diagnoses and the positive event interaction were both non-significant with  $p$ 's of .751 and .105, respectively.

Third, models to predict associations between number of daily stressors and daily positive affect moderated by the severity factors (see Table 7) determined that each additional stressor an individual reported was significantly associated with a .745 decrease in positive affect ( $p < .001$ ). Positive affect decreased on days when parents reported daily stressors, but parents who reported more versus less daily stressors on average had comparable daily positive affect. The longevity of the child's disability status and the longevity by stressor interaction were non-significant with  $p$ 's equal to .064 and .263, respectively. The number of disability diagnoses was non-significant ( $p = .08$ ), but its interaction with number of stressors was significant ( $p < .01$ ). On average, each additional disability diagnosis was associated with a positive affect decrease of .473, and for each additional disability diagnosis the child has, the impact of each stressor was reduced by .208 (see Figure 4). The number of comorbid mental health diagnoses and the stressor interaction were both significant ( $p$ 's  $< .05$ ). On average, each additional comorbid mental health diagnosis was associated with a negative affect decrease of .728, and for each additional mental health diagnosis the child has, the impact of each stressor on negative affect was reduced by .171 (see Figure 5).

Finally, a model was run to predict associations between number of daily positive events and daily positive affect moderated by the severity factors (see Table 8). In the model, each additional positive event an individual reported was significantly associated with a .751 increase in positive affect ( $p < .001$ ). The person mean of positive events was not significant ( $p < .596$ ). The longevity of the child's disability status and the longevity by positive event interaction were significant ( $p < .05$  and .001, respectively). A 1-year increase in longevity of diagnosis was associated with a .048 increase in positive affect. For each additional year a child has a disability,

each additional positive event is associated with a .006 decrease in positive affect on average (see Figure 6). The number of comorbid disability diagnoses was not significant ( $p = .696$ ), while the positive event interaction was significantly associated with daily positive affect ( $p < .01$ ). For each additional comorbid disability diagnosis, the positive effect of each positive event was reduced by .228 (see Figure 7). The number of comorbid mental health diagnoses was non-significant ( $p = .263$ ), but the interaction with positive events was significant ( $p < .01$ ). For each additional mental health diagnosis, the positive effect of each positive event was reduced by .158 (see Figure 8).



Table 3

*Multilevel model results assessing research question 1; parent's daily negative affect predicted by daily stressors (top) and daily positive events (bottom) moderated by child's disability status*

Variables	Coefficient	SE	p
<b>Daily Negative Affect</b>			
Intercept	.066	.021	<.01
Number of Stressors	.094	.012	<.001
Person-Mean of # of Stressors	.049	.024	<.05
Disability Status	.010	.024	.660
Disability Status x # of Stressors	.029	.015	.057
Income	3.22e-09	2.94e-09	.274
Income x # of Stressors	7.7e-10	2.63e-09	.770
<b>Daily Negative Affect</b>			
Intercept	.114	.029	<.001
Number of Positive Events	-.008	.011	.488
Person-Mean # of Positive Events	.036	.022	.101
Disability Status	.031	.023	.292
Disability Status x # of Positive Events	.022	.015	.144
Income	3.09e-09	3.60e-09	.392
Income x # of Positive Events	-1.43e-09	1.69e-09	.398

*Note.* SE indicates standard error of a given coefficient. (n=164)

Table 4

*Multilevel model results assessing research question 2; parent's daily positive affect predicted by daily stressors (top) and daily positive events (bottom) moderated by child's disability status*

Variables	Coefficient	SE	p
<b>Daily Positive Affect</b>			
Intercept	2.974	.091	<.001
Number of Stressors	-.065	.024	<.01
Person Mean # of Stressors	-.358	.101	<.001
Disability Status	-.115	.104	.268
Disability x # of Stressors	-.035	.032	.285
Income	2.13e-08	1.23e-08	.083
Income x # of Stressors	-1.02e-08	1.69e-09	.059
<b>Daily Positive Affect</b>			
Intercept	2.641	.117	<.001
Number of Positive Events	.062	.022	<.01
Person Mean # of Positive Events	.042	.086	.625
Disability Status	-.197	.111	.075
Disability Status x # Positive Events	-.024	.029	.412
Income	2.14e-08	1.31e-08	.103
Income x # of Positive Events	-2.06e-10	3.24e-09	.949

*Note.* SE indicates standard error of a given coefficient. (n = 164)

Table 5

*Multilevel model results assessing research question 3; parent's daily negative affect predicted by daily stressors moderated by child's disability severity*

Variables	Coefficient	SE	p
Intercept	.014	.578	.210
Number of Stressors	.215	.100	<.05
Person Mean # of Stressors	.165	.180	.359
Longevity of Disability	-.023	.009	<.01
Longevity of Disability x # of Stressors	-.001	.001	.344
Comorbid Disability Diagnoses (DD)	.146	.110	.186
Comorbid DD x # of Stressors	-.052	.036	.149
Comorbid Mental Health (MH)	.226	.105	<.05
Comorbid MH x # of Stressors	-.013	.035	.715
Coresidency	-.170	.104	.103
Married	-.166	.124	.182
Education	-.010	.016	.541
Parent Age	.013	.012	.276
Child Age	.013	.008	.117
Number of Children in Household	-.093	.048	.051
Parent Gender	-.147	.079	.063

*Note.* SE indicates standard error of a given coefficient. (n = 82)

Table 6

*Multilevel model results assessing research question 3; parent's daily negative affect predicted by daily positive experiences moderated by child's disability severity*

Variables	Coefficient	SE	p
Intercept	1.191	.542	.578
Number of Positive Events	-.394	.090	<.001
Person Mean # of Positive Events	-.157	.076	<.05
Longevity of Disability	-.024	.008	<.01
Longevity of Disability x # of Positive Events	.001	.001	.443
Comorbid Disability Diagnoses (DD)	-.148	.092	.110
Comorbid DD x # of Positive Events	.168	.034	<.001
Comorbid Mental Health (MH)	-.034	.107	.751
Comorbid MH x # of Positive Events	.046	.028	.105
Coresidency	-.162	.095	.088
Married	-.079	.114	.486
Education	-.002	.012	.894
Parent Age	.036	.010	<.001
Child Age	-.006	.009	.499
Number of Children in Household	-.109	.041	<.01
Parent Gender	-.132	.071	.064

*Note.* SE indicates standard error of a given coefficient. (n = 82)

Table 7

*Multilevel model results assessing research question 3; parent's daily positive affect predicted by daily stressors moderated by child's disability severity*

Variables	Coefficient	SE	<i>p</i>
Intercept	3.935	1.424	<.001
Number of Stressors	-.745	.211	<.001
Person Mean # of Stressors	.011	.444	.979
Longevity of Disability	.040	.022	.064
Longevity of Disability x # of Stressors	.002	.002	.263
Comorbid Disability Diagnoses (DD)	-.473	.271	.080
Comorbid DD x # of Stressors	.208	.076	<.01
Comorbid Mental Health (MH)	-.728	.258	<.01
Comorbid MH x # of Stressors	.171	.074	<.05
Coresidency	1.075	.257	<.001
Married	.075	.306	.807
Education	.082	.038	<.05
Parent Age	-.063	.029	<.05
Child Age	-.001	.020	.955
Number of Children in Household	.468	.117	<.001
Parent Gender	.187	.195	.338

*Note.* SE indicates standard error of a given coefficient. (n = 82)

Table 8

*Multilevel model results assessing research question 3; parent's daily positive affect predicted by daily positive events moderated by child's disability severity*

Variables	Coefficient	SE	<i>p</i>
Intercept	2.315	1.368	<.01
Number of Positive Events	.751	.186	<.001
Person Mean # of Positive Events	.102	.192	.596
Longevity of Disability	.048	.021	<.05
Longevity of Disability x # of Positive Events	-.006	.002	<.001
Comorbid Disability Diagnoses (DD)	-.088	.225	.696
Comorbid DD x # of Positive Events	-.228	.070	<.01
Comorbid Mental Health (MH)	-.296	.265	.263
Comorbid MH x # of Positive Events	-.158	.058	<.01
Coresidency	1.024	.240	<.001
Married	.022	.290	.940
Education	.076	.031	<.05
Parent Age	-.083	.026	<.01
Child Age	.018	.023	.442
Number of Children in Household	.476	.103	<.001
Parent Gender	.214	.181	.237

*Note.* SE indicates standard error of a given coefficient. (n = 82)

Figure 2

*Effects of daily experiences on daily wellbeing moderated by child's developmental disability (DD) status (n=164)*

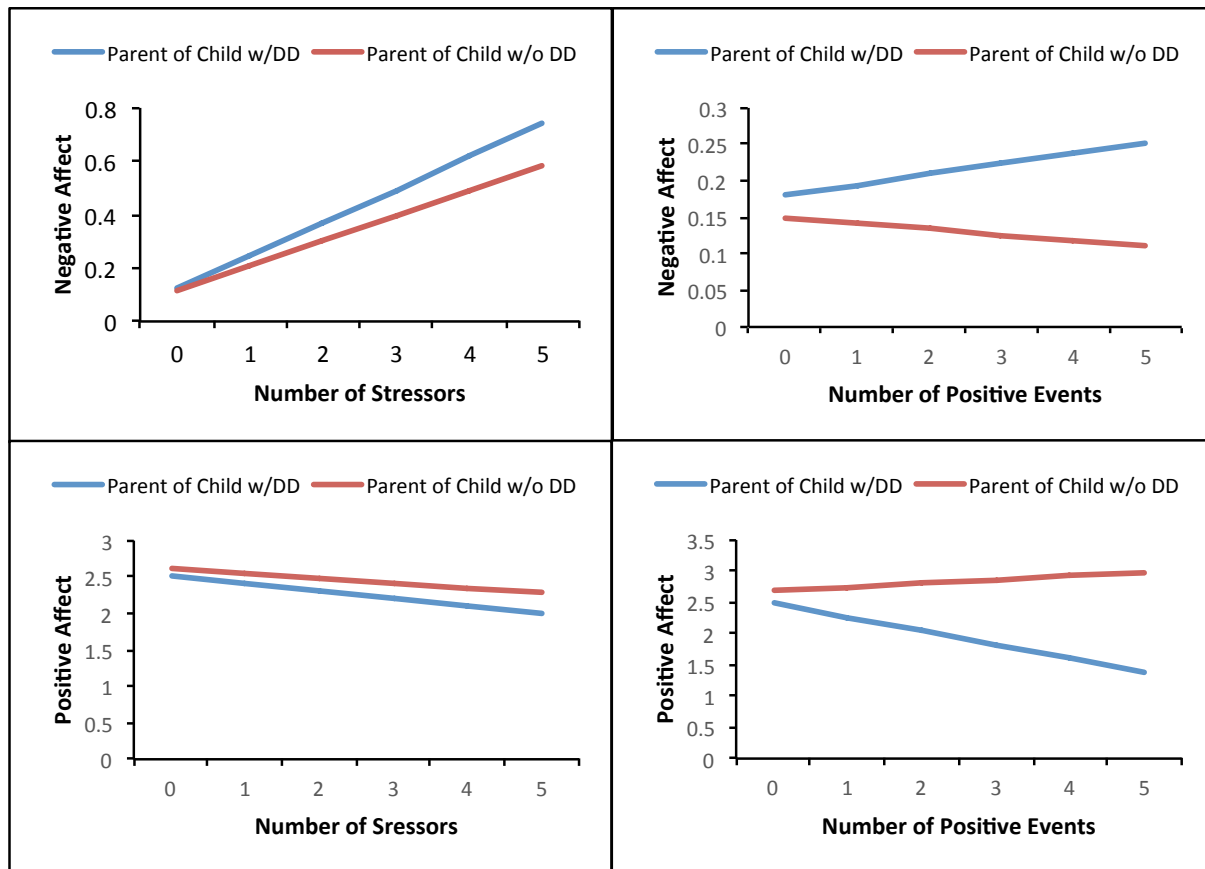


Figure 3

*Effect of positive events on parent's daily negative affect moderated by one additional comorbid disability diagnosis (DD) (n=82)*

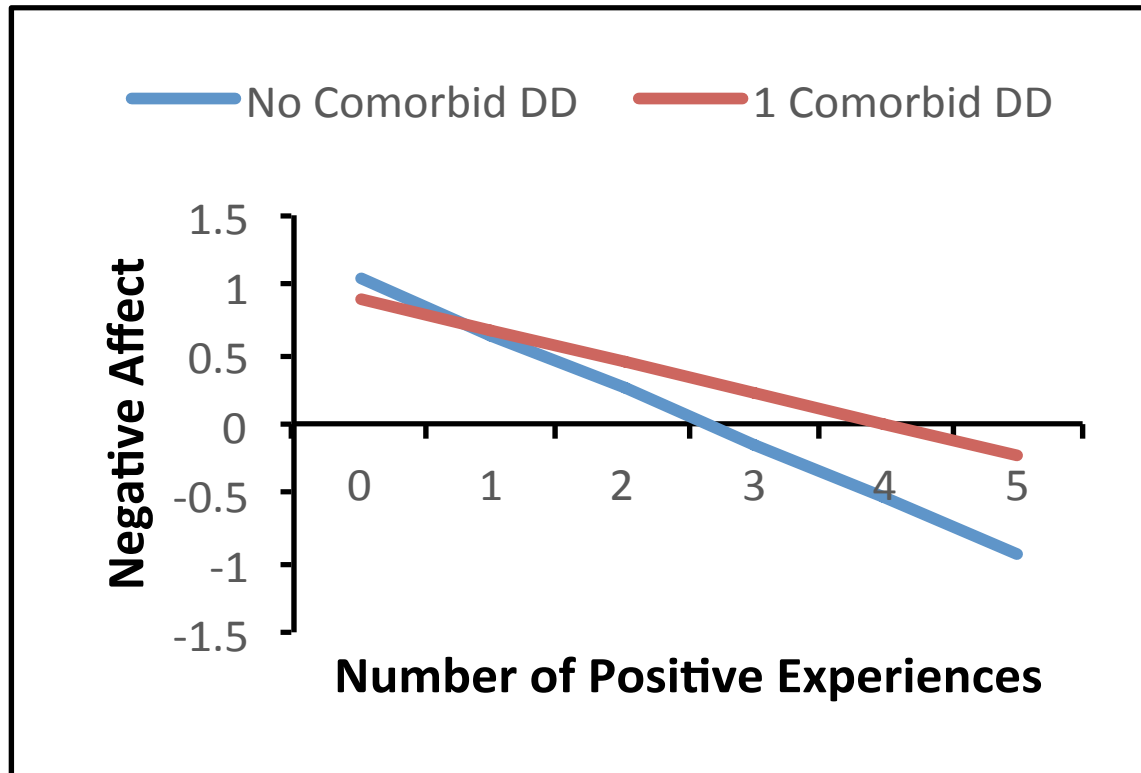




Figure 4

*Effect of stressors on parent's daily positive affect moderated by one additional comorbid disability diagnosis (DD) (n=82)*

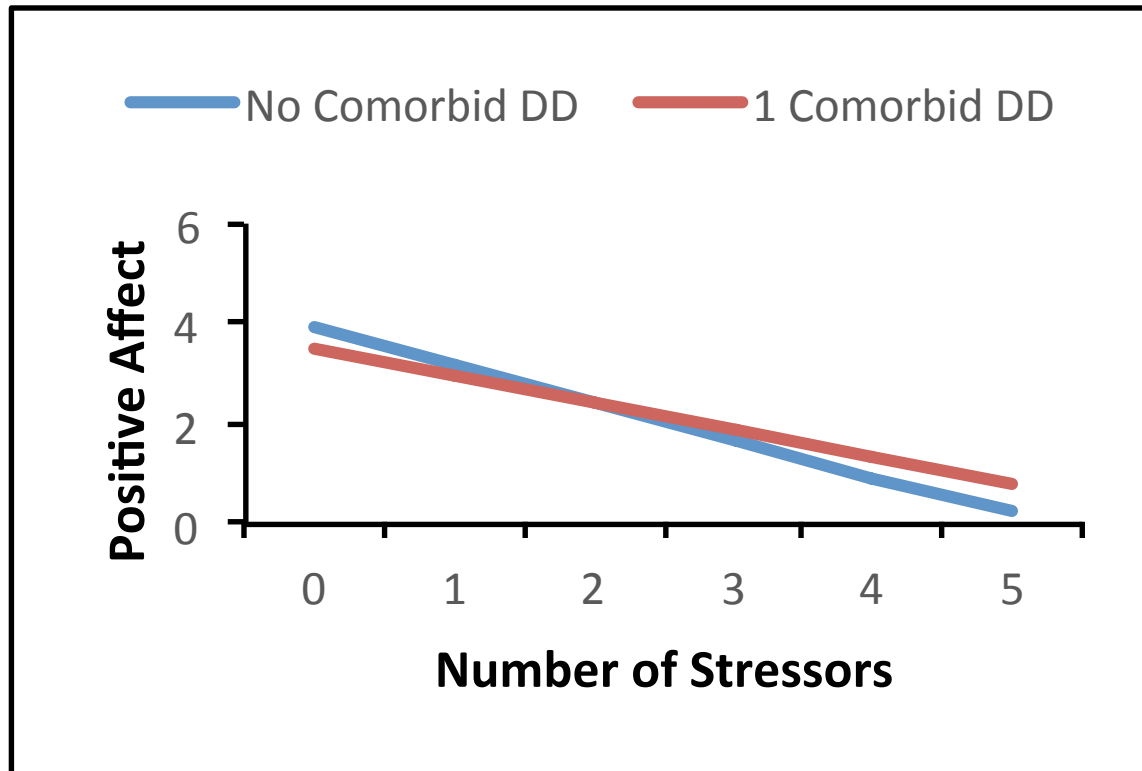


Figure 5

*Effect of stressors on parent's daily positive affect moderated by one additional comorbid mental health (MH) condition (n=82)*

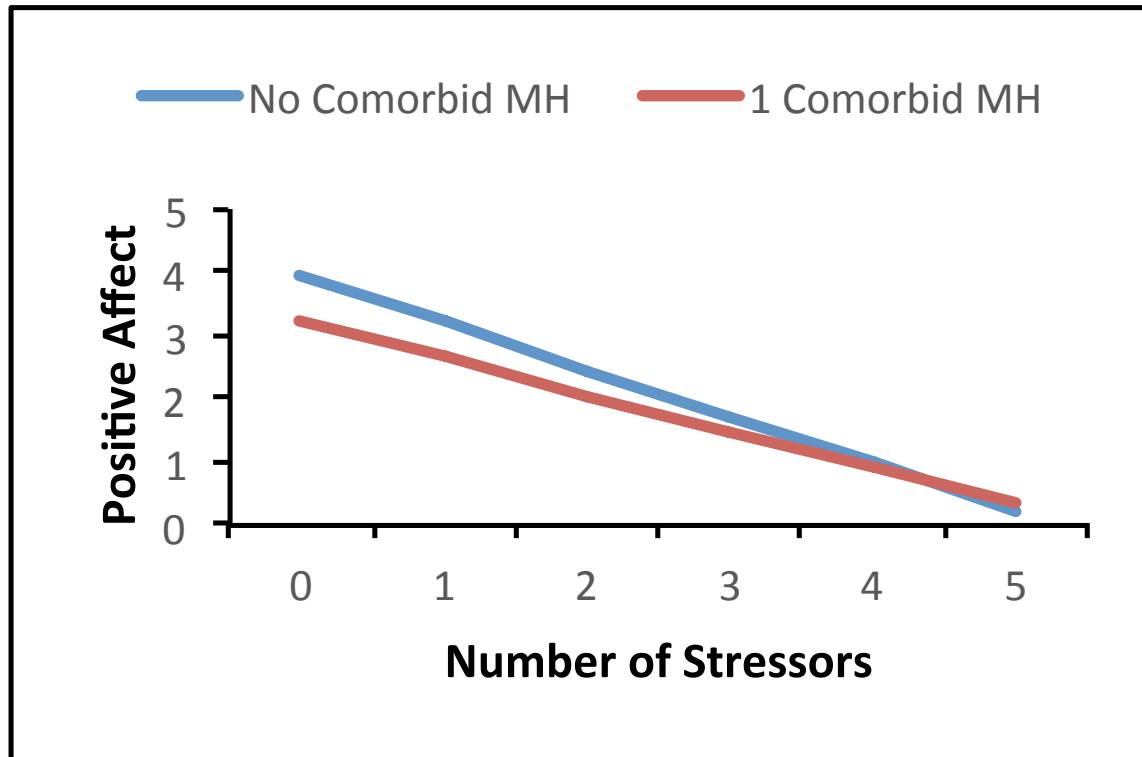


Figure 6

*Effect of positive experiences on parent's daily positive affect moderated by the child's disability diagnosis (DD) having a longevity of ten additional year (n=82)*

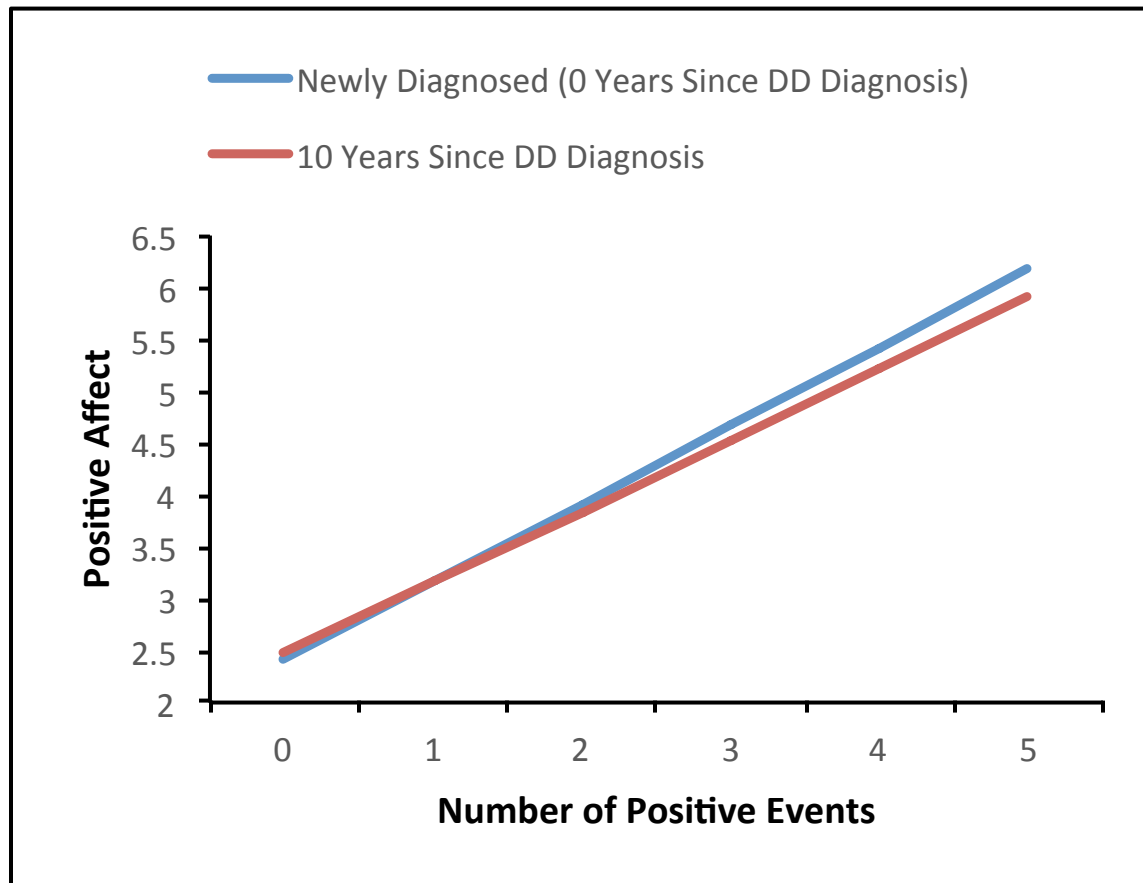


Figure 7

*Effect of positive experiences on parent's daily positive affect moderated by one additional comorbid disability diagnosis (DD) (n=82)*

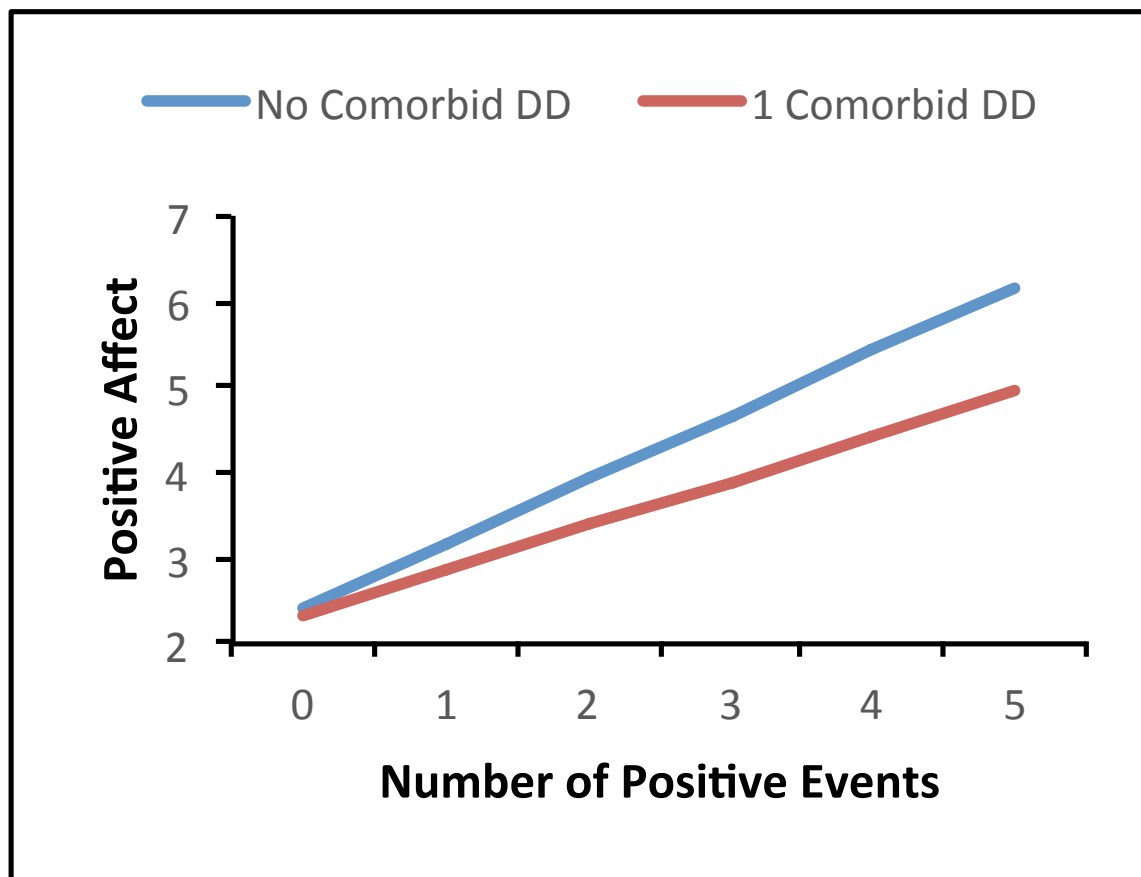
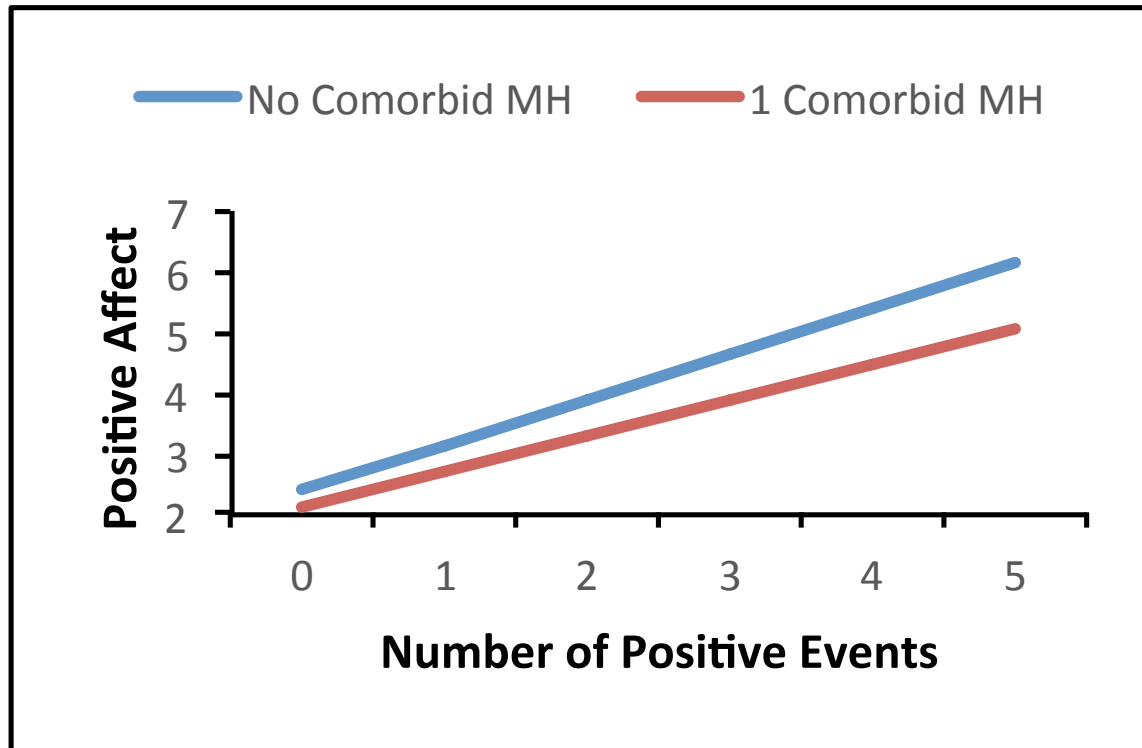


Figure 8

*Effect of positive experiences on parent's daily positive affect moderated by one additional comorbid mental health (MH) condition (n=82)*



## Chapter 5. Discussion

The lives of parents and their children are linked, and this is especially true among parents caring for a child with a disability, which complicates and strengthens the tie between the parent's and child's life course (Elder et al., 2015; Kyle, 2012, Mayer, 2004;). By examining aspects of the child, such as their disability status and its severity, we can better contextualize the chronic contexts in which these parents find themselves, and examine how those moderate their daily experiences and affect (Almeida et al., 2005; Miller et al., 2002; Seltzer et al., 2009). Overall, the current study's hypotheses were partially supported. Results of research questions one and two, which pertained to the context of disability moderating the effect of daily stressors and positive events on daily positive and negative affect, were consistent with previous research and the hypotheses made in the current study. Results of research question three, which examined whether all model results were further moderated by the severity of the child's disability, were complex and mixed, and warrant some discussion to differentiate what they may indicate.

### **Research Question 1: Effects of Daily Stressors and Child Disability Status on Daily Negative and Positive Affect**

As expected, experiencing increased numbers of daily stressors was associated with an increase in daily negative affect, and this effect was slightly greater for parents of children with a developmental disability. The impact of daily stressors on positive affect, however, did not differ by child disability status. The effects seen in the models of research question 1 partially support the hypotheses, with disability status significantly exacerbating the effect of daily stressors on daily negative affect, but not daily positive affect. This is consistent with research pertaining to

parent caregivers. Parents who provide care for a child with a disability have been shown to have higher levels of chronic stress, report higher numbers of daily stressors, and have worse overall and daily wellbeing (Miller et al., 2002; Seltzer et al., 2009).

Parents of children with disabilities show increased reactivity, likely due to the caregiver burden placed on them. Parents of children with a disability are fulfilling many roles (e.g., parent, spouse, employee, etc.), and in addition are serving multiple roles in service to their child (e.g., caregiver, nurse, etc.) (Richman et al., 2009; Satorius et al., 2005). Sometimes these roles are conflicting, and the compounding of responsibilities leads to a chronic stress context often referred to as caregiver burden (Satorius, Leff, Lopez-Ibor, Maj, & Okasha, 2005). In addition, parents heightened reactivity may be due to a threshold effect (i.e., the chronic stress in their lives is already so high that additional stressors are more burdensome), whereby caring for a child with a disability is in itself stressful, and therefore a disruption of daily patterns through introduction of new stressors poses a more tangible threat to their emotional wellbeing.

Although daily negative events differentially impact the negative affect of parents providing care for a child with a disability, their daily positive affect does not decrease significantly more compared to other parents. This suggests some stability in their lives, and that while their child's disability status may be traditionally viewed as a negative context or source of caregiving burden, these parents' positive emotionality is maintained. This is meaningful because, positive and negative affect are not two sides of a coin, and reflect distinct dimensions of emotional wellbeing (Watson, Clark & Tellegen, 1988).

## **Research Question 2: Effects of Daily Positive Experiences and Child Disability Status on Daily Negative and Positive Affect**

Daily positive events were associated with increases in daily positive affect, and decreases in daily negative affect. Parents caring for children with developmental disabilities not only experience positive events on a daily basis, but also exhibit daily wellbeing reactions comparable to parents of typically developing children. Findings were consistent with what was hypothesized, and parents of children with disabilities showed resilient patterns of daily wellbeing when experiencing daily positive events (i.e., they appear able to reap comparable daily wellbeing benefits of daily positive experiences).

Positive experiences serve as a protective factor that shield individuals from negative wellbeing outcomes, and they serve as a promotive factor that strengthens and fosters positive wellbeing, which is consistent with findings from the current and previous studies (Pressman & Cohen, 2005; Pressman et al., 2009). But, the current study takes this a step further by showing that parents of children with a disability, which is considered a source of chronic stress, still exhibit comparable promotive and protective wellbeing patterns when experiencing daily positive events. By assessing an individual's daily positive experiences and daily wellbeing, the current study is able to not only discuss daily risks and vulnerability (e.g., reactivity to daily stressors), but also daily resiliency (Hammen 2005; Horwitz, Briggs-Gowan, Storfer-Isser, & Carter, 2007; Kreider & Pepper, 2007; Satorius et al., 2005), such as that shown by parents of children with disabilities in models of daily positive events. In addition, positive and negative experiences are not mutually exclusive. And, as seen in the current study, parents of children



with and without disabilities may experience both negative and positive events, but their impact on daily wellbeing is not necessarily symmetric.

### **Research Question 3: Effect of Daily Experiences and Disability Severity on Daily Wellbeing**

For research question 3, disability severity was assessed among the population of parent caregivers who had a child with a disability ( $n = 82$ ). The pattern of results, pertaining to the associations between daily positive and negative events predicting daily positive and negative affect, were similar to those seen in research question 1 and 2 (see Table 5 – Table 8). We were especially interested in examining the addition of three factors that represent disability severity: longevity of disability diagnosis, number of comorbid disability diagnoses, and number of comorbid mental health diagnoses. These were all expected to further exacerbate the effects seen in previous models through heightened reactivity and emotionality associated with daily experiences.

#### *Main Effects of Severity Indicators*

Across all models, the main effect of longevity of disability diagnosis was associated with decreases in daily negative affect and increases in positive affect. Longevity is an indicator of the number of years that the child has been diagnosed with the primary or original disability, and does not reflect when comorbid diagnoses occurred. Even so, findings seem to indicate that longer standing diagnoses promote parents' daily positive wellbeing, and protect against daily negative wellbeing. This appears counterintuitive to what is occurring with the binary indicator of disability in research questions 1 and 2. This suggests that among parents of children with a disability, those that have had more time to adjust to the chronic stress context of caring for a

child with a disability, have learned to adapt overtime, and their patterns of daily wellbeing become more “normal”, or less maladaptive as seen in research questions 1 and 2. That is, parents who are new in their experience of caring for their child with a disability are more reactive to the daily stressors as reflected in their negative affect. This is also in disagreement with previous research, which suggested longevity of the chronic caregiving context would exacerbate the wellbeing effects of chronic and daily stressors and demands (Floyd & Gallagher, 1997). Although caring for a child with a disability is seen as a source of chronic stress, the way disability as a chronic context moderates the impacts of daily stress on daily wellbeing appears to change the longer the parent has been providing care.

The number of comorbid mental health conditions a child had is associated with parent’s increased daily negative affect and decreased daily positive affect, but only in models of daily stressors. Individual differences in the frequency of daily experiences may account for the differences in the moderating effects of comorbid mental health conditions on daily positive and negative affect. In addition, mental health conditions like depression are more likely to occur if there is a genetic or familial history (Tarleton & Porter, 2012). By not accounting for the parent’s possible psychological or mental health conditions, these analyses may not indicate the effect of caring for a child with a comorbid mental health condition, but a combination of the parent’s own mental health needs in conjunction with their caregiving demands.

There were no main effects of having a child with additional or comorbid disability diagnoses. This could be due to a ceiling effect in the number of comorbid disability diagnoses reported. Parents reported between 0 and 2 comorbid diagnoses, with a mean of 1.8 diagnoses reported. The high mean indicates that most parents reported 2 comorbid diagnoses, and this lack

of variability could account for a lack of its predictive power. Taken together, all of the main effects suggest that not all indicators of severity operate in the same way, and possibly that each indicator, although important in its own respect to the models, are not related to each other in a meaningful way as previously thought.

*Severity Indicators moderating the Effects of Daily Experiences on Daily Wellbeing*

In the model predicting the effect of parents' daily stressors on daily negative affect, there were no significant moderating effects by any of the severity indicators. This is possibly due to the fact that disability, as a chronic stress context, moderates the effect of daily stressors on daily negative affect, but beyond that further distinctions are not meaningful in the current study. Essentially, having a child with a disability is a strong enough moderator that in the current sample finer distinctions among parents of children with a disability are unnecessary. But, given the heterogeneity of disability diagnoses represented, and the restricted range of comorbid conditions endorsed, these findings may not hold up and should be examined again in future studies.

In the model predicting the effect of parent's daily stressors on positive affect, both comorbid disability diagnoses and comorbid mental health diagnoses had moderating effects. But, the effects were the opposite of what was expected. Parents of children with more reported comorbidities (i.e., considered more severe), had less reactive positive affect patterns for each additional daily stressor. One explanation is that children with more severe diagnoses, those that report more comorbid disorders, may qualify for additional governmental supports and clinical programs (Weedon et al., 2015). This addition of social supports may include in-home care, additional clinical interventions to treat or prevent chronic health conditions, and increased

financial assistance through Social Security Disability, and contribute to what may be a buffering effect in the model. That is, the diminished effect of daily stressors on parent's daily positive affect is due to the additional supports that their child's comorbid diagnoses qualify them to receive.

In the model predicting the effect of parent's daily positive experiences on negative affect, the number of comorbid disability diagnoses had a moderating effect. This effect was consistent with what was predicted, and more comorbid diagnoses diminished the positive and protective impact of daily positive events on parent's daily negative affect. That is, parents who had a child with more comorbid disability diagnoses would not reap as much, if any, benefit of additional daily positive events in buffering against daily negative wellbeing (i.e., daily positive events associated with decreases in daily negative affect). This is most likely due to the additional care, added financial burden, and the specific type of care (e.g., ADLs) that parents are providing for a child with multiple disability diagnoses (Vitaliano et al., 2003; Satorius et al., 2005). These additional care needs, which often come with comorbid diagnoses, further exacerbate the chronic stress context of caring for a child with a disability by adding additional caregiving demands. In addition, although the current study did not assess the child's healthcare needs, chronic health conditions are more likely to occur among individuals with a disability, and each additional disability diagnosis increases those odds (Schieve et al., 2012). Chronic health conditions, which often accompany comorbid disability diagnoses, would add additional caregiving demands, furthering the caregiving burden, and increasing parents chronic stress levels, thus making them more reactive to additional daily stressors as seen in the model.

Interpretations of the effect of daily positive experiences on negative affect, and the moderating effect of comorbid disability diagnoses, should be done cautiously. Relatively few parents of children with a disability reported more than three positive events on a given day, and therefore estimates of daily negative affect are not entirely accurate. The restricted range of positive events reported has led to estimates of negative affect that are less than zero (see Figure 3), which are impossible and not interpretable. Therefore, these estimates should not be extrapolated beyond reports of three daily positive events.

In models of daily positive experiences predicting parents' daily positive affect, all severity factors had a moderating effect. All indicators of severity had the expected moderating effect, whereby the positive impact of positive events on daily positive affect was diminished as severity increased (i.e., more years diagnosed with a disability, more comorbid disability diagnoses, and more comorbid mental health diagnoses). This is consistent with previous research, which found that the chronic stress level of parents is positively correlated with and increases as the number of co-morbid disorders increase (Richman et al., 2009). This higher level of chronic stress, due to the number of comorbid diagnoses (both disability and mental health), would lead to more reports of daily stressors, and more reactivity to additional daily stressors. By their nature, children with multiple diagnoses require additional time, and often more extensive care, due to the ways in which the disabilities manifest and interact (e.g., limited functionality in multiple domains require parents to provide care for ADLs such as bathing, dressing, bathroom, etc.) (Hinojosa et al., 2012). The added caregiving demands, greater caregiver burden, and additional supports provided for children with comorbid disorders could lead to higher chronic

stress among parents, which could confer risk for being more emotionally reactive to additional daily stressors.

Overall, the moderating effect of the disability severity factors seem to be more associated with models that include positive events and/or positive affect. This may be due to the methodological differences in the way data was collected. Measures of negativity (i.e., daily stressors and negative affect) were collected using conventional gold-standard measures (PANAS), but positive measures were adapted and created as the antithesis of the negative measure. This assumes that positive experiences and positive affect are orthogonal to their negative counterparts, which is not proven, and may not reflect the range of an individual's true daily experiences or affect. In addition, measures of positive affect and positive experiences were asked in a way that was relative (e. g., since this time yesterday did you have an interaction that someone would consider particularly positive). These measures may be more reflective of how parents think others perceive them. Based on the way society treats and views disability as a negative context, these negative views may be exacerbated among parents who have a child with a more severe disability, and therefore their answers are partially reflective of social biases toward individuals with disabilities and their caregivers (Kreider & Pepper, 2007; Richman et al., 2009). The socially engrained bias toward disability, in tandem with the relative way the questions were posed, may have influenced parents' perception and report of daily positive experiences (i.e., they were more likely to not identify an experience as positive because someone else may not view it as positive).

## **Limitations and Future Directions**

The current study does have some limitations, including a small sample size, which hinders generalizability to other populations of parents caring for children with a disability. The small sample size also means that the number of disability diagnoses represented is relatively narrow. Developmental disabilities include a multitude of diagnoses, each of which presents its own challenges for parent caregivers, and not all of which are represented in the current study.

The wide range of ages present among the children with a disability could pose an additional threat to generalizability. Disability manifests differently, and has varied effects on parent caregivers' dependent on the age of the child, developmental stage, caregiving needs, and social situatedness in which the parent and child find themselves (Barker et al., 2010; Warfield et al., 1999). Age does not fully account for cohort differences, and as laws and regulations change over time, new cohorts of individuals and their parents will have very different social, financial, and day-to-day supports provided. Which may change how disability as a source of chronic stress moderates the effects of daily experiences on daily wellbeing. Finally, only three indicators of severity were included in analyses. Although this is an improvement on the traditional binary approach (i.e., defining disability as yes/no disability is present), additional indicators could help elucidate how disability severity functions within the daily lives of individuals with disabilities and their parents.

Additional studies need to be conducted that examine the proximal processes (i.e., processes that occur on a regular basis, daily, over and extended period of time, chronically) in the daily lives of parent caregivers and their children. Disability as a context is varied (e.g., experiential differences between and within diagnostic categories), and even the addition of

disability severity in the current study does not capture the full effect that the child's disability has on the parent's daily wellbeing. Like many contexts, disability is not static, and the demands of caring for a child with a disability may change day-to-day dependent on that child's needs. By accounting for these relational and proximal processes, future studies could illustrate how disability as a source of caregiver burden not only affects the parent's daily wellbeing, but in itself may change daily.

Covariates were included in the current models that had been shown in previous studies to moderate the relationship between daily experiences and affect (see Almeida et al., 2005). Although specific hypotheses and interpretations did not focus on the covariates, some, such as the number of children in the family, had significant moderating effects on results in the current study. Whereby, among parents of children with a disability, parents with more children reported better daily wellbeing. Inclusion of covariates provides a rigorous test of the contribution of severity to predicting experience-affect associations, independent of known social and demographic resilience/vulnerability factors. Further, the influence of these covariates can be explored in future research to determine whether they confer differential resilience/vulnerability among parents of children with disabilities.

Future studies should also consider creation of a composite score that represents overall disability severity, rather than relying on separate components. By creating a standardized severity score, differentiating and predicting between parent differences in caregiving burden and wellbeing outcomes would be easier and more accurate. In addition, a composite score would have practical applications by easing and streamlining data collection, as well as being



informative for practitioners when considering who is most at need (e.g., experiencing more risk due to having a child or being a child with a more severe disability) for healthcare interventions and preventative care measures.

## Chapter 6. Conclusion

Results from the current study found that the daily lives of parents caring for a child with a disability are diverse and complex. Compared to their matched counterparts, parents of children with developmental disabilities experienced significantly greater increases in negative affect associated with the experience of daily stressors. In contrast, parents of children with a disability exhibited comparable increases in daily positive affect associated with their daily positive experiences. With respect to severity of disability, the longevity of the child's disability diagnosis, the number of comorbid disability diagnoses, and the number of comorbid mental health diagnoses, did selectively moderate daily experience-wellbeing associations, but not in a symmetric fashion across indicators.

Taken together, the daily experiences and daily wellbeing of parents caring for a child with a disability cannot be understood and defined merely by knowing their child's disability status. Parents of children with a disability are vulnerable because of the chronic stress context of caring for a child with a disability, and they show more reactive patterns of daily wellbeing when experiencing daily stressors. However, parents of children with a disability also show patterns of resiliency in their daily wellbeing. Despite the chronic stress of caring for a child with a disability parents experience daily positive events, and reap similar benefits of daily positive experiences when compared to parents of typically developing children. Daily positive events were associated with adaptive wellbeing patterns, seen in the current study as decreased daily negative and increased daily positive affect. The current study attempted to better contextualize and understand the daily lives of caregiving parents by moving beyond a binary definition of

disability (yes/no a disability is present), and findings suggest that severity of disability is a complex phenomenon in need of continued empirical investigation.

These findings have implications for disability research and practice. Future research should continue to explore ways to better define disability, and disability severity may serve as a useful way to further contextualize the lives of caregiving parents. The current study suggests that when working with parents, clinicians should consider not only the risk the disability and its severity serves to the child's health and wellbeing, which is standard practice, but the parent's health and wellbeing as well. The current study moves beyond a deficit perspective and highlights the importance of both positive and negative experiences in the lives of parents caring for a child with a disability. Future disability policy should follow from models such as these, and work to diminish the occurrence and effects of negative experiences, but also encourage and support the effects of positive experiences. Factors used to indicate disability severity, which highlight aspects of vulnerability in the lives of the parent and child, are important areas for future policy intervention.

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## APPENDICES



## Appendix 1. Daily Stressors and Daily Positive Event Items

### *Daily Stressors Scale: 7 items*

1. “Did you have an argument or disagreement with anyone since (this time/we spoke) yesterday?”
2. “Since (this time/we spoke) yesterday, did anything happen that you could have argued about but you decided to let pass in order to avoid a disagreement?”
3. “Since (this time/we spoke) yesterday, did anything happen at work or school (other than what you already mentioned) that most people would consider stressful?”
4. “Since (this time/we spoke) yesterday, did anything happen at home (other than what you already mentioned) that most people would consider stressful?”
5. “Many people experience discrimination on the basis of such things as race, sex, or age. Did anything like this happen to you since (this time/we spoke) yesterday?”
6. “Since (this time/we spoke) yesterday, did anything happen to a close friend or relative (other than what you’ve already mentioned) that turned out to be stressful for you?”
7. “Did anything else happen to you since (this time/we spoke) yesterday that people would consider stressful?”

### *Daily Positive Events Scale: 5 items*

1. “Did you have an interaction with someone that most people would consider particularly positive (for example, sharing a good laugh with someone, or having a good conversation) since (this time/ we spoke) yesterday?”
2. “Since (this time/we spoke) yesterday, did you have an experience at (work/volunteer position) that most people would consider particularly positive?”
3. “Since (this time/we spoke) yesterday, did you have an experience at home that most people would consider particularly positive?”
4. “Since (this time/we spoke) yesterday, did anything happen to a close friend or relative (other than what you’ve already mentioned) that turned out to be particularly positive for you?”
5. “Did anything else happen to you since (this time/we spoke) yesterday that most people would consider particularly positive?”

## Appendix 2. Daily Positive and Negative Affect Scales

### *Daily Positive Affect Scale: 13 items*

(How much of the time today did you feel...)

1. “in good spirits?”
2. “cheerful?”
3. “extremely happy?”
4. “calm and peaceful?”
5. “satisfied?”
6. “full of life?”
7. “close to others?”
8. “like you belong?”
9. “enthusiastic?”
10. “attentive?”
11. “proud?”
12. “active?”
13. “confident?”

### *Daily Negative Affect Scale: 14 items*

(How much of the time today did you feel...)

1. “restless or fidgety?”
2. “nervous?”
3. “worthless?”
4. “so sad nothing cheer you up?”
5. “everything was an effort?”
6. “hopeless?”
7. “lonely?”
8. “afraid?”
9. “jittery?”
10. “irritable?”
11. “ashamed?”
12. “upset?”
13. “angry?”
14. “frustrated?”

