

Copyright

by

Natalie Raff

May 2016

PREDICTING PARENTING STRESS IN PARENTS OF ADOLESCENTS WITH
AUTISM SPECTRUM DISORDER: EXAMINING PARENT PERCEPTIONS

A Dissertation Presented to the
Faculty of the College of Education
University of Houston

In Partial Fulfillment
of the Requirements for the Degree

Doctor of Philosophy

by

Natalie Raff

May, 2016

PREDICTING PARENTING STRESS IN PARENTS OF ADOLESCENTS WITH
AUTISM SPECTRUM DISORDER: EXAMINING PARENT PERCEPTIONS

A Dissertation for the Degree
Doctor of Philosophy

by

Natalie Raff

Approved by Dissertation Committee:

Dr. Sarah S. Mire, Chairperson

Dr. Samuel McQuillin, Committee Member

Dr. Andrew Daire, Committee Member

Dr. Leslie Frankel, Committee Member

Dr. Katherine Loveland, Committee Member

Dr. Robert McPherson, Dean
College of Education

May 2016

Acknowledgement

This dissertation would not have been possible without my advisor and mentor, Dr. Sarah Mire. Your support and encouragement have been invaluable to me throughout this process. The enthusiasm and passion you have for your work is truly inspiring and has helped me to find ways to do work that is both clinically and personally meaningful. You have impacted my development as a psychologist and a professional more than you know. I feel truly lucky to be able to work with you and look forward to continued collaboration and friendship.

I would also like to acknowledge my wonderful dissertation committee: Dr. Sarah Mire, Dr. Sam McQuillin, Dr. Andrew Daire, Dr. Leslie Frankel, and Dr. Katherine Loveland. I greatly appreciate the unique expertise each of you contributed to my dissertation. As a committee, you challenged me to consider my project from many perspectives and helped me to see the potential impact of my work. I would especially like to thank Dr. Katherine Loveland. The time I spent working with you at your clinic served as inspiration for this dissertation and I have been consistently inspired by the innovative and important work you do to benefit those with Autism Spectrum Disorder and their families.

I must also thank Dr. Thomas Kubiszyn. I have so much admiration and respect for the work you did as director of our program, as well as the work you have done to better the field of school psychology. You have helped me to develop as a professional and I know that your lessons will continue to stick with me throughout my career. Most importantly, you helped me to develop confidence in myself and my skills, and for this I will be forever grateful.

To my cohort—Sarah, Allison, Christie, Brittany, Erika, and Elizabeth—I could not have asked for a better group of people to spend the past five years with. Your friendship and support means so much to me. Sarah and Allison, thank you for keeping me on track with my dissertation timeline. I can't imagine going through this process without you! Sarah, thank you for being the best cheerleader and friend and always encouraging me to celebrate each step of the process.

Most importantly, I must thank my family and friends. I feel incredibly lucky to have such wonderful people in my life. Without your love, support, and encouragement, I would not be where I am today. To my parents and grandparents—you have always had confidence in me, even when I may not have had confidence in myself and this has given me the strength to reach my highest goals. Your continued support throughout each step of this long road means everything to me.

PREDICTING PARENTING STRESS IN PARENTS OF ADOLESCENTS WITH
AUTISM SPECTRUM DISORDER: EXAMINING PARENT PERCEPTIONS

An Abstract
of a Dissertation Presented to the
Faculty of the College of Education
University of Houston

In Partial Fulfillment
of the Requirements for the degree

Doctor of Philosophy

by

Natalie Raff

May 2016

Raff, Natalie. "Predicting Parenting Stress In Parents Of Adolescents With Autism Spectrum Disorder: Examining Parent Perceptions" Unpublished Doctor of Education Dissertation, University of Houston, May 2016.

Abstract

For individuals with autism spectrum disorder (ASD), core symptoms (i.e., social communication deficits, restricted interests/repetitive behaviors) and associated emotional and behavioral problems create difficulties across areas of functioning. Moreover, while symptoms often change with age, some degree of impairment tends to persist across the lifespan. For these reasons, having a child with ASD creates unique caretaking challenges. Parents of individuals with ASD experience high levels of parenting stress at all stages of their child's life (e.g., early childhood, adolescence, adulthood). Adolescence is a challenging stage for parents of typically developing individuals, and parenting demands during adolescence are compounded when a child has ASD. Literature indicates that a variety of interrelated factors contribute to parenting stress. One theoretical model, the Double ABCX Model of Family Adjustment (McCubbin & Patterson, 1983), describes the complex interaction of factors contributing to how families adjust to stressors in their lives. In the context of parents of adolescents with ASD, this model provides a theoretical lens through which the impact of factors such as social support, coping, and cognitive appraisal of a stressor (i.e., how the impact of a stressor is defined) can be understood as they relate to parenting stress. Particularly lacking is literature examining how parents' perceptions about their child's ASD may affect their own parenting stress. This study investigated parent perceptions as predictors of parenting stress in parents of adolescents with ASD. The sample was drawn from across the U.S. and included 214 parents of adolescents (ages 12 to 19) with confirmed

ASD diagnoses. Six specific parent perceptions were examined, including perceptions about ASD (i.e., personal control over ASD, whether ASD can be controlled by treatment, the extent to which the disorder seems cyclical in nature, and how understandable the disorder seems) and parents' self-reported perceptions about available support (i.e., family-based support and social support). A multiple regression was conducted to investigate whether parent perceptions significantly predicted parenting stress. The model accounted for 43.3% of the overall variance in parenting stress; three specific types of perceptions uniquely contributed to parenting stress. Perceptions about family based support and treatment control predicted lower parenting stress, while perceptions about cyclical nature of the disorder predicted higher parenting stress. In addition, positive coping was examined as a potential moderator of the relationship between parent perceptions and parenting stress, though findings did not support a moderating effect of positive coping in this sample. Overall, results of this study helped identify several perception types (i.e., family based support, treatment control, cyclical nature of the disorder) that may contribute to the stress experienced by parents of adolescents with ASD. These results underscore the importance of understanding parents' perceptions in research and clinical work focused on these families. Findings may inform the development of cognitively focused, targeted interventions to reduce (or even prevent) stress among parents of adolescents with ASD, given that perceptions found to contribute to parenting stress in this study likely are amenable to change.

Table of Contents

| Chapter | Page |
|--|------|
| Chapter I Introduction..... | 1 |
| Chapter II Literature Review | 5 |
| Autism Spectrum Disorder (ASD) | 5 |
| The Broad Impact of ASD | 15 |
| Parenting Stress | 19 |
| ASD and Parent Coping..... | 24 |
| ASD and Social Support | 27 |
| The Double ABCX Model of Family Adaptation and ASD | 29 |
| Parent Perceptions | 32 |
| Gaps in the Current Literature | 38 |
| Aims of the Current Study | 40 |
| Chapter III Method..... | 41 |
| Recruitment | 41 |
| Participants..... | 43 |
| Measures | 44 |
| Statistical Analyses | 55 |
| Chapter IV Results | 57 |
| Primary analyses | 57 |
| Chapter V Discussion..... | 64 |
| Clinical Implications | 69 |
| Limitations | 70 |

| | |
|--|-----|
| Future Directions | 72 |
| Summary & Conclusions | 74 |
| References | 76 |
| Appendix A Participation Questionnaire | 112 |
| Appendix B Family Adjustment Measure | 116 |
| Appendix C An Adaptation of the Revised Illness Perception Questionnaire | 119 |
| Appendix D IRB Approval Letter | 123 |

List of Tables

| Table | Page |
|---|------|
| 1. Demographic Characteristics of the Study Sample..... | 93 |
| 2. Raw Score Mean, Standard Deviation and Ranges for Study Variables..... | 94 |
| 3. Parenting Stress in the Study Sample..... | 95 |
| 4. Breakdown of Responses to Parent Perceived Severity Item..... | 96 |
| 5. Correlation Matrix for Study Variables..... | 97 |
| 6. Results of Multiple Regression Predicting Parenting Stress..... | 98 |
| 7. Positive Coping as a Moderator in the Relationship Between Family Based Support and Parenting Stress..... | 99 |
| 8. Positive Coping as a Moderator in the Relationship Between Social Support and Parenting Stress..... | 100 |
| 9. Positive Coping as a Moderator in the Relationship Between Personal Control and Parenting Stress..... | 101 |
| 10. Positive Coping as a Moderator in the Relationship Between Treatment Control and Parenting Stress..... | 102 |
| 11. Positive Coping as a Moderator in the Relationship Between Illness Coherence and Parenting Stress..... | 103 |
| 12. Positive Coping as a Moderator in the Relationship Between Timeline Cyclical and Parenting Stress..... | 104 |
| 13. Examination of Positive Coping as a Moderator in the Relationship Between Family Based Support and Parenting Stress with Severity Covariate..... | 105 |
| 14. Examination of Positive Coping as a Moderator in the Relationship Between Social Support and Parenting Stress with Severity Covariate..... | 106 |
| 15. Examination of Positive Coping as a Moderator in the Relationship Between Personal Control and Parenting Stress with Severity Covariate..... | 107 |
| 16. Examination of Positive Coping as a Moderator in the Relationship Between Treatment Control and Parenting Stress with Severity Covariate..... | 108 |
| 17. Examination of Positive Coping as a Moderator in the Relationship Between Illness Coherence and Parenting Stress with Severity Covariate..... | 109 |

| | |
|--|-----|
| 18. Examination of Positive Coping as a Moderator in the Relationship Between Timeline Cyclical and Parenting Stress with Severity Covariate..... | 110 |
|--|-----|

List of Figures

| Table | Page |
|--|------|
| 1. Conceptual diagram of positive coping as a moderator in the relationship between parent perceptions and parenting stress..... | 111 |

Chapter I

Introduction

ASD is a complex neurodevelopmental disorder, as the presentation of core and associated symptoms (e.g., emotional, behavioral, medical) vary widely across individuals, but also across the life course (American Psychological Association, 2013). Individuals with ASD are often adversely affected across a variety of areas of functioning, and for the majority of individuals with ASD, impairment related to the disorder persists into adulthood (Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004). Impairments related to ASD typically have wide-ranging effects at the family level and parents are highly affected by the challenges of raising a child with ASD (Baghdadli, Pry, Michelon, & Rattaz, 2014; Morgan, 1988).

The literature clearly indicates that parents of children with ASD experience high levels of stress (Hayes & Watson, 2013), and this stress has been documented across age groups from parents of young children (e.g., Davis & Carter, 2008) to parents of adolescents and adults (e.g., Lounds, Seltzer, Greenberg, & Shattuck, 2007). Existing studies on parenting stress in families of children with ASD often examine stress in parents of children across a broad age range (e.g., childhood through adolescence; Schieve et al., 2011), parents of young children (Osborn & Reed, 2009), or parents of adolescents and adults within the same study sample (Barker et al., 2011; Lounds et al., 2007). The fewest number of studies focus specifically on the parenting stress experienced by parents of adolescents with ASD.

Adolescence can be a particularly challenging time for individuals with ASD, as well as for their parents, as challenges related to ASD are coupled with difficulties related

to normative developmental changes (Cadman et al., 2012; Cridland, Jones, Caputi, & Magee, 2014). Despite the fact that adolescence is noted as a particularly challenging time for parents of typically developing children (Pasley & Gecas, 1984), studies examining parental stress during this time in families of individuals with ASD are limited. Understanding factors that relate to parenting stress during specific developmental periods or age groups is important due to changes occurring across the life course, such as: a) parenting challenges related to specific developmental periods (e.g., school readiness, independent living skills, employment), b) potential changes in ASD symptoms and/or symptoms of comorbid disorders, and c) contextual changes related to parent or family resources (e.g., coping and social support, availability of treatments and services for ASD).

Studies have documented a variety of interrelated factors that may affect parenting stress. These include characteristics of the child (e.g., ASD severity, behavior problems), as well as characteristics of the parent (e.g., parent perceptions, mental health). Additionally, studies of parent stress and ASD often examine available resources to protect against stress, such as social support and parent coping (e.g., Zablotsky, Bradshaw, & Stuart, 2013). Social support is generally regarded as having a positive impact on parent outcomes (Bristol, 1984; Paynter, Riley, Beamish, Davies, & Milford, 2013), although the effects of parental coping may depend upon particular coping styles or methods used (Hall et al., 2012). For instance, problem-focused or more active styles of coping in families of children with disabilities may be related to better outcomes, while emotion-focused coping or disengagement may relate to poorer outcomes (Hastings et al., 2005; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008).

Parent perceptions have been investigated in a variety of studies as they relate to overall family outcomes. Many such studies have employed the framework of the Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983), a family stress model that has been applied to the family experience of caring for a child with ASD with the purpose of examining factors that may lead to positive outcomes (e.g., Bristol, 1987). Across studies examining this model in families of individuals with ASD, different constructs and measures have been used to examine parents' subjective 'appraisals' related to caring for a child with ASD, such as the positive or negative impact of raising a child with ASD, stress associated with this role, sense of self-blame, and the use of cognitive reframing (McStay, Trembath, & Dissanayake, 2014).

One particular measure of parental perceptions that arose from the context of health research and was later adapted to relate to ASD is the Revised Illness Perception Questionnaire for ASD (IPQ-RA; Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010). This measure examines parents' perceptions about their child's ASD and has been linked to parent behavior in terms of the treatment choices that parents make for their children (Al Anbar et al., 2010; Mire, Gealy, Kubiszyn, Burrige, & Goin-Kochel, 2015). However, specific ASD related perceptions from the IPQ-RA have not been investigated with regard to parent stress.

A particular challenge in studying factors related to parenting stress is that constructs such as stress, perceptions, and coping are not static—they often change across time in response to the immediate context (Lazarus & Folkman, 1984). For this reason, research examining parental stress and its' predictors among parents of young children, for example, cannot necessarily be generalized to parents of adolescents with ASD.

Though the literature shows that parenting stress among parents of individuals with ASD persists from early childhood into adulthood, less is known about parenting stress during adolescence and how parent perceptions about ASD, social support, and coping may be related to parenting stress within this group. This study aims to further examine some of the complex factors known to affect parenting stress in a sample of parents of adolescents with ASD. This study examined the extent to which parent perceptions related to ASD (e.g., perceptions about the ability to control ASD, the predictability of the disorder) and social support may contribute to parenting stress, as well as the role that coping may play in this relationship.

Consideration of factors that may contribute to parenting stress during this particular stage of life may inform the development of parenting stress interventions that are more closely tailored to meet a unique set of needs. Factors such as parent perceptions and coping relate to cognitions and behaviors, which may be malleable targets for treatment. Further, since parents of adolescents with ASD typically continue to experience stress, intervention during adolescence may help reduce parenting stress prior to adulthood.

Chapter II

Literature Review

Autism Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by two main symptom areas: social communication deficits and restrictive/repetitive behaviors, activities, or interests. ASD symptoms are often recognized early in the developmental period. Current diagnostic prevalence estimates are as high as 1 in 68 and the disorder is diagnosed in about 4.5 times as many males as females (Christensen et al., 2016). Though some symptoms may lessen across the lifespan for many individuals with ASD, the disorder is generally considered to be life long (Howlin et al., 2012).

Core ASD symptoms. While authors of the Diagnostic and Statistical Manual of Mental Disorders (4th edition; DSM-IV-TR; APA, 2000) took a categorical approach to classifying individuals with a similar set of symptoms into subtypes (e.g., autistic disorder, Asperger's disorder) under the broader category of pervasive developmental disorders (PDD), the current conceptualization of ASD within DSM-5 (APA, 2013) takes a more dimensional approach to diagnosis. This dimensional approach, informed by decades of ASD research, allows for diagnoses that capture the wide variety of presentations of the disorder. The variability across individuals with ASD relates to the presentation and quality of core ASD symptoms as well as the identification of other features that are not specific to ASD, such as comorbid symptoms or other medical conditions (Grzadzinski, Huerta, & Lord, 2013). This variability is conveyed through “specifiers” and core symptom severity levels used to convey information about core and associated symptoms, level of functioning, and symptom manifestation (APA, 2013).

Within the two broad core symptom areas (social communication and restrictive/repetitive behaviors, activities, or interests), specific difficulties and deficits can vary among individuals diagnosed with ASD, and may change across the life span. In terms of social communication and interaction, the DSM-5 states that individuals with ASD must have deficits in social-emotional reciprocity (i.e., back and forth conversation), deficits in nonverbal communication (i.e., body language and facial expressions), and deficits in forming, maintaining, and understanding relationships (APA, 2013).

Restrictive and repetitive behaviors, interests and activities may also vary greatly from person to person and may also change across the lifespan. The DSM-5 acknowledges the variety of possible symptom presentations that may fall within this category, requiring that at least two be present. These specific manifestations of restrictive and repetitive behaviors may include: repetitive movements (e.g., hand flapping), use of objects (e.g., lining up toys) or speech (e.g., echolalia); insistence on sameness or ritualized behavior; restricted interests that are abnormal in type or intensity; and sensory sensitivity (e.g., hyper- or hypo-reactivity) or an unusual interest in sensory aspects of the environment.

DSM-5 also allows for the description of symptom severity by providing a metric to describe how much support a person with ASD may need in relation to a particular domain. For each of the two core symptom domains (i.e., social communication; and restrictive or repetitive behaviors, interests, or activities) the level of support needed is recorded. Severity levels are described as Level 1 “*requiring support*”, Level 2 “*requiring substantial support*”, and Level 3 “*requiring very substantial support*.”

Additionally, DSM-5 allows for the identification of other symptoms that are not diagnostic or exclusive to ASD, but that research has shown may be associated with the disorder. These “specifiers” relate to associated difficulties (e.g., with intellectual impairment) and comorbid disorders (e.g., “associated with another neurodevelopmental, mental or behavioral disorder”), and can be used to provide more individualized diagnoses, but also to more accurately classify particular groups of individuals who may fall within the broad dimensional category of ASD (Grzadzinski et al., 2013). Specifiers listed in the DSM-5 that can be used in a diagnosis of ASD include: language impairment, impairment, other medical or genetic conditions or environmental factors, other neurodevelopmental, behavioral and mental disorders, and catatonia (APA, 2013).

Emotional and behavioral comorbidities. Emotional and behavioral problems commonly occur in persons with ASD (e.g., APA, 2013; Leyfer et al., 2006; Simonoff et al., 2008). A number of studies have found that among individuals with ASD, 60% or more have at least one comorbid disorder (e.g., Amr et al., 2012; Gjevik et al., 2011; Leyfer et al., 2006; Simonoff et al., 2008). In a study of children and adolescents with ASD, Simonoff et al. (2008) found that 41% met criteria for two or more comorbid psychiatric disorders. Across studies examining comorbidities in ASD, some of the most common comorbid diagnoses include anxiety and mood disorders (e.g., generalized anxiety, social phobia, depressive disorders), attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), and obsessive-compulsive disorder (OCD) (Leyfer et al., 2006; Mattila et al., 2010; Simonoff et al., 2008).

The presence of comorbid disorders in individuals with ASD often leads to greater overall impairment and has implications for treatment (Leyfer et al., 2006;

Simonoff et al., 2008). Comorbid emotional or behavioral problems in those with ASD compound impairment. For example, the presence of specific comorbid anxiety disorders may be related to greater impairment in social skills (Bellini, 2004; Sukhodolsky et al., 2008). Sikora, Vora, Coury, and Rosenberg (2012) found that children with ASD and significant ADHD symptoms had greater impairments in adaptive behavior and lower quality of life than those with ASD who had fewer ADHD symptoms.

Other comorbidities in ASD. One of the more common comorbidities in ASD is intellectual disability (ID). ID is characterized by cognitive impairment (generally defined by an IQ that is two standard deviations or more below the mean of 100) and deficits in adaptive functioning (i.e., self-care and independent living skills), and the severity of ID can range from mild to profound, depending on the degree of functional impairment (APA, 2015). Prevalence rates of ID in those with ASD vary across the literature, but a number of studies have identified rates at or above 50% (Charman et al., 2011; La Malfa, Lassi, Bertelli, Salvini, & Placidi, 2004; Matson & Shoemaker, 2009). Charman et al. (2011) found that in a sample of 75 children, 55% met the criteria for ID. Within the sample, only 16% fell within the moderate to severe range of ID, with about 39% falling within the mild range of impairment.

Findings have consistently shown that individuals with ASD who are also diagnosed with ID have a poorer prognosis (Matson & Shoemaker, 2009). Those with lower IQ have been found to have higher levels of challenging behaviors (e.g., self injury, aggression; Matson & Shoemaker, 2009). Further, these individuals may show less improvement in symptoms across the lifespan (Seltzer, Shattuck, Abbeduto, &

Greenberg, 2004) requiring a greater level of support into adulthood (Howlin, Goode, Hutton, & Rutter, 2004).

There are also a number of medical conditions that are commonly comorbid with ASD including seizure disorders, sleep disorders, gastrointestinal problems, metabolic disorders and hormonal dysfunction (Bauman, 2010). These medical conditions can impact quality of life (Isaksen et al., 2013) and may affect participation in and outcomes of intervention (Bauman, 2010; Eriksson et al., 2013). Considering core symptoms, and possible comorbid emotional, behavioral, and health conditions in individuals with ASD, deficits and difficulties may span a wide array of areas of functioning.

ASD across the lifespan. ASD symptoms are often recognized within the first two years of life, but may be identified earlier or later depending on the severity of developmental delays (APA, 2013). Some of the first symptoms to emerge are often communication deficits or deficits in nonverbal social behavior such as eye contact or atypical play. A study by Shumway et al. (2011) found that 62% of the study sample displayed ASD symptoms within the first year of life. There may also be a number of different “onset patterns,” as approximately 30% of young children with ASD reportedly experience developmental skill loss or regression at an early age (Shumway et al., 2011). According to DSM-5, symptoms are most marked during early childhood, after which many children begin to show gains in some areas of deficit (APA, 2013).

Changes in ASD core symptoms. Studies examining the trajectory of ASD across the life course have typically found overall decreases in the severity of ASD core symptoms, particularly restrictive repetitive behaviors, across the lifespan (i.e., from childhood to adulthood; Esbensen, Mailick-Seltzer, Lam, & Bodfish, 2009; Shattuck et

al., 2007; Seltzer et al., 2004; Woodman, Smith, Greenberg, & Mailick, 2014). However, there may be a smaller subset of individuals who show deterioration over the lifetime, often characterized by worsening of other ASD or psychiatric symptoms (Farley & McMahon, 2014). For example, Shattuck et al. (2007) examined symptom change across a 4.5-year period in a group of adolescents and adults with ASD. Overall, results suggested improvements in verbal communication, social and emotional reciprocity and restrictive/repetitive behaviors, though a significant change was not found for nonverbal communication. Though there was an overall trend of improvement, some individuals' symptoms remained constant (22.9% for verbal communication; 54.4% for nonverbal communication); and symptoms worsened for a smaller portion of the sample (14.5% for social reciprocity; 25.7% for verbal communication). Factors predictive of these outcomes included language skills and IQ. While the presence of comorbid intellectual disability predicted less symptom change over time, better verbal ability was related to greater improvement.

Esbensen et al. (2009) found similar results in a cross-sectional study examining restrictive and repetitive behaviors. Restrictive and repetitive behaviors of a variety of types (e.g., restricted interests, ritualistic behavior, self-injurious behavior) lessened with age, though motor stereotypies were somewhat more persistent in individuals who also were diagnosed with ID. While findings across the literature indicate decreases in some core symptoms by adulthood, some level of symptomatology tends to remain (i.e., individuals are generally not symptom free), contributing to the lifelong difficulties individuals with ASD face (Farley & McMahon, 2014; Seltzer et al., 2004).

Changes in emotional and behavioral problems. Emotional and behavioral problems also change across the lifespan, though findings in this area are more varied, depending upon the specific type of problem or symptom being examined, as well as age and IQ. A study by Woodman et al. (2014) examined change in maladaptive behaviors (e.g., self-injury, aggression, withdrawal, repetitive habits) longitudinally over the course of eight and a half years. Findings showed that 43% of individuals with ASD showed improvement in externalizing behaviors over the study period, while for 37% of the sample, behaviors remained stable. For maladaptive behaviors related to internalizing (e.g., repetitive habits, withdrawal, inattention), percentages of those who showed improvement were similar to those whose symptoms remained stable (43% and 42%, respectively). Though the behaviors of some individuals worsened, a lower percentage of individuals had declining trajectories across all behavior categories (i.e., below 20%; Woodman et al., 2014).

Conclusions of longitudinal and cross-sectional studies examining the prevalence of comorbid psychiatric disorders across the lifespan have varied, likely in relation to the wide variety of characteristics of study samples (e.g., age group, IQ), measures used to examine comorbid symptomatology. For example, some studies have identified significant relationships between age and comorbid disorders such as anxiety (e.g., Davis et al., 2011; Van steensel et al., 2011), and depression (Mayes, Calhoun, & Murray, 2011), such that percentages of those with these particular comorbidities increase with age; though, others have not found significant effects of age with respect to these particular comorbidities (e.g., Gjevik et al., 2011; Strang et al., 2012).

Studies examining adult outcomes in individuals with ASD have identified much variability related to things like overall level of independence, employment status, and residential status (Farley & McMahon, 2014; Howlin & Moss, 2012). Differences in outcomes such as the level of supports and intensity of care required may relate to characteristics such as IQ (Howlin, Goode, Hutton, & Rutter, 2004), though poor functioning in adulthood is common for those across ranges of intellectual functioning (Eaves & Ho, 2008). The risk for disengagement from education and employment is greater for those with ASD than for individuals with other disabilities (Shattuck et al., 2012).

Changing needs. For all children, including those with ASD, needs change across developmental stages. For example, learning and academic needs may be most relevant during the school age years, while needs related to employment and independent living are more relevant as adulthood is approaching. Needs related to emotional and behavioral functioning may be particularly important areas of focus for individuals with ASD as they transition out of high school (Taylor & Seltzer, 2010), as individuals may have difficulty finding and accessing fulfilling daily activities post-high school, which can exacerbate behavioral difficulties. Needs in the area of adaptive behavior (e.g., self care) tend to persist across the lifespan, though needs related to specific adaptive skills may differ. For example, young children may require more intervention in basic self-care skills such as toileting and eating, while older adolescents and adults may require intervention to improve skills needed for independent living (e.g., household tasks, cooking).

Needs during adolescence. New areas of need often emerge during adolescence for individuals with ASD and their families. These needs may be related to emotional and behavioral difficulties, developmental changes associated with puberty, planning for the future, or navigating increasingly complex social situations.

In terms of emotional and behavioral functioning, adolescents with ASD may have higher rates of clinically significant anxiety symptoms (Vasa et al., 2013) and more difficulty with executive functioning (Rosenthal et al., 2013) than younger children. Simonoff et al. (2013) found that comorbid emotional and behavioral problems such as hyperactivity, conduct problems, emotional problems, and peer relationship problems were persistent across four years of adolescence (ages 12 to 16).

Further, parents of adolescents with ASD must navigate issues related to puberty and address their children's increased needs for independence. Specific issues that may present challenges around this time include the desire for increased levels of privacy, issues related to sexuality, hygiene, and concerns about safety and potential victimization (Koegel et al., 2014). Further, mothers of female adolescents with ASD have noted particular challenges related to sex-specific puberty issues (e.g., menstruation) and the potential for sexual vulnerability (Cridland et al., 2014). While these concerns are common in parents of typically developing adolescents, they may be complicated by ASD core deficits, particularly social deficits, and emotional and behavioral problems.

When children with ASD reach puberty, needs related to the future come to the forefront for families. These include the need for postsecondary transition planning (i.e., transition out of educational settings), concerns about future employment and living situations, and consideration of guardianship issues (Morrell & Palmer, 2006; Van

Bourgondien & Griffin, 2011; Van Bourgondien et al., 2014). As the transition out of high school and into adult life can be prolonged or present difficulties in individuals with ASD, planning for this stage of life typically must begin early.

For students in public schools, postsecondary transition planning is one of the services mandated by the Individuals with Disabilities Education Improvement Act (IDEIA, 2004). This planning includes a variety of components, includes involvement from the child, the school, and often the family, and is typically mandated to begin before age 16, though states may mandate that this process begin earlier. Specific areas of concern for youth with ASD transitioning out of high school include independence in functional or adaptive skills (e.g., self-care, community skills), career skills (e.g., specific job skills, career exploration), self-management (i.e., monitoring of own behaviors), and self-determination (e.g., making choices and problem solving) (Schall, Wehman & Carr, 2014).

While this period of transition can be challenging even for typically developing youth and their families, the core symptoms of ASD may compound these difficulties. Since individuals with ASD have core deficits in social communication, and often lag well behind their typically developing peers in the development of these skills, adolescence can be particularly challenging as it is a time when the social environment becomes more complex and the demand for conversational skills increases (Laugeson & Ellingsen, 2014). Further, new challenges may present themselves including navigating romantic relationships and increasingly challenging social situations and social rules related to the workplace (Laugeson & Ellingsen, 2014).

Despite increasing difficulties during this period of life and the many areas of need that emerge, fewer evidence-based treatments exist for adolescents as compared to younger children. A recent report by Wong et al. (2013) found that the greatest amount of evidence-based treatments targeted young children, with significantly fewer targeted adolescents and adults with ASD. Interventions targeting vocationally related outcomes (i.e., needs relevant to adolescents and adults) were among the least targeted areas (Wong et al., 2013). A study by Edwards, Watkins, Lotfizadeh, and Poling (2012) lends additional support to these findings, based upon findings that the number of studies including children older than age 8 steadily declined with increasing age (Edwards et al., 2012). Findings of this kind highlight the potential lack of resources (i.e., available evidence-based interventions) to meet families' needs during the adolescent years.

The Broad Impact of ASD

Aside from the effects that ASD-related deficits have on the lives of individuals with ASD, the disorder has a broad ranging impact on the context within which the individual lives. According to Bronfenbrenner's Ecological System's Theory (Bronfenbrenner, 1979; 2005), children grow and develop within the context of multiple, interrelated systems. These systems include those that are more directly tied to the individual (e.g., the family), as well as those that the individual may interact with less directly (i.e., cultural group, parents' place of employment). These systems are conceptualized as being "nested" around the individual. Despite whether the individual interacts with a particular system more directly (e.g., direct interaction with family members on a daily basis) or indirectly (e.g., the effects that caring for a child with ASD may have on a parents' job), these nested systems affect the development of the

individual (Bronfenbrenner, 1979). While these contextual factors affect how the child develops, the child also possesses a set of individual characteristics that affect the various contextual environments within which the child lives. This interaction between the child and the child's environment is bidirectional, as these factors are constantly interacting and in flux across the course of the child's life (Bronfenbrenner, 1979).

Bronfenbrenner's theory provides a framework for understanding the ways in which a child with ASD may affect, and be affected by, various layers of the contextual environment. For example, each child with ASD possesses a set of individual characteristics such as IQ, the severity and presentation of ASD symptoms, as well as behavioral, emotional, or medical problems that may be associated with the disorder. These characteristics affect how the child grows and develops, but also affect the systems that the child is a part of. Further, the child with ASD is also a product of the context in which he or she grows up. For example, the severity of a child's maladaptive behaviors may vary as a function of characteristics of the child's environment (e.g., parenting practices or access to behavioral services).

ASD and the family system. In order to care for a child with ASD, families must often make changes within the family system (Morgan, 1988). The author describes these changes as relating to the shift in family roles and the lifestyle changes that can result from the demands associated with ASD, demands that families may not have adequate resources to meet. Resources required to protect against stressors may include a variety of personal and family strengths such as economic resources, role flexibility, family cohesion, and social or community support (Burr & Klein, 1994; McCubbin & Patterson, 1983). Parents often find that the child with ASD becomes the "center of their

lives”, limiting freedom and independence in daily life (Meyers, Mackintosh, & Goin-Kochel, 2009). Families’ lives may be restructured to accommodate the needs of the child with ASD, and families may focus their personal resources on providing short-term solutions to the child’s difficulties rather than allocating those resources to other needs of the whole family (Morgan, 1988).

When demands are greater than the resources a family possesses, an imbalance or disruption occurs within the family, which can be conceptualized as poor family adaptation (or maladaptation). However, families may also experience positive adaptation (i.e., bonadaptation), in which there is balance between family demands and family resources to meet such demands and in which the family is able to maintain its integrity and control over environmental factors and continue to develop (McCubbin & Patterson, 1983)

The process families undergo in adjusting to meet demands is ever evolving. Families continue to adjust to the needs that arise over time, resulting in a particular state of family adaptation (McCubbin & Patterson, 1983). This ongoing change process is particularly relevant to the context of families of individuals with ASD because, concurrently with adolescent development, ASD symptoms and associated needs change across the lifespan. Families of adolescents with ASD, for example, are likely to have experienced a variety of previous adjustments within the family in order to meet their child’s demands throughout childhood, but likely face continued adjustments related to this transitional phase of life.

Most notably, the individual characteristics of the child with ASD affect the immediate family. For example, behavioral problems have been found to increase

caregiver stress (Lecavalier, Leone, & Wiltz, 2006) and decrease maternal well-being (Lounds et al., 2007). Characteristics like ASD severity, aberrant behaviors, and adaptive behavior may also have an effect on the quality of life of parents of adolescents with ASD (Baghdadli et al., 2014).

Other factors, such as needs associated with therapy for ASD may deplete family resources (e.g., monetary resources and time needed for therapy). On the other hand, certain parental and family characteristics may affect the child. For instance, several studies have found that family level of adaptability, or a families' collective ability to adapt in the face of stress, may have a significant impact on child behavior problems in youth with ASD (Baker, Seltzer, Greenberg, & Kaslow, 2011; Orsmond, Lin, & Seltzer, 2007). Woodman et al. (2014) found that higher levels of maternal praise were associated with greater improvement in child ASD symptoms from adolescence to adulthood (Woodman et al., 2014).

Siblings of the child with ASD may also be affected. Numerous studies have examined the impact of having a sibling with ASD in terms of sibling adjustment, emotional and behavioral problems and self-concept (Orsmond & Seltzer, 2007). A number of studies have identified negative effects of having a sibling with ASD, such as being at a higher risk for adjustment problems as compared to children with typically developing siblings (Smith & Perry, 2005). There is also some evidence to suggest siblings of individuals with ASD have social and emotional difficulties that may persist into adulthood, though few studies have examined this (Orsmond & Seltzer, 2007). Across studies examining sibling outcomes, effects seem to be small and it has been noted that sibling characteristics may influence findings (Orsmond & Seltzer, 2007).

Conversely, several studies have failed to identify any significant negative effects of having a sibling with ASD (e.g., Kaminsky & Dewey, 2002; Rao & Beidel, 2009).

Parenting Stress

Stress has been defined in different ways across the literature. One such view is that stress, rather than being a simple cause and effect reaction, is instead a transactional process involving a variety of environmental, situational, and individual factors (Tunali & Power, 1993). Lazarus and Folkman (1984) describe psychological stress as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p. 19).

Parenting is an inherently challenging responsibility, which tends to generate some degree of stress on parents (Crnic & Greenberg, 1990; Deater-Deckard & Scarr, 1996). According to Crnic & Greenberg (1990), the compounding effect of “daily hassles” (i.e., normative minor tasks and challenges that occur on a daily basis), is an important contributor of parenting stress outcomes. While this study focused on daily challenges in the lives of mothers of young children, there are different parenting challenges that may relate to parenting stress across different stages of a child’s life. For example, for parents of young children the nature of parenting tasks tends to change as the child develops a greater repertoire of abilities and behaviors (Ballenski & Cook, 1982).

Parents’ perceptions of their competency may also change as the child develops. Parents of adolescents often perceive greater challenges, and feel less competent, than parents of younger children (Bellinski & Cook, 1982). Parents typically find adolescence

to be the most difficult stage of parenting (Pasley & Gecas, 1984). Challenges during this stage often result from developmental changes leading to an increased need for autonomy and greater parent-child conflict (Small, Eastman, & Cornelius, 1988; Putnick et al., 2010).

Parents of children with disabilities face normative challenges inherent to parenting, but also experience a set of challenges that are more specific to caring for a child with a disability. Caring for a child with a disability usually requires resources such as time, money, and energy above and beyond those needed to care for a child without a disability. Parents of children with disabilities may experience difficulty accessing care, dissatisfaction with the quality of care, as well as difficulties related to the financial resources and time required to access adequate care (Vohra et al., 2014). Children with disabilities may also require a greater number of healthcare visits as compared to typically developing children (Daire, Munyon, Carlson, Kimemia, & Mitcham, 2011), adding to the financial and time-related burden placed on families.

ASD and parenting stress. Considering the broad impact of ASD, and the challenges and demands associated with parenting across the lifespan, parents of individuals with ASD often find their personal and family resources exceeded. The result is an increase in stress. Studies have consistently shown high levels of stress in parents of children with ASD (e.g., Griffith, Hastings, Nash, & Hill, 2010; Hayes & Watson, 2013). Hayes and Watson (2013) found parents of children with ASD to be significantly more stressed than parents of typically developing children, as well as parents of children with other disabilities (e.g., Down syndrome, ID). High levels of parenting stress have been identified in both mothers and fathers of children with ASD, and across age groups

ranging from parents of newly diagnosed children (Davis & Carter, 2008) to parents of adolescents and adults (Smith et al., 2010; Seltzer et al., 2010).

Factors contributing to parenting stress. A number of unique challenges faced by parents of children with ASD may contribute to parenting stress. Parents of children with ASD experience a number of difficulties related to ASD treatment. With an ever-expanding number of treatments available to parents of children with ASD, decisions about which to pursue can be complex and stressful, as parents must consider the needs of the child as well as the entire family (Herbert, 2014). Aside from treatment selection, parents of children with ASD may be more likely than parents of children with other disabilities (i.e., other developmental disabilities, mental health conditions) to report challenges such as difficulty using community services and dissatisfaction with the availability of family-centered care (Vohra, 2014). Further, exhaustion and financial strain often result from extensive treatment including components such as special schools, special diets, and testing that is often not covered by insurance (Myers, Mackintosh, & Goin-Kochel, 2009).

Another aspect of ASD that creates added challenge is the ambiguity surrounding the disorder. One aspect of this is the lack of a clear etiology of the disorder (O'Brien, 2007). Parents hold a wide variety of causal beliefs related to ASD, and may experience negative emotions related to causal beliefs including self-blame and guilt (Herbert & Kouloglioti, 2010). Another factor that contributes to the ambiguity about the etiology of ASD is that it is not an obvious physical disability (i.e., individuals with ASD typically do not look like they have a particular disability). Therefore, it may be difficult for others to understanding the challenges experienced by the individual (Tunali & Power, 1993),

leading parents to feel judged or mistreated by others at times when out with their child in public (Myers et al., 2009).

Child characteristics. A study by Kissel and Nelson (2014) examined the impact of parent-reported ASD severity on parent stress, family functioning, and social support in parents of children with ASD. Findings showed that mothers who perceived their child's ASD as more severe had higher stress levels and poorer personal functioning (i.e., individual's perception of their functioning within the family) compared with parents who perceived their child's ASD as less severe. Ingersoll and Hambrick (2011) also found that parents who perceive their child's autism to be more severe also tend to report higher depression and stress levels.

In addition to stress related to the severity of ASD core symptoms, studies have found behavior problems in children with ASD contribute significantly to parent stress (e.g., Lecavalier et al., 2006; McStay et al., 2014; Rao & Beidel, 2009) and affect parent mental health (Blacher & McIntyre, 2006; Hastings et al., 2005). Specifically, Lecavalier et al. (2006) found that conduct problems and lack of prosocial behavior were most strongly associated with caregiver stress. Further, behavior problems may make a more significant contribution to parenting stress than other child characteristics like ASD severity, IQ, or adaptive behavior (Lecavalier et al., 2006). While the majority of the parents in the study by Lecavalier and colleagues had children with an IQ below 70 (i.e., in the intellectual disability range), findings from Rao and Beidel (2009) support similar findings related to the impact of child behavioral problems in a sample of parents of high functioning youth with ASD (i.e., those with an IQ in the average range or above).

Further, behavior problems appear to impact parenting stress into the adolescent and adult years (Lounds et al., 2007).

Findings related to specific predictors of parent stress may differ by child age group. Osborne and Reed (2009) examined predictors of parent stress between two age groups: children ages 2 to 4, and children ages 5 to 16. For those with school age children (i.e., ages 5 to 15) parent stress was associated more strongly associated with child behavior problems than with ASD severity. Conversely, for parents of young children with ASD under the age of 4 years, ASD severity was more predictive of parent stress than behavior problems. They hypothesized that the influence of severity in parents of children in the younger age group may be related to the stress produced by the initial ASD diagnosis (Osborne & Reed, 2009).

Reciprocal effects of parenting stress and child characteristics. A number of studies illustrate the complex relationship between a variety of factors, such as parent characteristics, coping and social support, and child behaviors, that contribute to the stress experienced by parents of children with ASD (e.g., Ingersoll & Hambrick, 2011). Further, parent and child characteristics and behaviors do not operate in isolation. A number of studies have posited that the relationship between child and parent stress is a reciprocal one (i.e., behavior problems increase parent stress, parent stress increases behavioral problems) that evolves over time (Osborne et al., 2009; Lecavlier et al., 2006; Zaidman-Zait et al., 2014). According to Fong (1991), mothers with high levels of stress made more negative cognitive appraisals of behaviors and had more negative emotional reactions, which in turn may have an effect on the child. This reciprocal relationship

highlights the importance of better understanding factors that lead to parenting stress, as parenting stress may have negative effects on the parent as well as the child.

Parenting stress during adolescence. Parents of adolescents with ASD often experience similar parenting challenges that result in stress in parents of typically developing children, as well as challenges related to parenting a child with ASD. The burden of caring for adolescents with neurodevelopmental disorders as they move towards adulthood is high (Cadman et al., 2012) and caregivers of adolescents with ASD may experience a burden that is greater than that of parents of adolescents with other disorders, such as ADHD. Parents of adolescents with ASD may experience a number of unmet needs related to their adolescents' mental health (e.g., depression and anxiety), the potential for exploitation and risk, and needs related to social relationships (Camden et al., 2012). On top of all of these needs, by the time a child has reached adolescence the chronic nature of parenting stress (i.e., "wear and tear" over time) may lead to parent burnout (Smith et al., 2008; Morgan, 1988).

ASD and Parent Coping

Understanding the ways in which a family copes with the stress present in their lives is a crucial aspect related to family outcomes, whether negative or positive. As defined by Lazarus and Folkman (1984), the process of coping includes efforts to manage internal and external demands using both cognitive and behavioral mechanisms. Literature examining coping may refer to particular coping styles (e.g., emotion-focused coping, problem-based coping) or coping methods (i.e., seeking social support), and may relate to cognitive aspects (e.g., cognitive reframing) as well as those that are more behavioral (e.g., accessing resources, planning for the future; Burr & Klein, 1994).

Considering the demands on families of children with disabilities, coping and how it affects parent and family outcomes is a topic that is well-researched. Across the literature, coping methods that have been linked to positive outcomes in families of children with disabilities include empowerment, using problem-focused coping strategies (e.g., active coping, planning), social involvement and accessing social support, and distribution of caregiver burden (Daire et al., 2014; Singer & Powers, 1993; Smith et al., 2008). For example, Hall et al. (2012) found that parents who exhibited a lower stress profile tended to use active methods to cope, such as educating family members and taking steps towards planning for the future. Other methods of coping may relate to poorer outcomes in families of children with disabilities, such as emotion-focused coping methods (Hastings et al., 2005; Smith et al., 2008), or coping through distancing and avoidance (Sivberg, 2002).

Literature surrounding families of children with ASD and coping has employed both quantitative and qualitative methods and examines a variety of constructs related to coping (e.g., coping styles, specific methods of coping; Lai & Oei, 2014). Lai and Oei (2014) conducted a meta-analysis of the coping literature related to ASD and examined findings across 37 studies. Findings indicated that parents of children with ASD use a wide range of strategies and methods to cope, many of which can be categorized coping into four domains: active coping, spiritual coping, cognitive reframing, and problem solving. The two most commonly used coping strategies in parents of children with ASD included problem-focused coping (i.e., practical forms of coping directly targeting the stressor) and seeking social support (Lai & Oei, 2014). Further, parents of children with ASD tend to use the active avoidance coping style (i.e., distancing and escape including

both physical and cognitive aspects of “escape”) more than parents of typically developing children (Sivberg, 2002; Lai & Oei, 2014).

There are a variety of factors that influence the coping methods or styles used by parents of children with ASD, including parent characteristics (e.g., culture, age, gender, psychopathology) and child characteristics (age, adaptive functioning, behavior problems) (Lai & Oei, 2014). Further, literature examining coping in families of children with ASD supports the notion that coping changes over time (Smith et al., 2008).

Few studies have examined coping in parents of children with ASD across the lifespan. Smith et al. (2008) compared coping styles in mothers of toddlers and mothers of adolescents with ASD. For mothers of toddlers, more problem-focused coping and less emotion-focused coping related to better maternal well-being. Mothers of adolescents used more emotional coping in the form of behavioral disengagement (e.g., withdrawing from coping efforts) than mothers of toddlers (Smith et al., 2008). The study also found that coping had a “buffering” effect on the relationship between child ASD symptom severity and maternal well-being (e.g., use of problem focused coping protected against the negative impact of ASD severity on maternal well-being), and that these effects were much stronger for mothers of adolescents than mothers of toddlers.

Gray (2006) examined change in coping strategies across an 8-to-10 year period in a group of families of children with ASD ranging from age 4 to 19. Findings indicated that parents’ coping styles tended to shift from problem-focused to emotion-focused coping as children aged. Further, the number of reported coping methods decreased over time (Gray, 2006).

ASD and Social Support

Aside from coping, social support is an important resource related to family adjustment and adaptation outcomes (McCubbin & Patterson, 1983). Social support plays an important role in outcomes for families of children with ASD. Social support has been associated with lower parenting stress (Bristol, 1984; Paynter et al., 2013) and a lack of such support may contribute to poorer parent well-being and mental health outcomes (Boyd, 2002; Ingersoll & Hambrick, 2011). Social support can include experiences such as meaningful, stable relationships, and participation in community groups and activities.

According to Cohen and Wills (1985) social support can include the following: emotional support (e.g., conveying esteem and acceptance), informational support (e.g., aiding in understanding and coping by providing information), social companionship (spending time with others), and instrumental support (providing material resources or services). Specific measurement methods used to quantify social support vary across the literature. Measures of this construct may include methods that examine the perceived helpfulness of supportive relationships in a person's life, or methods assessing the size of a person's social network through a numbered list of supportive individuals in a person's life.

Schieve et al. (2011) examined parenting stress and aggravation among parents of children with ASD and parents of typically developing children. The study assessed a number of parent and family characteristics, including social support. In this study social support was operationalized as including social capital in the neighborhood (e.g., people in the neighborhood can be counted on, are helpful, can be trusted with child, etc.), as

well others other individuals the parent could ‘turn to for emotional support.’ Lack of someone that the parent could turn to for emotional support, as well as low levels of neighborhood social capital were significantly associated with high parenting aggravation (Schieve et al., 2011). In a culturally diverse sample of mothers of nine-year-olds with ASD, Bishop, Richler, Cain and Lord (2007) found that levels of perceived social support significantly predicted the perceived negative impact of parenting a child with a disability. Those who reported some social support felt also perceived a less negative impact of having a child with ASD as compared to those who reported little or no social support.

Bristol (1987) found social support to be related to some, but not all indicators of positive family adaptation in mothers of children with ASD. Specifically, perceived access to helpful social support from a variety of sources (e.g., spouses, family members, other parents) was a significant predictor of some aspects of family adaptation (i.e., marital adjustment and parenting quality), but not to others such as mothers’ depressive symptoms.

Barker et al. (2011) examined the effect of social support and negative life events on parental well-being in parents of adolescents and adults with ASD in a longitudinal study examining outcomes across a 10-year period. Researchers examined social support by asking parents to list members of their social networks by whom they felt supported. Mothers reported greater levels of anxiety when social support networks were lower and when they experienced a greater number of stressful life events (Barker et al., 2011).

While social support is generally regarded as a protective factor in families of individuals with ASD, the helpfulness of social support or the specific parent or family

outcomes that are impacted may be variable across different groups. For instance, Tehee et al. (2009) examined the helpfulness of social support to across parents of children ranging from ages 3 to 18, by four age groups. These authors found that parents of children ages 11-to-14 years had significantly higher scores on a measure of perceived helpfulness of social support than did parents of children in the 15-to-18 year age group and the 3-to-6 year age group.

Lin, Orsmond, Coster, and Cohn (2011) examined the effects of social support on families of adolescents and adults with ASD from Taiwanese and American cultures. For the sample of mothers from the U.S., social support was associated with family adaptability (i.e., higher levels of family adaptability in those with a greater amount of social support), though social support was not associated family cohesion. For the Taiwanese sample, social support was not associated with either family adaptability or cohesion. Further, social support was not significantly related to aspects of maternal well-being (e.g., maternal anxiety and depression) in either group.

The Double ABCX Model of Family Adaptation and ASD

Theoretical frameworks, such as the Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983), provide a way of conceptualizing how a variety of factors, such as coping and social support, relate to the process of family adaptation. The model, adapted from Hill's (1958) theory on the family stress process, represents an expanded view of the processes that families undergo in response to stressors over time. The Double ABCX Model acknowledges that the overall strain that a family experiences may result from specific stressors or events (e.g., a child being diagnosed with a disability), as well as the "pile up" or accumulation of a variety of stressors over time

(e.g., efforts to cope over time, normative family transitions). Other components involved in the overall family adaptation include the families' resources for meeting the demands of stressors (e.g., social support); the meaning a family ascribes to the stressful situation (i.e., perceptions and cognitions about the difficulty of the stressor); and coping methods.

McCubbin and Patterson (1983) describe the imbalance that can be created in families when situations require more resources than a family possesses. Families facing particular stressors or hardships often attempt to make adjustments (i.e., changes in coping, acquiring additional resources) in order to overcome these difficulties. Stress results when the demand of stressors outweighs the families' capacities and resources to overcome these challenges (McCubbin & Patterson, 1983).

The Double ABCX model has been applied to ASD with the goal of understanding factors that may indicate positive or negative adaptation in families of children with ASD (e.g., Bristol et al., 1987; McStay et al., 2014). Across studies using the Double ABCX model to examine outcomes in relation to ASD, the following factors have been identified as related to negative adaptation: more child behavior problems (Manning, Wainwright, & Bennett, 2011; Pakenham et al., 2005; Paynter et al., 2013; McStay et al., 2014); more deficits in child adaptive behavior (Hall & Graff, 2011); higher ASD severity (Stuart & McGrew, 2008); more "pile up demands" (i.e., family demands not directly related to ASD) within the family (Bristol, 1987; Pakenham et al., 2005); coping with active avoidance (Paynter et al., 2013) or passive avoidance coping (Stuart & McGrew, 2009). Alternatively, contributors to positive adaptation include greater social support (Bristol, 1987; Simon-Tov & Kaniel, 2011); sense of coherence

(i.e., sense that one's environment is predictable and understandable; McStay et al., 2014; Pozo et al., 2014; Siman-Tov & Kaniel, 2011); positive appraisals of the stressor (i.e., perceived positive aspects of having a child with a disability; Paynter et al., 2013) or reframing (Manning et al., 2011); and active coping (Bristol, 1987). Taken together, these studies highlight numerous factors that may contribute to the way in which a family adapts to the stressors related to caring for a child with ASD. However, it should be noted that some studies examining similar predictors have yielded different findings depending upon operationalization of family adaptation. For example, while Stuart and McGrew (2008) found ASD severity to be a significant predictor of caregiver burden, though Paynter et al. (2013) did not find ASD severity to be a significant contributor to parenting stress.

The differences in outcomes across studies using this model in ASD research may be related to differences in operationalization of variables involved in the model. Family adaptation is described by McCubbin and Patterson (1983) as a “descriptive criterion,” and thus has been operationalized in a variety of ways across studies. For example, while several studies have measured “family adaptation” through family characteristics such as family environment, family distress, or family quality of life (McStay, 2014), the majority of studies have operationalized family adaptation through measures examining parental characteristics (e.g., parenting stress, mental health, quality of life or marriage quality). Similarly, studies have employed differing measures to examine predictor of family adaptation (i.e., components of the Double ABCX model), such as the selection of measures of ASD-related stressors (i.e., ASD severity, child behavior problems, adaptive behavior). While studies examining factors related to family adaptation within the context

of the Double ABCX model have included parents of children at various ages, little is known about the relationship between these factors at particular stages of the child's life (e.g., adolescence), despite the fact that ASD-related stressors and with many other factors within the model likely differ at different stages of development.

Parent Perceptions

Studies applying the Double ABCX Model to the stressors associated with parenting children with ASD have examined the role that parent perceptions or appraisals (i.e., parents' perceptions of the impact that the child's ASD has on their lives) may play in overall family outcomes. Some studies using the Double ABCX model as a framework for examining the adjustment of parents of children with ASD have focused on general parent perceptions, such as parents' sense of coherence (Pozo et al., 2014), while others have assessed parental perceptions directly related to ASD, such as the perceived positive and negative aspects of raising a child with ASD (Bristol, 1987; Paynter et al., 2103; Stuart & McGrew, 2008; Packenham et al., 2004).

While the examination of parent perceptions related to ASD within the Double ABCX framework makes a unique contribution to the literature, the majority of studies do not examine how these perceptions may differ at different points in a child's life. This is an important consideration with respect to the fact that ASD related symptoms change across the lifespan, just as other variables examine in the context of the Double ABCX model (e.g., coping) also evolve over time (Tunali & Power, 2002).

In parents of children with disabilities, the initial diagnosis may lead to a shift in parents' perceptions of their children. Parents shift their cognitions surrounding the child and the child's difficulties to form a cognitive representation of the 'problem' (Avdi,

Griffin, & Brough, 2000). In forming this new cognitive representation, parents must integrate new and existing information, such as information about the child's developments as compared to typical development, symptoms that are associated with a diagnosable condition, and thoughts about stigma that are associated with disability (Avdi et al., 2000). While parents' cognitive representations of their child's disorder likely evolve as the child ages, they must continue to integrate information from multiple sources.

Perceptions research: Illness representation models. Research focusing on the importance of perceptions can be traced back to Wilhelm Wundt, an early pioneer of the experimental study of the conscious experience of thoughts and observations (cognitive processes; Hergenhahn, 1992). Wundt described mental processing as a passive and automatic, and described perception as more important than reality (Hergenhahn, 1992). These early ideas about the automatic perceptions formed as part of a person's conscious experience have provided the basis for other theories in psychology that emphasize the importance of cognitions, such as cognitive therapy and cognitive-behavioral therapy (Beck, 2011). Cognitive-behavioral theory assumes that cognitions are related to behaviors and emotions, creating a cyclical interaction (Beck, 2011). Further, it is assumed that cognitions can be examined (or monitored) and altered, leading to behavior change (Beck, 1995).

While ASD is not generally considered to be an 'illness', ASD related deficits produce lifelong challenges for individuals with ASD and their families, similar to that of a chronic illness. For this reason, mechanisms used for studying perceptions related to

chronic illness may inform research examining the perceptions of parents of children with ASD.

In the health field, the study of illness representation examines the impact of perceptions on emotional, behavioral, and physical health outcomes. This concept of examining cognitions related to illness originated with Leventhal's early research in the 1960's examining cognitive and emotional responses to threatening situations. From this work came Leventhal's Parallel Process Model (Leventhal, 1970), which involves both cognitive and emotional responses that are implicitly generated in response to a health threat and describes how these cognitive and emotional responses lead to cognitive representations. In 1984, the model was revised to emphasize the role that a person's perceptions and interpretations play in their behavior and management of demanding situations (Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997).

Leventhal's (1984) model of illness representation provides a theoretical framework underlying the mental representations individuals with chronic illnesses form to understand and make meaning out of their illness. The model contains five specific components: a) illness cause (how illness came about); b) the consequences of an illness (impact on life); c) illness identity (beliefs and knowledge about illness); d) illness timeline (ideas about course of the illness); and e) ideas about curability and controllability of the illness (personal empowerment and feelings of treatment efficacy).

In 1996, Weinman and colleagues developed the Illness Perception Questionnaire (IPQ), a measure of Leventhal's five key components of illness perception. In 2002, the measure was revised by Moss-Morris and colleagues in order to measure additional themes related to illness perception. The IPQ, and its revision, IPQ-R have been used in

studies to examine the perceptions of individuals with a wide variety of health conditions (e.g., cancer, diabetes, HIV), as well as the perceptions of those who have caretaking responsibilities for a person with a chronic illness, such as parents (e.g., Salewski, 2003; Brooks, Rowley, Broadbent, & Petrie, 2012). Studies examining illness perceptions have identified associations between perceptions and specific emotional, behavioral, and health outcomes such as the use of particular coping strategies, psychological well-being, social functioning, and vitality (Haggar & Orbell, 2003). Other studies have identified relations between particular illness perceptions and health behaviors such as treatment adherence (Horne & Weinman, 2002), or the choice of a particular treatment to pursue (Al Anbar et al., 2010; Mire et al., 2015).

Haggar and Orbell (2003) examined specific illness perceptions (e.g., illness consequences, controllability, identity) and their relation to particular coping styles and behavioral outcomes. Perceptions of high controllability were related to more positive methods of coping including problem-focused coping, cognitive reappraisal, and seeking social support. Perceptions of illness-related consequences as more serious, and strong illness identity were associated with a greater use of emotion-focused coping and coping by avoidance or denial (Haggar & Orbell, 2003). Additionally, perceptions of strong illness related consequences, illness chronicity, and strong illness identity were related to more maladaptive outcomes including poorer psychological well-being and social functioning, decreased vitality and increased psychological distress. Perceptions of high illness controllability, on the other hand, were associated with more adaptive psychological outcomes (i.e., increased well-being and vitality; Haggar & Orbell, 2003).

Cousino and Hazen (2013) analyzed a number of studies across the literature examining the perceptions of parents of adolescents with chronic illnesses and their relation to parenting stress. The study showed that for parents of adolescents with chronic illness, factors specifically linked to the illness, such as perceived severity of the illness, played a much smaller role in contributing to parenting stress than did other parent perceptions of a more subjective nature, such as perceptions about the child's vulnerability or greater feelings of responsibility for treatment outcomes (Bourdeau, Mullins, Carpentier, Colletti, & Wolfe-Christensen, 2007; Mullins et al., 2007).

Illness perception research and ASD. ASD, while not considered by most as an 'illness', is a chronic condition in that there are lifelong challenges associated with the diagnosis. In this vein, theories of illness representation represent a useful framework that can be applied to understanding how parents' perceptions about their child's ASD may impact emotional and behavioral outcomes of individuals and families. Relatedly, measures of illness representation such as the IPQ-R (Moss-Morris et al., 2002) are applicable to measurement of this construct within the ASD population. Despite the importance of perceptions in the adaptation process that families of children with ASD undergo, few studies have examined illness perceptions, specifically, within this population.

Al Anbar and colleagues (2010) modified the wording of the IPQ-R to make it appropriate for use with parents with ASD. These authors then examined how illness perceptions contributed to French parents' information seeking and treatment choices for their children with ASD (Al Anbar et al., 2010). Findings from Al Anbar et al. (2010) showed that increased perception of the seriousness of the disorder (measured by the

IPQ-RA Consequences subscale) was associated with the use of more educative treatment methods (e.g., Picture Exchange Communication System [PECS]); whereas those who had more negative emotional representations related to the child's ASD were less likely to use educative methods. Parents who perceived the disorder to be highly unpredictable (i.e., low illness coherence) pursued more treatment with psychotropic medications. Those parents with a greater sense personal control related to their child's disorder were less likely to pursue treatment with psychotropic medications (e.g., pharmaceuticals) or metabolic treatments (e.g., special diets, vitamins).

In the Al Anbar et al. (2010) study, variables related to perceived ASD cause and cyclical timeline of the disorder appeared to influence how parents sought information about the disorder. Those who perceived the cause of ASD cause to be linked to more personal factors (e.g., smoking during pregnancy) were less likely to seek information from other parents or attend ASD related conventions to gain knowledge. Additionally, parents who viewed their child's ASD as having a highly cyclical timeline (i.e., viewed the child's particular symptoms as coming and going in cycles), were less likely to attend trainings (Al Anbar et al., 2010).

Similarly, in a U.S. sample, Mire et al. (2015), found that several aspects of parent perceptions measured by the IPQ-RA were predictive of treatment categories (e.g., school-based speech therapy, intensive behavioral therapy, psychotropic medication) chosen. Specifically, parent perceptions from the IPQ-RA regarding the number of symptoms parents attributed to their child's ASD (Identity), treatment control, and ASD timeline (Chronicity) significantly predicted parents' choices of particular treatment categories (e.g., intensive behavioral treatment, school-based speech therapy,

psychotropic medication). Further, these perceptions had slightly higher predictive value than did other child and family factors known to influence treatment decisions such as ASD severity, verbal ability, or parent education level.

Given findings from the broader literature relating illness perceptions to a number of outcomes (e.g., psychological well-being, vitality, coping behavior, health adherence) and ASD-specific studies identifying associations between illness perceptions and treatments that parents chose to pursue for their children, additional research is needed to determine whether illness perceptions may play a role in other parent outcomes, such as parenting stress.

Gaps in the Current Literature

ASD is a lifelong disorder, but symptom presentation changes across the life course. From early childhood through adulthood, ASD presents a variety of challenges to individuals and their families, and these families have an evolving set of needs. Volkmar et al. (2014) posited that despite the increasing number of individuals being diagnosed with ASD, as well as the continued expansion of research in the area, there is still a lack of knowledge about the challenges faced by individuals with ASD and their families' during adolescence and adulthood.

Further research on families of adolescents with ASD is important, as this group is distinct from families of children with ASD at other stages of life (e.g., early childhood, adulthood). Specifically, studies often include adolescents in study samples with children or adults, rather than examining this distinct group, despite the fact that the needs of adolescents and their families are often unique (e.g., puberty, transition planning; Smith & Anderson, 2013). Adolescents with ASD are approaching or

undergoing normative developmental changes, but with the added challenges related to ASD. These changes lead to new demands, with the majority of the burden falling to parents.

Research has clearly established that families of individuals with ASD, and parents in particular, experience high levels of stress. Further, their stress levels are often higher than those of parents of typically developing children as well as other types of disabilities (Hayes & Watson, 2013). Research examining stress and coping among families of children with ASD often recognizes the contribution of interrelated factors, which may include child behavior problems, severity of impairments, perceptions about the child or family and social support (Manning et al., 2011; McStay, 2014; Osborne & Reed, 2009). Research also describes resources such as social support, and coping that help families to resist ASD-related stressors (McStay et al., 2014; Smith et al., 2008).

The way a person appraises a stressful situation influences their feelings and subsequent actions taken to reduce that stress (Lazarus & Folkman, 1984). In relation to ASD, theories such as Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983) have illustrated the importance of understanding the interrelation between factors like stressors, perceptions about such stressors, coping, and resources that may protect against stress such as social support. While the Double ABCX framework has been applied to families of children with ASD, less is known about the nature of the relationships between specific types of perceptions and parent stress, particularly in parents of adolescents with ASD.

Further, perceptions related to demanding situations evolve over time due to new challenges and stressors and changes in the availability of resources to meet such

challenges (Lazarus & Folkman, 1984). With this in mind, perceptions related to ASD and social support, likely differ in parents of adolescents with ASD. Given the unique demands and stressors families of adolescents face, research is needed to better understand the how parents' perceptions about their adolescents' ASD, social support, and coping may relate to the parenting stress experienced during this stage of life.

Aims of the Current Study

To address these gaps, the primary aims of this study were to understand the types of parent perceptions that potentially contribute to stress in parents of adolescent with ASD, and to examine the role that coping might play in this relationship. Specifically, this study aims addressed three specific questions.

First, do parents' perceptions about ASD (i.e., perceptions about personal control over ASD, whether ASD can be controlled by treatment, the extent to which ASD presentation seems cyclical rather than stable, and how understandable the disorder seems) and self-reported perceptions about their social support (i.e., family-based support and social support) significantly predict parenting stress? Second, does positive coping (e.g., actively seeking information about ASD and communicating needs) moderate the relationship between parent perceptions and parenting stress? Third, does the previously stated relationship between perceptions, parenting stress, and coping differ when controlling for parent-perceived ASD severity?

Chapter III

Method

Recruitment

The study sample included parents of adolescents with confirmed clinical diagnoses of ASD. Diagnoses were confirmed through rigorous phenotyping, which included administration of the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and Autism Diagnostic Interview Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003) by research-reliable examiners during these families' participation in the national, multi-site Simons Simplex Collection (SSC; Fischbach & Lord, 2010). Families who participated in the SSC met the following inclusionary criteria: a) one child between the ages of 4 years and 17 years, 11 months with symptoms characteristic of an ASD diagnosis; b) the child had at least one unaffected sibling; c) no close relative could be diagnosed with an ASD; d) the affected child had a minimum non-verbal IQ of 24 months (for children ages 4 to 6 years, 11 months) or 30 months (for children ages 7 to 17 years, 11 months); and e) both biological parents were available for DNA collection. The SSC data collection took place across 12 North American sites between 2008 and 2011 and was funded by the Simons Foundation Autism Research Initiative (SFARI); the SSC includes data from approximately 2,700 families from across the sites. Following the SSC study completion, the Simons Foundation Autism Research Initiative and the Interactive Autism Network (IAN) created a partnership--SSC@IAN--which maintains contact with SSC families who chose to be included in this effort (n = 1,325 families).

In the fall of 2014, the parents of SSC children who had consented to being informed of future study opportunities were invited to participate in a national re-

contacting study on parent perceptions and family stress and the implications for treatment seeking. All families who consented at the time of their SSC participation to be contacted about future research studies were recruited for the University of Houston's School Psychology Autism Research Collaboration (UH*sparc) project entitled *Parent Perceptions, Stress, and Treatment* (PeP). The UH*sparc PeP study team provided collaborated with SSC@IAN, who contacted families about their opportunity to participate. Families who authorized UH*sparc to contact them directly were sent a standard email explaining further study details and a link to the online survey, which included a variety of measures. Accounting for the time period during which SSC data were collected (between 2008 and 2011), as well as the three year time period between the end of the SSC data collection and the beginning of recruitment for the PeP study (Fall of 2014), children of parents invited to participate in the PeP study ranged in age from 10-to-26 years. Both mothers and fathers had the opportunity to participate in the study. Between November 2014 and June 2015, 362 parents of children from the SSC participated in the PeP data collection (44% of those invited to participate); 214 were parents of adolescents (ages 12-19).

The current study was conducted with this subsample (i.e., parents of adolescents; $n = 214$) from the larger PeP study ($n = 362$). Data were collected from the SSC parents through administration of the study measures via an online survey using the Qualtrics platform. Measures collected as part of the larger PeP study included a participation questionnaire created by the study team, the Revised Illness Perception Questionnaire for ASD (IPQ-RA; Al Anbar et al., 2010; Mire et al., 2015), the Family Adjustment Measure (FAM; Daire, Dominguez, Carlson, & Case-Pease, 2014), the Parenting Stress Index, 4th

Edition (PSI-4) or the Stress Index for Parents of Adolescents (SIPA; Sheras, Abidin, & Konold, 1998) depending upon the age of the child, and a treatment history questionnaire to collect data on the types of treatments parents selected for their children and at different ages. All study measures were included in a single Qualtrics-based survey. Those who completed the survey were able to enter a drawing for one of four iPad Minis. Data from several of the above mentioned measures were analyzed within this study, including the following: the participation questionnaire, the SIPA, the IPQ-RA, and the FAM.

Participants

Based on prior participation in the SSC, all participants in the current study have a record of confirmed clinical diagnoses of ASD. The majority (83.2%) of participants were female (i.e., child's mother or female guardian), while 16.8% were male (e.g., child's father or male guardian). Within this sample, there were 12 sets of parents for which both mother and father participated in this study. Parental age for the sample ranged from 32-to-61 years old, with an average parent age of 47.23 years ($SD = 5.15$). Participants varied in their level of education, ranging in their highest degree completed from "less than a high school degree" to those who obtained a doctorate. The mean yearly family income was \$131,279.10 ($SD = \$115,252.47$); 44.8% of the sample reported making upwards of \$100,000 per year.

The majority of parent participants (94.4%) reported sharing parenting responsibilities with another person (e.g., child's other parent, parent's spouse or partner), and 89.7% reported the person with whom they share this responsibility lives in the same household. Parents whose children were over the age of 18 were asked several additional

questions. Of those participants whose children were over age 18, 75.9% (22 parents) reported that they maintain guardianship. Of parents within the sample whose children were over the age of 18, only one reported that their child was currently employed.

Child ages ranged from 12-to-19 years ($M = 14.63$, $SD = 2.14$). The majority of parents reported that their child with ASD currently lives with them (93.9%), while 6.1% of the sample reported that their child with ASD lives outside of their home (e.g., residential school, living with a roommate, living with his/her other parent). Additional details about study participants are included in Table 1.

Measures

Participant questionnaire. To measure demographic information, a participant questionnaire was developed for the purpose of the larger (PeP) study. The measure was used to capture basic demographic information as well as information about the child's ASD. This questionnaire is included in Appendix A. The participation questionnaire included basic demographic items (e.g., parent's age, current zip code, education level, current household income). The questionnaire also asks whether the parent shares parenting responsibilities with another person, and if so, additional follow up questions were presented. Regarding the child with ASD, parents were asked to provide the child's age and if the child was over the age of 18, several follow up questions are asked regarding guardianship, living arrangements, and employment status.

The participation questionnaire also included three items created to gather information about a parent's perspectives on the severity of the child's ASD symptoms. These three items were rated on a 7-point Likert scale. Two items queried specific types of symptoms within the two broad symptom domains of ASD (i.e., social communication

and restrictive/repetitive behaviors, interests and activities). Short descriptions, based on DSM-5 (APA, 2013) language regarding severity levels, corresponded to the Likert scale and were included as anchors for ratings. For example, a rating of a “1” on the social communication item was described as “unnoticeable, even without support or treatment”, while a rating of a “7” was described as being severe “...even with very substantial support or treatment in place.” One item, which queried overall ASD symptom severity, was used in the present study (see Appendix A, item 12). The item asked parents to rate overall ASD severity and included the following descriptors of ratings: 1 (“*no symptoms*”), 3 (“*mild symptoms*”), 5 (“*moderate symptoms*”) and 7 (“*severe symptoms*”).

The Stress Index for Parents of Adolescents (SIPA). To measure overall parenting stress, the Stress Index for Parents of Adolescents (SIPA; Sheras, Abidin, & Konold, 1998) was used. The SIPA is a 112-item measure of parenting stress for parents of adolescents, ages 11-19 years. The SIPA was created to represent parenting challenges specific adolescence that contribute to parenting stress. The SIPA yields a total score, the Index of Total Parenting Stress (TS), which reflects the overall stress experienced as a function of parenting a particular adolescent. It also yields domain scores across several domains of parenting stress including an Adolescent Domain (AD), Parent Domain (PD), Adolescent-Parent Relationship Domain (APRD), and a Life Stressors (LS) scale.

Two of the domains, the Adolescent and Parent domains include subscales. The AD provides a measure of parent perceived characteristics (e.g., mood, behavior) of the adolescent. This domain has four subscales: Moodiness/Emotional Lability (MEL), Social Isolation/Withdrawal (ISO), Delinquency/Antisocial (DEL), and Failure to

Achieve or Persevere (ACH). The PD measures how parenting responsibilities affect other areas of a parents' life. This domain includes the following subscales: Life Restrictions (LR), Relationship with Spouse/Partner (REL), Social Alienation (SOC), and Incompetence/Guilt (INC). The APRD examines how a parent perceives his or her relationship with the adolescent related to areas such as communication and affection. The LS index provides a measure of the number of stressful life events (i.e., events within or outside the family environment that impact parenting) occurring in the immediate family within the past 12 months. Items in this index inquire about events such as divorce, death of a family member or close friend, or a change in income. Items within the AD, PD, and APRD require parents to select a response that best represents the extent to which they agree from the following choices: strongly disagree, disagree, not sure, agree, or strongly agree. For the LS scale, parents are instructed to indicate whether or not ("yes" or "no") a particular event has occurred.

Items across the AD, PD, and APRD (90 items) are included in the Index of Total Parenting Stress. The Life Stressors scale is separate and is not included in the Index of Total Parenting. SIPA raw scores can be converted into percentile scores, which provide a measure of parent stress relative to the normative sample used in the development of the measure. For example, a percentile score of 85 means that the score is equal to or higher than scores of 85% of parents in the original normative sample. A higher percentile score indicates greater stress. Percentile scores can be interpreted within the context of the following descriptive classifications: within normal limits (<85th percentile), Borderline (85th to 89th percentile), Clinically Significant (90th to 94th percentile), and Clinically Severe (95th to 100th percentile). SIPA raw scores can also be

converted into T scores, which have a mean of 50 and a standard deviation of 10, though authors recommend the use of percentile scores for normative comparisons.

The normative sample for the SIPA included 778 U.S. parents of adolescents ages 11-19. Parent mean age was 42.58 years ($SD = 5.75$). Respondents were mostly female (70.3%), Caucasian (79.5%), and married (77.1%). Education levels of parents ranged from 'less than high school' to graduate or professional degrees. To establish a set of clinical norms, a sample ($n = 124$) of parents of adolescents with clinical diagnoses of mood disorders, attention-deficit/hyperactivity disorder, oppositional-defiant disorder, conduct disorder, and or anxiety disorders was included in the development of the measure. The SIPA authors determined that separate norms for a) gender of parent and b) age of adolescent were not needed based upon a lack of significant effects of gender or adolescent age on the Total Parenting Stress Index.

The SIPA has good internal consistency with alpha coefficients above .90 across domains ($AD = .95$, $PD = .94$, $APR = .91$) and a Total Parenting Stress index alpha coefficient of .97. Across subscales, alpha coefficients ranged from .81 (SOC) to .90 (DEL, MEL, and ACH). Test-retest reliability was established across a four-week period with a sample of 46 parents from the normative sample. The reliability coefficient for the Total Parenting Stress Index was .93, while coefficients for the SIPA domain scores ranged from .87 (PD) to .91 (APR). Subscale test-retest reliability coefficients ranged from .74 (SOC) to .91 (ACH).

Convergent validity was established with the Parenting Alliance Inventory (PAI; Abidin & Brunner, 1995), yielding a significant inverse relationship between parenting stress and quality of the parenting alliance in a study of 713 parents of adolescents. To

examine convergent validity of the SIPA domains with other clinical measures, authors examined correlations between the SIPA and a variety of other measures including the following: The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001), the Coping Responses Inventory (CRI; Moos, 1993), the Family Adaptability and Cohesion Evaluation Scales III (FACES III; Olson, Portner, & Lavee, 1985) and the Dyadic Adjustment Scale (DAS; Spanier, 1976). Significant positive correlations were found between the Total Parenting Stress Index and the following subscales or measures: the CBCL (Internalizing, Externalizing and Total Problems) and the CRI (Cognitive Avoidance, Acceptance or Resignation and Seeking Alternative Rewards subscales). Significant negative correlations were found between the Total Parenting Stress Index and the CRI Positive Reappraisal scale and the FACES III Cohesion scale. Correlations between specific SIPA domains and these subscales of these measures varied.

Discriminant validity was established by comparison of specific normative and clinical groups expected to differ significantly in parent stress levels (e.g., SIPA clinical sample versus SIPA normative sample, parents whose adolescent did or did not have a history of delinquent behavior). Findings showed that all SIPA domain scores differentiated between parents whose children had a history of mental health treatment and those that did not, parents who reported a history of delinquent behavior and those that did not, and parent who reported that their adolescent had a history of suicidal behavior and those that did not. Significant differences in SIPA scores were also found between the normative sample and the clinical sample. Mean SIPA domain scores are available in the technical manual for a number of clinical samples such as adolescents with mood disorders and ADHD.

The manual does not include a clinical sample of adolescents with ASD. However, the SIPA has been used as an outcome measure studies of parents of adolescents with ASD (e.g., Rao & Beidel, 2009), and the companion measure for younger children, the Parenting Stress Index (Abidin, 1995), has been used extensively in the literature to examine stress in parents of children with ASD (Hayes & Watson, 2013). Within the current study, the Total Parenting Stress Index was used as a measure of overall parenting stress. For this study, SIPA raw scores were converted to t-scores to increase interpretability of results.

The Family Adjustment Measure (FAM). The Family Adjustment Measure (FAM; Daire, Dominguez, Carlson, & Case-Pease, 2014) was used to measure parents' support and coping in the proposed study. The FAM is a 30-item questionnaire examining how families adjust to having a child with special needs (i.e., a disability affecting cognitive skills, physical ability, communication, social/emotional functioning or adaptive/life skills). The measure yields four subscales; no total score is derived. The four subscales (Parental Distress, Family Based Support, Social Support, and Positive Coping) measure protective and risk factors related to family adjustment among families of children with disabilities. Items include statements about parenting a child with a disability, which are rated by a parent on a 1-to-5 Likert scale.

The 7-item Parental Distress scale measures emotions (e.g., sadness, anger) felt in relation to parenting a child with a disability, with items such as "as a parent of a child with a disability, I feel burdened." The 7-item Family-Based Support scale measures feelings of loyalty, respect and harmony within the family and marital relationship (e.g., "we respect each other in our family"). The 10-item Social Support scale measures

perceptions related to the helpfulness and use of informational and social support. The 6-item Positive Coping Skills scale measures aspects of coping related to positive adjustment, such as seeking knowledge about the child's disability, communicating concerns, planning, and resolving issues related to the child's disability.

To develop the FAM, Daire et al. (2014) examined effective coping strategies for families of children with disabilities across the literature and developed 75 initial items. A sample of 368 parents of children with disabilities participated in the validation of the measure. The study sample included parents over the age of 18 who were in monogamous relationships and had one or more children with special needs. The majority of parent respondents were female (79.9%) and White/non-Hispanic (86.1%) with a mean age of 43.58 ($SD = 8.91$). Children of participants had a variety of disabilities (e.g., autism, emotional disturbance, traumatic brain injury, orthopedic impairment) and a mean age of 10.22 ($SD = 7.13$). Results of exploratory and confirmatory factor analyses yielded four factors, which explained 51% of the variance and lead to the development of the four subscales of the measure.

The measure showed good internal consistency as evidenced by Cronbach's alpha values ranging from .81 (Positive Coping) to .92 (Parental Distress). Authors investigated the validity of the measure by examining correlations with the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), a 10-item measure of a person's perception of their stress level, and Relationship Assessment Scale (RAS; Hendrick, 1988; Hendrick, Dicke, & Hendrick, 1998), a 7-item measure of relationship satisfaction. FAM subscales were significantly correlated with the PSS with correlations ranging from $-.317$ ($p < .01$) to $.562$ ($p < .01$). The Parent Distress subscale was positively correlated

with the measure while the other three subscales (Social Support, Family-Based Support, Positive Coping) were negatively correlated. FAM subscales also showed significant correlations with the RAS ranging from $-.274$ ($p < .01$) to $.793$ ($p < .01$). Relationship satisfaction was negatively correlated with the Parent Distress scale and positively correlated with the three other subscales. While Daire et al. (2014) included 128 parents of children with Autism (34.8%) in the sample used to develop the measure; it has not been used in a study of parents of children with ASD, exclusively.

Permission to use the FAM was obtained from the first author of the measure. Subscales examined included the following: Family Based Support, Social Support, and Positive Coping. These subscales measure constructs often examined in the parenting stress literature in studies of parents of children with ASD. The Parental Distress scale was used in this study as it captures emotional reactions (e.g., anger, disappointment), which can be distinguished from other subscales that align more closely with the studies' focus on cognitions (i.e., perceptions about support) and behaviors (e.g., coping). This measure is included in Appendix B.

The Revised Illness Perception Questionnaire-ASD (IPQ-RA). Moss-Morris and colleagues (2002) created the Illness Perception Questionnaire Revised (IPQ-R), and expanded version of the IPQ, which included three additional subscales and improved psychometric properties of the measure. Additional subscales measured emotional representations of illness (i.e., emotions resulting from the illness), illness coherence (i.e., understanding the illness itself), and the cyclical nature of illness. The IPQ-R also separated the cure/control subscale into two distinct subscales, one measuring personal control and the other measuring treatment control (i.e., expectations about treatment

outcome). Moss-Morris et al., (2002) examined the factors structure of the measure, yielding seven illness perception subscales with good internal consistency (Cronbach's alpha values ranging from .79 to .89). The IPQ-R also includes two additional scales measuring illness identity (e.g., symptoms individuals associate with their illness) and perceived causes of the illness.

The IPQ-R has been used as a self report measure to examine perceptions related to variety of illnesses (e.g., Horne, Cooper, Fisher, Buick, & Weinman, 2001; Jopson & Moss-Morris, 2003) and has been used to measure caregiver perceptions about a number of health conditions (Brooks, Rowley, Broadbent, & Petrie, 2012; Sawleski, 2003). A number of versions of the measure for specific illnesses can be obtained from the Illness Perception Questionnaire website (<http://www.uib.no/ipq/index.html>).

The Revised Illness Perception Questionnaire for ASD (IPQ-RA) was created in 2010 by Al Anbar and colleagues as a modification of the IPQ-R to measure parents' perceptions of their child's ASD. Modifications were made in three main areas. Authors changed references in the IPQ-R from "illness" to "disorder" to more accurately characterize the way most parents of children with ASD conceptualize it. Secondly, language was modified to reflect a parent perspective rather than being a self-report measure. Lastly, authors modified symptoms examined to relate specifically to ASD. Al Anbar and colleagues investigated the measure in a sample of 89 parents of children with diagnoses of autism, pervasive developmental disorder, and Asperger's syndrome. Findings included internal consistency reliability ranging from acceptable to very good on six of the seven IPQ-R subscales ($\alpha = .69$ to $.81$), with a slightly lower reliability ($\alpha = .62$) on the treatment control subscale (Al Anbar et al., 2010).

The version of the IPQ-RA (Al Anbar et al., 2010), used in the current study includes slight modifications made by Mire and colleagues (2015). These modifications included a) changes in the wording of items and instructions to refer to “the child’s ASD” rather than referring to ASD as a disorder, b) listing a potential cause as “genetics” instead of “heredity-runs in my family”, and c) the inclusion of four additional potential causes of ASD from recent literature (e.g., “toxins found in vaccines/immunizations.”

The IPQ-RA used in the current study yields a total of nine subscale scores. As with other versions of this measure, no total score is computed. Seven subscales related to specific illness perceptions are yielded including the following: Timeline (acute/chronic), Consequences, Personal Control, Treatment Control, Illness Coherence, Timeline Cyclical, and Emotional Representations. The IPQ-RA also includes a Causes subscale (e.g., possible causes of ASD) and an Identity subscale, which examines specific symptoms and whether they are related to the child’s ASD. Items are rated on a 1 (“*strongly disagree*”) to 5 (“*strongly agree*”) Likert scale, and subscale total scores are derived from summing these items scores for the items on the respective subscales. The measure includes two timeline subscales: the 6-item Timeline (acute/chronic) subscale and the 4-item Timeline Cyclical subscale includes four items and measures parents’ perceptions of how cyclical or unpredictable ASD is perceived to be (e.g., “My child’s symptoms of ASD come and go in cycles”). The Personal Control subscale (6 items) relates to the extent to which a parent feels in control of the child’s ASD, and includes items like, “my actions will have no effect on my child’s ASD.” Treatment Control, a 5-item subscale, measures the extent to which parents feel treatment will be effective for their child’s ASD. For example, “The negative effects of my child’s ASD can be

prevented (avoided) by treatment.” The Illness Coherence subscale (5 items) measures the extent to which parents understand their child’s ASD. This subscale includes items about whether the child’s ASD is “puzzling” or whether it “makes sense” to the parent.

On the IPQ-RA, high scores on the Identity, Timeline (acute/chronic), Timeline Cyclical, and Consequences subscales represent stronger ‘Illness’ beliefs (e.g., many symptoms associated with ASD, a highly chronic or cyclical presentation of the illness, or many negative consequences of the illness, respectively). For the Treatment Control, Personal Control, and Illness Coherence subscales, high scores represent positive beliefs about the illness (e.g., ability to be controlled or understood) (Using and Scoring the IPQ-R, no date).

The version of the IPQ-RA as modified by Mire et al. (2015) was obtained from the first author as part of the PeP study. The current study used the illness perception items of the measure (see Appendix C, items 1 through 38 in the “personal views” section). The following illness perception subscales were used as a measure of parents’ perceptions of their child’s ASD: Treatment Control, Personal Control, Timeline Cyclical, and Illness Coherence. These subscales were selected because they focus on specific types of cognitions parents may have about the disorder, rather than emotions (e.g., Emotional Representation subscale). The timeline acute/chronic subscale was not used as a predictor in this study because it was assumed that as parents of adolescents with ASD, this sample would not be likely to view the disorder acute (e.g., something that “would pass quickly”).

Statistical Analyses

An inferential approach was used to investigate whether parents' perceptions about ASD and support had a significant effect on parenting stress, and to determine whether positive coping moderated this relationship. Variables in this study included a number of subscale and composite scores from the previously described measures. Independent variables, or predictors, within the study included four subscale scores from the IPQ-RA (Treatment Control, Personal Control, Timeline Cyclical, Illness Coherence), and two subscales of the FAM (Family Based Support and Social Support). The dependent variable, parenting stress, was the Total Parenting Stress Index score from the SIPA. Positive coping was examined as a moderator and was measured by the Positive Coping Skills subscale of the FAM. Parent perceived severity was included as a covariate and was measured by one item from the participation questionnaire. Data were analyzed using IBM SPSS Version 21 software.

Testing Assumptions. Before completing analyses, a number of assumptions were explored. To examine the normality of residuals, visual examination was conducted by examining histograms and probability-probability (P-P) plots of residual values. Data were also examined for potential outliers both visually (scatterplots and box plots) and statistically. To determine the influence of potential outliers, Cook's distance was examined and values greater than 1 were determined to be influential (Cook & Weisburg, 1982). The Durbin-Watson statistic was used to examine independence of error, with uncorrelated error terms being close to a value of 2 (Durbin & Watson, 1951). Homoscedasticity of the data was examined visually with scatterplots of the residual values plotted against predicted values. In order to check for multicollinearity, the

Variance Inflation Factor (VIF) and the tolerance statistic were examined. VIF values greater than 10 (tolerance of .10 or less) indicated problems with multicollinearity.

Power. Power analyses were conducted using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007) to determine the effect size needed to sufficiently power the intended analyses. Power analyses were completed for multiple regression tests used in this study. For 214 participants, with power set to .80, the p-value set at .05, and 6 predictors, the minimally detectable f-squared effect size was .03 for adequately powered analyses, which is considered to be small by traditional standards. For a multiple regression with 3 predictors (moderation analyses) using the same sample with power set to .80, and the p-value set at .05, the same f squared effect size (.03) was needed for adequately powered analyses.

Handling missing data. The percentage of missing data points for each variable was examined. Within this study missing data were less than 10%, and as such, only pairwise completed cases were included, which is consistent with threshold recommendations suggested by Tabachnik and Fidell (2001).

Chapter IV

Results

Descriptive analyses were used to provide information about participants' ratings on the measures used in this study. In terms of parenting stress, the sample had a mean t -score of 54.90 ($SD = 8.39$) as measured by the SIPA Total Parenting Stress Index. Based on SIPA interpretive categories, 68.5% of parents' scores fell within normal limits, 17% fell within the borderline range, 7% fell within the clinically significant range, and 7.5% fell within the clinically severe range. Parents reported an average overall severity rating of 3.97 ($SD = 1.37$), which falls between "mild" and "moderate" severity. Other measures used in this study yield raw scores and do not include descriptive classifications for interpretation. Additional data describing the sample with respect to study measures are summarized in Tables 2, 3, and 4. Pearson correlations between study variables are presented in Table 5

Primary analyses

Research question 1. The first hypothesis, that parent perceptions would significantly predict parenting stress, was supported. Investigation of this research question was represented with the following regression formula:

$$Y = \beta_o + \beta_1 X1 + \beta_2 X2 + b\beta_3 X3 + \beta_4 X4 + \beta_5 X5 + \beta_6 X6 + \varepsilon \quad (1)$$

where Y represents the predicted outcome (i.e., parenting stress), β_o is the intercept, β_1 through β_6 represent the regression slopes for the for predictor variables $X1$ through $X6$ (i.e., perception subscales for Treatment Control, Personal Control, Timeline Cyclical, Illness Coherence, Social support, Family Based Support), and ε represents the error term. Predictors within this equation were centered (by subtracting the mean from each

value) and scaled (by dividing each value by the standard deviation) to aid in the interpretability of the results.

The overall model fit was examined to determine the extent to which parent perceptions contributed to parenting stress. Regression coefficients for each of the six types of perceptions were examined for significance to determine which predictors contribute significantly to the overall model. Partial correlations were used to examine the strength and direction of relationships between individual predictors and parenting stress while controlling for the effects of other predictors in the model. Squared partial correlations were examined to determine the percentage of variance accounted for by each individual predictor found to be significant in the model.

Assumptions for this multiple regression analysis were met. There was independence of residuals as assessed by a Durbin-Watson statistic of 2.019. There was homoscedasticity of the data based on visual inspection of a scatterplot of regression standardized residuals against regression standardized predicted values. VIF and tolerance values fell within specified limits (below 10 and above .10, respectively) and no significant multicollinearity was detected. Based on an examination of Cook's distances, there were no outliers determined to be highly influential. Residuals approximated normality upon visual inspection of a normal probability plot.

For this multiple regression analysis, the following parent perceptions were examined as predictors: Treatment Control, Personal Control, Timeline Cyclical, Illness Coherence, Social Support, and Family Based Support. Together, these variables significantly predicted Total Parenting Stress $F(6,187) = 25.53, p < .001, \text{adj } R^2 = .43$.

According to these findings, the six-predictor model accounted for about 43.3% of the variance within the model.

Three predictors added significantly to the model. Family Based Support was significant, $B = -3.81$, $t(187) = -7.61$, $p < .001$, partial correlation = $-.49$, indicating a negative relation such that for every standard deviation increase in family based support, there is a 3.81 point decrease in the Total Parenting Stress t-score. Family Based Support accounted for approximately 23.62% of the variance in Total Parenting Stress.

Timeline Cyclical was significant, $B = 2.23$, $t(187) = 4.48$, $p < .001$, partial correlation = $.31$, which indicates a positive relation such that for every standard deviation increase in Timeline Cyclical, there is a 2.23 point increase in the Total Parenting Stress t-score. Perceptions about cyclical nature of the disorder accounted for 9.67% of the overall variance in Total Parenting Stress.

Treatment Control was significant, $B = -1.35$, $t(187) = -2.45$, $p < .05$, partial correlation = $-.18$, indicating a negative relation such that for every standard deviation increase in Treatment Control, there is a 1.35 point decrease in the Total Parenting Stress t-score. Treatment Control accounted for 3.10% of the overall variance in Total Parenting Stress.

Regression coefficients and standard errors for scaled predictors are listed in Table 6. It should be noted that with the inclusion of additional predictors in the model, the numerator degrees of freedom becomes inflated, which may reduce power. Given that this model included six predictors, exploratory analyses were conducted to examine whether individual predictors that were not found to be significant in the six-predictor model were significant when examined individually in simple regression analyses.

Research question 2. The second hypothesis, that positive coping would moderate the relationship between parent perceptions and parenting stress, was not supported in this study. A moderator model was used to answer this research question. Within this model, an interaction term (specific parent perception x Positive Coping Skills) was added to the basic multiple regression formula examining parent perceptions and their relations to parenting stress. Figure 1 shows a conceptual diagram of the relationship that was examined within the moderation analysis. For predictors ($X1, X2, X3, X4, X5, X6$) equations below represent the equations used to examine the effect of positive coping on each predictor (represented by a separate equation):

$$Y = \beta_0 + \beta_1 X1 + \beta_2 Z + \beta_3 XZ + \varepsilon$$

$$Y = \beta_0 + \beta_1 X2 + \beta_2 Z + \beta_3 XZ + \varepsilon$$

$$Y = \beta_0 + \beta_1 X3 + \beta_2 Z + \beta_3 XZ + \varepsilon$$

$$Y = \beta_0 + \beta_1 X4 + \beta_2 Z + \beta_3 XZ + \varepsilon$$

$$Y = \beta_0 + \beta_1 X5 + \beta_2 Z + \beta_3 XZ + \varepsilon$$

$$Y = \beta_0 + \beta_1 X6 + \beta_2 Z + \beta_3 XZ + \varepsilon$$

In each basic moderation model, Y represents the predicted outcome (i.e., parenting stress), β_0 represents the intercept, β_1, β_2 , and β_3 represent the regression slopes of predictors X, Z , and XZ , respectively. Variables $X1, X2, X3, X4, X5$, or $X6$ (in separate equations) correspond to each of the 6 perceptions used as predictors in the model, Z represents positive coping (i.e., the moderator variable), XZ represents the interaction term formed by multiplying the specific predictor ($X1, X2, X3, X4, X5$ or $X6$) and the positive coping variable, and ε represents the error term. All predictors were centered (i.e., the mean was subtracted from each individual score) to reduce the multicollinearity

introduced by entering the interaction term (Aiken & West, 1991). Predictors were also scaled by dividing the centered value by the standard deviation to aid in the interpretability of findings.

Across the six regression analyses that were conducted to examine moderation for each predictor, the majority of assumptions were met (i.e., there were no major violations). Exceptions to this included models examining moderation of the relationships between Treatment Control and Parenting Stress, and Illness Coherence and Parenting Stress. For these two analyses, the assumption of independence of error was not met. Durbin Watson values for these models were .122 and .286, respectively, which indicated possible autocorrelation.

To examine Positive Coping Skills as a moderator in the relationships between predictors and Total Parenting Stress, the predictor and the moderator variable were entered in the first step of the regression analysis. The interaction term was entered in the second step of the regression analysis. Results from the moderator analyses were null, as reported in Tables 7 - 12. Thus, Positive Coping Skills was not a significant moderator of the relationship between any of the parent perceptions examined (e.g., type of illness perception or perception of support) and Total Parenting Stress.

Research question 3. The data analysis plan for addressing the final research question was dependent upon Positive Coping Skills functioning as a significant moderator in the relationship between each predictor (i.e., perception type) and Total Parenting Stress with a measure of parent perceived severity added as a covariate within the previous moderation models to determine whether effects still hold when controlling for parent perceived ASD severity. Formulas are provided below:

$$Y = \beta_0 + \beta_1 X1 + \beta_2 Z + \beta_3 XZ + \beta_4 C1 + \varepsilon$$

$$Y = \beta_0 + \beta_1 X2 + \beta_2 Z + \beta_3 XZ + \beta_4 C1 + \varepsilon$$

$$Y = \beta_0 + \beta_1 X3 + \beta_2 Z + \beta_3 XZ + \beta_4 C1 + \varepsilon$$

$$Y = \beta_0 + \beta_1 X4 + \beta_2 Z + \beta_3 XZ + \beta_4 C1 + \varepsilon$$

$$Y = \beta_0 + \beta_1 X5 + \beta_2 Z + \beta_3 XZ + \beta_4 C1 + \varepsilon$$

$$Y = \beta_0 + \beta_1 X6 + \beta_2 Z + \beta_3 XZ + \beta_4 C1 + \varepsilon$$

where $C1$ is introduced as the covariate (parent perceived ASD severity). Y represents the predicted outcome (Total Parenting Stress), β_0 represents the intercept, β_1 , β_2 , and β_3 represent the regression slopes of predictors X , Z , and XZ , respectively. Variables $X1$, $X2$, $X3$, $X4$, $X5$, or $X6$ (in separate equations) correspond to each of the six perception types used as predictors in the model and Z represents positive coping (i.e., the moderator variable). XZ represents the interaction term formed by multiplying the specific predictor ($X1$, $X2$, $X3$, $X4$, $X5$ or $X6$) and Positive Coping Skills.

The third research question was intended to explore whether parent-perceived ASD severity affected the previously explored moderation. Considering that individuals diagnosed with ASD are a heterogeneous group with respect to symptom presentation and severity, it is important to examine the impact of parent perceptions and social support on parenting stress, while taking into account parents' perceptions of their child's ASD severity. Given that positive coping did not emerge as a significant moderator in any of the relationships between perceptions and parenting stress, results could not be interpreted as planned. However, ASD severity was added to the null moderation models. Parent perceived ASD severity did significantly contributed to the overall variance within each model. Results of the six models examined are presented in Tables 13 – 18.

Exploratory analyses. In order to explore whether predictors found to be non-significant in the first research question (Social Support, Personal Control, and Illness Coherence) may be significant given additional power, simple linear regressions were run for each predictor separately. Given additional power by examining single predictors rather than the six predictors included in the original model, these predictors contributed significantly to Total Parenting Stress. Social Support was a significant predictor of Total Parenting Stress, $F(1, 195) = 23.27, p < .001, \text{adj } R^2 = .10$. Personal Control was a significant predictor of Total Parenting Stress, $F(1, 197) = 16.12, p < .001, \text{adj } R^2 = .08$. Illness Coherence was a significant predictor of Total Parenting Stress, $F(1, 196) = 17.54, p < .001, \text{adj } R^2 = .07$. Social Support, Personal Control, and Illness coherence (in separate models) accounted for 10.2%, 7.7%, and 7.1%, of the overall variance in Total Parenting Stress, respectively.

Chapter V

Discussion

The purpose of this study was to better understand how parent perceptions contribute to the stress experienced by parents of adolescents with ASD. Three specific research questions were examined. The first research question was aimed at understanding whether parents' perceptions about their child's ASD and their social and family support significantly predicted parenting stress. As expected, results of the study indicated that parents' perceptions did contribute to parenting stress. This finding lends support to theories such as the Double ABCX Model of Family Adjustment (McCubbin & Patterson, 1983), which emphasizes the importance of cognitive appraisal in the process of adjusting to a particular stressor. There is no existing literature examining parent perception of ASD from the perspective of illness representation (the theoretical basis for the IPQ-RA) as it relates to parenting stress in families of children or adolescents with ASD. However, findings from health literature show that illness-related perceptions are associated with outcomes such as psychological well-being, social functioning, and vitality (Haggar & Orbell, 2003).

Of the six different perception types examined in this study, findings indicated that three were particularly important in understanding parenting stress: a) perceived support within the family, b) perceptions about the ability of treatment to control ASD, and c) perceptions the cyclical nature of the disorder. Greater perceived family support and perceptions regarding treatment control were related to lower parenting stress, while perceptions about the cyclical nature of the disorder were related to higher parenting stress.

Relations between ASD-specific perceptions (Treatment Control and Timeline Cyclical) and parenting stress in this study were consistent with findings from illness perception literature. According to Haggard and Orbell (2003), illness perceptions related to controllability were associated with more positive well-being and adaptive outcomes, while perceptions related to illness timeline were negatively related to such outcomes.

Findings of the current study suggest that perceptions about the cyclical nature of the disorder may ultimately make parenting more challenging and stressful, whereas perceptions related to treatment control may have the opposite effect (i.e., decreased parenting challenges or parenting perceived as less stressful). With the complexity involved in selecting treatments for children with ASD (Herbert, 2014) as well as the significant financial and personal resources (e.g., energy, time) needed to carrying out treatment (Myers et al., 2009; Vohra, 2014), it follows that parents' views on whether treatment will control symptoms would contribute to stress levels considering the resources invested.

It is not surprising that parents' views of ASD as cyclical were related to higher parenting stress given that the Timeline Cyclical subscale as measured in this study is defined by frequent change and unpredictability. Viewing the disorder as cyclical in nature is likely to impact the caretaking role, as parents may not know what to expect from their child on a day-to-day or long-term basis (i.e., outcomes later in life). Aside from the general challenges parents may face when ASD feels unpredictable, it is possible that parents' views of the disorder as being cyclical in nature would further complicate the process of treatment selection.

It was expected that both Social Support and Family Based Support would significantly contribute to parenting stress, as higher levels of support typically relate to more positive parent and family outcomes (Cohen & Willis, 1985; Tehee et al., 2009). However, only Family Based Support made a significant contribution to Total Parenting Stress in the current study. Further, Family Based Support was the strongest predictor of parenting stress within this study. This suggests that perceived support within the family is a particularly important kind of support within this sample. Feelings of support within the family may serve as a resource for parents, lessening the experience of stress. It may also be that perceived support within the family relates to actual assistance from family members in taking on difficult parenting tasks and responsibilities, which could decrease the stress experienced by a parent.

That Social Support was not a significant contributor to parenting stress is surprising, given the literature on the association between social support and positive parent outcomes and lower stress (Cohen & Willis, 1985; Schieve et al., 2011). While findings in the current study seems to contradict previous literature, social support can be broadly defined and studies examining support rarely separate out support within the family from general social support (e.g., support groups, friends). However, the measure used in this study (e.g., the FAM) includes a distinct scale to separate out family based support from social support. For this reason, it is possible that the way in which “support” was measured in this study resulted in a seeming divergence from other literature in the area.

It possible that within this sample, feeling supported within the family was impactful in a way that support from others (e.g., support groups, friends) was not.

Additionally, the construct of social support as defined by the Social Support subscale of the FAM includes items related to community support (e.g., support groups) and resources and informational support. It may be that resources and informational support are less impactful for families of adolescents than they might be for parents of younger children whose diagnoses are likely more recent. It is possible that families with more recent diagnoses have less experience and understanding of the disorder and than families who have been dealing with the disorder for a longer period of time (i.e., parents of adolescents).

Further, these findings could be unique to this specific sample of parents of adolescents. As a function of participation in the SSC, a rigorous study requiring participation of both parents, support within the family may be more readily available than it might be in samples that better represent different family structures (e.g., single parent families). It is also possible that social support may be perceived as less important when family support is higher (i.e., “outside” social support is not needed). Families lacking family support, on the other hand, may place a higher value on these “outside” sources of support.

Based on previous literature associating problem focused coping with better family outcomes (Smith et al., 2008), it was expected that that parents’ use of positive coping (e.g., actively seeking information about ASD and communicating needs) would moderate the relationship between perceptions and parenting stress. This was based on literature such as Smith et al. (2008), who found that parent coping styles had “buffering” effects on the relationship between ASD symptom severity and parent mental health outcomes among parents of adolescents.

In the current study, it was hypothesized that positive coping would act as a “buffer” against parenting stress for perceptions that increase stress (e.g., ASD as cyclical and unpredictable) and act synergistically (i.e., enhance the relationship) for those perceptions related to lower parenting stress (e.g., perceptions that treatment can control ASD). Contrary to study hypotheses, positive coping did not have a significant effect on relationships between specific parent perceptions and parenting stress.

The fact that positive coping did not function as hypothesized in the current study may relate to the specific type of coping examined. The FAM subscale used to measure positive coping within this study is focused on coping mechanisms that are active and problem focused in nature, as these are typically regarded in the literature as being protective against stress and mental health difficulties among parents of children with disabilities (Bristol, 1987; Daire et al., 2014; Smith et al., 2008). However, findings from Smith et al. (2008) showed that parents of adolescents with ASD used emotion focused coping, as well as problem-focused coping. It is possible that for this specific sample, other types of coping, such as emotion-focused coping might have impacted outcomes.

Considering that individuals diagnosed with ASD are a heterogeneous group with respect to symptom presentation and severity, the third aim of this study was to examine the effect of positive coping on the relationships between parent perceptions and parenting stress, while taking into account parents’ perceptions of their child’s ASD severity. Due to findings of the previous study hypothesis (i.e., positive coping did *not* affect the nature of relationships between perceptions and parenting stress), the effect of severity on this relationship could not be examined. Nevertheless, parent perceived severity did contribute to overall parenting stress, such that increases in parent perceived

severity were associated with increases in parenting stress. This finding is consistent with previous findings associating greater ASD severity with greater parenting stress (Ingersoll & Hambrick, 2011; Kissel & Nelson, 2014), despite the fact that the construct of parent perceived ASD severity in this study was distinct from measures of ASD severity in other studies.

Because only three of the six predictors examined in this study contributed uniquely to parenting stress, and the fact that a large portion of the variance in parenting stress remained unexplained, several additional analyses were conducted to further explore study hypotheses. Predictors that did not significantly contribute to overall parenting stress when examined along with the other six predictors (i.e., Social Support, Personal Control, Illness Coherence) were examined independently as predictors of parenting stress. Findings showed that these three perception types did, individually, contribute to parenting stress, though contributions were small. Additional research is needed to better understand the contributions of these perceptions as well as other factors that might provide additional understanding about the parenting stress experienced by parents of adolescents.

Clinical Implications

Given that parents' perceptions regarding family based support, the ability of treatment to control ASD, and the cyclical nature of the disorder played a significant role in predicting parenting stress, these may be helpful factors to consider in clinical practice. Importantly, these specific factors (i.e., perceptions) may be amenable to change. For example, cognitive behavioral methods may be used to restructure cognitions that may contribute to higher parenting stress (e.g., ASD as cyclical and unpredictable or views

that treatment will not be effective). Perception types that contributed to parenting stress in this study may also be important aspects to assess and consider to create individualized treatment plans for families of adolescents with ASD. Further, such perceptions may be helpful to consider in the creation of novel treatment programs aimed at reducing or preventing the stress experienced by parents of adolescents with ASD. As Cappe, Wolff, Bobet, and Adrien (2011) noted, there is a need for cognitive-behavioral interventions aimed at modifying dysfunctional beliefs regarding raising a child with ASD and educating parents on positive ways to handle stress.

Family Based Support appears to have the greatest effect on parenting stress of all of the perception types examined in the study, and this has major implications for treating families of adolescents with ASD. These findings emphasize the need for treatment focused on bolstering family relationships. This is particularly important given the bidirectional relationship that has been identified between parental stress and behavioral difficulties in families of individuals with ASD (Osborne et al., 2009; Lecavlier et al.; Zaidman-Zait et al., 2014). Based on this research, parental stress reduction may also improve outcomes for the adolescent with ASD. This underscores the importance of targeting not just the adolescent with ASD, but the entire family, in treatment. Further, family intervention provided during adolescence may improve the transition to adulthood, a pivotal stage during which evidence-based interventions for those with ASD are lacking (Taylor et al., 2012; Wong et al., 2013).

Limitations

While this study has important implications for research and clinical practice focused on families of adolescents with ASD, there are several limitations that should be

considered with regards to interpretation of the findings. Several factors related to the study sample may limit generalizability of the findings. First, families within this study had a high average family income, and the majority shared parenting responsibilities within another parent living within the same household. Due to this, results may not generalize to families with lower income levels or different family structures who may have different experiences with stress and coping. Second, the majority of participants were female, though 16.8% were male caregivers, but differences in the perceptions of male and female caregivers were not examined as part of this study.

Limitations with regard to measurement also should be considered. While the SIPA (Sheras, Abidin, & Konold, 1998) has been used in studies of parents of children with ASD, the measure was not created for use with this population and may not adequately capture aspects of parenting stress relevant to this specific sample. Additionally, independent variables within this study were examined using subscales of several measures (i.e., the IPQ-RA and FAM).

These subscales were selected from measures that had been developed (or adapted in the case of the IPQ-RA) for use with families of children with disabilities. The FAM (Daire et al., 2014) was created for use with parents of children with a wide variety of disabilities (e.g., physical, developmental). While 34.8% of the normative sample for this measure had children with ASD, the measure was not specifically normed for this population. The IPQ-RA, while adapted specifically for families of children with ASD, has not been normed on families of adolescents. Specific subscales from these measures were appropriate selections from this study because they allowed for the examination of types of perceptions that have been linked in previous research to parenting stress or

other parent and family outcomes. However, the use of subscales (as compared to a measure with a greater number of items) may affect the reliability and validity of the measure.

Lastly, the measure of parent perceived severity used in this study consisted of a one-item rating. This item was created for use in this study and was intended to provide a quantified “snapshot” of parents’ views on the current severity of their child’s overall ASD symptoms. There are no existing psychometric properties available for this measure. Due to this, it is unclear how precisely this item reflects parents’ views of ASD symptom severity and whether the item may also reflect parent perceptions of other aspects of a child’s overall presentation (e.g., cognitive and adaptive functioning, behavioral problems).

Future Directions

Perceptions examined in this study explained a portion of the variance in parenting stress, but ultimately, more information is needed to understand the complexity of factors contributing to parenting stress within this population. There are a number of additional variables not examined in the present study that may improve understanding of the stress experienced by this particular group of parents.

Child behavioral problems have been associated with increased parenting stress and poorer parent mental health in previous studies (e.g., Lecavalier et al., 2006; Lounds et al., 2007). The present study examined parents’ perceptions about ASD, but did not include specific measures of behavioral problems. Future studies should examine the impact of specific behavioral problems alongside perceptions about ASD.

Perceived support within the family was an important contributor to parenting stress within this study. Items in the Family Based Support subscale touch on a variety of ways families may feel supported, such as “dealing with stress as a family”, “marital harmony” or “respect”. Future studies should delve deeper into family-related factors and perceptions to better understanding how such constructs might contribute to parenting stress, as these may have important implications for family intervention. For example, previous studies have examined aspects of the family such as family coherence (McStay et al., 2014). Additionally, demographic characteristics of families should be examined within the context of parenting stress and family support. For example, information such as the number of family members living in the home, or the number of family members who share caretaking responsibilities may impact these variables.

Given that perception types examined in this study originated adapted from health-related research, there may be other helpful constructs or measures that could be examined in the context of parenting stress in parents of adolescents with ASD. For example, a measure of illness uncertainty (e.g., Mishel, 1983) may be a worthy addition to future studies as this construct is conceptualized as a cognitive stressor associated with poor adjustment (Wright, Afari, & Zautra, 2009).

Due to the fact that perceptions are not static (i.e., fluid across time), it may be important to examine differences in parenting perceptions across different age groups (e.g., early childhood, middle childhood, adolescence, adulthood). It may be that findings in this study would differ from findings of a similar study with a sample of parents of young children or adults. Further, parents’ perceptions may vary related to the changes in ASD symptoms and comorbid symptoms that take place across the lifespan,

and studies examining parents' perceptions across the course of several years are warranted.

Due to the fact that this study included a sample of parents whose adolescents ranged from age 12 to 19, there was likely variability in the challenges parents faced depending on child age. For example, adolescents within this age range may be in different stages of puberty, may be experiencing different kinds of life transitions, and families may be at different places in the process of transition planning. Given these possible sources of variability, it may also be important for future studies to examine whether the age of the adolescent plays a role in parenting stress.

Similarly, it may be beneficial for future studies of parents of adolescents with ASD to collect data on particular types of challenges faced by families. For example, parents of adolescents who are just beginning puberty may be dealing with different challenges than those further along in their physical development. This may be important to consider given that adolescents progress through these physical, social, and emotional changes at different speeds. Additionally, parents may be at different stages of the transition planning process, which likely has some bearing on the stress families' experiences. The creation of a measure specific to the challenges commonly faced by parents of adolescents with ASD may allow for a better understanding of how specific parenting challenges during this transitional time relate to overall parenting stress.

Summary & Conclusions

While the existence of higher levels of parenting stress among parents of children with ASD is well established, even when compared to children with other diagnoses—*why* this occurs is less understood (Hayes & Watson, 2013). Theoretical models such as

the Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983) highlight the role of cognitive appraisal in the process of understanding and coping with stressors and the kinds of parent perceptions examined within the study represent one way of examining the cognitive appraisals parents may form during the process of caring for a child with ASD.

The study focused on a parents of adolescents with ASD, a subgroup less often represented in the literature than studies that include younger children—despite the very unique parenting and family challenges that arise during this developmental period (Smith & Anderson, 2013). Given that constructs examined in this study (i.e., perceptions, coping, stress) are known to change over time, an examination of factors contributing to parenting stress during this time is warranted as it may look different during adolescence than during childhood or adulthood.

Results of this study contribute to the literature by investigating one particular avenue, parent perceptions, that is a part of the complex array of factors contributing to the parenting stress. Specifically, results underscore the importance of understanding parents' perceptions about ASD and family support in research and clinical practice. Further, the study highlights the need for continued research aimed at better understanding the wide variety of factors affecting parenting stress in parents of adolescents with ASD.

References

- Abidin, R. R., & Brunner, J. F. (1995). Development of a parenting alliance inventory. *Journal of Clinical Child Psychology, 24*(1), 31-40.
- Al Anbar, N. N., Dardennes, R. M., Prado-Netto, A., Kaye, K., & Contejean, Y. (2010). Treatment choices in autism spectrum disorder: The role of parental illness perceptions. *Research in Developmental Disabilities, 31*(3), 817-828.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Amr, M., Raddad, D., El-Mehesh, F., Bakr, A., Sallam, K., & Amin, T. (2012). Comorbid psychiatric disorders in Arab children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6*, 240–248.
- Avdi, E., Griffin, C., & Brough, S. (2000). Parents' constructions of the 'problem' during assessment and diagnosis of their child for an autistic spectrum disorder. *Journal of Health Psychology, 5*(2), 241-54.
- Baghdadli, A., Pry, R., Michelon, C., & Rattaz, C. (2014). Impact of autism in adolescents on parental quality of life. *Quality of Life Research, 23*(6), 1859-1868.
- Baker, J., Seltzer, M., Greenberg, J., & Kaslow, N. J. (2011). Longitudinal effects of adaptability on behavior problems and maternal depression in families of adolescents with autism. *Journal of Family Psychology, 25*(4), 601-609.
- Ballenski, C., & Cook, A. (1982). Mothers' perceptions of their competence in managing selected parenting tasks. *Family Relations, 31*(4), 489-494.

- Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*, (2), 551-561.
- Bauman, M. (2010). Medical comorbidities in autism: Challenges to diagnosis and treatment. *Neurotherapeutics*, 7(3), 320-327.
- Beck, J. S. (2011). *Cognitive behavior therapy: Basics and beyond*. New York: Guilford Press.
- Bellini, S. (2004). Social skill deficits and anxiety in high-functioning adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 19(2), 78-86. doi: 10.1177/10883576040190020201
- Bishop, S. L., Richler, J., Cain, A. C., & Lord, C. (2007). Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal on Mental Retardation*, 112(6), 450-461.
- Bourdeau, T. L., Mullins, L. L., Carpentier, M. Y., Colletti, C. J. M., & Wolfe-Christensen, C. (2007). An examination of parenting variables and child self-care behavior across disease groups. *Journal of Developmental and Physical Disabilities*, 19, 125-134.
- Bristol, M. M. (1987). Mothers of children with autism or communication disorders: successful adaptation and the double ABCX model. *Journal of Autism and Developmental Disorders*, 17(4), 469-86.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, Mass: Harvard University Press.

- Brooks, S., Rowley, S., Broadbent, E., & Petrie, K. J. (2012). Illness perception ratings of high-risk newborns by mothers and clinicians: Relationship to illness severity and maternal stress. *Health Psychology, 31*(5), 632-639.
- Cadman, T., Eklund, H., Howley, D., Hayward, H., Clarke, H., Findon, J., ... Glaser, K. (2012). Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. *Journal of the American Academy of Child & Adolescent Psychiatry, 9*(9), 879-888.
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J. L. (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Quality of Life Research, 20*(8), 1279-1294.
- Charman, T., Taylor, E., Auriol, D., Cockerill, H., Brown, J., & Baird, G. (2005). Outcome at 7 years of children diagnosed with autism at age 2: Predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time. *Journal of Child Psychology and Psychiatry, 46*(5), 500-513.
- Christensen, D. L., Baio, J., Braun, K. V., Bilder, D., Charles, J., Constantino, J. N., ... Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years — autism and developmental disabilities monitoring network, 11 Sites, United States, 2012. *MMWR Surveill Summ: 65*(No. SS-3):1–23. Retrieved from <http://dx.doi.org/10.15585/mmwr.ss6503a1>
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological bulletin, 98*(2), 310.

- Cook, R. D., & Weisberg, S. (1982). *Residuals and influence in regression*. New York, NY: Chapman & Hall.
- Cousino, M., & Hazen, R. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*, 38(8), 809-828.
- Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders*, 44(6), 1261-1274.
- Crníc, K. A., & Greenberg, M. T. (1990). Minor parenting stresses with young children. *Child Development*, 61(5), 1628-37.
- Daire, A. P., Dominguez, V. N., Carlson, R. G., & Case-Pease, J. (2014). Family adjustment measure: Scale construction and validation. *Measurement and Evaluation in Counseling and Development*, 2, 91-101.
- Daire, A. P., Munyon, M. D., Carlson, R. G., Kimemia, M., & Mitcham, M. (2011). Examining distress of parents of children with and without special needs. *Journal of Mental Health Counseling*, 33(2), 177.
- Davis, N., & Carter, A. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism & Developmental Disorders*, 38(7), 1278-1291.
- Davis, T. E., Hess, J. A., Moree, B. N., Fodstad, J. C., Dempsey, T., Jenkins, W. S., & Matson, J. L. (2011). Anxiety symptoms across the lifespan in people diagnosed with autistic disorder. *Research in Autism Spectrum Disorders*, 5(1), 112-118.

- Deater-Deckard, K., Scarr, S., & Levant, R. F. (1996). Parenting stress among dual-earner mothers and fathers: Are there gender differences? *Journal of Family Psychology, 10*(1), 45-59.
- Eaves, Linda C., & Ho, Helena H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(4), 739-747.
- Edwards, T. L., Watkins, E. E., Lotfizadeh, A. D., & Poling, A. (2012). Intervention research to benefit people with autism: How old are the participants? *Research in Autism Spectrum Disorders, 6*(3), 996-999.
- Eriksson, M., Westerlund, A., Hedvall, J., Åmark, &., Gillberg, P., & Fernell, C. (2013). Medical conditions affect the outcome of early intervention in preschool children with autism spectrum disorders. *European Child & Adolescent Psychiatry, 22*(1), 23-33.
- Esbensen, A., Seltzer, J., Lam, M., & Bodfish, M. (2009). Age-related differences in restricted repetitive behaviors in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(1), 57-66.
- Farley, M. & McMahon, B. (2014). Range of outcomes and challenges in middle and later life. In F. R. Volkmar, B. Reichow & J. C. McPartland (Eds.), *Adolescents and Adults with Autism Spectrum Disorders* (211-238). New York: Springer.
- Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191.
- Fischbach, G. D., & Lord, C. (2010). The simons simplex collection: A resource for identification of autism genetic risk factors. *Neuron, 68*, 192-5.

doi:10.1016/j.neuron.2010.10.006

- Fong, P. (1991). Cognitive appraisals in high- and low-stress mothers of adolescents with autism. *Journal of Consulting and Clinical Psychology*, 59(3), 471-4.
- Gjevik, E., Eldevik, S., Fjæran-Granum, T., & Sponheim, E. (2011). Kiddie-SADS reveals high rates of DSM-IV disorders in children and adolescents with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 41, 761–769.
- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976.
- Grzadzinski, R., Huerta, M., & Lord, C. (2013). DSM-5 and autism spectrum disorders (ASDs): An opportunity for identifying ASD subtypes. *Molecular Autism*, 4(12), 1-6.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *18*(2), 141-184.
- Hall, H., & Graff, J. (2011). The Relationships Among Adaptive Behaviors of Children with Autism, Family Support, Parenting Stress, and Coping. *Issues in Comprehensive Pediatric Nursing*, 34(1), 4-25.
- Hall, H., Neely-Barnes, S., Graff, J., Krcek, T., Roberts, R., & Hankins, J. (2012). Parental stress in families of children with a genetic disorder and the resiliency model of family stress, adjustment, and adaptation. *Issues in Comprehensive Pediatric Nursing*, 35(1), 24-44.
- Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and

- fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35(5), 635-644.
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 3, 629-642.
- Hebert, E. B., & Koulouglioti, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in Comprehensive Pediatric Nursing*, 33(3), 149-163.
- Hergenhahn, B. R. (1992). *An introduction to the history of psychology*. Belmont, CA: Wadsworth Pub. Co.
- Horne, R., & Weinman, J. (2002). Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychology and Health*, 17(1), 17-32.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45(2), 212-229.
- Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, 57(5), 275-283.
- Ingersoll, B., & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 337-344.

- Jopson, N. M., & Moss-Morris, R. (2003). The role of illness severity and illness representations in adjusting to multiple sclerosis. *Journal of Psychosomatic Research*, 54(6), 503-511.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43(2), 225-232.
- Kissel, S., & Nelson, W. (2014). Parents' perceptions of the severity of their child's autistic behaviors and differences in parental stress, family functioning, and social support. *Focus on Autism and Other Developmental Disabilities*, 31(2), 152-160.
- Koegel, L. K., Detar, W.J., Fox, A. & Koegel, R. L. (2014). Romantic relationships, sexuality, and autism spectrum disorders. In F. R. Volkmar, B. Reichow & J. C. McPartland (Eds.), *Adolescents and Adults with Autism Spectrum Disorders*. New York: Springer.
- Lai, W. W., & Oei, T. S. (2014). Coping in parents and caregivers of children with autism spectrum disorders (ASD): a review. *Review Journal of Autism and Developmental Disorders*, 1(3), 207-224.
- La Malfa, G., Lassi, S., Bertelli, M., Salvini, R., & Placidi, G. F. (2004). Autism and intellectual disability: A study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research*, 48(3), 262-267.
- Laugeson, E. A., & Ellingsen, R. (2014). Range of outcomes and challenges in middle and later life. In F. R. Volkmar, B. Reichow & J. C. McPartland (Eds.), *Adolescents and Adults with Autism Spectrum Disorders* (211-238). New York: Springer.

- Lazarus, R. S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, 55, 234–247.
- Lazarus, R. S., & Folkman, S. (1984). *Stress appraisal, and coping*. New York: Springer.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183.
- Leventhal, H. (1970). Findings and theory in the study of fear communications. *Advances in Experimental Social Psychology*. 5, 119-186.
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E., Patrick-Miller, L., & Robitaille, C. (1997). Illness representations: Theoretical foundations. In K. J. Petrie & J. Weinman (Eds.), *Perceptions of health and illness*. (pp. 19-45). Amsterdam: Harwood Academic Publishers.
- Leventhal, H., Nerenz, D. R., & Steele, D. S. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor, and J. E. Singer (Eds.), *Handbook of psychology and health- Volume IV* (pp. 219-252). Amsterdam: Harwood Academic Publishers.
- Lin, L. Y., Orsmond, G. I., Coster, W. J., & Cohn, E. S. (2011). Families of adolescents and adults with autism spectrum disorders in Taiwan: The role of social support and coping in family adaptation and maternal well-being. *Research in Autism Spectrum Disorders*, 5(1), 144-156.
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2012). *Autism diagnostic observation schedule second edition manual*. Los Angeles, CA: Western Psychological Services.

- Lounds, J., Seltzer, M. M., Greenberg, J. S., & Shattuck, P. (2007). Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal well-being. *American Journal on Mental Retardation*, 112, 401–417.
- Manning, M. M., Wainwright, L., & Bennett, J. (2011). The double ABCX model of adaptation in racially diverse families with a school-age child with autism. *Journal of Autism and Developmental Disorders*, 3, 320-331.
- Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities: A Multidisciplinary Journal*, 30(6), 1107-1114.
- McCubbin, H., & Patterson, J. (1983). The family stress process: The double ABC model of adjustment and adaptation. *Marriage & Family Review*, 6(1-2), 7-37.
- McStay, R. L., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model. *Journal of Autism and Developmental Disorders*, 44(12), 3101-3118.
- Mire, S. S., Gealy, W., Kubiszyn, T., Burrige, A. B., & Goin-Kochel, R. P. (2015). Parent perceptions about autism spectrum disorder influence treatment choices. *Focus on Autism and Other Developmental Disabilities*. doi: 10.1177/1088357615610547
- Mishel, M. H. (1983). Parents' perception of uncertainty concerning their hospitalized child. *Nursing Research*, 32, 324–330.

- Morgan, S. B. (1988). The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism and Developmental Disorders*, 18(2), 263-280.
- Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology & Health*, 17(1), 1-16.
- Mullins, L. L., Wolfe-Christensen, C., Pai, A. L. H., Carpentier, M. Y., Gillaspy, S., Cheek, J., & Page, M. (2007). The relationship of parental overprotection, perceived child vulnerability, and parenting stress to uncertainty in youth with chronic illness. *Journal of Pediatric Psychology*, 32, 973–982.
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3(3), 670-684.
- O'Brien, M. (2007). Ambiguous loss in families of children with autism spectrum disorders. *Family Relations*, 56(2), 135-146.
- Orsmond, G. I., Lin, L., & Seltzer, M. (2007). Mothers of adolescents and adults with autism: Parenting multiple children with disabilities. *Intellectual and Developmental Disabilities*, 45(4), 257-270.
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(4), 313-320.

- Osborne, L., & Reed, P. (2009). The relationship between parenting stress and behavior problems of children with autistic spectrum disorders. *Exceptional Children*, 76(1), 54-73.
- Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with asperger syndrome: an application of the double ABCX model of family adjustment. *Autism: The International Journal of Research and Practice*, 9(2), 191-212.
- Pasley, K., & Gecas, V. (1984). Stresses and satisfactions of the parental role. *The Personnel and Guidance Journal*, 62(7), 400-404.
- Paynter, J., Riley, E., Beamish, W., Davies, M., & Milford, T. (2013). The double ABCX model of family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service. *Research in Autism Spectrum Disorders*, 7(10), 1183-1195.
- Pozo, P., Sarriá, E., & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model. *Journal of Intellectual Disability Research*, 5, 442-458.
- Putnick, D., Bornstein, M., Hendricks, C., Painter, K., Suwalsky, J., & Collins, W. (2010). Stability, continuity, and similarity of parenting stress in European American mothers and fathers across their child's transition to adolescence. *Parenting*, 10(1), 60-77.
- Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification*, 33(4), 437-451.

- Rosenthal, M., Wallace, G., Lawson, R., Wills, M., Dixon, E., Yerys, B., . . . Rao, Stephen M. (2013). Impairments in real-world executive function increase from childhood to adolescence in autism spectrum disorders. *Neuropsychology*, 27(1), 13-18.
- Rutter M, Le Couteur A, Lord C. (2003). *Autism diagnostic interview revised manual*. Los Angeles, CA: Western Psychological Services.
- Salewski, C. (2003). Illness representations in families with a chronically ill adolescent: Differences between family members and impact on patients' outcome variables. *Journal of Health Psychology*, 8(5), 587-98.
- Schieve, L. A., Boulet, S. L., Kogan, M. D., Yeargin-Allsopp, M., Boyle, C. A., Visser, S. N., ... & Rice, C. (2011). Parenting aggravation and autism spectrum disorders: 2007 national survey of children's health. *Disability and Health Journal*, 4(3), 143-152.
- Seltzer, M. M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C., & Stawski, R. S. (2010). Maternal cortisol levels and behavior problems in adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, 40(4), 457-469.
- Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*, 33(6), 565–581.
- Seltzer, M., Shattuck, P., Abbeduto, L., Greenberg, J., & Piven, Joseph. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 10(4), 234-247.

Shattuck, P. T., Seltzer, M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., . . .

Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37(9), 1735-1747.

Sheras, P. L., Abidin, R. R., & Konold, T. R. (1998). *Stress index for parents of adolescents*. Psychological Assessment Resources, Inc.: Lutz, FL.

Shumway, S., Thurm, A., Swedo, S. E., Deprey, L., Barnett, L., Amaral, D. G., . . .

Ozonoff, S. (2011). Brief report: Symptom onset patterns and functional outcomes in young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 41(12), 1727-1732.

Sikora, D., Vora, P., Coury, D., & Rosenberg, D. (2012). Attention-deficit/hyperactivity disorder symptoms, adaptive functioning, and quality of life in children with autism spectrum disorder. *Pediatrics*, 130, 91-97.

Siman-Tov, A., & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders*, 41, 879–890. doi:10.1007/s10803-010-1112-x.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008).

Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(8), 921.

- Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism: The International Journal of Research and Practice*, 6(4), 397-409.
- Small, S., Eastman, A., & Cornelius, G. (1988). Adolescent autonomy and parental stress. *Journal of Youth and Adolescence*, 17(5), 377-391.
- Smith, L. E., & Anderson, K. A. (2013). The roles and needs of families of adolescents with ASD. *Remedial and Special Education*, 35(2), 114-122.
- Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2012). Adults with autism: Outcomes, family effects, and the multi-family group psychoeducation model. *Current Psychiatry Reports*, 14, 732–738. doi:10.1007/s11920-012-0328-1
- Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2014). The family context of autism spectrum disorders: Influence on the behavioral phenotype and quality of life. *Child and Adolescent Psychiatric Clinics of North America*, 23, 145-155.
- Smith, L. E., Greenberg, J. S., & Seltzer, M. M. (2012). Social support and well-being at mid-life among mothers of adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 1818–1826. doi:10.1007/s10803-011-1420-9
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40(2), 167-178.
- Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A. S. (2008). A comparative analysis of well-being and coping among mothers of toddlers and

- mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders*, 38(5), 876-889.
- Strang, J. F., Kenworthy, L., Daniolos, P., Case, L., Wills, M. C., Martin, A., & Wallace, G. L. (2012). Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Research in Autism Spectrum Disorders*, 6(1), 406-412.
- Stuart, M., & McGrew, J. H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders*, 3, 86–97.
doi:10.1016/j.rasd.2008.04.006
- Sukhodolsky, Denis G., Scahill, Lawrence, Gadow, Kenneth D., Arnold, L. Eugene, Aman, Michael G., McDougle, Christopher J., . . . Vitiello, Benedetto. (2008). Parent-rated anxiety symptoms in children with pervasive developmental disorders: Frequency and association with core autism symptoms and cognitive functioning. *Journal of Abnormal Child Psychology*, 36(1), 117-128.
- Taylor, J. L., McPheeters, M. L., Sathe, N. A., Dove, D., Veenstra-VanderWeele, J., & Warren, Z. (2012). A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics*, 130(3), 531.
- Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 34-42.
- Tunali, B., & Power, T. G. (1993). Creating satisfaction: A psychological perspective on stress and coping in families of handicapped children. *Journal of child psychology and psychiatry*, 34(6), 945-957.

- Tunali, B., & Power, T., G. (2002). Coping by redefinition: Cognitive appraisals in mothers of children with and without autism. *Journal of Autism and Developmental Disorders*, 32(1), 25-34.
- Using and Scoring the IPQ-R. (no date). Retrieved from <http://www.uib.no/ipq/>
- Van Steensel, F. J., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical child and family psychology review*, 14(3), 302-317.
- Vasa, R. A., Kalb, L., Mazurek, M., Kanne, S., Freedman, B., Keefer, A., . . . Murray, D. (2013). Age-related differences in the prevalence and correlates of anxiety in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7(11), 1358-1369.
- Vohra, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*, 18(7), 815-826.
- Volkmar, F. R., Reichow, B., & McPartland, J. C. (2014). *Adolescents and adults with autism spectrum disorders*. New York: Springer.
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: a new method for assessing the cognitive representation of illness. *Psychology and Health*, 11(3), 431-445.
- Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., ... Schultz, T. R. (2013). *Evidence-based practices for children, youth, and young adults with autism spectrum disorder*. Chapel Hill, NC: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.

- Woodman, A. C., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2015). Change in autism symptoms and maladaptive behaviors in adolescence and adulthood: The role of positive family processes. *Journal of autism and developmental disorders*, 45(1), 111-126.
- Wright, L., Afari, J., & Zautra, N. (2009). The illness uncertainty concept: A review. *Current Pain and Headache Reports*, 13(2), 133-138.
- Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 43(6), 1380-1393.
- Zaidman-Zait, Anat, Mirenda, Pat, Duku, Eric, Szatmari, Peter, Georgiades, Stelios, Volden, Joanne, . . . Thompson, Ann. (2014). Examination of bidirectional relationships between parent stress and two types of problem behavior in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(8), 1908-1917.

*Table 1**Demographic Characteristics of the Study Sample*

| Demographic Category | n | % of sample |
|------------------------------|-----|-------------|
| Gender | | |
| <i>Male</i> | 36 | 16.8% |
| <i>Female</i> | 178 | 83.2% |
| Age | | |
| <i>30 to 39</i> | 14 | 6.5% |
| <i>40 to 49</i> | 132 | 61.7% |
| <i>50 to 59</i> | 67 | 31.3% |
| <i>60 +</i> | 1 | 0.5% |
| Education Level | | |
| <i>Less than high school</i> | 1 | 0.5% |
| <i>High school</i> | 142 | 19.6% |
| <i>Associates</i> | 24 | 11.2% |
| <i>Bachelors</i> | 77 | 36.0% |
| <i>Masters</i> | 52 | 24.0% |
| <i>Doctorate</i> | 18 | 8.4% |
| Child Age | | |
| <i>12</i> | 41 | 19.2% |
| <i>13</i> | 39 | 18.2% |
| <i>14</i> | 34 | 15.9% |
| <i>15</i> | 32 | 15.0% |
| <i>16</i> | 24 | 11.2% |
| <i>17</i> | 15 | 7.0% |
| <i>18</i> | 15 | 7.0% |
| <i>19</i> | 14 | 6.5% |

Note. N = 214

*Table 2**Raw Score Mean, Standard Deviation and Ranges for Study Variables*

| Measure/subscale | Mean (SD) | Range |
|---------------------------|--------------|---------|
| Participant Questionnaire | | |
| ASD Severity | 3.97 (1.37) | 2 - 7 |
| IPQ-RA | | |
| Timeline Cyclical | 10.65 (3.46) | 4 - 20 |
| Personal Control | 22.6 (4.28) | 6 - 30 |
| Treatment Control | 16.82 (3.38) | 5 - 25 |
| Illness Coherence | 17.35 (4.03) | 5 - 25 |
| FAM | | |
| Family Based Support | 28.67 (4.80) | 12 - 35 |
| Social Support | 29.64 (7.37) | 10 - 50 |
| Positive Coping Skills | 24.98 (3.17) | 15 - 30 |

Note. IPQ-RA = The Revised Illness Perception Questionnaire-ASD; FAM = Family Adjustment Measure.

*Table 3**Parenting Stress in the Study Sample*

| Measure/Composite | Mean (<i>SD</i>) | Range |
|---------------------------------|--------------------|-------------|
| SIPA | | |
| Total Stress (t-score) | 54.90 (8.39) | 33 - 80 |
| SIPA Descriptive Classification | n | % of sample |
| Within normal limits | 151 | 68.5% |
| Borderline | 34 | 17% |
| Clinically Significant | 14 | 7% |
| Clinically Severe | 15 | 7.5% |

Note. SIPA = Stress Index for Parents of Adolescents.

For descriptive categories, Within normal limits = 85th percentile or below;
 Borderline = 85th to 89th percentile; Clinically significant = 90th to 94th percentile;
 Clinically severe = 95th percentile and above.

*Table 4**Breakdown of Responses to Parent Perceived Severity Item*

| Severity Rating | <i>n</i> | % of sample |
|----------------------------|----------|-------------|
| 1 (“No symptoms”) | 0 | 0% |
| 2 | 30 | 14% |
| 3 (“Mild symptoms”) | 62 | 29% |
| 4 | 49 | 22.9% |
| 5 (“Moderate symptoms”) | 39 | 18.2% |
| 6 | 26 | 12.1% |
| 7 (Severe Symptoms”) | 8 | 3.7% |

Table 5

Correlation Matrix for Study Variables

| | FBS ^a | SS ^a | PCS ^a | TXC ^b | PC ^b | TMC ^b | IC ^b |
|---------------------|------------------|-----------------|------------------|------------------|-----------------|------------------|-----------------|
| Total Stress (SIPA) | -.52** | -.33** | -.29** | -.22** | -.29** | .34** | -.28** |
| FBS ^a | | .36** | .48** | -.009 | .17* | -.02 | .11 |
| SS ^a | | | .39** | .15* | .15* | -.07 | .12 |
| PCS ^a | | | | .04 | .28** | -.04 | .11 |
| TXC ^b | | | | | .51** | -.02 | .07 |
| PC ^b | | | | | | -.03 | .12 |
| TMC ^b | | | | | | | -.34** |

Note. SIPA = Stress Index for Parents of Adolescents; FBS = Family Based Support; SS = Social Support; PCS = Positive Coping Skills; TXC = Treatment Control; PC = Personal Control; TMC = Timeline Cyclical; IC = Illness Coherence.

^a Subscale of the Family Adjustment Measure. ^b Subscale of the Illness Perception Questionnaire Revised for Autism.

*p < .05, ** p < .01

Table 6

Results of Multiple Regression Predicting Parenting Stress

| Variable | B | SE _B | β |
|----------------------|--------|-----------------|---------|
| Intercept | 55.068 | .458 | |
| Family Based Support | -3.808 | .500 | -.453** |
| Timeline Cyclical | 2.231 | .498 | .262** |
| Treatment Control | -1.347 | .550 | -.158* |
| Social Support | -.896 | .505 | -.105 |
| Personal Control | -.684 | .537 | -.083 |
| Illness Coherence | -.862 | .493 | -.103 |
| R^2 | | .450 | |
| F | | 25.527 | |

Note. Variables were centered at their means and scaled (divided by standard deviation).

B = unstandardized regression coefficient; SE_B = Standard error of the coefficient; β = standardized coefficient

* $p < .05$; ** $p < .001$

Table 7

Examination of Positive Coping as a Moderator in the Relationship Between Family Based Support and Parenting Stress

| Variable | B | SE _B | β |
|----------------------|--------|-----------------|----------|
| Intercept | 55.166 | .552 | |
| Positive Coping | -.494 | .579 | -.059 |
| Family Based Support | -4.275 | .589 | -.507*** |
| Interaction Term | -.537 | .429 | -.077 |
| R^2 | | .280 | |
| F | | 25.224*** | |

Note. p <.05*, p <.01**, p <.001***

Table 8

Examination of Positive Coping as a Moderator in the Relationship Between Social Support and Parenting Stress

| Variable | B | SE _B | β |
|------------------|--------|-----------------|---------|
| Intercept | 55.230 | .589 | |
| Positive Coping | -1.746 | .611 | -.210** |
| Social Support | -1.977 | .634 | -.232** |
| Interaction Term | -.427 | .469 | -.062 |
| R^2 | | .144 | |
| F | | 10.838*** | |

Note. p <.05*, p <.01**, p <.001***

Table 9

Examination of Positive Coping as a Moderator in the Relationship Between Personal Control and Parenting Stress

| Variable | B | SE _B | β |
|------------------|--------|-----------------|---------|
| Intercept | 55.118 | .584 | |
| Positive Coping | -1.966 | .587 | -.234** |
| Personal Control | -1.738 | .583 | -.210** |
| Interaction Term | -.586 | .542 | -.073 |
| R^2 | | .136 | |
| F | | 10.143*** | |

Note. p <.05*, p <.01**, p <.001***

Table 10

Examination of Positive Coping as a Moderator in the Relationship Between Treatment Control and Parenting Stress

| Variable | B | SE _B | β |
|-------------------|--------|-----------------|----------|
| Intercept | 55.120 | .556 | |
| Positive Coping | -2.477 | .553 | -.298*** |
| Treatment Control | -1.434 | .612 | -.169* |
| Interaction Term | -.929 | .622 | -.108 |
| R^2 | | .148 | |
| F | | 11.183*** | |

Note. p <.05*, p <.01**, p <.001***

Table 11

Examination of Positive Coping as a Moderator in the Relationship Between Illness Coherence and Parenting Stress

| Variable | B | SE _B | β |
|-------------------|--------|-----------------|----------|
| Intercept | 55.012 | .557 | |
| Positive Coping | -2.228 | .555 | -.267*** |
| Illness Coherence | -2.098 | .558 | -.251*** |
| Interaction Term | -.247 | .488 | -.034 |
| R^2 | | .147 | |
| F | | 11.165*** | |

Note. $p < .05^*$, $p < .01^{**}$, $p < .001^{***}$

Table 12

Examination of Positive Coping as a Moderator in the Relationship Between Timeline Cyclical and Parenting Stress

| Variable | B | SE _B | β |
|-------------------|--------|-----------------|----------|
| Intercept | 54.924 | .539 | |
| Positive Coping | -2.395 | .537 | -.287*** |
| Timeline Cyclical | 2.721 | .548 | .321*** |
| Interaction Term | .544 | .529 | .067 |
| R^2 | | .197 | |
| F | | 15.928*** | |

Note. p <.05*, p <.01**, p <.001***

Table 13

Examination of Positive Coping as a Moderator in the Relationship Between Family Based Support and Parenting Stress with Severity Covariate

| Variable | B | SE _B | β |
|----------------------|--------|-----------------|----------|
| Intercept | 55.161 | .522 | |
| Severity | 2.411 | .494 | .086*** |
| Positive Coping | -.714 | .549 | -.086 |
| Family Based Support | -4.228 | .557 | -.501*** |
| Interaction Term | -.382 | .407 | -.055 |
| R^2 | | .360 | |
| F | | 27.111*** | |

Note. $p < .05^*$, $p < .01^{**}$, $p < .001^{***}$

Table 14

Examination of Positive Coping as a Moderator in the Relationship Between Social Support and Parenting Stress with Severity Covariate

| Variable | B | SE _B | β |
|------------------|--------|-----------------|----------|
| Intercept | 55.165 | | |
| Severity | 2.427 | .548 | .287*** |
| Positive Coping | -1.851 | .584 | -.223** |
| Social Support | -2.192 | .607 | -.257*** |
| Interaction Term | -.111 | .454 | -.016 |
| R^2 | | .223 | |
| F | | 13.814*** | |

Note. $p < .05^*$, $p < .01^{**}$, $p < .001^{***}$

Table 15

Examination of Positive Coping as a Moderator in the Relationship Between Personal Control and Parenting Stress with Severity Covariate

| Variable | B | SE _B | β |
|------------------|--------|-----------------|----------|
| Intercept | 55.196 | .564 | |
| Severity | 2.183 | .557 | .258*** |
| Positive Coping | -2.278 | .572 | -.271*** |
| Personal Control | -1.346 | .572 | -.162* |
| Interaction Term | -.594 | .523 | -.074 |
| R^2 | | .199 | |
| F | | 12.012*** | |

Note. $p < .05^*$, $p < .01^{**}$, $p < .001^{***}$

Table 16

Examination of Positive Coping as a Moderator in the Relationship Between Treatment Control and Parenting Stress with Severity Covariate

| Variable | B | SE _B | β |
|-------------------|--------|-----------------|----------|
| Intercept | 55.151 | .541 | |
| Severity | 1.973 | .563 | .232** |
| Positive Coping | -2.652 | .540 | -.319*** |
| Treatment Control | -1.122 | .601 | -.132 |
| Interaction Term | -.737 | .607 | -.086 |
| R^2 | | .199 | |
| F | | 11.942 | |

Note. $p < .05^*$, $p < .01^{**}$, $p < .001^{***}$

Table 17

Examination of Positive Coping as a Moderator in the Relationship Between Illness Coherence and Parenting Stress with Severity Covariate

| Variable | B | SE _B | β |
|-------------------|--------|-----------------|----------|
| Intercept | 55.058 | .542 | |
| Severity | 1.993 | .572 | .235** |
| Positive Coping | -2.467 | .544 | -.296*** |
| Illness Coherence | -1.530 | .567 | -.183* |
| Interaction Term | -.135 | .476 | -.018 |
| R^2 | | .197 | |
| F | | 11.888*** | |

Note. p <.05*, p <.01**, p <.001***

Table 18

Examination of Positive Coping as a Moderator in the Relationship Between Timeline Cyclical and Parenting Stress with Severity Covariate

| Variable | B | SE _B | β |
|-------------------|--------|-----------------|----------|
| Intercept | 54.990 | .527 | |
| Severity | 1.769 | .557 | .209** |
| Positive Coping | -2.569 | .528 | -.308*** |
| Timeline Cyclical | 2.229 | .557 | .263*** |
| Interaction Term | .478 | .518 | .058 |
| R^2 | | .237 | |
| F | | 15.027*** | |

Note. p <.05*, p <.01**, p <.001***

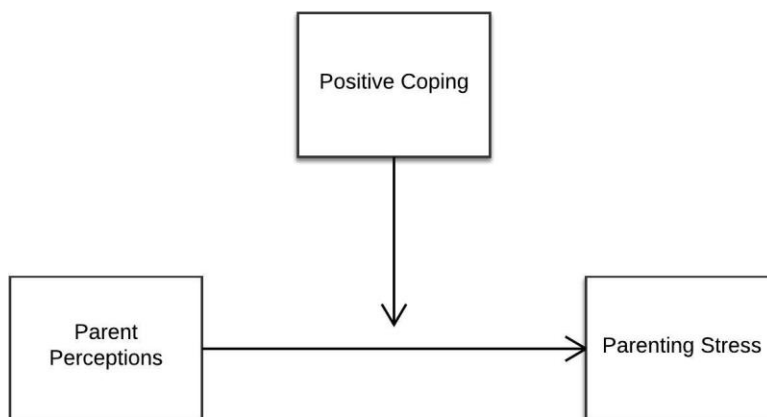


Figure 1. *Conceptual diagram of positive coping as a moderator in the relationship between parent perceptions and parenting stress. Parent perceptions, in this model, included six specific perceptions, each investigated separately.*

Appendix A Participation Questionnaire

Thank you for participating in this study! First, we want to ask you a few general questions to get started. Throughout all the questions that you will answer today, we use the terms “autism spectrum disorder” and “ASD”. These include more specific diagnoses that your child may have received in the past, like “autistic disorder” (or “autism”), “Asperger’s syndrome”, or “Pervasive Developmental Disorder Not Otherwise Specified” (or “PDD-NOS”).

Please answer the following questions:

What is today’s date? ____/____/____

1. How old is your child today? [Provide check boxes for ages in years from 5 yo to 24+yo]

If 18+:

Please check those that apply to your child:

- I still maintain legal guardianship over my son/daughter.
- My son/daughter is employed.

If checked:

- Independently
- With assistance (i.e., sheltered employment)
- What type of work does s/he do? _____

2. What is your relationship to the child with ASD in your family?

- mother/female legal guardian
- father/male legal guardian
- other (please specify): _____

3. What is your current age? ____ years

4. What is your highest level of education?
- Less than high school
 - Associate's degree
 - Bachelor's degree
 - Master's degree
 - Doctoral degree (e.g., PhD, MD, DDS, OD, etc.)
5. What is your family's current household income? _____
6. Does your child with ASD currently live with you?
- Yes
 - No
 - Where does the child live?
 - With his/her other parent
 - Independently or with peer roommate (i.e., apartment, college dorm, etc)
 - Other (please specify): _____
7. Do you have a spouse, partner, or other significant person with whom you share parenting responsibilities for your child with ASD?
- No
 - Yes

If "yes".....What is the relationship of that person to your child with ASD:

- A person who lives in the SAME household with me:
 - The child's other parent
 - My own spouse/partner, who shares parenting responsibilities
 - The child's grandparent(s)
 - Other family

- Friend
- A person who does NOT live in the same household with me:
 - The child's other parent
 - My own spouse/partner
 - The child's grandparent(s)
 - Other family
 - Friend

8. In what zip code do you currently live? ____ ____ ____ ____ ____

9. In what zip code did your family live when you participated in the SSC? ____ ____ ____ ____ ____

10. How severe are your child's *social communication* symptoms?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|--|---|---|---|--|
| unnoticeable, <u>even without</u> support or treatment | | <u>without supports</u> in place, social communication problems are noticeable-- ex: though <i>uses complete sentences and converses</i> may have trouble starting conversations, responses to others may be unusual, and/or may not be extremely interested in back-and-forth conversations | | <u>even with supports</u> or treatment in place, social communication problems are noticeable-- ex: <i>speaks simple sentences</i> but has limited initiation of social interaction, often unusual responses to others, | | <u>even with very substantial support</u> or treatment problems with social communication are severe- ex: <i>few or no words of intelligible speech</i> and makes no or few attempts at social interaction (usually to meet needs), and/or may be minimally responsive to others |

11. How severe are the your child's *restricted, repetitive behavior* symptoms?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|--|---|---|
| unnoticeable, <u>even</u> <u>without</u> support or treatment | | inflexible behavior interferes with functioning in one or more settings; has difficulty switching between activities; problems with organization and planning lessens independence | | inflexible behavior, trouble coping with change, or other restricted/ repetitive behaviors are frequent enough to be obvious to a casual observer and interfere with functioning in many settings; has distress and/or difficulty changing focus or action | | inflexible behavior, extreme difficulty coping with change, or other restricted/ repetitive behaviors very much interfere with functioning in every setting; great distress and difficulty changing focus or action |

12. Please give an estimate how severe, OVERALL, you believe your child's ASD symptoms are:

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|-------------|---|---------------|---|-------------------|---|-----------------|
| no symptoms | | mild symptoms | | moderate symptoms | | severe symptoms |

Appendix B

Family Adjustment Measure



Andrew Daire, Vanessa Dominguez, & Wanda Wade

Please rate how frequently you identify with the following statements.

| Questions | Answer Choices | | | | |
|--|-----------------------------------|------------------------------------|---------------------------------------|--|---|
| 1. As a parent of a child with a disability I feel disappointment. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 2. We respect each other in our family. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 3. I actively seek information I need regarding my child's disability. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 4. As a parent of a child with a disability I feel numbness. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 5. As a parent of a child with a disability I feel angry. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 6. I can communicate questions regarding my child's disability. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 7. I feel depression because I have a child with a disability. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 8. I participate in social support groups. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 9. As a parent of a child with a disability I feel burdened. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |

| | | | | | |
|--|-----------------------------------|------------------------------------|---------------------------------------|--|---|
| 10. Our family is involved in community activities. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 11. Social supports for my family have helped to reframe situations in a positive manner. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 12. Our family has resources for dealing with my child's disability. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 13. The identification of local resources helped me plan for my child's future. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 14. I can communicate concerns regarding my child's disability. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 15. We deal with stress as a family. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 16. There is marital harmony in our family. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 17. Social supports for my family have helped to eliminate stress. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 18. There is loyalty in our family. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 19. The identification of local and regional resources has helped me access services to help raise my child. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 20. I have social supports for my family. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 21. I feel supported by my spouse, partner, or significant other. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 22. I know how to set priorities. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 23. I am organized when it comes to my child with a disability. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 24. Our family has developed positive coping skills. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 25. We care about each other in our family. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 26. I feel devastated because I have a child with a disability. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |

© 2012 University of Central Florida Marriage & Family Research Institute – www.mfri.ucf.edu.

ALL RIGHTS RESERVED. This assessment cannot be duplicated without expressed written permission from the UCF MFRI.

| | | | | | |
|---|-----------------------------------|------------------------------------|---------------------------------------|--|---|
| 27. I realize/acknowledge that there are informational supports for me as a resource. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 28. As a parent of a child with a disability I feel shock. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 29. I resolve issues regarding my child when they happen. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |
| 30. Our family receives social support. | Never <input type="checkbox"/> | Rarely <input type="checkbox"/> | Sometimes <input type="checkbox"/> | Frequently <input type="checkbox"/> | Almost Always <input type="checkbox"/> |

© 2012 University of Central Florida Marriage & Family Research Institute – www.mfri.ucf.edu.

ALL RIGHTS RESERVED. This assessment cannot be duplicated without expressed written permission from the UCF MFRI.

Appendix C

An Adaptation of the Revised Illness Perception Questionnaire

(Moss-Morris et al., 2002)

Below are a number of symptoms associated with ASDs that you may or may not have seen in your child. Please indicate by checking yes or no, if you observe any of these symptoms, and whether you think these symptoms are related to your child's ASD diagnosis.

Please provide one response for each column, per question.

| | | I have observed this symptom in my child. | I believe this symptom is associated with my child's ASD. |
|----|--|--|---|
| | | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 1 | Prefers to be alone | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2 | Resists physical forms of affection | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3 | Easily agitated | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4 | Unusual habits or rituals | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5 | Poor eye contact | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 6 | Becomes fixed on small details | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 7 | Talks less than expected for age, or does not talk at all | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 8 | Repeats words or phrases that have no meaning or are out of context | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 9 | Has repetitive movements | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 10 | Has difficulty with small changes | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 11 | Does not pretend | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 12 | Is more interested in objects than people | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 13 | Does not respond to name | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 14 | Does not point out things that interest him/her | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Yes <input type="checkbox"/> No |

We are interested in your own personal views of how you see your child's ASD. Please indicate how much you agree or disagree with the following statements about your child's ASD by checking the appropriate box.

| | Views | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree |
|----|--|--------------------------|--------------------------|-----------------------------------|--------------------------|--------------------------|
| 1 | My child's ASD will last a short time. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 | My child's ASD is likely to be permanent rather than temporary. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3 | My child's ASD will last a long time. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 | My child's ASD will pass quickly. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5 | I expect my child will have this illness for the rest of his/her life. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6 | My child's ASD is a serious condition. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7 | My child's ASD has major consequences on my life. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8 | My child's ASD does not have much effect on my life. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9 | My child's ASD strongly affects the way others see me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10 | My child's ASD has serious financial consequences. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11 | My child's ASD causes difficulties for those who are close to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12 | There is a lot I can do to control my child's ASD symptoms. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13 | What I do can determine whether my child's ASD gets better or worse. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14 | The course of my child's ASD depends on me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15 | Nothing I do will affect my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16 | I have the power to affect my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17 | My actions will have no affect on the outcome of my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18 | My child's ASD will improve with time. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19 | There is very little that can be done to improve my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20 | Treatment for my child's ASD will be effective in curing him/her. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | Views | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree |
|----|---|--------------------------|--------------------------|-----------------------------------|--------------------------|--------------------------|
| 21 | The negative effects of my child's ASD can be prevented (avoided) by treatment. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22 | Treatment can control my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23 | There is nothing which can help my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 24 | The symptoms of my child's ASD are puzzling. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25 | My child's ASD is a mystery to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 26 | I don't understand my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 27 | My child's ASD doesn't make sense to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 28 | I have a clear picture or understanding of my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29 | The symptoms of my child's ASD change a great deal from day to day. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 30 | My child's symptoms of ASD come and go in cycles. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 31 | My child's ASD is very unpredictable. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32 | My child goes through cycles in which his/her ASD gets better and worse. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 33 | I get depressed when I think about my child's ASD. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 34 | When I think about my child's ASD I get upset. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 35 | My child's ASD makes me feel angry. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 36 | My child's ASD does not worry me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 37 | That my child has ASD makes me feel anxious. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 38 | My child's ASD makes me feel afraid. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Causes of Your Child's Autism Spectrum Disorder (ASD)

We are interested in what you consider as likely contributing factors to your child's autism spectrum disorder (ASD). There is no correct answer to this question. What interests us most is your own perspective on the factors that may have caused your child's ASD rather than what others, including a physician or other professional may have suggested. Below is a list of some parents' opinions. Please indicate to what extent you agree or disagree with these causes by checking the appropriate box.

| | Possible Causes | Strongly disagree | Disagree | Neither disagree nor agree | Agree |
|----|--|--------------------------|--------------------------|----------------------------|--------------------------|
| 1 | General life stress | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 | Genetics | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3 | A germ or virus | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 | Diet or eating habits | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5 | Chance or bad luck | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6 | Poor medical care in the past | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7 | Environmental pollution | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8 | My own behavior or decisions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9 | In utero stress or accident | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10 | Mental attitude/negative views | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11 | Family worries about ASD | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12 | Will of God | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13 | My own emotional state (e.g., depression, anxiety) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14 | My or my partner's age | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15 | My own alcohol consumption | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16 | My own tobacco consumption | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17 | Accident or injury | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18 | My child's brain structure | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19 | Deterioration of my child's immunity | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20 | Toxins found in vaccines/immunizations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 21 | Stress at birth | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

On the lines below, please rank order the three most important causal factors you believe underlie your child's ASD. You may use reasons from the table above or add any other opinions.

For me, the most likely contributing factors are:

1. _____
2. _____
3. _____

Appendix D

IRB Approval Letter

UNIVERSITY of HOUSTON

DIVISION OF RESEARCH

February 10, 2016

Ms. Natalie Raff
c/o Dr. Sarah Mire
Psychological, Health, and Learning Sciences

Dear Ms. Natalie Raff,

Based upon your request for exempt status, an administrative review of your research proposal entitled "Predicting Parenting Stress in Parents of Adolescents with Autism Spectrum Disorder" was conducted on December 9, 2015.

At that time, your request for exemption under **Category 4** was approved pending modification of your proposed procedures/documents.

The changes you have made adequately respond to the identified contingencies. As long as you continue using procedures described in this project, you do not have to reapply for review. * Any modification of this approved protocol will require review and further approval. Please contact me to ascertain the appropriate mechanism.

If you have any questions, please contact Alicia Vargas at (713) 743-9215.

Sincerely yours,



Kirstin Rochford, MPH, CIP, CPIA
Director, Research Compliance

*Approvals for exempt protocols will be valid for 5 years beyond the approval date. Approval for this project will expire **February 9, 2021**. If the project is completed prior to this date, a final report should be filed to close the protocol. If the project will continue after this date, you will need to reapply for approval if you wish to avoid an interruption of your data collection.

Protocol Number: 16177-EX