

**Understanding Strengths and Needs of Families Affected by Autism Spectrum  
Disorder: The Role of Risk and Resilience Factors in Family Adjustment**

by  
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## Abstract

**Background:** Autism spectrum disorder (ASD) affects not only a diagnosed child but the entire family system. Researchers have continuously documented challenges and negative consequences of ASD on families (e.g., Baker-Ericzen et al., 2005; Estes et al., 2009; Hoffman et al., 2009; Myers et al., 2009; Phetrasuwan & Shandor Miles, 2009).

However, raising a child with ASD also is associated with positive impacts on the family system, though these are infrequently studied. The Resiliency Model of Stress, Adaptation, and Adjustment (McCubbin & McCubbin, 1996) outlines both positive and negative processes involved in a family's response to a stressor (i.e., child's diagnosis of ASD). This theory posits that a family achieves successful or positive adjustment by utilizing resiliency factors to balance demands and risk factors. The *Family Adjustment Measure* (FAM; Daire et al., 2014) has been validated to assess both risk and resilience factors among families of children with a range of disabilities. Recently, the FAM was used to predict families of children with ASD who may experience clinically significant stress (McKee et al., 2020). Such findings suggest clinical utility of the FAM, but additional study with ASD-affected families is necessary. **Purpose:** The overarching aim of this study was to further explore validity of the FAM when used with families of children with ASD and thereby to enhance understanding of family adjustment in families of autistic children by examining latent structures of family adjustment regarding both risk and resilience factors. **Methods:** Data collected as part of a larger study examining parent perceptions, stress, family adjustment, and treatments sought amongst parents of youths with confirmed diagnoses of ASD were analyzed. The final sample size for the current study included 359 parents (319 mothers/female guardians, 40

fathers/male guardians). The 30-item FAM was fully completed by all participating parents. The FAM subscales include Parental Distress, Family Based Support, Social Support, and Positive Coping. To examine the factor structure of family adjustment in families of children with ASD, as measured by the FAM: a confirmatory factor analysis (CFA) was completed to determine relationships between the factors and the theorized underlying latent constructs. **Results:** The CFA utilizing the original four-factor model yielded a significant  $\chi^2$  ( $p < .001$ ), rejecting that the model perfectly fit to the data. Some model fit indices indicated adequate fit (RMSEA = .07), while others suggested poor fit (CFI = .83, TLI = .85). Due to some model misspecification, relationships within the model were respecified. This was done using case-by-case analysis with review of model fit after each covariance was added. The resulting, final four-factor model indicated adequate and improved fit to the data across all modification indices (RMSEA = .06, CFI = .90, TLI = .92). **Conclusion:** The FAM's original four-factor structure was verified in a sample of parents of children and adolescents with confirmed clinical diagnoses of ASD, though additional complexity was added to the model to account for differences within this data set. Future studies should include further study of the FAM for this population, including consideration of a structural equation model (SEM) to account for family, child, and individual characteristics that may influence the risk and resilience factors contributing to overall family adjustment, as improved understanding of family adjustment can lead to improved treatment outcomes for children and their families.

*Keywords:* autism spectrum disorder, ASD, Family Adjustment Measure, resilience

## Table of Contents

Chapter	Page
I. Introduction	1
II. Review of Literature	6
Autism Spectrum Disorder	6
Changing Conceptualizations of ASD	9
Theoretical Models	10
Ecological Systems Theory	10
Family Systems Theory	11
Family Stress and Adjustment/Adaptation	11
Impact of ASD on the Family System	14
Risk Factors for Families of Children with ASD	17
Resilience Factors in Families of Children with ASD	20
Family Adjustment	26
ASD and Family Adjustment	26
Measures of Family Adjustment	28
Current Study Purpose and Aims	36
III. Method	38
Recruitment	38
Participants	39
Procedures	41
Measures	41
Demographic Questionnaire	41
Family Adjustment Measure (FAM; Daire et al., 2014)	42
Statistical Analyses	43
Preliminary Analyses	43
Primary Analyses: Relational Structure of FAM Factors	44
Power	46
Handling Missing Data	47
IV. Results	49
Primary Analyses	51
V. Discussion	59
Clinical Implications	62
Limitations	64
Future Directions	67
Summary and Conclusions	68
References	70
Appendix A Family Adjustment Measure	96
Appendix B University IRB Approval	99

## List of Tables

Table	Page
1. Inter-correlations Among FAM Subscales.....	49
2. Descriptive Information for FAM Items.....	50
3. Parameter Estimates for Adjusted Four-Factor FAM CFA Model.....	57



## List of Figures

Figure	Page
1. Hypothesized Four-Factor CFA Model of FAM.....	52
2. Adjusted Four-Factor CFA Model of FAM.....	56

## **Chapter I**

### **Introduction**

Autism spectrum disorder (ASD) is a lifelong disorder, but the presence and expression of symptoms varies across individuals and throughout the lifespan (Volkmar et al., 2011). The varied presentation of symptoms within an individual present evolving needs for the individual, as well as the family system (Gau et al., 2012). Though ASD is a diagnosis given to an individual, it has an impact on the entire family due to the bidirectional and reciprocal relationship between the individual and the family system (Hastings & Beck, 2004; Lecavalier et al., 2006). This underscores the need to not only address concerns within the individual child, but also within the family.

Researchers have clearly established the presence of challenges and negative impacts experienced by families of children with ASD (e.g., Baker-Ericzen et al., 2005; Estes et al., 2009; Hoffman et al., 2009; Myers et al., 2009; Phetrasuwan & Shandor Miles, 2009). Significant demands and challenges are encountered by families of children with ASD, including high rates of parenting stress (Duarte et al., 2005; Estes et al., 2009; Hayes & Watson, 2013; Rao & Beidel, 2009), psychological distress (Benson & Karlof, 2009; Ekas et al., 2010; Olsson & Hwang, 2001), and negative physical consequences (Lovell et al., 2012; Ruiz-Robledillo et al., 2014). Parents of children with ASD are reported to experience significantly more stress than parents of typically developing children (Baker-Ericzen et al., 2005, Duarte et al., 2005; Hoffman et al., 2009; Rao & Beidel, 2009) or parents of children with other developmental disabilities (Estes et al., 2009; Hayes & Watson, 2013; Schieve et al., 2007). Parents' mental health is also affected, with higher rates of depression (Benson & Karlof, 2009; Gau et al., 2012;

Olsson & Hwang, 2001) and lower rates of well-being (Abbeduto et al., 2004; Ekas et al., 2010).

Despite the risk factors and challenges encountered by families of children with ASD, some families are able to offset the negative impacts by utilizing strengths or resilience factors. Resilience factors result from approaching a stressful event with a set of skills/resources that allows oneself to successfully cope with the stressor (Rutter, 1993). These resilience factors can buffer the negative impacts of risk factors. Successful strategies include positive coping (Benson, 2010; Taylor & Stanton, 2007), such as using helpful cognitive and behavioral strategies or styles, and social support (Nabors et al., 2013; Pottie & Ingram, 2008), which may include both informal and formal sources. Adaptive coping styles (i.e., problem-focused or active coping) have been linked to positive mental health outcomes for parents (Dabrowska & Pisula, 2010; Ekas et al., 2009; Hastings et al., 2005; Pottie & Ingram, 2008). Social support includes the resources provided by family and friends (both practical and emotional support) and those provided by professionals through interventions (Barker et al., 2011).

Even though families also report positive impacts on their family after learning their child has ASD (e.g., Bayat, 2007; Myers et al., 2009; Phelps et al., 2009), this is less studied. Rather, research with families of children with ASD has been primarily focused on indicators of dysfunction within families. However, better understanding the complex factors contributing to successful and unsuccessful adjustment within families requires consideration of a strengths-based model (Donaldson et al., 2017; Hawley & DeHaan, 1996). The Resiliency Model of Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996) outlines both positive and negative processes involved in a family's

response to a stressor (e.g., receiving a diagnosis of ASD), and in this model, families' successful (positive) adjustment is achieved via resiliency factors that mitigate risk factors, thereby restoring harmony and balance to the family.

Raising a child with ASD contributes to both risk and resiliency in parent and family outcomes, and the reciprocal relationship between these factors influence the overall family functioning and adjustment to that diagnosis. Positive family adjustment, or *bonadjustment*, is characterized by the restoration of harmony and balance, using existing resources, with only minimal changes to the established patterns of family functioning (McCubbin & McCubbin, 1996). Achieving positive or successful family adjustment involves psychological growth in family members or improved family functioning (Lazarus & Folkman, 1984), as well as parental well-being (Lord et al., 2008), which in turn, has a reciprocal effect on the child with ASD (Ingersoll & Hambrick, 2011). Minimal research has focused on the overall construct of family adjustment specifically for families of children with ASD, despite the unique experience that these families encounter compared to parents of both typically developing children and children with other diagnoses. Further, while there are individual measures to assess aspects that may contribute to family adjustment, there are very few measures that attempt to concurrently measure both the risk and resilience factors that contribute to family adjustment.

The *Family Adjustment Measure* (FAM; Daire et al., 2014) is an instrument that seeks to address this gap by exploring both the challenges and the strengths encountered by families of children with special needs. The utility of this measure with families raising children with autism are not adequately explored, however. Two studies have

addressed the factor structure of the FAM (Daire et al., 2014; Dominguez-O'Hare, 2018), but neither study specifically examined the factor structure for families of children with ASD, instead sampling either families of children with all types of special needs (including some with ASD) or families of children with disabilities from lower socioeconomic and ethnic-minority backgrounds. The FAM has been used by McKee and colleagues (2020), who established validity of the FAM for predicting clinically significant stress among families of children with ASD. These results suggest the clinical utility of the FAM for families of children with ASD, but additional study of this measure with families of children with ASD is needed to better understand its validity and possible use within this population.

This was the purpose of the current study, which aimed to explore validity of the FAM when used with families of children with ASD, thereby potentially enhancing understanding of family adjustment by examining both risk and resilience factors. More specifically, in this study, we sought to clarify the construct of family adjustment as measured by the FAM as it relates to families of children with ASD and to evaluate the psychometric properties of the FAM for this sample. Ultimately, consideration of family adjustment for ASD-affected families may inform the development of targeted interventions that are tailored to and closely aligned with the factors contributing to family adjustment, which can meet individual families' needs for more successful adjustment. Both risk and resilience factors are malleable and can be addressed via specific interventions. Further, establishing the usefulness of the FAM for families of children with ASD can allow practitioners and researchers to quickly assess specific areas

in need of intervention. Yet sufficient measurement is needed in order to accomplish these goals.

## Chapter II

### Review of Literature

#### Autism Spectrum Disorder

The *Diagnostic and Statistical Manual – Fifth Edition* (DSM-5) characterizes autism spectrum disorder (ASD) by the presence of the following characteristics: deficits in social communication across contexts (e.g., issues with social-emotional reciprocity, understanding relationships) and restricted interests and repetitive behaviors (e.g., insistence on sameness, preoccupation with unusual objects; American Psychiatric Association [APA], 2013). The DSM-5 also highlights the spectrum nature of the disorder. Specifically, the separate diagnoses of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder - Not Otherwise Specified defined in the DSM IV-TR (APA, 2000) were eliminated in the DSM-5 by defining criteria, severity levels, and accompanying impairments for the single diagnosis of ASD (APA, 2013). Although there are specific criteria and guidelines for deficits in social communication, social interaction, and restricted, repetitive patterns of behavior, interests, or activities, the manifestation of these symptoms in each child or individual with ASD varies by age and severity. ASD is further specified for each individual by indicating whether the diagnosis is with or without accompanying intellectual impairment; with or without accompanying language impairment; and associated with known medical, genetic, or environmental factors (APA, 2013). Thus, individuals with ASD demonstrate different social interaction, language, cognitive, and behavioral profiles.

Approximately 1 in 44 children in the U.S. are diagnosed with ASD (Maenner et al., 2021). Importantly, ASD occurs in all racial, ethnic, and socioeconomic groups

(Fombonne, 2009), though the prevalence of an autism diagnosis differs across race and ethnicity even after accounting for socioeconomic status (Durkin et al., 2017; Mandell et al., 2009). Males are approximately four times more likely than females to be diagnosed with ASD (Maenner et al., 2021). No single etiology has been identified; however, genetic mechanisms are believed to play an important role, and more than 1,200 genes have now been implicated in ASD (Simons Foundation Autism Research Initiative [SFARI], 2022). Regardless of etiology, researchers agree that early intervention is critical in maximizing outcomes (Warren et al., 2011).

Individuals with ASD may have comorbid intellectual concerns, medical and health diagnoses, and impaired adaptive behavior skills (Simonoff et al., 2008). Mental health diagnoses such as intellectual disability, attention deficit/hyperactivity disorder, anxiety disorders, and mood disorders have a high rate of comorbidity with ASD (e.g., Leyfer et al., 2006; Simonoff et al., 2008). In fact, comorbid psychiatric diagnoses in ASD have been found to occur in as many as 87% of affected children (Kogan et al., 2009). While some children with ASD have intellectual disabilities, others have average to above-average intelligence but are still socially impaired (Volker et al., 2009). Some children with ASD demonstrate significant challenging behaviors (Kanne et al., 2009). Moreover, the heterogeneity of ASD yields a wide range of symptom presentation, severity levels, and potential co-morbid conditions, which, in turn, likely contributes to ambiguity in a family's recognition of early red flags (Zwaigenbaum et al., 2015).

A diagnosis of ASD can be given at any point in an individual's life, though there is frequently a delay between an initial concern regarding a child's development (85% noted concerns before age 3) and a resulting diagnosis (average age of diagnosis is four



years, four months), with 30% of children not receiving a formal diagnosis of ASD before age 8 (CDC, 2018). Long-term impairments affect psychological, adaptive, interpersonal, and educational areas of functioning (Matthews et al., 2015; Russell et al., 2012). A variety of interventions have demonstrated improvements in the impairments associated with ASD, including applied behavioral analysis, speech therapy, and occupational therapy (Volkmar et al., 2011). However, the prognosis for a child with ASD is influenced by a variety of factors, including the child's characteristics, the time of diagnosis, family resources, and type and amount of intervention received (Sutera et al., 2007). Parent-mediated interventions, wherein parents serve as their child's interventionist, are successful in remediating challenging behaviors in children with ASD (Rosenbrock et al., 2021). By utilizing family-focused interventions, outcomes for families and their children with ASD are more likely to improve.

Because ASD is a pervasive and chronic condition, children with ASD experience impairment into adulthood (Volkmar et al., 2011). As individuals with ASD progress from childhood into adulthood, studies typically show overall decreases in ASD core symptom severity, particularly with restrictive and repetitive behaviors (Shattuck et al., 2007; Seltzer et al., 2004; Woodman et al., 2015). However, some individuals demonstrate an increase in symptomatology, both in respect to core ASD symptoms as well as in psychiatric symptomatology (Farley & McMahon, 2014). Though prognosis into adulthood widely varies across individuals with ASD, some individuals pursue university-level education and maintain full-time employment as adults (Howlin et al., 2004). However, many children with ASD become dependent on their parents and require long-term support into adulthood (Seltzer et al., 2001; Van Bourgondien et al., 2014).

The long-term challenges for individuals with ASD necessitate that parents and other caregivers provide some degree of care or decision-making for their children with ASD into adulthood (Van Bourgondien et al., 2014).

### ***Changing Conceptualizations of ASD***

Historically, research and practice have focused primarily on identifying deficits as a means to provide appropriate diagnoses and to target specific areas for intervention. While this model is useful for accurate diagnosis, it remains rooted in fixating on the skills or abilities that are lacking within a child or family. However, there is increased focus in the literature to shift from this deficit-based model towards a strengths-based model (Donaldson et al., 2017; Hawley & DeHaan, 1996).

Traditionally, researchers and clinicians have embraced a “medical model” of autism, in which deficits are highlighted in order to eliminate symptoms, normalize the individual, and emphasize “curing” ASD (Kapp et al., 2013). Others have approached ASD from a social model of disability, which captures the increased emphasis on changing discriminatory social mechanisms and removing barriers so that people with disabilities can achieve equality in society (Thomas, 2004). The ASD community has further concretized this notion by suggesting a neurodiversity perspective, in which autism and other neurological conditions are considered natural differences rather than disorders (Sarrett, 2016). Neurodiversity highlights unique strengths, challenges, and differences as being central to one’s identity (Kapp et al., 2013), and interventions are primarily used to capitalize on one’s strengths to support one’s challenges, while still respecting the uniqueness of the individual. Some of the benefits of this strengths-based notion include increased self-advocacy (Calzada et al., 2012), increased self-

determination and engagement in a sense of community (Donaldson et al., 2017), and increased quality of life (Biggs & Carter, 2016). Donaldson et al. (2017) challenge practitioners to partner with families impacted by ASD from a strengths-based perspective in order to jointly establish priorities for intervention outcomes and using strengths to support challenges.

### **Theoretical Models**

ASD is considered a complex diagnosis that broadly impacts the individual as well as the family across the lifespan and across multiple settings (Cidav et al., 2012; Leyfer et al., 2006; Seltzer et al., 2003). As such, there are a variety of theoretical and conceptual systems that have provided a background context for research and practice as it relates to families of children with ASD.

#### ***Ecological Systems Theory***

Ecological systems theory asserts that families, like individuals, are influenced by the environments in which they are embedded (Bronfenbrenner, 1979). Individuals are nested within multiple small and large systems. The child and his/her family are part of a microsystem (i.e., aspects of the environment in which individuals and families engage frequently) and the mesosystem (a system of microsystems that interact with one another including the family, school, neighborhood, etc.). It also includes the exosystem (the larger community) and the macrosystem (the nation, political and economic systems, history, culture). Ecological systems theory further purports that the bi-directional influences between individuals and their multiple environments that are shared, yet also unique, contextual factors.

### ***Family Systems Theory***

While the ecological systems theory focuses on the how the individual is nested within multiple systems with bidirectional influences, similarly, the family systems theory accounts for the effects that both individuals and their separate subsystems have on one another and are affected by the family, and the system is considered a whole entity rather than separate parts (FST; Minuchin, 1985; Seligman & Darling, 2017). Subsystems include the relationship between parents, relationships between siblings, as well as parent-child subsystems. Each subsystem also has a permeable or semipermeable boundary as the subsystems interact with each other to fulfill family functions. From the FST perspective, all family members and the interactions between them contribute to the functioning of the family unit (White & Hughes, 2018). As such, there are significant ways in which having a child with a disability impacts all family members, just as all family members impact the child with a disability.

### ***Family Stress and Adjustment/Adaptation***

The foundational Family Stress Model (Hill, 1949) developed the ABCX formulation to specify the variables that account for observed differences among families in their positive adaptations to stressful situations: “A (the stressor) – interacting with B (the family’s resources) – interacting with C (the definition the family makes of the event) – to produce X (the crisis)” (p. 141). McCubbin and Patterson (1983) extended the ABCX model into the Double ABCX Model of Family Behavior, with the addition of post-crisis variables to explain how families recover from crisis and achieve adaptation. This model was later incorporated into a process model, the Family Adjustment and Adaptation Response (FAAR; McCubbin & Patterson, 1983), to describe the processes

by which families overcome crises to reestablish pre-crisis adjustment, resulting in post-crisis adaptation. In the FAAR model, families seek homeostasis by balancing its demands (stressors) with its capabilities (resources and coping behaviors), while ascribing meaning to what is happening and how they can deal with it, and the family's efforts to achieve balanced functioning results in family adjustment or family adaptation, on a continuum from good to poor.

**Resiliency Model of Family Stress, Adjustment, and Adaptation.** In an effort to understand the complex factors – both positive and negative - impacting a family system, McCubbin and McCubbin (1996) proposed the Resiliency Model of Family Stress, Adjustment, and Adaptation. While this model is not specific to ASD, it is applicable to the various dynamics influencing the family system. This model provides a theoretical framework outlining the processes involved in a family's response to a stressor, such as the child receiving a diagnosis of ASD. A family faced with a stressor must adjust to the impact of this stressor to achieve a state of well-being and equilibrium in all domains of family functioning (McCubbin & McCubbin, 1996). Positive adjustment, or *bonadjustment*, is characterized by the restoration of this harmony and balance, using existing resources, with only minimal changes to the family's previously established patterns. *Maladjustment*, on the other hand, occurs when demands exceed capabilities, and the family cannot achieve harmony and stability. This state of maladjustment results in a family crisis, characterized by disharmony, imbalance, and disorganization, the resolution of which demands substantial changes in the family's patterns of interaction and functioning. Initiating these changes marks the beginning of the adaptation phase.

According to the McCubbin and McCubbin (1996) model, success in the adaptation phase is determined by the interaction of multiple factors in the family: patterns of functioning (both newly instituted and established), internal resources (e.g., cohesion, adaptability, communication, problem solving, family hardiness), support network, appraisal of the situation and of the stressor (which is shaped by the family schema or view of themselves in relation to the environment, and their sense of coherence, culture, and spirituality/religion), and problem-solving and coping skills. *Bonadaptation* is achieved if new patterns of family functioning are adopted and are successfully integrated into the family's schema, resulting in harmony and balance in the family unit. However, if the family's attempts at change are unsuccessful, or if these changes cannot be accepted by family members and incorporated into the family schema, the process results in *maladaptation*, and the family returns to the crisis situation, in which the cycle repeats itself. McCubbin and McCubbin (1996) noted that the outcome of the process is visible in the level of family adjustment/adaptation and that the strengths and resources that correlate with family adjustment/adaptation are regarded as family resilience qualities.

For families of children with ASD, the family must adjust to ongoing crises (i.e., stressors), such as receiving a diagnosis of ASD or managing child behavioral difficulties. The goal of families achieving *bonadjustment* requires using their existing resources (e.g., family's internal resources, family's support network) in order to restore harmony and balance in family functioning. The successful adjustment, or *bonadjustment*, occurs as a result of balancing these resilience factors with the negative impacts/risk factors and permits more positive outcomes for families. Understanding

these factors as they relate to families of children with ASD is central to the current study. The subsequent sections will describe elements of the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996) as they apply to families of children with ASD.

### **Impact of ASD on the Family System**

Family dynamics are altered when a child is diagnosed with ASD, and families continually adjust to meet the needs and strengths that vary throughout a child's development and lifespan (Gau et al., 2012). Characteristics of the individual with ASD directly impact the immediate family. For example, child behavioral difficulties increase caregiver stress (Hoffman et al., 2009; Lecavalier et al., 2006; Phetrasuwan & Shandor Miles, 2009) and decrease maternal well-being (Lee, 2013). However, the relationship between child behavior problems and parent and family well-being is generally thought to be bidirectional (Hastings & Beck, 2004; Lecavalier et al., 2006).

Kelly et al. (2008) found that increased family conflict predicted higher rates of anxiety/depression in children with ASD, and higher rates of anxiety/depression in children with ASD, in turn, predicted increased ASD symptomatology. Further, negative family relationships affected ASD symptom manifestation and child anxiety/depression more than positive family interactions. Parents not only experience significant stress related to caring for their child with ASD, but this stress can also influence their ability to effectively parent their child, which could potentially have a long-term effect on the quality of the parent-child relationship, the emotional development of any siblings in the home, and the overall family system.

The subsystem of the spousal relationship is also affected by ASD. Many parents of children with ASD experience less marital happiness and family cohesion compared to families of children who are typically developing (Higgins et al., 2005). Families are strained by competing commitments between caring for their child and maintaining quality relationships with other family members (Divan et al., 2012). In fact, as children with ASD age, parents report having more distance in their marital relationships (Doron & Sharabany, 2013). However, higher marital quality is related to lower parent stress and fewer depressive symptoms (Kersh et al., 2006), as well as an increased ability to cope with stressors (Siman-Tov & Kaniel, 2011), including for spouses raising children with ASD. Parents who reported above-average marital satisfaction perceived less burden from their adolescent or adult child with ASD compared to parents who reported below-average marital satisfaction (Hartley et al., 2011). Despite difficulties in the spousal relationship and marital quality, having a child with ASD does not necessarily predict divorce. In fact, a scoping review suggested that divorce rates of parents of children with ASD may be lower than the national average rates of divorce (Saini et al., 2015), perhaps attributable to the need for both parents to work together in order for the family to function well as a unit.

Siblings of a child with ASD are also affected. Rivers and Stoneman (2003) noted that when marital stress was higher, the sibling relationship between typically developing children and their siblings with ASD was compromised, though sibling relationships are also negatively affected in families without children with autism when marital stress is elevated (Orsmond et al., 2009). More specifically, typically developing siblings reported less satisfaction with the sibling relationship and perceived having more negative



behaviors and fewer positive behaviors directed by them toward their siblings with ASD. Several studies have identified the negative impacts of having a sibling with ASD, including increased risk of adjustment difficulties (Smith & Perry, 2005) and social and emotional difficulties (Orsmond & Seltzer, 2007). However, other studies did not find any significant negative effects of having a sibling with ASD (e.g., Dempsey et al., 2012; Rao & Beidel, 2009), and many typically developing siblings have positive relationships with their autistic sibling (Rivers & Stoneman, 2003).

Families also encounter practical challenges associated with raising a child with ASD. These demands include time pressures (Sawyer et al., 2010), financial burdens (Parish et al., 2015), higher healthcare costs (Wang et al., 2013), difficulty accessing medical care (Vohra et al., 2014), and advocating for their children's education (Starr & Foy, 2012). Parents report a sense of isolation because of a perceived lack of understanding in society and an increased need for vigilance in parenting (Woodgate et al., 2008). Stress in parents of children with ASD may, in part, be the result of added financial burdens for the family, such as missed days of work, leaving a job because of lack of childcare options, or increased medical expenses (Kogan et al., 2008; Montes & Halterman, 2008). Families of a child with ASD are less likely to have two parents working than those with children without a health limitation (Cidav et al., 2012). Further exacerbating the economic burden, mothers of children with ASD earn 35% less than mothers of children with other health conditions and 56% less than mothers of children with no health limitations; this may be related to lower likelihood of employment but also working fewer average hours per week (Cidav et al., 2012).

### ***Risk Factors for Families of Children with ASD***

As discussed previously, significant demands and challenges are encountered by families of children with ASD, and considerable research has focused on the parent and family outcomes. Much of the outcome research has focused on the difficulties and negative impacts on ASD-impacted families. These difficulties and challenging outcomes are considered risk factors or vulnerabilities to successful or positive family adjustment, leading to maladjustment when the demands outstrip the resources (McCubbin & McCubbin, 1996).

**Parenting Stress in Families of Children with ASD.** Parenting stress specifically involves the stress that parents experience in the process of raising children, including the subjective experiences of distress (e.g., emotional pain and anxiety), cognitions and beliefs (e.g., expectations as to what is “normal”), and attributions (e.g., self-doubt, perceived lack of control; Deater-Deckard, 2004). It is both an antecedent and a consequence of various aspects of parenting and everyday life, but it has profound implications in family and child functioning. Parenting stress is defined as “a set of processes that lead to aversive psychological and physiological reactions arising from attempts to adapt to the demands of parents,” (Deater-Deckard, 2004, p. 6). It has been associated with low parenting satisfaction and external locus of control (Mouton & Tuma, 1988), insecure attachments between children and their mothers and fathers (Jarvis & Creasey, 1991), and increased aggression and inattention in children with insecure attachments (Tharner et al., 2012).

ASD affects both the individual and family system across the lifespan, impacting parents of individuals with ASD in a way that personal and family resources are

exceeded, often resulting in parenting stress. Families who have a child with ASD experience higher levels of stress compared to those with typically developing children (Duarte et al., 2005; Hoffman et al., 2009; Rao & Beidel, 2009) or those with children with other developmental delays or special needs (Estes et al., 2009; Hayes & Watson, 2013; Schieve et al., 2007). While high levels of parenting stress are documented across parents, mothers of children with ASD report higher parenting stress than fathers (Davis & Carter, 2008; Hastings et al., 2005; Tehee et al., 2009). These stressors may revolve around the caretaking, behavioral, and physical demands associated with raising a child with ASD (Lee et al., 2008). In fact, mothers of children with ASD were more involved in the care of their children than fathers and had more parenting stress; thus, it is possible that parental involvement may mediate the relationship between stress and parent gender (Tehee et al., 2009).

Several other factors that are unique to parents of ASD may also contribute to parenting stress. Etiology of ASD remains unclear (Eissa et al., 2018), which adds ambiguity to the disorder. Families hold a variety of causal beliefs regarding ASD, impacting their responses to stress, coping strategies, and the treatments they seek out and implement for their children (Brewton et al., 2021). ASD is also considered an “invisible” disorder in that individuals with ASD do not have an obvious physical handicap, which may lead to others having difficulty with identifying the child as having challenges (Tunali & Power, 1993) or leading to parental self-consciousness and worry about being judged by others if their child has difficulties in public (Myers et al., 2009). Finally, parents of children with ASD are tasked with the responsibility of navigating treatment selection, obtaining treatment services, participating in interventions, and

coordinating between treatment providers.

In addition to parenting stress, there are also psychological, emotional, and physical impacts on parents of children with ASD. Benson and Karlof (2009) found that raising a child with ASD resulted in significant psychological distress for many parents through the process of stress proliferation, (i.e., the tendency for stressors to create additional stressors), and increased symptom severity led to increased stress proliferation, resulting in higher rates of depressed mood in parents. In fact, Ekas et al. (2010) found that parents with ASD-affected children had lower well-being and higher mental health concerns. Researchers have identified elevated levels of depression and anxiety in parents of children with ASD compared to both parents of typically developing children and parents of children with other developmental disabilities (Benson & Karlof, 2009; Gau et al., 2012; Olsson & Hwang, 2001). Mothers of children with ASD displayed lower levels of well-being compared to mothers of children with other developmental disabilities (Abbeduto et al., 2004). Further, fathers of children with ASD experienced significantly less distress than mothers, and in fact, had depression scores comparable with the general population (Olsson & Hwang, 2001). Similarly, Hastings (2003) reported that mothers experienced more anxiety compared to fathers.

Negative consequences on the health of caregivers of individuals with developmental disabilities, including ASD, have been widely documented (Lovell et al., 2012; Ruiz-Robledillo & Moya-Albiol, 2013; Ruiz-Robledillo et al., 2014). Parents of children with ASD also had more fatigue (Smith et al., 2010), poorer sleep quality (Lee, 2013), and more physical impairments than parents of both typically developing children (Allik et al., 2006) and children with other disabilities (Mugno et al., 2007). Mothers of

children with ASD reported having less time for leisure activities compared to mothers of children without disabilities (Smith et al., 2010), which may impact their stress levels.

### ***Resilience Factors in Families of Children with ASD***

Families cope with stressors in a variety of ways and understanding the factors contributing to *bonadjustment* or positive family adjustment are crucial. The process of coping includes management of internal and external demands using both cognitive and behavioral mechanisms (Lazarus & Folkman, 1984). While some families have risk factors that exacerbate their difficulties with coping with a stressor, other families possess resilience factors and use adaptive strategies that successfully decrease risk factors.

Regardless of the enormity of a stressor, there is considerable variability in the individual's response to psychosocial adversity. A subset of individuals often has a unique response to a stressor or event in which, despite risk factors, the detrimental effects are minimized. This resistance to adversity has been coined as "invulnerability" (Rutter, 1985), or more recently, "resilience" (Rutter, 1993). Resilience does not result from a lack of exposure to risk, but instead, it can occur when an individual approaches a stressor/event at a time and in a way that one can cope successfully with the challenge (Rutter, 1993). Lloyd and Hastings (2009) defined psychological resilience as heightened well-being and diminished psychological distress. This resistance to risk occurs by way of protective mechanisms that enhance people's ability to cope with stressful or disadvantageous circumstances (Rutter, 1993). As is discussed in the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996), a family's use of internal resources or resilience factors in the face of stress factors or crisis such as is encountered in the aforementioned difficulties of raising a child with ASD, can

improve parent functioning, which in turn, improves overall family functioning, restoring balance and harmony within the family system.

There are some studies that document families' perspectives on positive impacts of having a child with ASD (Bayat, 2007; Phelps et al., 2009). For example, parents of children with ASD have reported enjoying their child's personality traits, seeing their child being happy, and watching their child be successful (Little & Clark, 2006). Moreover, despite substantial stresses many mothers of children with ASD are similarly close to their children compared to mothers of typically developing children (Hoffman et al., 2009; Montes & Halterman 2007). These positive effects can strengthen the family unit, though there is much less emphasis on benefits/strengths among ASD-affected families in the literature.

**Positive Coping.** Research findings on parental coping include specific coping styles (e.g., emotion-focused coping, problem-based coping) as well as specific coping strategies or resources (e.g., social support), and coping strategies may be cognitive (e.g., reframing) or behavioral (e.g., seeking out resources) in nature (Burr & Klein, 1994). Coping styles and methods that have been linked to poorer family outcomes include emotion-focused coping (Hastings et al., 2005; Smith et al., 2008), avoidance and disengagement (Lai & Oei, 2014), and self-blame (Rodrigue et al., 1990). Pottie and Ingram (2008) identified four coping styles that predicted decreased mood for parents of children with ASD: escape, blaming, withdrawal, and helplessness. Among parents of children with ASD, frequent use of emotion-focused coping (e.g., disengagement, denial, wishful thinking) contributed to more stress, internalizing symptoms, anger, and negative

affect (Abbeduto et al., 2004; Ekas et al., 2009; Ingersoll & Hambrick, 2011; Pottie & Ingram, 2008).

However, some parents adapt and adjust to raising a child with autism by using a variety of strategies, including positive coping. Among parents of children with ASD, the use of adaptive coping strategies has been linked to positive mental health outcomes (Benson, 2010; Penley et al., 2002; Taylor & Stanton, 2007). Specifically, using problem-focused/active coping (e.g., seeking social support, cognitive reframing, planning) was related to less internalizing symptoms, anger, and negative mood symptoms (Dabrowska & Pisula, 2010; Ekas et al., 2009). In fact, positive coping strategies moderated the effects of child ASD symptomatology on mothers' depression, anger, and well-being (Benson, 2014).

Lai and Oei (2014) conducted a meta-analysis of studies specific to coping methods used by parents of children with ASD, and the two most commonly reported coping strategies included problem-focused coping (e.g., seeking instrumental support, planning, problem-solving, confrontation, compromising, changing expectations, and sense-making) and seeking social support (from immediate and extended family, friends, coworkers, and healthcare professionals). While parents of children with ASD used both adaptive and maladaptive coping strategies, more parents used adaptive coping methods across studies (Lai & Oei, 2014). Similarly, Pottie and Ingram (2008) identified five coping styles that predicted higher levels of positive mood for parents of children with ASD: problem-focused, social support, positive reframing, emotional regulation, and compromise coping.

Families of children with ASD appear to change or select different coping styles/methods over time (Smith et al., 2008). Mothers of toddlers with ASD who used problem-focused coping had better maternal well-being than mothers of adolescents with ASD who used emotion-focused coping, because problem-focused coping had a “buffering” effect on the relationship between child ASD symptom severity and maternal well-being (Smith et al., 2008). In a longitudinal study of families of children with ASD, parents’ coping styles shifted from problem-focused to emotion-focused over time as their children aged (Gray, 2006). Parents became more likely to cope through their religious faith and other emotion-focused strategies, including appreciation of their child’s good qualities and achievements (Gray, 2006). This may be indicative of child age, improvement in child behavior problems over time, or rather, it may reflect *bonadaptation* or positive family adjustment/adaptation occurring over time.

**Social Support.** Social support is another important strategy or resource that families of children with ASD might use to enhance their family adjustment. Resilient parents are able to cope with stress, and social support is considered to be a key factor that aids family resiliency and adjustment (McCubbin et al., 1996). The definition of social support varies throughout the literature, and specific subtypes and measurement methods used to categorize or quantify social support vary widely. Social support is comprised of: emotional support (i.e., conveying esteem and acceptance), informational support (i.e., aiding in understanding and coping by providing information), social companionship (e.g., spending time with others), and instrumental support (i.e., providing material resources or services; Cohen & Wills, 1985). Social support includes emotional and practical support from family and friends, often referred to as informal support, in



addition to formal support services via health resources and therapeutic interventions (Barker et al., 2011).

All forms of support have been shown to manage levels of depression by enhancing positive characteristics, such as optimism (Karst & Van Hecke, 2012; Nabors et al., 2013). Receiving daily social support predicted improved parental mood for parents of children with ASD (Pottie & Ingram, 2008). Further, social support has been related to less psychological distress (Bromley et al., 2004; Lovell et al., 2012), less depressed mood (Benson, 2012), more positive affect and life satisfaction (Ekas et al., 2010), higher parenting efficacy (Weiss, 2002), better mental health-related quality of life (Khanna et al., 2011), and lower blood pressure (Gallagher & Whiteley, 2012). In addition, social networks that provide support have been positively related to self-efficacy and psychological well-being over time (Benson, 2016).

Notably, *perceived* quality of available support has been found to be more important to coping than the quantity of support available (Lovell et al., 2012; McConnell et al., 2014; Weiss et al., 2013). The degree to which social support was helpful served as a mediator between the build-up of stressors and family hardiness (i.e., a family's sense of control over life events and stressors and confidence that they can endure challenges; Weiss et al., 2013). Social support has also served as a significant mediator between resilience and perceived general health in caregivers (Ruiz-Robledillo et al., 2014).

In one study, families displayed higher family life congruence (i.e., positive adaptation when their everyday family routine is at once aligned with their values and aspirations and congruent with the needs and interests of family members) under conditions of high social support (McConnell et al., 2014). In fact, these researchers

found that social support was the factor that contributed most to families' abilities to adapt to stressors and feel balanced, even when considering child behavior problems and financial hardship. Additionally, perceived social support predicted changes over an 18-month period in the well-being of mothers of young adults with ASD, above and beyond the impact of the child's behavior problems (Smith et al., 2012).

Regarding specific types of social support, family-based support has been associated with optimism, while both family and friend support has been linked with higher maternal well-being (Ekas et al., 2016). There is little research examining support group participation for parents of children with ASD, though one study found that 66% of parents indicated that they had participated in a support group (a form of formal support) as a result of their child's ASD diagnosis (Mandell & Salzer, 2007), while another study found that 75% of parents had participated in some form of parent support group (Clifford & Minnes, 2013). Informal social support mediated caregiver stress and parental quality of life, but no effect was found regarding formal support for these parents (Marsack & Samuel, 2017).

Despite the positive effects of social supports, there are significant differences in the engagement of community resources between parents of children with and without special needs (Daire et al., 2011). In fact, some parents of children with ASD have reported low levels of formal support overall (Glazzard & Overall, 2012). Moreover, parents of children with ASD often encounter barriers when accessing and utilizing social support. Families of children with ASD may limit participation in community activities (Lam et al., 2010), including lower attendance at religious services, more absences from school, and less participation in organized activities compared with typically developing

children or children with ADHD (Lee et al., 2008). Families may also have had a bad experience or been unhappy with the options for social support available for them.

Families of children with ASD were most satisfied with family relations and least with community and civic involvement compared with families with typically developing children and with families of a child with Down syndrome (Brown et al., 2006).

Children's schools are an important source of maternal support when there are no close family members to help (Luong et al., 2009); however, the support and education provided by mainstream settings may also be a source of dissatisfaction for parents of children with ASD (Renty & Roeyers, 2006).

### **Family Adjustment**

When a family encounters a stressful event (e.g., a new diagnosis), it can activate a range of physical and emotional impacts across parents and family systems. In some families, the reaction might be devastation, a feeling of loss, or harm; for other families, the event might be considered an obstacle, yet one with positive implications, inciting psychological growth among some family members or heightened overall family functioning. This wide range of possible responses or subjective interpretations are the essence of family adjustment (Lazarus & Folkman, 1984).

### ***ASD and Family Adjustment***

Research on families of children with developmental disabilities, and with ASD specifically, has been dominated by a deficit view that emphasizes the problems and risks without taking into consideration the families' potential for adaptation and resilience (Gardiner & Iarocci, 2012). Families' responses to having a child with ASD may vary significantly between families (Bayat, 2007; Midence & O'Neill, 1999), but families also

have the potential for change in their subjective experience at different developmental time points across the life cycle. Adjustment to a child's diagnosis plays an important role in parental well-being (Lord et al., 2008), yet little research has examined adjustment within the context of a family with a child with ASD. Altieri and von Kluge (2009) found that although all parents reported some degree of devastation after their child's initial diagnosis of ASD, some parents were able to recover quickly. In fact, many caregivers have reported having a simultaneous experience of positive and negative emotions, including selflessness, compassion, and an enhanced sense of life purpose in the face of career roles and responsibilities (Bekhet et al., 2012; Weiss et al., 2012; Zhang et al., 2013).

In a qualitative study, parents reported their experiences of having a child with ASD, and the following themes emerged: stress, child behavior and demands of therapy, impact on parents' personal well-being and relationship, impact on the family as a whole, and social isolation (Myers et al., 2009). Parents provided more responses about the challenges than the positive aspects of raising their children. However, there were positive themes expressed regarding child behavior, parents' personal well-being and relationship, and the impact on the family as a whole. Similarly, in another qualitative study, parents of children with ASD expressed a broad continuum of emotions, and parents unanimously reported that the diagnosis of his or her child having ASD was a life-altering event (Altieri & von Kluge, 2009). All the families in the study reported some degree of despair, sadness, denial, confusion, and anger after the diagnosis. These same parents also reported positive learning experiences, personal improvement, friendships, strengthening of the family, and love of their child. Further, they reported

increased appreciation of life, not taking things for granted, patience, compassion, acceptance, empathy towards each other, and understanding-- all of which they attributed as a result of having a child with ASD.

Successful adjustment for parents of children with ASD appears to be related to the ability to find meaning in their parenting experience (Pakenham et al., 2005). Problematic child behaviors and resulting parental mental health concerns were partially mediated by the parents' acceptance of their child's diagnosis (Weiss, 2002). The balancing that occurs between risk and resilience factors leads to *bonadjustment*, harmony, stability, and positive family adjustment (McCubbin & McCubbin, 1996). Though ASD-affected families are likely to experience the aforementioned challenges and risks that might prevent *bonadjustment* and lead to *maladjustment*, they also have unique capabilities for resilience, which can help them cope successfully and ultimately contribute to balance and harmony within the family.

### ***Measures of Family Adjustment***

As noted in the previous section, many studies evaluate the construct of family adjustment within the context of a qualitative study. Quantitative studies of family adjustment are sparse, however. One potential reason for this is the challenging process of measuring both risk and resilience factors within a single measure, rather than measuring individual facets of adjustment via separate tools. There have been some instruments developed with addressing the need to concurrently measure positive and negative aspects of family functioning, however.

The Family Impact of Childhood Disability (FICD; Trute & Hiebert-Murphy, 2002) scale was developed to assess the impact of a child with developmental disabilities

on the family by gathering parent positive and negative appraisals about having a child with a disability. The FICD demonstrated good internal consistency ( $\alpha = .88$  for negative appraisals,  $\alpha = .71$  for positive appraisals) and test-retest reliability over a 7-year interval ( $r = .64, p < .001$ ). It also appeared to be conceptually and empirically different from a measure of overall family functioning (Family Assessment Measure III – Short Form, FAM-SF; Skinner et al., 1995). The FICD was also determined to be a significant predictor of future parenting stress of mothers and fathers using the Parenting Stress Index, Short Form (PSI-SF; Abidin, 1995) seven years later. The participants in the FICD (Trute & Hiebert-Murphy, 2002) validation study consisted of parents of children with a wide range of disabilities (many of which involved hearing, visual, or physical impairments, developmental delay, or Down syndrome); no documentation of including parents of children with ASD were noted.

Da Paz et al. (2018) administered a novel self-report measure, Adjustment to the Diagnosis of Autism (ADA), to assess caregiver adjustment to parenting a child diagnosed with ASD. The ADA demonstrated high internal consistency ( $\alpha = .74$  at baseline and  $\alpha = .78$  at 18 months). They defined adaptive adjustment as demonstrating high levels of diagnosis acceptance and low levels of self-blame and despair. Factor analysis revealed a three-factor solution that accounted for 32.47% of the variance with primary loadings ranging from 0.30 to 0.75. The protective factor of acceptance was associated with lower depressive symptoms ( $r = -.34, p < .001$ ) and perceived stress ( $r = -.27, p = .01$ ). Caregivers with higher levels of self-blame had higher caregiving burden ( $r = .25, p = .02$ ) and parental stress ( $r = .25, p = .02$ ), along with lower life satisfaction ( $r = -.31, p < .001$ ) and self-acceptance ( $r = -.29, p = .02$ ). Despair was also significantly

related to caregiving burden ( $r = .52, p < .001$ ), depression ( $r = .26, p = .01$ ), parental stress ( $r = .51, p < .001$ ), and perceived stress ( $r = .24, p = .03$ ), along with being related to lower life satisfaction ( $r = -.41, p < .001$ ), relationship satisfaction ( $r = -.24, p = .03$ ), purpose in life ( $r = -.23, p = .03$ ), and self-acceptance ( $r = -.43, p < .001$ ).

***Family Adjustment Measure (FAM).*** Daire et al. (2014) constructed a measure intended to assess family adjustment specific to parents of children with special needs and to determine what relationship existed between family adjustment factors and measures of perceived stress and the parental relationship. The focus of this measure was to measure both risk and resilience factors that may contribute to family adjustment in order to have a tool for both research and clinical use in providing targeted support for families of children with disabilities. The development of this measure and its validity with families of children with ASD are central to the current study.

Daire et al. (2014) initially proposed 75 items based on an extensive literature review to a sample of 368 parents of children with disabilities. The majority of 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 ( $SD = 7.13$ ). Parents of children with ASD accounted for 34.8% of the sample.

In the initial phase of the study, the sample was divided in half in order to split participants into separate samples for the exploratory factor analysis (EFA;  $n = 194$ ) and the confirmatory factor analysis (CFA,  $n = 174$ ). Phase one included the exploratory factor analysis with a varimax rotation, which yielded 46 items loading on five factors. Phase two of the study included the second half of the sample. The confirmatory factor

analysis included the 46 items identified in the EFA. Four components represented 51% of the cumulative variance, with components contributing 24.36%, 11.48%, 9.21%, and 5.75%, respectively, and 30 items loaded strongly on the four identified factors. The resulting *Family Adjustment Measure* (FAM) yielded a factor structure with the following named subscales: Parental Distress, Social Support, Family-Based Support, and Positive Coping Skills (Daire et al., 2014). The resulting FAM showed good internal consistency across the subscales: Positive Coping Skills ( $\alpha = .81$ ), Family-Based Support ( $\alpha = .90$ ), Social Support ( $\alpha = .90$ ), and Parental Distress ( $\alpha = .91$ ). This measure is included in the Appendix.

Daire et al. (2014) further investigated the new measure by examining concurrent validity with the Perceived Stress Scale (PSS; Cohen et al., 1983), a 10-item measure of a person's perception of their stress level, and the Relationship Assessment Scale (RAS; Hendrick, 1988; Hendrick et al., 1998), a 7-item measure of relationship satisfaction. The PSS was chosen as it was a brief tool to measure the perception of stress. The PSS demonstrated high reliability in its study with the FAM ( $\alpha = .91$ ). The PSS correlated with Parental Distress ( $r = .56$ ), Social Support ( $r = -.33$ ), Family-Based Support ( $r = -.46$ ), and Positive Coping Skills ( $r = -.32$ ). For this study, perceived stress reflected a relationship with parental distress. The RAS was chosen as it was a brief instrument that captured relationship satisfaction in participants. The RAS demonstrated high reliability in its study with the FAM ( $\alpha = .93$ ). The RAS correlated with Parental Distress ( $r = -.27$ ), Social Support ( $r = .29$ ), Family-Based Support ( $r = .78$ ), and Positive Coping Skills ( $r = .27$ ). For this study, as relationship satisfaction increased, support within the family also increased. Further, families that had social and informational support reported higher



relationship satisfaction and less perceived stress. As the FAM total score did not correlate highly with either the RAS or PSS, it was determined that only the subscales were good indicators of family adjustment as opposed to the FAM total score. Further, convergent validity was only established for the Parental Distress and Family-Based Support subscales, and convergent validity was not addressed for Social Support or Positive Coping Skills subscales.

Dominguez-O'Hare (2018) sought to further study the FAM and its validity with more diverse families, as the FAM was originally developed based on data gathered from a sample of predominantly middle- to upper income White mothers. The goals of the study were to conduct a confirmatory factor analysis (CFA) with the original FAM four-factor model in a racially, ethnically, and socioeconomically diverse sample; determine whether the factor structure underlying the FAM at the individual level was similar to the structure at the couple level; and to assess internal consistency of the FAM with the diverse sample. Data collection was completed as part of a relationship education workshop program that was provided to low- and moderate-income, ethnically minoritized couples. Participants included 102 opposite-sex couples that had children with disabilities. Ethnic and racial composition was as follows: 18.1% Black/African American, 1.5% Asian-American, 32.4% White, 41.2% Other; 61.3% identified as Hispanic/Latino and 36.3% identified as non-Hispanic. The average monthly income was \$1,350.85, and the average years of education were 13.6. The average age of children with disabilities was 11.37, and 59.9% of the children were male. Child disability was parent-reported and included 17.9% in physical development, 22.8% in cognitive development, 33.1% in communication development, and 12.7% in adaptive

development. No specific disability information was obtained as part of the study (e.g., participants whose children had ASD).

In the initial CFA, the FAM model did not adequately fit the data ( $\chi^2 = 1368.57$ ,  $p < .001$ ), as indicated by CFI (.71) and TLI (.69) values lower than desired for good model fit. The RMSEA (.11) and SRMR (.13) values were also both outside of the desirable ranges. The correlations between Parental Distress and the other three subscales were negative, while the other subscales (Family-Based Support, Social Support, and Positive Coping Skills) correlated positively with each other ( $p < .001$ ). However, Family-Based Support and Parental Distress did not significantly correlate with each other. As the initial CFA did not adequately fit the data, Dominguez-O'Hare (2018) conducted an exploratory factor analysis (EFA) using principal axis factoring. The KMO value was .87, and Bartlett's Test of Sphericity supported factorability of the correlation matrix ( $\chi^2 = 3599.81$ ,  $p < .001$ ). A four-factor solution explained 58.15% of the total variance, with factors contributing 28.58%, 15.74%, 8.04%, and 5.79%, respectively. Oblique rotation was used due to the shared variance between items, and items were dropped if they did not load at .32 or if they were cross-loaded. Analyses were then re-run with items below .50 suppressed. The factor structure yielded a shorter, 16-item measure, called the *Family Adjustment Measure for Diverse Families* (FAM-DF) on four factors: Parental Distress (PD), Social Support (SS), Family-Based Support (FBS), and Positive Coping Skills (PCS). Parental Distress was composed of seven items (factor loadings ranged from .72 to .87; accounted for 37.51% of variance,  $\alpha = .93$ ); Social Support was composed of three items (factor loadings ranged from .54 to .77, accounted for 14.86% of variance,  $\alpha = .71$ ); Family-Based Support was composed of three items (factor loadings

ranged from  $-.63$  to  $-.79$ , accounted for 11.46% of variance,  $\alpha = .76$ ); and Positive Coping Skills was composed of three items (factor loadings ranged from  $.54$  to  $.91$ , accounted for 7.42% of variance,  $\alpha = .81$ ).

A multilevel CFA was conducted to address the participants being nested within couples. The ICC values ranged from  $.26$  to  $.67$ , with all items above  $.05$ , indicating that the effects of the couple strongly impacted the FAM subscale scores. While the Chi Square Test of Model Fit was 252.88 ( $p < .01$ ), the RMSEA was  $.04$ , CFI was  $.97$ , and TLI was  $.96$ . The SRMR for within-group and between-group levels were  $.08$  and  $.16$ , respectively. Dominguez-O'Hare concluded that the two-level model FAM-DF fit better for individual parents of children with disabilities while accounting for couple influence on factor scores. Future directions were noted to need more specific studies of the FAM with children diagnosed with specific types of disabilities in order to consider how experiences with various diagnoses might be addressed at home, in school, and/or in interventions.

More recently, McKee et al. (2019) studied the use of the original FAM in a sample wholly comprised of families of children with ASD in order to further establish its validity with this population. Specifically, receiver-operating characteristics (ROC) analyses were used to establish validity of the FAM subscales for predicting of clinically significant stress among families of children with ASD (McKee et al., 2020). Data were drawn from a sample of 362 families of children with a confirmed clinical diagnosis of ASD, and ROC analyses were completed separately for parents of children (age 12 or younger) and parents of adolescents (age 13 or higher) to account for the unique stressors and demands across developmental stages. To evaluate the diagnostic accuracy of each

FAM subscale for identifying families at-risk for clinically-significant parenting stress, the Total Stress scores from the *Parenting Stress Index – Fourth Edition – Short-Form* (PSI-4-SF; Abidin, 2012) or *Stress Index for Parents of Adolescents* (SIPA; Sheras et al., 1998) (depending on child age) were used as a criterion for their respective groups. Internal consistency was established for both the parents of children and parents of adolescents groups using Cronbach alpha for each of the FAM subscales. Concurrent validity was established with correlations of the FAM subscale scores with the PSI-4-SF Total Score and the SIPA Total Score. Based on the ROC analyses, the Parental Distress subscale had good overall detecting power for clinically significant parenting stress in both groups of parents (McKee et al., 2019).

While Daire et al. (2014) established convergent validity of the FAM for two of the subscales and established construct validity of the measure for families of children with a wide-range of disabilities in the formation of a four-factor structural model, this original study did not specifically address the validity of the measure for families of children with ASD nor were the participants required to have confirmed clinical diagnoses. As such, only 34.8% of the sample self-reported having a child with ASD which may limit the generalizability of the measure to other families of children with ASD. Dominguez-O'Hare (2018) further sought to establish the validity of the FAM with a more diverse sample, though this sample did not specifically identify the child's disability (e.g., ASD). Lastly, McKee et al. (2020) used an ASD-specific sample in the study of the FAM but only sought to establish convergent validity of the measure to predict clinically significant stress within the sample. As such, further study of the FAM's validity and its usefulness with families of children with ASD is needed.

As stated previously, very few studies have considered the measurement of family adjustment specifically for families of children with ASD and even fewer studies have utilized the FAM with this population. As noted throughout, families of children with ASD share an experience that differs from families of children that are typically developing and from those with children with other diagnoses. This unique experience necessitates the understanding of family adjustment from a lens that specifically applies to this population.

### **Current Study Purpose and Aims**

The primary aim of this study was to further validate the FAM when administered to families of children with ASD. The latent factor structure including risk and resilience factors was examined to establish construct validity of the FAM with this population. The research question that was central to the proposed study was: Is the FAM instrument a valid measure of family adjustment factors when administered to parents of children with ASD?

Based on the previous study of the FAM (Daire et al., 2014), it was expected that family adjustment among families of those with autistic children was comprised of both risk and resilience factors, including Parental Distress, Positive Coping Skills, Social Support, and Family-Based Support. This was expected given that families of children with ASD were included in the previous study; however, families of children with ASD were not the majority of the previous sample and were included based on self-reported diagnoses. Further, the FAM has been utilized to predict whether families of children with ASD may experience clinically significant stress (McKee et al., 2019), but further exploration of this instrument, including the resilience factors of family adjustment, the

relations between the factors, and the construct validity of the FAM with this population, remains necessary before clinical use (i.e., to identify families that may have high risk factors or low resilience factors and to tailor treatments specific to families).

## Chapter III

### Method

#### Recruitment

The current sample included parents who participated in the national, multi-site Simons Simplex Collection (SSC; Fischbach & Lord, 2010). All participating families had children and adolescents with confirmed clinical diagnoses of ASD, provided by research-reliable examiners using the *Autism Diagnostic Observation Schedule* (ADOS; Lord et al., 2000) and *Autism Diagnostic Interview Revised* (ADI-R; Rutter et al., 2003) as part of families' participation in the SSC. Families were required to meet the following inclusionary criteria at the time of their SSC participation: a) have a child between the ages of 4 years and 17 years, 11 months with an ASD diagnosis; b) the child had at least one unaffected sibling (though this criterion was relaxed such that 20% of the sample could be an only child); c) no first- through third-degree relative could be diagnosed with/suspected to have 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 2,658 families across all sites. Following the SSC study completion, the SFARI 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).

Beginning in November 2014, SSC families who previously consented to being re-contacted for 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 to be re-contacted (1,325 parents) at the time of their SSC participation were recruited for the University of Houston's School Psychology Autism Research Collaboration (UH\*sparc) project entitled *Parent Perceptions, Stress, and Treatment* (PeP), and data collection was completed with the help of SSC@IAN. The UH\*sparc PeP study team provided information about the PeP study to SSC@IAN, who, in turn, contacted SSC families with the opportunity to be contacted by UH\*sparc regarding the PeP study. Families who agreed to be contacted directly by UH\*sparc (589 parents, representing 44% of SSC families invited by SSC@IAN to participate) were told that they should expect a standard email explaining further study details and a link to an online survey. Data collection for the PeP study occurred from November 2014 through June 2015. The initial PeP study was completed by 361 parents during this first recontact.

UH\*sparc completed two additional recontacts of SSC families at the Baylor College of Medicine (BCM) SSC site in 2016. During these recontacts, 45 additional parents completed the PeP study measures.

### **Participants**

The total PeP data collection resulted in 407 parents of children and adolescents from the SSC. There were 28 pairs of parents of the same child that participated in the PeP study measures. To prevent violation of the assumption of independence among observations, data from one parent from each pair was randomly selected to be included



for the current study. Twenty additional parents were excluded from the current study due to not answering one or more of the FAM questions, as the FAM data was the primary focus of the current study. The final subsample for the current study included 359 parents of children and adolescents.

As stated in the recruitment description, all children and adolescents in the current study received confirmed clinical diagnoses of ASD during their participation in the SSC. The majority (88.9%) of parent participants were female (i.e., child's mother or female guardian), while 11.1% of parent participants were male (i.e., child's father or male guardian). Parental age for this sample ranged between the ages of 29-69 years old, with an average parental age of 46.16 years ( $SD = 5.84$ ). Parental education level ranged from "less than a high school diploma" to those who completed a doctoral degree, with the majority having obtained at least a bachelor's degree (64.9%).

The overall family income ranged from \$8,000 to \$1,000,000 with an average income of \$127,103.70 ( $SD = \$98,428.48$ ); 53.1% of the subsample reported income over \$100,000 per year. The majority of parent participants (95%) reported sharing parenting responsibilities with someone else at the time of the PeP study participation, with 90.3% of parents living in the same household as the person they share parenting responsibilities with. Families were located across the United States with 30.6% located in the South, 21.4% located in the West, 19.8% located in the Midwest, and 17.8% located in the Northeast.

Child ages at the time of the current study ranged between the ages of 7 and 23 years ( $M = 13.69$ ,  $SD = 3.42$ ). The majority of the children were male (83%). Child race was predominantly White (79.4%), and ethnicity was reported to be predominantly non-

Hispanic (86.6%). African American (2.8%), Asian (2.5%), Multiracial (5.8%), or Other (3.9%) child races were also reported.

## **Procedures**

Data were collected from the SSC parents via an online survey using the Qualtrics platform. Measures collected as part of the larger PeP study included a demographic questionnaire created by the study team; the *Revised Illness Perception Questionnaire for ASD* (IPQ-RA; Al Anbar et al., 2010; Mire et al., 2018); the *Family Adjustment Measure* (FAM; Daire et al., 2014); the *Parenting Stress Index, 4<sup>th</sup> Edition- Short Form* (PSI-4-SF; Abidin, 2012) or the *Stress Index for Parents of Adolescents* (SIPA; Sheras et al., 1998), depending upon the age of the child; and a treatment history questionnaire regarding the types of treatments parents selected for their children and the ages at which these treatments were used. All study measures were included in a single Qualtrics-based survey. For the current study, data were drawn from the FAM along with the demographic questionnaire.

## **Measures**

### ***Demographic Questionnaire***

To measure demographic information, a questionnaire was developed by the PeP study team. The measure was used to capture basic demographic information and parental perspectives regarding his/her child's ASD. The questionnaire included items ascertaining the parent's age, current zip code, education level, current household income, and whether the parent shared parenting responsibilities with another person. If parenting responsibilities were shared, additional follow up questions were presented about the other caregiver. Regarding the child with ASD, parents were asked to provide

the child's current age, and if the child was over the age of 18, several follow-up questions were asked about guardianship, living arrangements, and employment status.

***Family Adjustment Measure (FAM; Daire et al., 2014)***

The *Family Adjustment Measure* (FAM; Daire et al., 2014) was utilized to measure family adjustment in the current study (see Appendix). As described earlier in the paper, the FAM is a 30-item measure examining parent perceptions of his/her family supports, social supports, coping, and distress related to raising a child with special needs. It takes approximately 15 minutes to complete, and items include statements about parenting a child with a disability, which are rated on a 1-to-5 Likert scale (“*Never*”, “*Rarely*”, “*Sometimes*”, “*Frequently*”, “*Almost Always*”). It currently contains four subscales: a) Parental Distress, b) Family Based Support, c) Social Support, and d) Positive Coping Skills.

The Parental Distress subscale is comprised of seven items (refer to Table 3 for the survey items) and measures emotions (e.g., sadness, anger) felt in relation to parenting a child with a disability. For example, “*As a parent of a child with a disability I feel disappointment.*” The Family-Based Support subscale is comprised of seven items (refer to Table 3 for the survey items) and measures feelings of loyalty, respect, and harmony within the family and marital relationship. For example, “*We respect each other in our family.*” The Social Support subscale is comprised of 10 items (refer to Table 3 for the survey items) and measures perceptions related to helpfulness and the use of social support. For example, “*I participate in social support groups.*” The Positive Coping Skills subscale is comprised of six items (refer to Table 3 for the survey items) and

measures aspects of coping related to positive adjustment. For example, “*I actively seek information I need regrading my child’s disability.*”

Permission to use the FAM and publish the items was obtained from the first author of the measure. Subscale scores are raw scores, and no total score is derived. At this time, raw score comparison is limited to progress monitoring for an individual or family, though cut-point scores have been established for predicting clinically significant parenting stress in families of children with ASD (McKee et al., 2020). Extensive details about this instrument were previously referenced in the literature review.

### **Statistical Analyses**

To investigate the use of the FAM for families of children with ASD, all 30 items from the FAM were utilized. All analyses were conducted using IBM SPSS (Version 27.0) and AMOS (Version 27.0) software packages.

### ***Preliminary Analyses***

First, descriptive analyses were run to summarize demographic information about the sample (e.g., parent gender, parent age, parent education level, family income, shared parenting responsibilities, region, child age, child gender, child race, child ethnicity). This information was gathered from the demographic questionnaire and was summarized in the participants section above. Region was recoded as a categorical variable based on zip codes that were mapped and categorized in alignment with the U.S. Census Bureau’s Regions and Divisions (2010), which included the four major Regions of the United States include the West, Midwest, South, and Northeast.

***Primary Analyses: Relational Structure of FAM Factors***

The hypothesis, that the *Family Adjustment Measure* (FAM) measures the previously proposed four factors of family adjustment, was evaluated using confirmatory factor analysis (CFA). CFA deals with the relationships between observed measures or indicators and latent variables or factors. Further, CFA verifies the number of underlying dimensions of the instrument (factors) and the pattern of item-factor relationships (factor loadings; Brown, 2015). CFA requires pre-specification of all aspects of the factor model; thus, the previously established factor structure of the FAM was used.

Maximum likelihood (ML) estimation was used to estimate the factor model obtained because it maximizes the likelihood of the parameters of an assumed probability distribution, given some observed data, so that under the assumed statistical model, the observed data is the most probable. ML estimation produces a statistical evaluation of how well the factor solution could explain the relationships among the indicators and is favored because of its ability to produce a wide range of fit indices (Brown, 2015). ML is an estimator that provides full information in that one can evaluate for goodness-of-fit and statistical inferences including significance testing and estimation of confidence intervals. ML estimation assumes multivariate normality in the data, a large sample size, and continuous indicators (Brown, 2015).

The CFA solution was evaluated for overall goodness-of-fit, whether there are localized areas of strain (i.e., specific points of poor fit), and the size, interpretability, and statistical significance of the model's parameter estimates (Brown, 2015). Goodness-of-fit indices are reported in three categories: absolute fit (i.e., assess model fit at an absolute level), fit adjusting for model parsimony (i.e., incorporates a penalty function for poor

model parsimony), and comparative of incremental fit (i.e., evaluates the fit of a user-generated solution in relation to a nested baseline model). Absolute fit was examined by chi-square and standardized root mean square residual (SRMR). If chi-square is statistically significant at the alpha level of .05, it supports the alternative hypothesis (i.e., that the four previously established factors do not fit the FAM data among families of children with ASD). However, little weight is given to this fit index as it tends to be biased when sample sizes are large (Jöreskog & Sörbom, 1993). The SRMR value of 0.0 would indicate a perfect fit (i.e., a smaller SRMR value indicates better model fit; Byrne, 2016).

Parsimony correction indices were examined using root mean square error of approximation (RMSEA; Steiger & Lind, 1980). RMSEA values of 0.0 indicate a perfect fit (i.e., a value closer to 0 indicates better model fit). The confidence interval (CI) is also reported as it reflects the precision of the RMSEA, and the closeness of model fit was also examined using the RMSEA (Browne & Cudeck, 1993), with nonsignificant probability values viewed in accord with acceptable model fit.

Comparison of model fit indices included the Tucker-Lewis index (TLI; Tucker & Lewis, 1973) and the comparative fit index (CFI; Bentler, 1990). CFI and TLI values closer to one imply a good model fit. While there may be some discrepancy across goodness-of-fit indices, the following guidelines were used to determine reasonably good fit between the model and the observed data (using ML estimation): (1) SRMR values close to .05 or below (Byrne, 2016); (2) RMSEA values close to .06 or below (Hu & Bentler, 1999); (3) CFI values close to .95 or greater (Hu & Bentler, 1999); and (4) TLI values close to .95 or greater (Tucker & Lewis, 1973). In addition, acceptable model fit

would be indicated with the following fit index cut-off values: (1) CFI at or above .90 (Bentler, 1990); (2) TLI at or above .90 (Tucker & Lewis, 1973); (3) RMSEA at or below .08 (Browne & Cudek, 1993; Byrne, 2016); and (4) SRMR at or below .08 (Hu & Bentler, 1999).

Localized areas of strain should also be evaluated. To identify focal areas of misfit in a CFA solution, residuals and modification indices were examined. The size of standardized residuals is influenced by sample size; therefore, standardized residuals that are equal to or greater than the absolute value of 2.58 indicate a statistically significant score at the .01 alpha level (Byrne, 2016). Modification indices can also be determined for each fixed parameter, which reflects an approximation of how much the overall model chi-square will decrease if the fixed or constrained parameter is freely estimated (Brown, 2015). Each modification index should be examined using expected parameter change (EPC) as it provides an approximation of how much a parameter might change in a positive or negative direction if it is freely estimated. Modification indices were examined in the current study to determine whether specific observed variables should be loaded on different factors (if theoretically plausible), removed from the CFA model, or if additional commonality in the residuals should be considered. As such, modification indices were considered on a case-by-case basis to determine if it made substantive sense for there to be commonality in the residuals.

### ***Power***

In CFA, power applies to both the testing of the model (e.g., sensitivity of chi-square to detect model misspecifications) and the model parameter estimates (i.e., the probability of detecting a statistically significant parameter estimate; Brown, 2015).

Many general rules have been proposed regarding the necessary sample size for CFA to achieve precise and statistically significant model parameter estimates, as well as reliable indices of overall fit, including minimum sample size (e.g.,  $N > 100-200$ ), a minimum number of cases for each freed parameter (e.g., at least 5-10 cases), and a minimum number of cases per indicator in the model (Bentler & Chou, 1987; Ding et al., 1995). As such, the current sample size and distribution of cases reflected an adequately powered CFA.

### ***Handling Missing Data***

As stated previously, there were 28 dyads of parents that both completed the study measures, and one parent was eliminated at random in order to not violate the assumption of independence among observations. Due to the primary focus of the current study being the analysis of the FAM, listwise deletion was conducted for any participants with one or more responses missing from the FAM items. Twenty cases were removed for the current study due to missing one or more FAM item responses. Of the 20 cases removed, seven participants did not answer any of the FAM items, one participant completed less than 50% of items (missing 16 items), five participants were missing 6% or more (2 or more items) responses, and seven participants were only missing one item response. The items with the largest number of missing responses (13 missing) were items 16 and 21. One item (30) had 12 missing responses, and one item (17) had 11 missing responses. All other items had 10 or less missing responses. Given this distribution of missing responses, missing data may have been due to respondent fatigue and are assumed to be missing completely at random (MCAR). Further, demographic characteristics were examined for included and excluded cases, and the only significant difference between



the groups included the gender of the parent participant,  $t(405) = -.47, p < .001$ , with more males (fathers/male guardians) in the excluded cases. However, of the excluded cases, there was also a significant difference between the groups of dyad participants and non-dyad participants for the gender of the parent participant  $t(46) = .83, p < .001$ , with more males (fathers/male guardians) in the dyad group. This reflects that though the excluded cases included more males (fathers/male guardians), the majority of those male participants were in the randomly selected dyad pairs that were excluded.

## Chapter IV

### Results

Descriptive analyses were used to provide information about participants' ratings on the measures used in this study. Pearson correlations between FAM subscales are presented in Table 1. FAM item responses ranged from 1 (“*Never*”), 2 (“*Rarely*”), 3 (“*Sometimes*”), 4 (“*Frequently*”), and 5 (“*Almost Always*”); item response descriptive information is included in Table 2.

**Table 1**

*Inter-correlations Among FAM Subscales*

Subscale	1	2	3
1. Parental Distress	--		
2. Positive Coping	-.21**	--	
3. Family-Based Support	-.42**	.44**	--
4. Social Support	-.17**	.41**	.33**

*Notes.* \*\* $p < .01$

**Table 2***Descriptive Information for FAM Items*

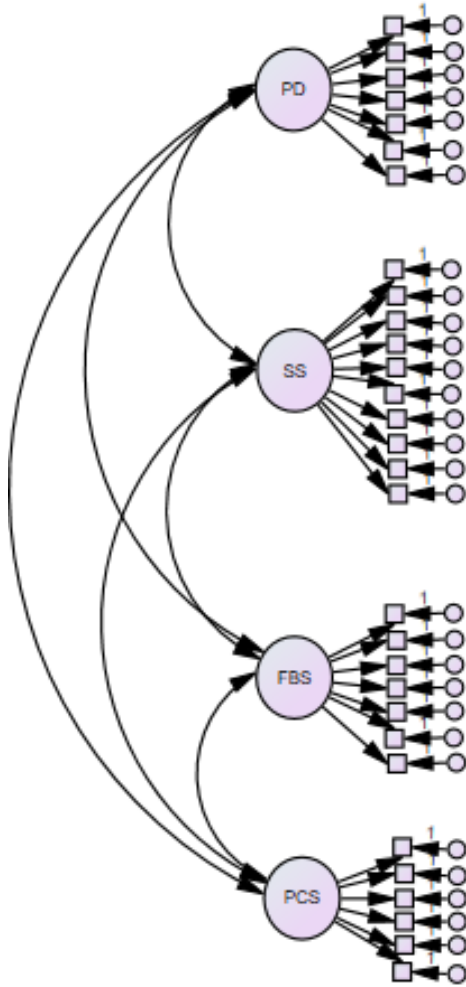
Scale/Item	<i>M</i> <sup>a</sup>	<i>SD</i>
Parental Distress		
1. As a parent of a child with a disability I feel disappointment.	2.71	0.92
4. As a parent of a child with a disability I feel numbness.	2.12	0.99
5. As a parent of a child with a disability I feel angry.	2.36	0.90
7. I feel depression because I have a child with a disability.	2.29	0.97
9. As a parent of a child with a disability I feel burdened.	2.66	1.11
26. I feel devastated because I have a child with a disability.	1.94	0.99
28. As a parent of a child with a disability I feel shock.	1.74	0.88
Positive Coping		
3. I actively seek information I need regarding my child's disability.	4.25	0.80
6. I can communicate questions regarding my child's disability.	4.32	0.76
14. I can communicate concerns regarding my child's disability.	4.15	0.83
22. I know how to set priorities.	4.18	0.70
23. I am organized when it comes to my child with a disability.	4.00	0.81
29. I resolve issues regarding my child when they happen.	4.26	0.73
Family-Based Support		
2. We respect each other in our family.	4.34	0.74
15. We deal with stress as a family.	3.66	0.97
16. There is marital harmony in our family.	3.87	1.12
18. There is loyalty in our family.	4.40	0.79
21. I feel supported by my spouse, partner, or significant other.	4.08	1.05
24. Our family has developed positive coping skills.	3.87	0.81
25. We care about each other in our family.	4.65	0.60
Social Support		
8. I participate in social support groups.	2.17	1.15
10. Our family is involved in community activities.	3.21	1.10
11. Social supports for my family have helped to reframe situations in a positive manner.	2.89	1.13
12. Our family has resources for dealing with my child's disability.	3.59	0.99
13. The identification of local resources helped me plan for my child's future.	3.01	1.06
17. Social supports for my family have helped to eliminate stress.	2.89	1.09
19. The identification of local and regional resources has helped me access services to help raise my child.	3.13	1.14
20. I have social supports for my family.	3.19	1.14
27. I realize/acknowledge that there are informational supports for me as a resource.	3.91	0.90
30. Our family receives social support.	2.86	1.21

Notes. <sup>a</sup> Responses ranged from 1-to-5 ("Never", "Rarely", "Sometimes", "Frequently",

"Almost Always").

### **Confirmatory Factor Analysis**

Using AMOS (Version 27.0), CFA was used to examine the factor structure of family adjustment as measured by the FAM based on prior work with this measure (Daire et al., 2014). Family adjustment was measured with 30-items hypothesized to load on a four-factor model (Parental Distress, Positive Coping, Family-Based Support, Social Support). Parental Distress was measured with seven items; Positive Coping was measured with six items; Family-Based Support was measured with seven items; and Social Support was measured with ten items. The hypothesized model is represented in Figure 1.

**Figure 1***Hypothesized Four-Factor CFA Model of FAM*

*Notes.* Parental Distress (PD; Items 1, 4, 5, 7, 9, 26, 28); Social Support (SS; Items 8, 10-13, 17, 19, 20, 27, 30); Family-Based Support (FBS; Items 2, 15, 16, 18, 21, 24, 25); Positive Coping Skills (PCS; Items 3, 6, 14, 22, 23, 29).

Based on the four-factor model fit indices, some indicated adequate fit (RMSEA = .07 [.07 - .08], SRMR = .072), while other indices suggested poor fit (CFI = .83, TLI = .85). Additionally, the model chi-square estimate (1328.75) was significant ( $p < .001$ ),

though this estimate tends to be biased with large sample sizes (Jöreskog & Sörbom, 1993).

Given these findings, modification indices were examined to determine whether adjustments to the model might improve overall model fit. Associations between the residuals were examined, as residuals are typically uncorrelated in CFA models, and consideration of this commonality within the model may significantly improve model fit if the suggested residuals are correlated. After examining the modification indices for this model, the highest was initially considered (65.31). These residuals were associated with items 6 and 14 on the FAM. Upon examination of these items, both items were part of the Positive Coping Skills subscale and shared common language (i.e., *"I can communicate questions regarding my child's disability"*; *"I can communicate concerns regarding my child's disability"*). The model was then adjusted by adding in a correlation between the residuals of these two items (6 & 14). Model fit indices were again evaluated and indicated only slightly improved model fit (RMSEA = .07 [.06 - .07]; SRMR = .071; CFI = .85; TLI = .86).

Modification indices were again examined, and the highest was considered regarding commonality between the residuals (59.20). These residuals were associated with items 16 and 21 on the FAM. Upon examination of these items, both items were part of the Family-Based Support subscale and measured similar concepts of marital harmony/support (i.e., *"There is marital harmony in our family"*; *"I feel supported by my spouse, partner, or significant other"*). The model was then adjusted by adding in a correlation between the residuals of these two items (16 & 21). Model fit indices were

again evaluated and indicated only slightly improved model fit (RMSEA = .07 [.06 - .07]; SRMR = .07; CFI = .86; TLI = .87).

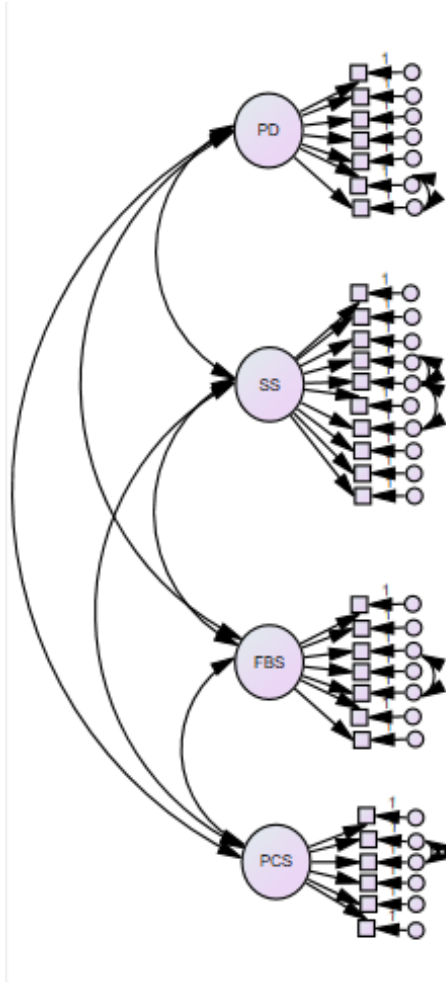
Modification indices were again examined, and the highest was considered regarding commonality between the residuals (49.59). These residuals were associated with items 13 and 19 on the FAM. Upon examination of these items, both items were part of the Social Support subscale and shared common language (i.e., “*The identification of local resources helped me plan for my child’s future*”; “*The identification of local and regional resources has helped me access services to help raise my child*”). The model was then adjusted by adding in a correlation between the residuals of these two items (13 & 19). Model fit indices were again evaluated and indicated only slightly improved model fit (RMSEA = .06 [.06 - .07]; SRMR = .07; CFI = .87; TLI = .88).

Modification indices were again examined, and the highest was considered regarding commonality between the residuals (48.83). These residuals were associated with items 18 and 25 on the FAM. Upon examination of these items, both items were part of the Family-Based Support subscale but did not share common language or shared meaning (i.e., “*There is loyalty in our family*”; “*We care about each other in our family*”). As such, it did not make conceptual sense to add in a correlation between these two residuals. The modification indices were re-examined, and the next highest was considered (46.64). These residuals were associated with items 12 and 13 on the FAM. Upon examination of these items, both items were part of the Social Support subscale and shared common language (i.e., “*Our family has resources for dealing with my child’s disability*”; “*The identification of local resources helped me plan for my child’s future*”). The model was then adjusted by adding in a correlation between the residuals of these

two items (12 & 13). Model fit indices were again evaluated and indicated only slightly improved model fit (RMSEA = .06 [.06 - .07]; SRMR = .07; CFI = .88; TLI = .89).

Modification indices were again examined, and the highest was considered regarding commonality between the residuals (46.35). These residuals were associated with items 22 and 23 on the FAM. Upon examination of these items, both items were part of the Positive Coping subscale but did not share common language or shared meaning (i.e., “*I know how to set priorities*”; “*I am organized when it comes to my child with a disability*”). As such, it did not make conceptual sense to add in a correlation between these two residuals. The modification indices were re-examined, and the next highest was considered (39.30). These residuals were associated with items 26 and 28 on the FAM. Upon examination of these items, both items were part of the Parental Distress subscale and shared common language (i.e., “*I feel devastated because I have a child with a disability*”; “*As a parent of a child with a disability I feel shock*”). The model was then adjusted by adding in a correlation between the residuals of these two items (26 & 28). Model fit indices were again evaluated and indicated adequate overall model fit (RMSEA = .06 [.06 - .06]; SRMR = .07; CFI = .90; TLI = .92). As such, this improved model (see Figure 2) is considered to appropriately fit to the data for the current study (see Table 3).



**Figure 2***Adjusted Four-Factor CFA Model of FAM*

*Notes.* Parental Distress (PD; Items 1, 4, 5, 7, 9, 26, 28); Social Support (SS; Items 8, 10-13, 17, 19, 20, 27, 30); Family-Based Support (FBS; Items 2, 15, 16, 18, 21, 24, 25); Positive Coping Skills (PCS; Items 3, 6, 14, 22, 23, 29).

**Table 3***Parameter Estimates for Adjusted Four-Factor FAM CFA Model*

Item	Unstandardized Estimate (SE)	Standardized Estimate
Parental Distress		
FAM1	0.98 (--)	.71
FAM4	1.12 (--)	.75
FAM5	1.00 (--)	.73
FAM7	1.20 (--)	.82
FAM9	1.19 (--)	.71
FAM26	1.20 (--)	.80
FAM28	1.00 (--)	.74
Positive Coping		
FAM3	0.67 (.08)	.45
FAM6	0.89 (--)	.63
FAM14	1.00 (--)	.64
FAM22	0.87 (--)	.66
FAM23	0.95 (--)	.63
FAM29	0.82 (.07)	.61
Family-Based Support		
FAM2	0.57 (--)	.68
FAM15	0.69 (--)	.63
FAM16	1.00 (--)	.79
FAM18	0.59 (--)	.67
FAM21	0.89 (--)	.75
FAM24	0.64 (--)	.70
FAM25	0.44 (--)	.66
Social Support		
FAM8	0.57 (.08)	.38
FAM10	0.74 (.07)	.51
FAM11	1.00 (--)	.68
FAM12	0.82 (--)	.64
FAM13	0.97 (--)	.70
FAM17	1.09 (--)	.76
FAM19	1.08 (--)	.73
FAM20	1.18 (--)	.79
FAM27	0.65 (.06)	.55
FAM30	1.21 (--)	.76
FBS with PD	-0.44	
SS with PD	-0.20	
SS with FBS	0.35	
PCS with PD	-0.25	
PCS with SS	0.46	
PCS with FBS	0.55	
e10 with e9	0.42	

e16 with e18	0.39
e25 with e27	0.36
e24 with e25	0.31
e6 with e7	0.33

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*Notes.* Dashes (--) indicate the standard error was not estimated.

Standardized residual covariances from the modified model were examined to look at local fit of the data. Covariances above 4 were considered for additional model specifications. Items 12 and 14 had a covariance of 4.91, though these items do not appear to reflect similar meanings or common language (i.e., “*Our family has resources for dealing with my child’s disability*”; “*I can communicate concerns regarding my child’s disability*”). Items 22 and 24 had a covariance of 4.40, though these items also do not seem to reflect common language or shared meanings (i.e., “*I know how to set priorities*”; “*Our family has developed positive coping skills*”). There were no other standardized residual covariances above 4. While further model specification does not make conceptual sense, this may indicate another area for consideration in future research for further model specifications.

Internal consistency and reliability within the FAM were also measured. The Cronbach’s alphas for the four factors were as follows: Parental Distress (PD)  $\alpha = .90$ , Positive Coping Skills (PCS)  $\alpha = .78$ , Family-Based Support (FBS)  $\alpha = .86$ , and Social Support (SS)  $\alpha = .88$ . This reflects a high level of consistency in the responses throughout the FAM measure by participants.

## **Chapter V**

### **Discussion**

The purpose of this study was to further validate the FAM (including risk and resilience factors) when administered to families of children with ASD. The research question examined whether the previously established factor structure of the FAM fit the measurement of family adjustment in a sample specifically comprised of families of children and adolescents with confirmed ASD diagnoses. As expected, results of the current study indicated a four-factor model that aligned with the factor structure of the FAM in Daire et al.'s (2014) previous work. However, further specifications were added to the structural model in the current study due to some additional commonality in the residuals.

While the revised model accounts for this commonality, it may be due to a method effect that might be driving some items to be correlated with each other, independent of the overall factor. That is, after the variance in the items is explained by the main factor of family adjustment, there is some residual left. A method effect such as shared wording or context, which are not directly related to the main construct of family adjustment, is then being measured, which can explain the commonality in the residuals. Specifically, on Parental Distress, a covariance was added between the residuals for items 26 and 28; for Positive Coping Skills, a covariance was added between the residuals for items 6 and 14; for Family-Based Support, a covariance was added between the residuals for items 16 and 21; and for Social Support, covariance were added between the residuals for items 12 and 13 and items 13 and 19. However, these method effects might be trivial, and modifications that were made might be a product of the current sample. As such,

future studies using a different sample should validate the proposed factor structure and the additional modifications made.

In the examination of the descriptive information for the FAM item responses, the mean responses appeared different across the FAM subscales. For example, all mean item responses on the Parental Distress items were between 1.74 and 2.71; for Positive Coping Skills, average item responses were between 4.00 to 4.32; for Family-Based Support, mean item responses fell between 3.66 and 4.65; and for Social Support, average item responses fell between 2.17 and 3.91. The highest average response was for “*We care about each other in our family*”, while the lowest average response was “*As a parent of a child with a disability I feel shock.*” Given the time that has passed since the initial diagnosis for this sample, it is not surprising that families reported low levels of shock. The largest standard deviation for an item was “*Our family receives social support*”, which may indicate that there is wide variability in a family’s perceptions of whether they have social support. This is consistent with previous literature indicating that some families of children with ASD reported lower levels of formal support (Glazzard & Overall, 2012) or engaged in community activities less than other families of children with disabilities (Lam et al., 2010, Lee et al., 2008).

The findings in this study lend support to the applicability of The Resiliency Model of Stress, Adaptation, and Adjustment (McCubbin & McCubbin, 1996) to families of children with autism, which emphasizes the role of both risk and resilience factors in a family’s ability to adapt and adjust to a stressor. While there is little existing literature examining family adjustment for families of children with ASD, there are notable differences in these families’ experiences compared to families of children with typical

development (Baker-Ericzen et al., 2005, Duarte et al., 2005; Hoffman et al., 2009; Rao & Beidel, 2009) and families of children with other types of disabilities (Estes et al., 2009; Hayes & Watson, 2013; Schieve et al., 2007). These differences may be reflected in the need for further specification of the structural model of the FAM as it was originally validated in families of children with many types of disabilities; however, given the confirmation of the four-factor model of family adjustment within this sample, it further validates the use of this measure for families of children with ASD. Daire et al. (2014) and Dominguez-O'Hare (2018) both examined the factor structure of the FAM in previous studies, though both samples included children with all types of special needs (including some families impacted by ASD). Families of children with ASD accounted for 34.8% of one sample (Daire et al., 2014), while Dominguez-O'Hare (2018) classified disabilities as physical, cognitive, communication, and/or adaptive developmental concerns. As such, further validation was needed for the use of the FAM with families of children with ASD.

Though both previously mentioned validation studies examined the factor structure of the FAM for families of children with a wide-range of disabilities, an ASD-specific study of the FAM was completed by McKee et al. (2020) in the examination of its use to predict clinically significant stress among families of children with confirmed clinical diagnoses of ASD through the use of receiver-operating characteristics (ROC) analyses. Concurrent validity was established with the correlations of the FAM subscale scores with the PSI-4-SF Total Score for parents of children with ASD and with the SIPA Total Score for parents of adolescents with ASD. A future direction of McKee and colleagues' (2020) work was examination of the FAM factor structure specific to families of children with

ASD. This current study confirmed the four-factor model reflective of the original validation study (Daire et al., 2014) and the revised *Family Adjustment Measure for Diverse Families* (FAM-DF; Dominguez-O'Hare, 2018). However, additional model specification was necessary to account for some commonality in the residuals.

All correlations among FAM subscales were significant and in the expected direction. Parental Distress was negatively correlated with all three positive/resilience factors (Social Support, Family-Based Support, Positive Coping Skills), and all positive/resilience factors were positively correlated with each other. The internal consistency for each subscale was acceptable to good for all subscales, which is consistent with both previous validation studies of the FAM (Daire et al., 2014) and FAM-DF (Dominguez-O'Hare, 2018).

In the examination of the standardized residual covariances, there appears to be some additional covariance that is not explained by the currently revised model in questions 12 and 14 and in questions 22 and 24. As it did not make conceptual sense to account for these commonalities in the current study, future researchers might want to make further modifications to the structural model or further model specifications to account for these findings.

### **Potential Clinical Implications**

Findings of the current study suggest that there may be clinical utility in the use of the FAM measure for families of children with ASD. Given that parent perceptions of family-based support, social support, and positive coping skills play a significant role in parenting stress in general, the FAM may be helpful to consider using in clinical practice. Importantly, these perceptions are amenable to change and could be assessed at various

points in time with the use of the FAM, thus offering guidance to clinicians about families' overall functioning. The risk and resilience factors measured by the FAM are important aspects to assess in clinical practice and to consider in creating individualized treatment plans for families of children and adolescents with ASD and support plans for their families.

As indicated in the Resiliency Model of Stress, Adaptation, and Adjustment (McCubbin & McCubbin, 1996), positive/protective factors can be utilized to minimize negative/risk factors, and in turn, the ongoing reflection on these factors can lead to improved adaptation and adjustment for the individual and family. Achieving positive or successful family adjustment involves psychological growth in family members or improved family functioning (Lazarus & Folkman, 1984), as well as parental well-being (Lord et al., 2008), which in turn, has a reciprocal effect on the child with ASD (Ingersoll & Hambrick, 2011). This emphasizes the importance of targeting parents/caregivers and the entire family in treatment, if possible, rather than just the individual with ASD. The FAM might be a useful tool in comparing the adjustment perceptions of each caregiver in order to address differences in these perceptions during treatment.

As there is a bidirectional influence on the child and family system, whether an individual or family is participating in therapy, improvements in one aspect of the system can lead to improved outcomes for the whole system (Hastings & Beck, 2004; Lecavalier et al., 2006). Given the bidirectional relationship between parental stress and child behavioral difficulties in families of children with ASD (Hoffman et al., 2009; Lecavalier et al., 2006; Phetrasuwan & Miles, 2009), parental stress reduction and monitoring will likely improve behavioral outcomes for children or adolescents with ASD. As parent



perceptions and experiences change across time as child behaviors and strengths/difficulties related to ASD change, it is important to consider change in risk/resilience factors across time (Cidav et al., 2012; Leyfer et al., 2006; Seltzer et al., 2003), particularly as time passes since the initial diagnosis of ASD. For such a purpose, the FAM might be useful as a monitoring or treatment progress tool to assess ongoing family adjustment. Family dynamics are altered with the presence of ASD, and families continually adjust to meet the needs and strengths that vary throughout a child's development and lifespan, particularly in response to the child's ASD (Gau et al., 2012), which may be enhanced with the use of the FAM in treatment.

### **Limitations**

This study has important implications for research and clinical practice with families of children and adolescents with ASD; however, these findings may be unique to this specific sample of parents of children and adolescents with ASD, which may limit generalizability of the findings. As is the case in much of the literature with parents/families of children with ASD, the majority of the respondents in the current sample were female (mothers/female guardians), and by eliminating a random participant in each of the parental dyads, many fathers/male guardians were removed from the resulting participants. While this consistency in respondents provides the opportunity for comparison of experiences across studies, it limits the perspectives obtained to primarily the mother/female guardian experience, which may be uniquely different from the father/male guardian experience. Previous research has found that mothers of children with ASD report higher parenting stress than fathers (Davis & Carter, 2008; Hastings et al., 2005; Tehee et al., 2009) and less distress and depression (Olsson & Hwang, 2001).

However, mothers of children with ASD have been found to be more involved in the care of their children than fathers, and though they had more parenting stress, it is possible that parental involvement may mediate the relationship between stress and parent gender (Tehee et al., 2009).

Another limitation to generalizability is that the majority of the current sample was White (79.4%) and non-Hispanic (86.6%). This homogeneity in the current sample significantly limits the generalizability of the findings to a more diverse population. A scoping review found that race, culture, socioeconomic status, and neighborhood contributed to age of diagnosis for ASD (Bishop-Fitzpatrick & Kind, 2017) with delayed diagnosis for African American and Latino children, children from lower-income households, and those in rural communities. This scoping review identified only nine studies that met inclusion criteria for disparities in healthcare in ASD. This is notable as there is limited research, particularly for ASD, that includes diverse samples and takes into consideration the unique impacts for these families and individuals. Future research is needed to include large, nationally representative samples as this is a large gap in the current literature.

The current study sample had a high average family income, high parental education level, and the majority of participants shared parenting responsibilities with another parent living within the same household. According to the U.S. Census Bureau's reports (2020, 2021), median household income in 2020 was \$67,521; 39.4% of naturalized citizens had a bachelor's degree or higher in 2019; and 70% of children lived with two parents in 2020. Due to these distinct differences between the current study's sample and the average U.S. family, results may not be generalizable to families with

lower household income levels, lower parental education levels, or different family compositions, who may have different experiences with risk and resilience factors as they contribute to family adjustment.

It is also notable that the current study sample was drawn from a sample of SSC participants, and the characteristics of those in the SSC sample are unique, even amongst families of children and adolescents with ASD. Participation in the SSC required rigorous contribution of both parents in research, which suggests the likelihood of higher family-based support. SSC participation also led to ongoing opportunities for collaboration and research participation, which may increase a family's likelihood of feeling a sense of community or social support network.

A considerable amount of time also passed between families' initial participation in the SSC (2008-2011) and their participation in the PeP study (2014). This is an important consideration in that the experiences of families immediately after a child's diagnosis are likely distinctly different than the experiences of families in which a long time has passed since that initial diagnosis. The experiences and perceptions of the participants in this sample were likely different at much earlier points in time and may not be reflective of parents in the early stages of diagnosis. Further, pandemic conditions occurred after the data collection of the PeP study, which might change the presentation of family adjustment and families' needs. While participants' children having confirmed clinical diagnoses of ASD is a strength of the current study, it is also a limitation of the sample's generalizability as many families of children with ASD may not have access to clinicians who could provide clinical diagnoses and instead have had their child evaluated by another source such as the public school.

## **Future Directions**

Additional work is needed in understanding family adjustment for families of children and adolescents with ASD. As this is an area with minimal research, better understanding of overall family adjustment, as well as the factors contributing to it are necessary in order to enhance treatment planning for families of children with ASD. While high levels of parenting stress are well-documented for families of children with ASD, much more information is needed regarding protective/resilience factors as well as the complexity of factors contributing to or alleviating risk factors.

Child, parent, and family characteristics all contribute to risk and resilience in family adjustment. Specifically, parental education levels (Zablotsky et al., 2013), family income levels (Duchovic et al., 2009; Mackintosh et al., 2005), and shared parenting responsibilities (Ekas et al., 2016) all contribute to improved outcomes for families. Future studies should examine the role of these influences on the risk and resilience factors contributing to family adjustment. As it relates to the FAM, a more detailed structural model should be studied that incorporates the influence of these demographic factors on positive coping, social support, family-based support, and parental distress. Other demographic factors should also be considered in future research, such as number of individuals living in the home, participation in community supports/groups, or the number of family members who share in caretaking responsibilities.

The FAM-DF (Dominguez-O'Hare, 2018) was validated for diverse families of children with disabilities. Future research should consider this reduced 16-item measure in its use for families of children with ASD from diverse backgrounds (race, ethnicity, income, education level). Comparison of the FAM-DF and overall FAM measure for

diverse families of children with ASD would be useful for determining whether a 16-item measure is as potentially clinically useful as the full 30-item measure. The FAM-DF was also validated as a two-level model to account for couple influence on factor scores. Future research is necessary to account for both parents/caregivers within a household to assess for commonalities or differences in perceptions within the same family.

While the FAM addresses aspects of risk and resilience, the construct of family adjustment as it relates to families of children with ASD needs much more consideration and research. Other aspects of risk and resilience should be considered in future studies such as family cohesion (e.g., Ekas et al., 2016; Higgins et al., 2005). As stated previously, ASD characteristics change over time as do perceptions from the various members within a family. Given this variability, it may be important to examine differences across child age groups (e.g., early childhood, middle childhood, adolescence, adulthood) and the length of time since initial diagnosis.

### **Summary and Conclusions**

The challenges encountered by families of children with ASD are well established, and while there is growing research about the positive impacts of having a child with ASD, understanding how these strengths and needs are balanced to yield successful family adjustment is still limited, particularly for this population. The Resiliency Model of Stress, Adaptation, and Adjustment (McCubbin & McCubbin, 1996) highlights the role of both risk and resilience factors in the process of adapting to a stressor or new diagnosis and later adjustment as a family. The FAM (Daire et al., 2014) measures both risk and resilience factors and was previously validated on a sample of parents of children with a wide range of disabilities.

This study aimed to better understand family adjustment through the use of the FAM in a confirmatory factor analysis with a sample wholly comprised of families of children and adolescents with ASD. While the CFA with the original four-factor model did not adequately fit the data, examination of the modification indices yielded some additional re-specification to the model by adding covariances between some of the item error terms. The resulting adjusted four-factor model indicated better fit to the data but reflected the overall four-factor model of the original study with some re-specification. This not only added to the validity of the FAM and its psychometric development, but it confirmed the overall four-factor model for a sample specific to families of children with ASD.

The current study enhances understanding of family adjustment for ASD-affected families, specifically regarding both risk and resilience factors. As both types of factors (risk and resilience) are amenable to change, results of this study may assist clinicians in providing more targeted treatments and recommendations that may be necessary to help families achieve successful adjustment and counteract the negative impacts that occur when unsuccessful adjustment occurs. Also, by establishing the utility of the FAM for this population, it will aid both practitioners and researchers in the usefulness of a quick, brief tool for assessing the strengths and needs in families of children with ASD across time. Future studies should include further study of the FAM for this population, including consideration of a model to determine family, child, and individual characteristics that may influence risk and resilience factors contributing to overall family adjustment. Additional study within this population must include a broader and more diverse sample to account for a wider range of families of children with ASD.

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## Appendix A

### Family Adjustment Measure



Marriage and Family Research Institute

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"/>

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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"/>

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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"/>

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## Appendix B

### University IRB Approval



February 20, 2015

Dr. Sarah Mire Educational Psychology

Dear Dr. Sarah Mire,

The University of Houston Committee for the Protection of Human Subjects (1) reviewed your research proposal entitled "Parental Perceptions and Family Stress: Implications for Treatment -Seeking for Children with Autism Spectrum Disorder" on February 20, 2015, according to institutional guidelines.

The Committee has given your project approval to begin the day following the current protocol's expiration , or immediately if already expired.

Reapplication will be required:

1. Annually
2. Prior to any change in the approved protocol
3. Upon development of unexpected problems or unusual complications

Thus, if you will still be collecting data under this project on **February 19, 2016**, you must reapply to this Committee for approval before this date if you wish to prevent an interruption of your data collection procedures.

If you have any questions, please contact Samoya Copeland at (713) 743-9534. Sincerely yours,

A handwritten signature in black ink, appearing to read "Daniel O'Connor".

Dr. Daniel O'Connor, Chair  
Committee for the Protection of Human Subjects (1)

PLEASE NOTE: (1) All subjects must receive a copy of the informed consent document. If you are using a consent document that requires subject signatures, remember that signed copies must be retained for a minimum of 3 years, or 5 years for externally supported projects. Signed consents from student projects will be retained by the

faculty sponsor. Faculty are responsible for retaining signed consents for their own projects; however, if the faculty leaves the university, access must be possible for UH in the event of an agency audit. (2) Research investigators will promptly report to the IRB any injuries or other unanticipated problems involving risks to subjects and others.

Protocol Number: 14217-01

Full Review:

Expedited Review: X

316 E. Cullen Building Houston, TX 77204-2015 (713) 743-9204 Fax: (713) 743-9577

COMMITTEES FOR THE PROTECTION OF HUMAN SUBJECTS.

