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THE DEVELOPMENT AND VALIDATION OF THE FAMILY  
EXPERIENCES WITH AUTISM SPECTRUM DISORDERS (FEASD)  
SCALE

Adam Moore  
*University of Rhode Island, adammmoore@yahoo.com*

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THE DEVELOPMENT AND VALIDATION OF THE  
FAMILY EXPERIENCES WITH AUTISM SPECTRUM  
DISORDERS (FEASD) SCALE

BY

ADAM MOORE

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE  
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DOCTOR OF PHILOSOPHY DISSERTATION  
OF  
ADAM MOORE

APPROVED:

Dissertation Committee:

Major Professor      Joanne Eichinger

Margaret Rogers

Karen Castagno

Paul LaCava

Karen Castagno  
DEAN OF FSEHD- RIC

Nasser H. Zawia  
DEAN OF THE URI GRADUATE SCHOOL

UNIVERSITY OF RHODE ISLAND  
AND  
RHODE ISLAND COLLEGE

2013

## **ABSTRACT**

Autism Spectrum Disorders (ASD) impacts 1 in 50 children in the United States (Centers for Disease Control and Prevention [CDC], 2013). This striking increase in the number of children with ASD affects families in a variety of ways.

The purpose of this study was to develop and validate a scale that measured the experiences of families of children with ASD in schools, health care settings, and in their families/communities. Family-centered care (American Academy of Pediatrics, 2003) principles were used to create the items in the scale. In addition to determining the psychometric properties of the scale, the second purpose of this study was to assess families' experiences with professionals in the health care, education, and community/familial settings with respect to the child's race/ethnicity, family household income, level of educational attainment of caregiver, race/ethnicity of doctor who diagnosed the child with ASD, and kind of doctor that diagnosed the child with ASD.

Four hundred sixty-six respondents completed the online scale and personal background questions over a period of four months. Principal components analysis was conducted on the "Family Experiences with Autism Spectrum Disorders" (FEASD) Scale, which indicated 3 factors were present. The three factors, "Family Support," "School Quality," and "Health Care Quality," account for 48.58% of the variance and had an overall coefficient alpha level of .92. Each factor was found to have coefficient alpha levels of .96, .89 and .70, all acceptable internal consistency values for a new scale (Stevens, 2002).

The multivariate analyses indicated two significant differences. First, families of children with ASD who reported a household income of \$100,000 - \$124,999 had more positive experiences on the “Family Support” Scale,  $F(9, 456) = 2.97, p = .002$ . Second, families who reported that a pediatrician diagnosed their child with ASD had more positive experiences on the “Total FEASD” Scale  $F(3, 410) = 4.36, p = .005$ , compared to those families who had a psychologist make the diagnosis. Limitations of the present study and future directions of research are included.

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## CHAPTER 1

### INTRODUCTION

#### **Autism Spectrum Disorder and Quality of Care**

The United States Centers for Disease Control and Prevention (CDC) report that 1 in 50 American children are diagnosed with Autism Spectrum Disorders (ASD) (Centers for Disease Control and Prevention [CDC], 2013). This is an increase in over 78% of ASD cases reported compared to ten years ago (CDC, 2013).

The Individuals with Disabilities Education Improvement Act (IDEIA) (2004) defines Autism as “a developmental disability significantly affecting verbal and nonverbal communication and social interaction, usually evident before age 3 that adversely affects a child’s educational performance. Other characteristics often associated with ASD are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child’s educational performance is adversely affected because the child has an emotional disturbance” [34 C.F.R. 300.8(c)(1)].

The *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)* categorized ASD into five different disabilities, each of which fall under the Pervasive Developmental Disorders (PDD) (American Psychiatric Association [APA], 2000). The *DSM-IV-TR* does not use the term ASD, although it is widely used in educational and health care settings.

The *DSM-IV-TR* five subcategories are: Autistic Disorder, Childhood Disintegrative Disorder, Rett's Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (APA, 2000). The recently published *DSM-V* (2013) made three major changes to the definition and diagnosis of Autism. First, the *DSM-V* eliminated the term PDD and replaced it with the term Autism Spectrum Disorder (ASD) that encompass Autistic Disorder, Asperger's Disorder, and PDD-NOS. The aforementioned three subcategories will not be listed as a diagnosis; rather persons will be labeled with Autism Spectrum Disorder. Second, the *DSM-V* eliminated the term Childhood Disintegrative Disorder and created a separate category for Rett's Disorder. Lastly, diagnostic criteria for ASD in the *DSM-V* will include deficits in social communication and restrictive repetitive behaviors, based on three levels of severity (1 = requiring support, 2 = requiring substantial support, 3 = requiring very substantial support) (APA, 2013).

Autism can impact a person in a myriad of ways (CDC, 2013). Some people with ASD have intellectual disabilities, while others have superior intelligence quotients. In addition, there may be a person with ASD who is unable to communicate verbally, often referred to as being "non-verbal," while another is a strong verbal communicator, who has no trouble speaking. While people with ASD have common challenges such as difficulty with social interaction, understanding non-verbal cues, and comprehending abstract language, there are differences. The severity of the symptoms, how they start, and the particular nature of the symptoms vary greatly. Each individual with ASD has strengths, challenges, hopes, and dreams. The physicians, educators, and other professionals who support people with ASD must

treat each as an individual (CDC, 2013).

Due to the varied impact that ASD can have on the neurological development and functioning of a person, researchers are urged to examine the various settings that impact the success of a person diagnosed with ASD (Bellin, Osteen, Heffernan, Levey, & Snyder-Vogel, 2011). For persons with significant disabilities, especially children, family members are often relied upon for sharing their perceptions of the quality of interaction with the child's doctors, teachers, extended family members, and people in the community (Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006; Strickland, McPherson, Weissman, van Dyck, Huang, & Newacheck, 2004). Families of children with ASD report having a more difficult experience in receiving quality support and outcomes in all three settings (Hagner, Kurtz, Cloutier, Arakelian, Brucker, & May, 2012; Hendricks & Wehman, 2009; Howlin, Goode, Hutton, & Rutter, 2004).

### **Selection of the Problem**

The literature presented above supports the idea that research be conducted to determine the experiences of families who have children diagnosed with ASD to better understand any perceptions of differences that may exist in their quality of support in various settings. It is well documented that racial/ethnic minorities are underrepresented in receiving a diagnosis of ASD (Lord & Bishop, 2010; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Morrier, Hess, & Heflin, 2008) which impacts the services that are provided to these children and their overall ability in making satisfactory social, emotional, and academic progress (Birkin, Anderson, Seymour, & Moore, 2008; Mandell, Morales,

Xie, Polsky, Stahmer, & Marcus, 2010; National Research Council, 2001; Zoints, Zoints, Harrison, & Bellinger, 2003). The studies examining the satisfaction of caregivers of children with ASD in regard to the education, health care, and community/familial support provided are limited (Mandell et al., 2007; Mandell et al., 2002; Morrier, et al., 2008). Addressing the challenges that families face in each of the three areas (education, health care, and community/familial support) is key to understanding the steps necessary to improve access and quality of interventions provided to all families.

### **Statement of Purpose**

The first purpose of this study was to develop a scale that measured the experiences of families with children with ASD. Family-centered care (American Academy of Pediatrics, 2003) was particularly important in the current study, as it provided a theoretical framework for the creation of the items in the scale used to measure the experiences of families of children with ASD.

Once the scale was developed with input from content experts and family members, the researcher determined the factor structure of the scale and the instrument's internal consistency. In addition to determining the psychometric properties of the scale, the second purpose of this study was to use the validated scale to assess families' experiences with professionals in the health care, education, and community/familial settings with respect to the child's race/ethnicity, family household income, level of educational attainment of caregiver, race or ethnicity of doctor who diagnosed the child with ASD, and kind of doctor that diagnosed the child with ASD.

## **Definition of Important Terms and Concepts**

*Autism Spectrum Disorders (ASD):* This term was used to refer to any person diagnosed with the *DSM-IV-TR* (APA, 2000) definition of pervasive developmental disorder (PDD). This included Autistic Disorder, Childhood Disintegrative Disorder, Rett's Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (APA, 2000).

*Disproportionality:* This term referred to the disproportionate representation by race and ethnicity of children with ASD (IDEIA, 2004).

*Family-Centered Care:* This term described a philosophy of interaction within the health care and education systems that places value on collaboration, communication, follow-through, flexibility, respect, competency, and partnership between the professional and the family members (American Academy of Pediatrics, 2003).

*Families of children with ASD:* This term referred to caregivers of people with ASD or a person diagnosed with the *DSM-IV-TR* (APA, 2000) definition of pervasive developmental disorder (PDD). This term may refer to parents or guardians, including grandparents, siblings, aunts, uncle, and other extended family members who are the primary caregiver of a child with ASD.

## CHAPTER 2

### REVIEW OF LITERATURE

#### **Disparities in ASD**

Like many families of children with disabilities, families of children with ASD navigate complex education and health care systems. While these systems pose difficulties for all families, caregivers of children with ASD have a particularly difficult journey, starting with receiving a diagnosis of ASD.

With the increase in children being diagnosed with ASD, research has begun to look at the epidemiological, social, racial, and environmental factors associated with the diagnosis. Fombonne (2003) and Yeargin-Allsopp, Rice, Karapurkar, Doernberg, Boyle, and Murphy (2003) have established that there is no known ethnic or racial difference in the epidemiology of autism. While biologically no difference exists, national data trends in ASD research suggest an under representation of racial/ethnic minorities diagnosed with ASD (Mandell et al., 2002). What factors account for these disparities?

Mandell et al. (2002) found that African American children were less likely to be given a diagnosis of ASD on the first visit to their health care provider. The researchers revealed that African American children were referred to specialty care later and required more specialty care visits to receive an ASD diagnosis than White children. In another study, Mandell et al. (2007) found that African American children were 2.6 times less likely to be diagnosed with ASD on their first visit to a physician compared to White children.

Palmer, Walker, Mandell, Bayles, and Miller (2010) studied 1184 Texas school districts to identify the incidence of ASD among Hispanic students. They found that Whites were two to three times more likely to have an ASD diagnosis compared to Hispanics. They found that socio-economic factors could not explain the under representation of Hispanic children diagnosed with ASD. Similarly, Begeer, El Bouk, Boussaid, Terwogt, and Koot (2008) found that pediatricians more often diagnosed Whites with ASD compared to their racial/ethnic minority counterparts.

Research has consistently shown that most states have some disproportional representation of children of color in the ASD category (Lord & Bishop, 2010). The findings of Morrier et al. (2008) are consistent with other studies of the disproportionality of racial/ethnic minorities with ASD: They suggest that socio-economic factors combined with race/ethnicity be studied to better determine the causes of the under representation. Furthermore, families of color who have been provided a diagnosis for their child must be included in research to better understand their experiences once diagnosed (Morrier et al., 2008).

### **Disparities Post Diagnosis**

Once a child receives a diagnosis of ASD, families continue to collaborate with health care and educational professionals. Carbone, Behl, Azor, and Murphy (2010) conducted a qualitative study to examine the differences in perspectives of pediatricians and families of children with ASD. The researchers interviewed five parents and nine pediatricians in separate focus groups. The pediatricians in the study cited lack of time and lack of care coordination as the major barriers to providing quality care to families. The parents shared that it was difficult to find a physician that

used family-centered practices. The parents indicated that they sought support from their provider in referring them to the services available for their child and felt frustrated and angry when physicians disregarded their concerns about their child's development and behavior. The five families also shared that they were often "isolated, angry, frustrated, and fatigued" in identifying services on their own (p. 320).

Studies have also examined the specific frustrations that families of color have with the educational system. Zoints et al. (2003) examined 24 African American families' experiences within the special education system. Specifically, families were interviewed about their perceptions of cultural sensitivity by teachers and other school professionals. Forty-one percent of the parents interviewed in the study were unaware of trainings to improve cultural sensitivity and understanding of teachers. Of those parents who were aware of trainings, 57% reported not seeing outward evidence of cross-cultural sensitivity from their child's teachers. Additionally, one of the six themes from the study was "issue of quality training among teachers and other school personnel" in regard to developing cultural sensitivity. This study indicates a further need to ensure culturally responsive educators teach all students.

In addition to differences in education and health care quality, the availability of services for families of children with ASD varies. Mandell et al. (2010) revealed that 2004 Medicaid claims for children with ASD were from predominantly White communities, with higher number of specialty pediatricians in the area, and with a greater number of students in special education based on the ASD diagnosis. This study suggests a great need to provide racial/ethnic minority groups with targeted

support to access the services provided through Medicaid at a rate similar to their White counterparts.

### **Family Support**

In addition to the impact of the education and health care systems, family member support is also an important aspect of raising a child with ASD. Bayat (2007) examined the experiences of 175 guardians with children diagnosed with autism between the ages 2 and 18. In their responses to three open-ended questions about raising a child with ASD, the researcher found subcategories of family resilience themes: (1) pulling resources together; (2) being connected; (3) making meaning out of adversity; (4) affirmation of strength and being more compassionate; and (5) spiritual experience and belief system. Sixty-two percent of families identified being closer as a family because of the diagnosis and 63% percent were able to make meaning out of the diagnosis. This research suggests that families need services that support family strengths and characteristics.

Families of children with autism have also indicated that religious involvement has been a positive support in coping with the challenges of having a child with special needs. Ekas, Whitman, and Shivers (2009) surveyed 119 mothers of children with autism about their religious practices and beliefs. The results of the study suggest that families who engage in religious activities have lower rates of stress and higher rates of satisfaction in life. This study suggests that support from religious organizations is an important part of life for families, particularly for families of color.

## **Family-Centered Care**

Family-centered care is widely cited in medicine and special education as a best practice for working with families and their children (Beatson, 2008; Dunst, 2002; Epley, Summers & Turnbull, 2010; King, Teplicky, King, & Rosenbaum, 2004; Kuo, Frick, & Minkovitz, 2011; Moore, Mah, & Trute, 2009; Rosenbaum, King, Law, King, & Evans, 1998; Tomasello, Manning, & Dulmus, 2010; Trute, 2007). Adopted by the American Academy of Pediatrics, family-centered care focused on “collaboration among patients, families, physicians, nurses, and other professionals for the planning delivery, and evaluation of health care as well as in the education of health care professionals” (American Academy of Pediatrics, 2003, p. 692).

Family-centered care principles emphasize the role, experiences, and needs of the family in caring for children with disabilities. “The family, (not the professional) is the constant in the child’s life; the family is the ultimate expert on the needs and well-being of the child; one cannot help a child without simultaneously helping a family (and often involve the community within which the family is nested); and whenever possible parents should be senior partners with professionals in the creation of service plans for their child” (Trute, 2007, p. 284).

These tenets are also part of family-centered education planning (Dunst, 2002; Epley et al., 2010; Hiebert-Murphy, Trute, & Wright, 2011; Tomasello et al., 2010; Trute, 2007). Family centered-care places value on collaboration, communication, follow-through, flexibility, respect, competency, and partnership between the professional and the family members (American Academy of Pediatrics, 2003). Families of children with disabilities report that professionals need to listen and learn

from parents, be culturally responsive to families, work as partners, and individualize how to support a family's unique needs (Goldfarb, Devine, Yingling, Hill, Moss, Ogburn, Roberts, Smith, & Pariseau, 2010).

Health care professionals that use family-centered practices recognize the cultural, linguistic, socioeconomic, ethnic and racial perspectives of families. This approach to medical care emphasizes that professionals highlight strengths of the family, and provide useful non-biased information and supports to families. When health care professionals utilize family-centered care, better outcomes in overall health care are reported (American Academy of Pediatrics, 2003). In addition, families report higher levels of satisfaction with their child's overall health care experience when family-centered care is reported (King et al., 2004). Within educational settings, families report better educational outcomes for their children when family-centered practices are used (Davies, 1995; Dunst & Trivette, 1996). However, family-centered care must be further investigated in community settings with diverse populations (Bellin et al., 2011).

Measuring the impact of family-centered care among various groups is important in understanding how to better care for families of children with ASD. Montes and Halterman (2011) used data from 35,386 families from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) to determine evidence of family-centered care. The authors define family-centered care as "an approach to medical care that recognizes that the family's perspective and input are important in clinical decision making, particularly in cases where the psychosocial and developmental needs of children are the central focus on care" (p. 297). Five

questions on the survey measure the caregiver's perception of their health care providers use of family-centered practice. These questions specifically asked families if they felt the physician listened to their concerns, treated them as partners and if they were responsive to the family's concerns. Montes and Halterman (2011) found significant differences between White families with and without children with ASD and Black families with and without children with ASD; Black families with children with ASD had the highest odds of not receiving family-centered care.

### **Family Related Variables**

Researchers have studied the relationship between differences in racial/ethnic identities, educational attainment, family income, and quality of health care and educational outcomes (De Valenzuela, Copeland, Qi, & Park, 2006; Fierros & Conroy, 2002; Knapp, Madden, & Marcu, 2010; Montes & Halterman, 2011; Morrier et al., 2008; Ngui & Flores, 2006; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007).

The racial/ethnic background has been used to determine differences in care in both health care and educational settings (Knapp, Madden, & Marcu, 2010; Montes & Halterman, 2011; Morrier, Hess, & Heflin, 2008; Ngui & Flores, 2006). Ngui and Flores (2006) found that African American and Hispanic families with children with disabilities had more dissatisfaction in their health care than their White counterparts. Thirteen percent of African Americans and 16% of Hispanics were dissatisfied with the level of family-centered medical care, compared to 7% of White parents. Also, Montes and Halterman (2011) found that African American families with children with ASD were less likely to receive family-centered care from physicians than White families. Similarly, families of color were less likely to report feeling like a partner in

their child's health care planning with their child's physician (Knapp, Madden, & Marcu, 2010).

In addition to the differences within the health care system, families of color, in particular families of color raising a child with a disability, have reported more negative experiences in regard to educational quality than White families (De Valenzuela et al., 2006; Fierros & Conroy, 2002).

Fierros and Conroy (2002) suggest that African American and Hispanic students with disabilities are more likely to be placed in restrictive settings, limiting their access to the general education curriculum. Additionally, the quality of special education services for students of color has been of concern. Approximately 75% of African American students with disabilities do not have employment two years after high school graduation compared to 47% of White students with disabilities. Five years after high school graduation, 50% of African Americans students with disabilities are not employed compared to 39% of White students with disabilities.

De Valenzuela et al. (2006) examined students with disabilities in a large urban school district in the southwestern United States. The researchers found the overall educational quality for students with disabilities to be significantly worse for students of color. African American, Hispanic and Native American students were more likely to be placed in the most restrictive setting or a placement in a separate class 60% or more of the time than White, Asian, and other students. The researcher suggested that students from these ethnic/racial minority groups had a lesser chance of access to general education.

The income level of a family also has been used to determine differences in care in both health care and educational settings (Knapp et al., 2010; Montes & Halterman, 2011; Morrier et al., 2008.) Knapp et al. (2010) examined factors associated with family-provider partnerships of Children with Special Health Care Needs (CSHCN). The authors examined the percentage of parents who reported “feeling like a partner” in the interactions with their child’s health care provider. In their study parents who identified as Black non-Hispanic (OR = 0.68;  $p < 0.001$ ), Hispanic (OR = 0.56;  $p < 0.001$ ), and “other” race/ethnicity (OR = 0.78;  $p < 0.05$ ) had a decreased odds of partnerships compared to the referent group of White non-Hispanics. Additionally, parents who reported household income below the federal poverty level were significantly associated with decreased odds of health care provider partnership (OR = 0.63;  $p < 0.001$ ).

Montes and Halterman (2011) examined the family-centered care questions on the NS-CSHCN 2005-2006 for 35,386 families who reported either White or Black only as their race. The researchers used 5 family-centered care survey questions in their statistical analyses. Parents of Black children reported significantly more negative experiences in regard to receiving family-centered care. On 4 of the 5 items, Black parents of children with ASD had 5 times greater odds of reporting “doctor did not spend enough time with [my] child,” > 3 times greater odds of reporting “doctors were only occasionally sensitive to [my] values and customs,” and > 2 times greater odds of reporting “doctors helped [me] feel like a partner in care sometimes or never” as compared to White parents of children with ASD.

Lastly, the level of education of a parent of a child with ASD also suggests differences in experiences in schools, health care settings, and their communities. Thomas et al. (2007) surveyed 383 caregivers in North Carolina to determine the characteristics associated with use of ASD services. Parents with more education have shown to have a greater chance of receiving access to quality care for their child with ASD. Caregivers with at least a college degree had two to four times odds of using some type of services. The services cited by families included direct therapy, such as occupational or speech therapies, as well as specific interventions such as Picture Exchange Communication Systems (PECS). Furthermore, Thomas et al. (2007) confirmed the findings of Newacheck, Hung, and Wright (2002) that families of color with children with ASD and parents with less education were less likely to receive services, such as occupational and speech therapy.

### **Health Care Provider Variables**

Health care providers have been shown to affect patients' satisfaction of care they have received (Horn, Mitchell, Wang, Joseph, & Wissow, 2012; Levinson et al., 2008; Rutten, Augustson, & Wanke, 2006). Among them, race was a factor related to the quality of care reported by patients (Cooper, Roter, Johnson, Ford, Steinwachs, & Powe, 2003; Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999; Saha, Arbelaez, & Cooper, 2003).

Cooper et al. (2003) recorded patient-doctor visits and found statistical differences between the patients with the same race/ethnicity as their physician compared to patients with a different race/ethnicity as their physician. The results

show the same racial groups have longer patient interactions and have more positive patient affect.

Saha et al. (2003) surveyed 6,299 people, 18 years of age or older, to determine racial differences in patient-physician relationships. The researchers utilized a telephone survey methodology that over-sampled people of color. A significant positive correlation between cultural sensitivity and overall quality of patient-physician interactions was found. People of color reported less satisfaction with their health care than Whites with statistically significant differences for the Hispanic and Asian groups. Blacks, Hispanics and Asians were less likely to receive appropriate health care services, including blood pressure monitoring and preventative care, compared to Whites.

Cooper-Patrick et al. (1999) surveyed 1,816 patients to determine how race/ethnicity of patients and physicians are associated with the physician's decision-making styles. Patients with a physician of the same race/ethnicity rated their interactions more participatory and more positive than patients with a physician of a different race/ethnicity as their own. Overall, the researchers found African Americans were more likely to rate their experiences with physicians of any race as less participatory and less positive than Whites.

In addition to the race of the physician, some medical specialties have utilized family-centered practices with positive outcomes (American Academy of Pediatrics, 2003). Pediatricians have led the field in adopting a policy that supports family-centered care. Johnson and Myers (2007) recommend that all pediatricians screen children at 9, 18, 24 or 30 months for developmental delays. This recommendation,

which is endorsed by The American Academy of Pediatrics, uses a family-centered care model.

### **Scale Development**

To develop a scale to measure respondents' experiences, it is important to establish validity and reliability of the instrument. In order to construct a scale that is both valid and reliable, it is critical for researchers to begin with a theory behind the construct that is being measured (DeVellis, 2003). Typically a theory is selected from literature on the topic being measured.

In addition to the importance of theory in scale design, it is also key to determine the specificity of the construct being studied. Scales can be used to measure very specific attitudes or broader constructs that intend to capture a global set of behaviors (DeVellis, 2003). In addition, scales can be intended for use in very specific settings. For example, some scales were designed for use in one setting, such as a school.

Lastly, the items used in a scale should be tested for validity (Groves, 1989; Groves, Dillman, Etinge, & Little, 2002; Lesser, Dillman, Carlson, Lorenz, Mason, & Willits, 2001). In scale psychometric research, content validity and construct validity are important to consider when developing a set of items on a scale. Content validity refers to the extent a measure comprises all aspects of the construct being measured (DeVellis, 2003). DeVellis (2003) recommends using content experts to examine the items to determine if the items are appropriate for the construct being measured. Construct validity refers to the degree that the instrument measures what it intends to measure. Many researchers use factor analysis to determine the statistical structure of

the instrument, in part to ensure the items created capture the construct being measured (Lesser et al., 2001).

### **Existing Instruments**

Some scales have been developed to measure family-centered practices within schools, health care settings, and community support (Bailey et al., 2011; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Kontos & Diamond, 2002; Maijala, Luukkaala, & Astedt-Kurki, 2009; Seid et al., 2001; Summers, Hoffman, Marquis, Turnbull, Poston, & Nelson, 2005; Thompson & Mazer, 2012). Other scales have been constructed to measure the experiences of a family's perception of care in each of the three settings previously mentioned, but not specific to family-centered practice. Several of these scales posed problems for use in the current study, as some were not developed for families of children with ASD, were not administered to parents, or had poor psychometric properties.

The first concern with the scales currently measuring families' experiences toward working with physicians, educators, family members and community agencies is the level of specificity. For each of the scales, the researchers did not target one particular population, but focused on a wide range of disabilities (Bailey et al., 2011; Hoffman et al., 2006; Kontos & Diamond, 2002; Maijala et al., 2009; Seid et al., 2001; Summers et al., 2005). Other scales were focused on one particular type of setting, such as a hospital critical care unit, limiting the use of the scale (Maijala, et.al. 2009).

A second concern was the psychometric properties of the scales. Tinsley and Tinsley (1987) recommend the number of respondents needed to validate a scale should be approximately ten times the number of items on the scales. For example, an

item pool of 60 questions would require 600 respondents. Thompson and Mazer (2012) developed a scale, “Parental Academic Support Scale (PASS),” to assess the frequency, importance, and modes parents used to communicate support with teachers in grades kindergarten through twelve. The five factors included: academic performance, classroom behavior, preparation, hostile peer interactions, and health, with coefficient alpha levels ranging from .74 to .87. The authors used a relatively small sample size (191 parents of children with and without disabilities) from the same district in the southern United States. Given that the scale only included 35 items, it did not meet one of the criteria established by Tinsley and Tinsley (1987) for sample size.

Bailey et al. (2011) developed a scale called the “Family Outcome Survey-Revised,” that measured family outcomes and helpfulness of early intervention service providers. The authors administered the 52-item scale to 265 parents from only two states, Texas and Illinois, which fell short of the recommended number of respondents to validate a 52-item scale according to Tinsley and Tinsley (1987).

“The Parent Perceptions of Care (PPC)” developed by Maijala et al. (2009) measured the experiences of families who had children who were hospitalized for acute care. While this scale was created using a clear theoretical framework, the psychometric properties of the instrument were of major concern considering only 91 respondents took part in this study, a very small number considering there were 63 items used to validate this instrument. This scale was developed using Maijala’s substantive theory of interaction, which categorized family members’ perceptions of their interaction with hospital staff. These factors were gaining consultative

sympathy, being disregarded, trusting the help received, and being disappointed in the help received. The scale developers used a coding procedure to ensure that the factors within the theory could be operationalized for the items on the scale. Seven experts assessed content validity to determine the content and clarity of scale. The scale was then piloted by 91 families at four research hospitals in Finland. Using item analyses, 23 items were deleted from the instrument after determining that these deletions would increase the overall coefficient alpha levels. The final instrument consisted of 40 items.

Kontos and Diamond (2002) validated a scale to examine the differences between ratings of parents with children in early intervention programs toward their early intervention providers in Indiana. “The Early Intervention Scale” contained four subscales: home-based therapies/instruction, centre-based therapies/instruction, medical health services, and service coordination. The initial 33-items were administered to 209 families, short of the recommendation by Tinsley and Tinsley (1987) for the number of respondents needed for validating the scale.

A third concern with previous scales is the absence of information about translations of the scales into other languages. Weeks, Swerissen, and Belfrage (2007) suggest researchers take careful consideration when translating instruments into other languages to avoid unintended cross-cultural differences. Back translation can cause errors in grammar, sentence structure, language difficulty level, inaccuracies, and inconsistencies when an instrument is translated from one language to another (Weeks et al., 2007). Some of the authors were unclear about the processes taken to translate

their instrument from English to another language (Seid et al., 2001; Summers et al., 2005).

“The Family-Professional Partnership Scale” developed by Summers et al. (2005) looked only at the experiences of families in the school setting, and did not incorporate the experiences of families in the health care setting. Likewise the scale addressed the professional as “[your] child’s service providers.” This language did not allow one to determine if a family had varied experiences among different service providers. For example, if a family felt collaboration with a speech and language pathologist was positive, but collaboration with a special educator was negative, the scale did not make this distinction. The scale was not specific to children with ASD. Additionally the researchers translated the scale into Spanish for families, but did not separate this information out to validate the scale in a second language (Weeks et al., 2007).

An additional scale for measuring health care quality developed by Seid et al. (2001) called, the “Parents’ Perceptions of Primary Care (P3C),” was given to parents of children in grades kindergarten through 6 in a large urban school district. The authors created six subscales: (1) continuity; (2) access; (3) contextual knowledge; (4) communication; (5) comprehensiveness; and (6) coordination. The English version of the scale was translated into Spanish, Vietnamese, and Tagalog, although it was unclear the procedures that the authors followed to conduct the translations. These data were not disaggregated to determine differences in the psychometric properties of the various translations of the scale. While the number of parents who completed the

scale was impressive (N = 3,371), Weeks et al. (2007) suggest that every language that an instrument is created in be validated separately.

Lastly, while the previously mentioned scales served a purpose in the research field, none of the scales targeted the experiences of families of children with ASD in schools, health care settings, and within their communities/extended families. For example, “The Family Quality of Life Scale” (2006) was developed to measure the quality of life of families of children with disabilities (Hoffman et al. 2006). The authors found five factors in their scale: (1) family interaction; (2) parenting; (3) emotional well-being; (4) physical/material well-being; and (5) disability-related support. The 25-item scale was validated with 280 parents of children with disabilities. The scale did not inquire about the professionals that the families worked with in caring for their children.

Table 1 summarizes the final validated components of the existing validated scales of measuring a family’s perception of quality of support in each of the three settings. Note, that the summary above reflected the procedures used to validate the scales. Thus, the number of items referenced previously may be different from the final items that are listed in Table 1, as authors may have deleted items during the validation.

Table 1  
Summary of Components of Published Scales

Author(s)/ Year/Title	Factor	Final Number of Items	Cronbach's Alpha	Number of Subjects
Bailey, Raspa, Olmsted, Novak, Sam, Humphreys, Nelson, Robinson, & Guillen (2011) <i>Family Outcomes Survey – Revised</i>	Understanding Your Child's Strengths, needs and Abilities	52	.73	265
	Knowing Your Rights and Advocating for Your Child		.78	
	Helping Your Child Develop & Learn		.87	
	Having Support Systems		.78	
	Accessing the Community		.91	
Hoffman, Marquis, Poston, Summers, & Turnbull (2006) <i>Family Quality of Life Scale</i>	Family Interaction	6	.92	280
	Parenting	6	.88	
	Emotional Well-Being	4	.80	
	Physical/Material Well-Being	5	.88	
	Disability-Related Support	4	.92	
Kontos, & Diamond (2002) <i>Early Intervention Scale</i>	Home-based therapies	6	.92	209
	Centre-based Therapies	6	.88	
	Health/Medical Services	4	.80	
	Service Coordination	5	.88	
Maijala, Luukkaala, & Astedt- Kurki (2009) <i>The Parent Perceptions of Care (PPC)</i>	Gaining consultative sympathy	14	.92	91
	Being Disregarded	10	.80	
	Trusting the Help Received	6	.85	
	Being Disappointed in the Help Received	10	.95	
Seid, Varni, Bermudez, Zivkovic, Far, Nelson, & Kurtin (2001) <i>Parents' Perceptions of Primary Care (P3C)</i>	Continuity	2	.75	3,371
	Access	4	.79	
	Contextual Knowledge	4	.92	
	Communication	4	.92	
	Comprehensiveness	5	.86	
	Coordination	4	.89	
Summers, Hoffman, Marquis, Turnbull, Poston, & Nelson (2005) <i>The Family-Professional Partnership Scale</i>	Child-Focused Relationships	9	.90	205
	Family-Focused Relationships	9	.88	
Thompson, & Mazer (2012) <i>Parental Academic Support Scale (PASS)</i>	Academic Performance	35	.87	191
	Classroom Behavior		.81	
	Preparation		.77	
	Hostile Peer Interactions		.74	
	Health		.74	

## **Research Summary**

Literature currently shows that children of color, specifically African Americans and Hispanics are under-represented in being diagnosed with Autism Spectrum Disorder nationally (Mandell et al., 2002; Palmer et al., 2010). This limits children from being afforded services that are often found to be most effective at young ages (Johnson & Myers, 2007). Studies show that the earlier a child is diagnosed with ASD, the better the prognosis (National Research Council, 2001). Given these data, the aim of the current scale is to determine the family-centered experiences that families of children with ASD are having in three settings that impact their care: schools, health care settings, and the community. After a review of scales that measure a family's experiences in these settings, none adequately reflected the specific goals of the current research project.

## **Research Questions**

The first portion of the study was to develop and validate the scale for use in English. Two questions were addressed in this part of the study.

Question #1: What was the factor structure of the scale? The literature presented previously explained the need to examine caregivers' experiences in three areas: health care, education, and community/family organizations.

Question #2: What was the internal consistency of the scale? Acceptable internal consistency is universally accepted at the Cronbach's Alpha level higher than .70; whereby below .70 is a less satisfactory level of internal consistency (DeVellis, 2003).

The second portion of the study used the newly developed scale with a sample of families of children with ASD. The following six hypotheses were tested:

Question #3: Were there differences between racial/ethnic minority groups on the scale? The researcher predicted that families with children of color (racial/ethnic minorities) would have more negative experiences on the scale and subscales than families with White children. Previous research suggested that families of color would rate their experiences in each of the three settings more negatively (De Valenzuela, Copeland, Qi, & Park, 2006; Fierros & Conroy, 2002; Knapp, Madden, & Marcu, 2010; Mandell et al., 2010; Montes & Halterman, 2011; Ngui & Flores, 2006; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Zoints et al., 2003). Therefore, in this study it was expected that families of color would have more negative experiences in schools, health care settings, and within their communities.

Question #4: Were there differences between families of different annual household income levels on the scale? The researcher predicted that families with higher incomes would have more positive experiences than families from lower incomes. Previous research suggested that families with greater socioeconomic status have more access to resources for their children with ASD (Knapp et al., 2010; Kogan, Strickland, Blumberg, Singh, Perrin, & van Dyck, 2008; Mandell et al., 2010; Montes & Halterman, 2011; Morrier et al., 2008). Therefore, in this study it was expected that families with higher income levels would have more positive experiences on each of the subscales.

Question #5a: Were there differences on the scale based on the race/ethnicity of the child and the race/ethnicity of the physician? The researcher predicted that

families with children of color who work with a physician of color would have more positive experiences than families with children of color who work with a White physician. Additionally, the researcher predicted that White families who work with a physician of color would have more positive experiences than families with children of color who work with a White physician. Previous research indicated differences between patients with the same race/ethnicity as their physician as compared to patients with a different race/ethnicity as their physician; specifically more positive experiences have been reported for patients with the same race/ethnicity as their physician (Cooper, Roter, Johnson, Ford, Steinwachs, & Powe, 2003; Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999; Saha, Arbelaez, & Cooper, 2003).

Question #6: Were there differences between the experiences of families based on the type of professional who made the diagnosis of ASD? The researcher predicted that families with children who are cared for by a pediatrician would have more positive experiences than families who worked with other health care providers who are not pediatricians. Family-centered care was adopted by the American Academy of Pediatrics as a guiding principle for caring for children (American Academy of Pediatrics, 2003). It was thus hypothesized that families who used pediatricians for their child's care would report more positive outcomes on the three subscales.

Question #7: Were there differences between the experiences of families based on the level of education attained? The researcher predicted that caregivers with more education would have more positive experiences than caregivers with less education.

Parents with more education have shown to have a greater chance of receiving access to quality care for their child with ASD (Thomas et al., 2007).

## CHAPTER 3

### METHODOLOGY

#### **Participants**

The respondents in this study were families of children with ASD from around the United States. The families included in the study had children that met the criteria in the *DSM-IV-TR* for Autistic Disorder, Childhood Disintegrative Disorder, Rett's Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (APA, 2000).

In this study, 91.9% of the respondents were mothers (n = 434), 4.2% were fathers (n = 20), with grandparents, siblings, and other family members comprising 2.5% (n = 12). There were 1.3% (n = 6) respondents who declined to answer this question.

Respondents from 45 states were represented in the data. Respondents were not represented from Alaska, Delaware, Nevada, North Dakota, or South Dakota. In this study 14.4% (n = 68) of the families were from Massachusetts; 9.5% (n = 45) of the families were from Michigan. These states represented the largest number of respondents in the sample. The remaining 43 states each represented between 7.4% (n = 35) and .2% (n = 1) of the data collected. Table 2 provides a breakdown of the number of respondents represented by each state.

Table 2  
*Respondent Data by State of Residence*

State	n	Percent
Alabama AL	8	1.7
Arizona AZ	4	.8
Arkansas AR	5	1.1
California CA	35	7.4
Colorado CO	7	1.5
Connecticut CT	7	1.5
Florida FL	22	4.7
Georgia GA	14	3.0
Hawaii HI	1	.2
Idaho ID	1	.2
Illinois IL	27	5.7
Indiana IN	9	1.9
Iowa IA	2	.4
Kansas KS	2	.4
Kentucky KY	5	1.1
Louisiana LA	3	.6
Maine ME	2	.4
Maryland MD	7	1.5
Massachusetts MA	68	14.4
Michigan MI	45	9.5
Minnesota MN	6	1.3
Mississippi MS	4	.8
Missouri MO	7	1.5
Montana MT	2	.4
Nebraska NE	1	.2
New Hampshire NH	4	.8
New Jersey NJ	6	1.3
New Mexico NM	13	2.8
New York NY	13	2.8
North Carolina NC	16	3.4
Ohio OH	17	3.6
Oklahoma OK	1	.2
Oregon OR	2	.4
Pennsylvania PA	13	2.8
Rhode Island RI	23	4.9
South Carolina SC	2	.4
Tennessee TN	2	.4
Texas TX	22	4.7
Utah UT	2	.4
Vermont VT	1	.2
Virginia VA	15	3.2
Washington WA	7	1.5
West Virginia WV	2	.4
Wisconsin WI	10	2.1
Wyoming WY	1	.2
Total	466	98.7
Missing	6	1.3

Families reported their child's race/ethnicity. In this study, 79.9% (n = 376) of the children were White, 9.7% (n = 46) were Hispanic, 4.9% (n = 23) were Black, 2.3% (n = 11) reported as other racial/ethnic minority, 1.5% (n = 7) were Asian, .4% (n = 2) were American Indian, and 1.5% (n = 7) respondents declined to answer this question. For the purpose of the present study, the researcher collapsed those families who indicated they were racial/ethnic minorities into one group in order to have an adequate sample size to conduct hypothesis testing. To conduct the MANOVA concerning the race/ethnicity of families, those respondents who indicated they were American Indian or Alaska Native, Asian, Black, Hispanic, or Other Minority were collapsed into one group for a total n of 89. See Table 3 for this information.

These data can be compared to data from the U.S. Census Bureau compiled in 2012. See Table 4 for this information (United States Census Bureau, 2012b).

Table 3  
*Child Data by Race/Ethnicity*

	N	Percent
American Indian or Alaska Native	2	.4
Asian	7	1.5
Black	23	4.9
Hispanic	46	9.7
White	376	79.7
Other Minority	11	2.3
Did Not Answer	7	1.5
Total	472	100

Table 4  
*U.S. Census Data on Race/Ethnicity, 2012*

	Percent
One Race	97.5
American Indian or Alaska Native	1.2
Asian	5.1
Black	13.1
Native Hawaiian & Other Pacific Islander	0.2
White	77.9
Two or more races	2.5
Hispanic or Latino (of any races)	16.9

Families who participated in the survey reported their approximate household income. Families who earned less than \$100,000 represented 64.2% (n = 303) of the data. Families who earned more than \$100,000 represented 27% (n = 127) of the data. Families who declined to answer the question about income level represented 7.6% (n = 36) of the data and 1.3% (n = 6) of the data were missing. See Table 5 for the break down of household income reported. (United States Census Bureau, 2012a).

Table 5  
*Respondent Household Income Data*

Income	n	Percent
\$0-\$24,999	52	11.0
\$25,000-\$49,999	76	16.1
\$50,000-\$74,999	93	19.7
\$75,000-\$99,999	82	17.4
\$100,000-\$124,999	56	11.9
\$125,000-\$149,999	24	5.1
\$150,000-\$174,999	23	4.9
\$175,000-\$199,999	10	2.1
\$200,000 and up	14	3.0
Did Not Answer	36	7.6
Total	466	98.7
Missing	6	1.3
	472	100.0

Families also reported their highest level of education. Table 6 provides the data of caregiver educational attainment level (United States Census Bureau, 2012a).

Table 6  
*Respondent Education Level*

Educational Attainment Level	n	Percent
Grade School (for example: Elementary or Middle/Junior High	4	.8
High School	99	21.0
Associate degree (for example: AA, AS)	84	17.8
Bachelor's degree (for example: BA, AB, BS)	151	32.0
Master's degree (for example: MA, MS, MEng, MEd, MBA)	96	20.3
Professional degree (for example: MD, DDS, DVM, LLB, JD)	19	4.0
Doctorate degree (for example: PhD, EdD)	13	2.8
Total	466	98.7
Missing	6	1.3

## **Instrumentation**

### **Personal Background Information**

Respondents were asked to answer thirteen personal background questions in the study. The families reported demographic information about their child with ASD: type of ASD diagnosed, race/ethnicity, year of birth, and gender. In addition, the families reported demographic information about themselves: relationship to the child with ASD, language mostly spoken at home, their race/ethnicity, city or town they resided in, state of residence, approximate household income, and their highest level of education completed. The families also reported the type of professional who diagnosed their child and the race/ethnicity of this professional.

### **Previously Published Scales**

The first part of the study involved completing a review of all of the scales previously developed that measure the experiences of families of children with ASD in schools, health care settings, family environment, and in their communities. Using journal databases at The University of Rhode Island and Brown University, the researcher completed seventeen extensive searches in psychology, medicine, education, sociology, and social work databases for scales that measured the experiences of families of children with ASD. The types of experiences that were searched for included schools, health care settings, their families (extended and immediate), their communities, and their places of worship. In addition, family-centered care scales were also searched for. There was a lack of published research on scales specifically designed for families of children with ASD, thus the researcher

broadened the search criteria to include scales created to measure the experiences of families with children with disabilities. This yielded more studies in the search.

As previously mentioned several of these scales posed problems for use in the current study (Bailey et al., 2011; Hoffman et al., 2006; Kontos & Diamond, 2002; Maijala et al., 2009; Seid et al., 2001; Summers et al., 2005; Thompson & Mazer, 2012). This process confirmed for the researcher that understanding the experiences of families of children with ASD were important to add to the literature base.

### **Item Development**

Family-centered care was chosen as the theoretical frame for the items developed for this study. Using the American Academy of Pediatrics (2003) definition of family-centered care, five components were used to develop the item pool of 62 items based on the literature on family-centered care. The researcher wrote items that fit into the five family-centered care components and from reviewing the previously mentioned scales developed. No items were taken directly from any of the previously published scales; the researcher used the items in the previously published scales to guide the development of items that were most pertinent to the three settings where families reported their experiences. Items were written as declarative statements. The scale developed in this study used a Likert-type or summative scale. The Likert-type scale provided valuable information on various “middle of the road data” which includes an undecided or neutral anchor that the Equal-Appearing Intervals Method would not provide (DeVellis, 2003).

The Likert-type scaling of the survey included response options “4 = strongly agree,” “3 = agree,” “2 = disagree,” and “1 = strongly disagree.” The Likert-type scale

contained the option of “Does not Apply” (NA) to ensure that respondents who felt that an item did not apply were able to select this option. For example, a family could have homeschooled their child, thus the items on the “School Support” Scale would not apply.

The item pool was divided into three areas: health care, family/community, and school. These settings were used to get a broad understanding of the types of interactions families of children with ASD experience with individuals in each of these settings. Each item was coded by the researcher to ensure that each of the five components of family-centered care were represented in the three settings being presented in the items. Positively and negatively worded items were constructed as recommended by Fowler (1995). The researcher also applied the guidelines of writing items that were not double-barreled and avoiding unintended question order effects (Dillman, Smyth, & Christian, 2009; Fowler, 1995).

Double-barreled items are problematic in scale design, as they include two concepts that make it difficult or impossible to distinguish what the item is measuring. An example of a double-barreled item is: “My child’s doctor listens to me and is caring.” There are two concepts that are being measured: listening and caring. Instead this item should be separated so that there are two items to assess each concept. In addition to creating items that were not double barreled, the researcher also followed the recommendation of Dillman et al. (2009) and Fowler (1995) to avoid unintended question order effects. The researcher grouped the items by topic and asked the demographic questions at the end of the instrument as to not influence the respondents’ answers to the items measuring their experiences.

Once the item pool was written, content validity was examined through expert and family feedback. The experts and families were from various locations around the country. The 62 items were sent to three experts based on the following: (1) had published research in the area of ASD within the last five years; (2) had at least five years of experience working in the field of ASD research; and (3) had a terminal degree in either education, psychology, or health care. Families of children with ASD were also invited to provide feedback. The families that provided feedback included one African American family from the Midwest, one Hispanic family from the Midwest, and one White family from the Northeast. All of the families who participated had a child with ASD. Using an adapted scale by Waltz and Bausell (1983), the six people rated all of the 62 items based on two criteria: relevance and clarity. Using a three point Likert-type scale (1 = not relevant or clear), (2 = item needs some revision to be relevant or clear) and (3 = item is relevant and clear), the experts and families were provided a form to fill out and return electronically. Four people typed directly on the form, while one person handwrote comments, scanned and emailed the form, and another person handwrote comments and faxed the form to the researcher. See Appendices A and B for a copy of the letters sent to the experts and families.

The researcher examined each item score for relevancy and clarity for any item that was rated with a 1 in either relevancy or clarity on the Likert-type scales by more than 2 respondents (experts or families). The content validity ratio (CVR) for each item was calculated using the following formula:  $CVR = (n_e - N/2) / N/2$  where CVR = content validity ratio,  $n_e$  = number of raters indicating “essential,” N = total number of

raters (Waltz & Bausell, 1983). The essential values in this study were those items scored by raters with either a 2 (item needs some revision to be relevant) or 3 (item is relevant) for relevancy. The CVR was calculated for each item and any item with a value of .75 or lower was examined more closely. In total, there were 11 items that received a CVR value of .75 or lower and were discarded from the final instrument because of the low interrater agreement (Waltz & Bausell, 1983).

In addition to rating the relevancy of the items, there were twelve items that were commented on by the experts and families in regard to their clarity. This qualitative information was used in discarding an additional 12 items from the instrument. A former educational statistics professor and a current special education professor at The University of Rhode Island reviewed the qualitative feedback provided by the six people and agreed with the researcher to eliminate the 23 items from the scale. The same special education professor was consulted about the final 39 items prior to sending out the final instrument to be piloted.

The next step in the process involved the researcher coding the 39 items. Using family-centered care literature, the researcher developed five codes describing aspects of family-centered care (American Academy of Pediatrics, 2003). Once the researcher coded the items, three professionals were trained and asked to code the items. Table 7 shows the codes the three professionals used to code the items within the scale. One professional was an ASD researcher and parent of a child with ASD from the Midwest, one was a special education teacher from the Northeast, and the third professional was a director of a youth community center from the Midwest. The researcher trained these professionals to code the items using examples of various

sample items that fall into each code. The professionals were able to ask questions about the process and then were asked to independently code the items. None of the professionals had difficulty understanding the directions and were able to code the 39 items successfully. See Appendix C for a copy of the letter sent to professionals who coded the items.

Table 7  
*Family-Centered Coding*

<b>Code</b>	<b>Definition</b>
Level of Information Sharing &/or Seeking	The extent to which a professional communicates with a family member (through sharing and seeking information)
Level of Respectful & Supportive Interactions	The extent to which a professional values or supports the family member or child
Level of Establishing Collaboration &/or Partnerships	The extent to which a professional offers to collaborate or create a partnership with the family member or another professional
Level of Competency	The extent to which a professional or parent has the level of knowledge, skills, and follow-through in supporting a child with ASD
Level of Access to Services	The extent to which a family is able to involve their child with ASD in supports, interventions, or services
Other	Please write down the code you feel best represents this item

After each of the professionals coded the items, inter-rater agreement was calculated by comparing the researcher's codes to the codes selected by the professionals. The researcher used the following formula: percentage agreement (number of agreements/number of agreements + number of disagreements). Interrater reliability with values of .80 are considered acceptable (Stevens, 2002). The interrater agreement for the three professionals was .82, .84, and .87.

Finally, the researcher calculated the readability level of the final 39 items on the scale using Flesch-Kincaid Grade level. This value was at the 6.0 grade level, well under the maximum grade level recommendation of 7.0 (Walsh & Volsko, 2008). Readability levels above the Flesch-Kincaid grade level of 7.0 have been shown to compromise comprehension, as the average reading level of an American is at the 7.0 grade level (Walsh & Volsko, 2008). The scale was named “The Family Experiences with Autism Spectrum Disorders” (FEASD) scale. See Appendix D for a copy of the FEASD Scale and personal background questions.

### **Web-based Scale**

The researcher used a web-based survey program, Survey Monkey, to create the online scale. The online scale was tailored to respondents using visual components such as color, size, and organization logo suggested to improve response rates (Dillman et al., 2009). The first page of the online survey was an Institutional Review Board (IRB) approved “Informed Consent for Anonymous Research” letter from the researcher (See Appendix E). The second page of the survey was a letter from the researcher informing the respondent of a voluntary drawing for \$25.00 to be entered into for completing the survey (See Appendix F). Respondents were informed that none of their responses from the scale would be linked to their contact information. The next three pages of the online survey contained the personal background questions and FEASD scale. Respondents answered the first question, “What type of ASD does your child have,” followed by the 39 items in the scale. The last 12 questions in the survey were demographic questions. No identifying information, such as the respondent’s name or contact information, was collected from

the caregiver to ensure subject anonymity. The last page of the online survey allowed a family to be redirected to a separate website to be entered into a drawing. This ensured that no respondent information would be linked to their survey responses. A customized web address was created for the study.

Once the FEASD was placed online, five people piloted the survey to ensure that all links worked correctly. The five people confirmed that the web-based FEASD Scale worked and the researcher began data collection. See Appendix G for a copy of the letter sent to individuals who piloted the survey.

## **Procedure**

### **Data Collection using FEASD**

Respondents were recruited from organizations that served families of children with ASD. The researcher contacted at least one organization or support group that served families of children with ASD in each state in the United States. See Appendices H-J for letters sent to organizations. Dillman et al. (2009) recommend following several procedures to increase the response rate in survey design. First, a pre-notice email was sent to the leader of the state organization from information obtained on the organization's website. A second email was sent three to seven days later with the link to the online survey. Any organization who agreed to contact their members or post information about completing the survey on their website was entered into a drawing for \$100.00 as an incentive for participating in the study.

Organizations were asked if they could provide contact information for other organizations that serve families of children with ASD to the researcher. This convenience sampling methodology is known as snowball sampling (Creswell, 2009;

Patton, 2002). Snowball sampling requires the researcher to start with a list of possible participants (in this case ASD organizations) and then each respondent is asked if he/she knows of other parents/guardians who would like to complete the scale (Creswell, 2009; Patton, 2002). This sampling methodology was selected since families of children with ASD are often connected with one another in various organizations and online support groups. Although this methodology was considered a type of convenience sample, the respondents in this study would be best recruited through snowball sampling.

As previously stated, respondents were given the option of clicking on a link to a second survey to provide their email address and their phone number to be entered into a drawing for \$25.00 at the end of the survey as an incentive to complete the survey. This procedure was employed so that no information that the respondent entered in the survey was linked to their contact information for the purpose of the drawing. The incentives were thoroughly explained to all respondents who completed the survey. The Organization for Autism Research (OAR) generously provided the researcher with a grant, which funded both the drawing for the respondents and the organizations who participated in the study.

After four months of data collection, the web-based survey was taken down. A total of 472 respondents completed the survey after four months of being available online. The data were downloaded into SPSS, a computer based statistical analysis program. After all data were collected, the incentives were distributed to the families and to an organization. Ten families in total were randomly selected to receive a

\$25.00 gift card. One organization that posted the link to the online survey was randomly selected to receive a \$100.00 donation from the researcher.

## CHAPTER 4

### RESULTS

#### **Overview of Data Analyses**

To answer the first two questions in the study, a data screening process was first employed in the data analysis. First, data were checked for accuracy, outliers, and missing values using SPSS 19. Assumptions for normality, linearity, heterogeneity of variance, and factorability of the correlation matrix were examined to ensure that all assumptions were met to perform the statistical tests. Second, the descriptive statistics of each item were examined using item means, standard deviations, range of scores, skew and kurtosis. Third, the psychometric properties of the scale were examined using principal components analysis. Lastly, the reliability of the scale was examined using coefficient alpha.

After deleting items on the FEASD Scale based on the results of the above statistical processes, the remaining research questions were tested. Research questions three through seven were tested by either Multivariate Analysis of Variance (MANOVA) or Multivariate Analysis of Covariance (MANCOVA), followed by Analysis of Variance (ANOVA) analyses and post hoc Tukey HSD analyses for MANOVA values that were statistically significant. All of the analyses were conducted using SPSS 19.

#### **Initial Screening of the Data**

The first step in the screening process was to examine the missing data. When examining individual responses, there were 503 people who completed the survey. However, only 472 people completed the items in the survey from the beginning to

end. It was discovered that 31 respondents answered only the first demographic question (Q1: What form of Autism Spectrum Disorder (ASD) does your child have?) out of 52 questions. These 31 respondents were eliminated from the study. Additionally 6 respondents did not answer the remaining demographic/personal questions following the Likert items. These respondents were also eliminated from the study. This results in a final sample of 466 respondents.

Using listwise deletion procedures, there was 18.4% missing data in the overall sample. Upon examining individual items using pairwise deletion, it was found that the most data missing on any one item was 1.5%. Thus, pairwise deletion was selected for all subsequent analyses.

Next, the data set was screened for univariate outliers. Thirteen univariate outliers were found to be greater than 3.29 standardized scores away from the mean. These items were checked for accuracy as well as patterns of respondent input. It was determined that the data were accurately entered and nothing appeared abnormal in the data set. With additional examination of the Extreme Values tables and charts (histograms and boxplots) for outliers, all scores were in the range of possible scores and no outliers were indicated.

Multivariate outliers were also screened for using Mahalanobis Distance procedure (Stevens, 2002). Mahalanobis distance can determine the multivariate outliers of a data set with fewer than 2,000 participants. Critical values were used for comparing the Mahalanobis distances (Pallant, 2001). The Extreme Values table provided the highest and lowest Mahalanobis distance values by each respondent. Only one respondent had a Mahalanobis value that exceeded the critical value of 26.12

(respondent's value = 28.24). This respondent's data were reviewed and were checked for accuracy and patterns. It was determined that the data were accurate so this respondent's data were included.

### **Item Analysis**

Prior to conducting the factor analysis, exploratory item analysis of the FEASD was conducted. The variables were examined for fit between their distributions and assumptions underlying multivariate analysis. The means of each item were calculated, with low means indicating a more negative experience in school, health care setting, or family support area. The higher mean score indicates a more positive experience in the school, health care setting, or family support area. Item means and standard deviations for each item are included in Appendix L.

In examining the item means, 32 items had a mean statistic in the center range of possible scores (2.5). Question 9 (In my place of worship my child is included in activities) had the lowest mean at 1.41. Question 33 (My child's doctor listens to my concerns about my child) had the highest mean at 3.14. Standard deviations were also computed for each item. Question 1 (The community where I live accepts my child) had the lowest standard deviation at 0.75. Questions 39, 10, 7, 31, 6, 30, 28, 3, 29, 34, and 35 all had standard deviations between 0.81 and 0.99, considered relatively small standard deviations. This indicates that there is not much variability among respondents' answers on these items.

The data were then examined for normality. Skew and kurtosis were examined for all 39 variables to determine if the data set was a normal distribution. Using the guidelines of two for skew and four for kurtosis, question 39 did not meet these

criteria for normal distribution (Stevens, 2002). Examining this item’s histogram confirmed this finding. The item was transformed using log10 reflection transformation. The histogram for the transformed item showed that the distribution was more normal than what was presented in the raw data. The transformation data met the assumptions for normality to conduct parametric statistics, thus the transformed data were included in all MANOVA tests. Table 8 shows the item skew and kurtosis in raw data and transformed data.

Table 8  
*Skew, Kurtosis, Transformation*

Item	Raw Data		Transformed Data	
	Skew	Kurtosis	Skew	Kurtosis
39 When I ask for information about my child's health, the doctor provides it.	-1.63	4.46	.096	-.228

## Results of Research Questions

### Psychometric Properties

*Questions #1 & 2: What is the factor structure of the scale and what is the internal consistency of the scale?*

The researcher used a parallel analysis statistical test to determine the number of components to retain in the principal components analysis (PCA) (Stevens, 2002). The Monte Carlo simulation for parallel analysis was conducted to determine the number of factors or components to retain in the PCA. Parallel analysis is an alternative method to the scree plot method or the Kaiser rule which suggests retaining eigenvalues greater than 1. The researcher used parallel analysis rather than the previously mentioned methods for determining the number of components to retain

because it has been a more robust method for determining the number of principal components to retain (Franklin, Gibson, Robertson, Pohlmann, & Fralish, 1995). Using the Monte Carlo simulation test in SPSS, the researcher determined that there were 4 components that were statistically significant to include in the PCA.

To determine the type of rotation that would be best for interpretation, the inter-factor correlation matrix was examined to determine if an orthogonal or an oblique rotation would best help interpret the factors. Orthogonal rotations are used when the rotated factors are uncorrelated; whereas oblique rotations are used when the rotated factors are correlated (Stevens, 2002). The FEASD factors were only minimally correlated, thus Varimax orthogonal rotation was selected for the analysis.

The PCA was conducted by forcing four components to be retained. When this analysis was conducted, the fourth component only had two items that loaded. This component had fewer than three items, the minimum number of items required for a component to be adequate for further analyses (Stevens, 2002). It is recommended that components with fewer than 3 items are unreliable and should be discarded (Stevens, 2002).

The researcher then conducted a PCA by forcing three components to be retained. When this analyses was conducted, all but two items on the scale loaded with values of .4 or above on the three components. To better understand what components did not load on the hypothesized factors, each item was examined to determine on which factor each loaded.

Upon examining the pattern and structure matrix of the Varimax rotation, two items had values less than .4: Item 4 (I pay a lot of money to get ASD services for my

child) and Item 7 (There are high quality, free community programs for my child). Based on this information, these items were excluded from the instrument.

After items 4 and 7 were deleted, the Cronbach's Alpha was calculated. For the first factor ("School Quality") the coefficient alpha was found to be very good at .96. The coefficient alpha for the second factor ("Health Care Quality") was good at .89, and the coefficient alpha for the third factor ("Family Support") was acceptable at .70. The overall coefficient alpha for the entire scale was very good at .92, accounting for 48.58% of the total variance of the scale. Table 9 contains the factor structure of the FEASD.

The researcher named the three factors. Factor 1, "School Quality," contained 18 items that intend to measure a family's experiences working with school officials. All of these items were hypothesized to load on this factor. Factor 2, "Health Care Quality," contained 11 items that intended to measure a family's experiences working with their child's physician. All of the items were hypothesized to load on this factor, as they were initially developed. Factor 3, "Family Support" contained 8 items that intended to measure a family's rating of how supported they feel from immediate and extended family members in regard to having a child with ASD.

Table 9  
*FEASD Factor Structure*

Item	Factor Loading			Communality
	1	2	3	
15 My child's teacher advocates for what is best for my child.	<b>.856</b>	.033	.083	.741
16 The school staff makes me an active partner in developing plans for my child.	<b>.833</b>	.035	.107	.706
19 My child's teacher respects me.	<b>.828</b>	.017	.084	.692
27 My child's teacher is not willing to work with me.	<b>.824</b>	.007	.053	.681
23 At my child's school, the staff members treat me like a partner.	<b>.818</b>	.029	.137	.689
12 My child's teacher finds helpful ways to include my child in lessons.	<b>.813</b>	.042	.048	.665
18 My child's teacher is knowledgeable about ASD interventions.	<b>.803</b>	.107	.088	.664
20 I am comfortable asking my child's teacher for suggestions.	<b>.796</b>	.065	.058	.640
24 My child's teacher does not provide enough academic support for my child.	<b>.792</b>	.036	.091	.636
11 My child's educational team does not accept my recommendations for education/treatment.	<b>.774</b>	-.002	.230	.651
17 My child's teacher supports my treatment choices for my child.	<b>.759</b>	.069	.065	.586
21 I am unhappy about the supports my child receives in school.	<b>.759</b>	.087	.175	.614
13 My child's teacher provides suggestions that help my child at home.	<b>.738</b>	.118	.084	.566
14 I am not comfortable asking my child's teacher for suggestions.	<b>.704</b>	.026	.009	.496
26 School staff help my child make friends.	<b>.678</b>	.138	.138	.498
25 The staff members at my child's school do not effectively include children with ASD.	<b>.673</b>	.097	.149	.484
28 School staff help connect me to other organizations to help my child.	<b>.585</b>	.148	.151	.387
22 I was an active team member in developing my child's Individualized Education Program (IEP).	<b>.457</b>	.045	.123	.226
36 My child's doctor helps me make decisions about my child's care.	.110	<b>.817</b>	.057	.683

34	My child's doctor is knowledgeable about ASD.	.057	<b>.774</b>	.022	.602
35	My child's doctor provides me with helpful information about ASD.	.065	<b>.770</b>	.040	.599
31	My child's doctor values my point of view.	-.008	<b>.735</b>	.108	.553
33	My child's doctor listens to my concerns about my child.	.060	<b>.735</b>	.148	.565
37	I do not trust the recommendations of my child's doctor.	.101	<b>.731</b>	.122	.559
32	I am not satisfied with the questions my child's doctor asks during office visits.	.070	<b>.719</b>	.045	.524
38	My child's doctor asks how I am doing.	.037	<b>.632</b>	.045	.403
29	My child's doctor does not refer my family to support services (such as family groups, children's groups, etc.).	.048	<b>.604</b>	.062	.371
39	When I ask for information about my child's health, the doctor provides it.	.101	<b>.471</b>	.111	.245
30	My child's doctor directs me to resources to help my family pay for services.	.016	<b>.435</b>	-.009	.189
2	There are family members that I trust to help care for my child.	.073	.055	<b>.703</b>	.502
8	When I have to leave the house, I trust others in my family to watch my child.	.075	-.044	<b>.701</b>	.499
6	My extended family (grandparents, uncles/aunts, cousins, etc.) accept my child.	.072	.052	<b>.674</b>	.462
10	My extended family (grandparents, uncles/aunts, cousins, etc.) do not understand the challenges of raising a child with ASD.	.091	.013	<b>.618</b>	.390
1	The community where I live accepts my child.	.331	.162	<b>.495</b>	.381
3	In my town there are community organizations that include people with ASD.	.251	.147	<b>.406</b>	.249
5	The leaders of my place of worship understand my child's needs.	.025	.091	<b>.359</b>	.138
9	In my place of worship my child is included in activities.	.033	.108	<b>.354</b>	.138
4	I pay a lot of money to get ASD services for my child.	.055	-.043	.330	.114
7	There are high quality, free community organizations that include people with ASD.	.154	.170	.326	.159
		$\alpha=.96$	$\alpha=.89$	$\alpha=.70$	

## Assessment of Independent and Dependent Variables

Research questions 3-7 examined the independent variables and their impact on the three factors developed on the FEASD; School Quality, Health Care Quality, and Family Support. To answer these questions MANOVAs or MANCOVAs were used. Prior to conducting MANOVAs homoscedasticity, multicollinearity, and bivariate correlations must be examined to ensure that MANOVAs can accurately be tested with the data. Table 10 has the FEASD means and standard deviations reported by scale and subscale scores.

Table 10  
*Means, Standard Deviations, and Ranges of Scores for FEASD*

Scale Name	M	SD	Range of Scores
School Quality	44.02	14.73	.00 – 72.0
Health care Quality	29.34	7.16	11.00-45.00
Family Support	18.86	4.87	6.00-31.00
Total FEASD Scale	92.21	19.72	23.00-142.00

N = 466

First, the assumptions of multicollinearity and singularity were examined. One way to determine multicollinearity was through analyzing the tolerance and variance inflation factor (VIF) among the variables (Stevens, 2002). The smaller the tolerance value, the more likely the variable is linear. Using the dependent variables of “School Quality,” “Health Care Quality,” and “Family Support” and the independent variables of “Diagnostician,” “Child’s Race/Ethnicity,” “Physician’s Race/Ethnicity,” “Parent’s Educational Level,” and “Family Income” the VIF values were all less than 2 for each combination, suggesting that the dependent variables were only moderately correlated.

Likewise, each of the tolerance values was under 1, confirming no violation of the assumption of multicollinearity. Table 11 displays the correlations between the three dependent variables. Correlations under 0.70 are acceptable, as this suggests only moderate correlation (Stevens, 2002). The highest correlation among the dependent variables was .307 (between “School Quality” and “Family Support”), although this value is below the 0.70 value that would be concerning (Stevens, 2002). These correlations and the tolerance and VIF values that were calculated indicate there was no violation of the assumption of multicollinearity for the study.

Table 11  
Correlation between DV1-3 and IV1-5

Variable	DV1	DV2	DV3	IV1	IV2	IV3	IV4	IV5
DV1	1							
DV2	.179**	1						
DV3	.307**	.218**	1					
IV1	-.127**	-.096*	-.109*	1				
IV2	-.047	-.049	.019	.013	1			
IV3	-.021	-.057	-.034	-.047	.111*	1		
IV4	.026	.003	.117*	-.068	-.010	-.105*	1	
IV5	.060	-.036	.134**	-.051	.085	-.005	.342**	1

Note. DV1 = School Quality; DV2 = Health care Quality; DV3 = Family Support; IV1 = Diagnostician; IV2 = Child’s Race/Ethnicity; IV3 = Physician’s Race/Ethnicity; IV4 = Parent’s Educational Level; IV5 = Family Income  
\* $p < .05$ ; \*\* $p < .01$

Lastly, the assumption of homogeneity of variance-covariance matrices was tested using the Box’s M Test of Equality of Covariance Matrices. The Box’s M test was calculated for each of the MANOVA analyses. Research question 3 which looked at experiences based on race/ethnicity, yielded a Box’s M test value of 13.37,  $p = .040$ ; research question 4 which looked at income, yielded a Box’s M test value of 51.30,  $p = .673$ ; research question 5, which looked at the child’s race/ethnicity and the

doctor race/ethnicity (as a covariate), yielded a Box's M test value of 13.37,  $p = .040$ ; research question 6, which looked at the type of professional that made the diagnosis of ASD, yielded a Box's M test value of 22.15,  $p = .24$ ; and research question 7, which looked at the educational level of parents, yielded a Box's M test value of 25.30,  $p = .759$ . None of these values were significant at  $p < .001$ , therefore the homogeneity of variance was not violated in this study.

*Question #3: Were there differences between racial/ethnic minority groups on the scale? The researcher predicted that families with children of color (racial/ethnic minorities) would have more negative experiences on the scale and subscales than families with White children.*

This question addressed the differences between experiences of families of color in schools, health care settings, and family support as compared to White families. A one-way between groups MANOVA using the independent variable of race/ethnicity was performed on four dependent variables (School Quality, Health care Quality, Family Support, and Total FEASD Scale). The sample size was found to be adequate to perform this analysis with 466 respondents. Multicollinearity, linearity, and assumptions of normality were all found to be satisfactory. There were no univariate or multivariate outliers at  $p < .001$ . Results indicated that there were no statistically main effects of race of the child across the three different factors, Wilks'  $\Lambda = .994$ ,  $F(3, 462) = .898$ ,  $p = .442$ , partial  $\eta^2 = .006$ . Thus, a child's race did not predict their family's ratings of experiences in schools, health care settings, or with their extended family.

*Question #4: Were there differences between families of different annual household income levels? The researcher predicted that families with higher incomes would have more positive experiences than families from lower incomes.*

The next question addressed the differences in income levels among the families who responded to the survey. The sample size was found to be adequate to perform this analysis with 466 respondents. Multicollinearity, linearity, and assumptions of normality were all found to be satisfactory. There were no univariate or multivariate outliers at  $p < .001$ . Results indicated a statistically significant main effect for families' experiences in the Family Support variable, Wilks'  $\Lambda = .908$ ,  $F(27, 1327) = 1.65$ ,  $p = .020$ , partial  $\eta^2 = .032$ . Partial  $\eta^2$  values indicate a small effect for income levels. When the dependent variables were examined separately, there was only one statistically significant difference found in "Family Support." This analysis was run using a Bonferroni adjusted alpha level of .01:  $F(9, 456) = 2.97$ ,  $p = .002$ , partial  $\eta^2 = .055$ . Post-hoc comparisons using a Tukey HSD test indicated that the mean scores for families with incomes of \$0-24,999 on the Family Support Scale ( $M = 16.88$ ,  $SD = 4.11$ ) were significantly different from families with incomes of \$100,000-\$124,999 ( $M = 20.32$ ,  $SD = 4.87$ ). Thus, families with income above \$100,000-\$124,999 were significantly more positive about their family experiences than were families with income below \$25,000.

*Question #5: Were there differences on the scale based on the race/ethnicity of the child and the race/ethnicity of the physician? The researcher predicted that families with children of color who work with a physician of color would have more positive experiences than families with children of color who work with a White physician.*

*Additionally, the researcher predicted that White families who work with a physician of color would have more positive experiences than families with children of color who work with a White physician.*

The next question addressed the differences in FEASD scale scores between the race of the family and the race of the physician who diagnosed their child with ASD as a covariate. A one-way between groups MANOVA using the independent variable of race/ethnicity of the child with ASD and a covariate of the race/ethnicity of the physician was performed on four dependent variables (School Quality, Health care Quality, Family Support, and Total FEASD Scale). The sample size was found to be adequate to perform this analysis with 466 respondents. Multicollinearity, linearity, and assumptions of normality were all found to be satisfactory. There were no univariate or multivariate outliers at  $p < .001$ .

Results indicated that there were no statistically significant main effects of a child's race/ethnicity when controlled by the physician's race/ethnicity across the four different factors Wilks'  $\Lambda = .990$ ,  $F(6, 922) = .802$ ,  $p = .568$ , partial  $\eta^2 = .005$ . A child's race/ethnicity, when controlled by the physician's race/ethnicity, did not predict their experiences in schools, health care settings, or family support. Families with children of color who worked with a physician of color had similar satisfaction levels as families with children of color who worked with a White physician in terms of their experiences in school, health care and family settings. Likewise, White families who worked with a physician of color had similar experiences as families with children of color who worked with a White physician in terms of their experiences in school, health care and family settings.

*Question #6: Were there differences between the experiences of families based on the type of professional who made the diagnosis of ASD? The researcher predicted that families with children who are cared for by a pediatrician would have more positive experiences than families who worked with other health care providers who are not pediatricians.*

The next question addressed the differences in a family's experiences based on the type of specialist that diagnosed their child with ASD. A one-way between groups MANOVA using the independent variable of the provider's specialty was performed on four dependent variables (School Quality, Health care Quality, Family Support, and Total FEASD Scale). The sample size was found to be adequate to perform this analysis with 414 respondents. This sample size is smaller than those of the other MANOVA analyses, as there were 52 respondents that selected "other" for the type of professional who diagnosed their child with ASD. It was determined these respondents did not provide information to test the differences between groups, thus these respondents' data were excluded from this MANOVA. Multicollinearity, linearity, and assumptions of normality were all found to be satisfactory. There were no univariate or multivariate outliers at  $p < .001$ .

Results indicated a statistically significant main effect for families' experiences in the Family Support variable, Wilks'  $\Lambda = .954$ ,  $F(9, 993) = 2.17$ ,  $p = .022$ , partial  $\eta^2 = .016$ . Partial  $\eta^2$  values indicate a small effect for type of doctor. When the dependent variables were examined separately, there was one statistically significant difference: Total FEASD Scale. The analysis for the Total FEASD Scale was run using a Bonferroni adjusted alpha level of .01:  $F(3, 410) = 4.36$ ,  $p = .005$ , partial  $\eta^2 =$

.031. Post-hoc comparisons using Tukey HSD indicated that mean scores for families who worked with a Pediatrician ( $M = 96.07$ ,  $SD = 20.87$ ) were significantly higher than the means scores for families who worked with a Psychologist ( $M = 87.68$ ,  $SD = 20.24$ ) in their experiences on the Total FEASD Scale.

These findings indicate that families who had a pediatrician as the person who diagnosed their child with ASD reported significantly more positive experiences overall on the FEASD Scale as compared to those families who had a psychologist diagnose their child with ASD.

*Question #7: Were there differences between the experiences of families based on the level of education attained? The researcher predicted that caregivers with more education would have more positive experiences than caregivers with less education.*

The next question addressed the differences in FEASD scale scores of parents with more education as compared to parents with less education. A one-way between groups MANOVA using the independent variable of education was performed on four dependent variables (School Quality, Health care Quality, Family Support, and Total FEASD Scale). The sample size was found to be adequate to perform this analysis with 466 respondents. Multicollinearity, linearity, and assumptions of normality were all found to be satisfactory. There were no univariate or multivariate outliers at  $p < .001$ . Results indicated that there were no statistically main effects of parents' highest educational attainment level across the four different factors Wilks'  $\Lambda = .953$ ,  $F(18, 1293) = 1.24$ ,  $p = .220$ , partial  $\eta^2 = .016$ . Thus, a parent's education did not predict their experiences in schools, health care settings, or family support.

## CHAPTER 5

### DISCUSSION

As the number of children diagnosed with ASD increases in the United States, it is vital to examine settings in which families of children with ASD most frequently navigate (Bellin, et al., 2011). Previous research suggests that families of children with ASD have a more difficult experience in schools, health care settings, and in their family lives (Hagner et al., 2012; Hendricks & Wehman, 2009; Howlin et al., 2004). However, no scales have been developed to measure the experiences of families of children with ASD in all three areas (Bailey et al., 2011; Hoffman et al., 2006; Kontos & Diamond, 2002; Maijala et al., 2009; Seid et al., 2001; Summers et al., 2005; Thompson & Mazer, 2012). Therefore, there were two main objectives of the current research study. The first purpose of this study was to develop a scale that measured the experiences of families with children with ASD. This involved creating the items used in the scale and calculating the psychometric properties of the scale including the factor structure and internal consistency of the scale to create a new validated instrument, The Family Experiences with Autism Spectrum Disorders (FEASD) Scale. The second purpose of the research study was to use the validated FEASD to assess families of children with ASD across five personal background questions.

#### **Psychometric Characteristics of the FEASD scale**

The researcher investigated psychometric properties of the FEASD scale. The 39 items were examined using principal components analysis. It was hypothesized that the items would load onto 3 factors: Community/Family Support,

School Quality, and Health Care Quality. The initial loadings were mostly consistent with this hypothesis.

The first factor, “Community/Family Support,” was hypothesized to have 10 items, but after the analysis, the subscale was reduced to eight items. Two items that were below the recommended loading of .4 were discarded from the final instrument. The decision to include items that focused on family support was based on the literature that has shown the importance of family support for caregivers of children with disabilities (Bayat, 2007; Ekas et al., 2009). Additionally, the guidelines of including subscales with three or more items and using items with correlations .4 or better were used (Stevens, 2002).

The second factor, “School Quality,” had 18 items, the same as hypothesized prior to the principal components analysis. There were no items that were eliminated from the scale based on the psychometric properties from the “School Quality” scale.

The third factor, “Health Care Quality,” had 11 items prior to the principal components analysis. After the psychometric properties were examined, all items were retained in the final scale. See Table 12 for the list of the final items on the FEASD scale.

Table 12  
*Final FEASD Scale Items by Subscale*

Subscale	FEASD Final Items
Factor 1: Family Support Scale $\alpha=.70$	<ol style="list-style-type: none"> <li>1. The community where I live accepts my child.</li> <li>2. There are family members that I trust to help care for my child.</li> <li>3. In my town there are community organizations that include people with ASD.</li> <li>4. The leaders of my place of worship understand my child's needs.</li> <li>5. My extended family (grandparents, uncles/aunts, cousins, etc.) accept my child.</li> <li>6. When I have to leave the house, I trust others in my family to watch my child.</li> <li>7. In my place of worship, my child is included in activities.</li> <li>8. My extended family (grandparents, uncles/aunts, cousins, etc.) do not understand the challenges of raising a child with ASD.</li> </ol>
Factor 2: School Quality Scale $\alpha=.96$	<ol style="list-style-type: none"> <li>9. My child's educational team does not accept my recommendations for education/treatment.</li> <li>10. My child's teacher finds helpful ways to include my child in lessons.</li> <li>11. My child's teacher provides suggestions that help my child at home.</li> <li>12. I am not comfortable asking my child's teacher for suggestions.</li> <li>13. My child's teacher advocates for what is best for my child.</li> <li>14. The school staff makes me an active partner in developing plans for my child.</li> <li>15. My child's teacher supports my treatment choices for my child.</li> <li>16. My child's teacher is knowledgeable about ASD interventions.</li> <li>17. My child's teacher respects me.</li> <li>18. I am comfortable asking my child's teacher for suggestions.</li> <li>19. I am unhappy about the supports my child receives in school.</li> <li>20. I was an active team member in developing my child's Individualized Education Program (IEP).</li> <li>21. At my child's school, the staff members treat me like a partner.</li> <li>22. My child's teacher does not provide enough academic support for my child.</li> <li>23. The staff members at my child's school do not effectively include children with ASD.</li> <li>24. School staff help my child make friends.</li> <li>25. My child's teacher is not willing to work with me.</li> <li>26. School staff help connect me to other organizations to help my child.</li> </ol>
Factor 3: Health Care Quality Scale $\alpha=.89$	<ol style="list-style-type: none"> <li>27. My child's doctor does not refer my family to support services (such as family groups, children's groups, etc.).</li> <li>28. My child's doctor directs me to resources to help my family pay for services.</li> <li>29. My child's doctor values my point of view.</li> <li>30. I am not satisfied with the questions my child's doctor asks during office visits.</li> <li>31. My child's doctor listens to my concerns about my child.</li> <li>32. My child's doctor is knowledgeable about ASD.</li> <li>33. My child's doctor provides me with helpful information about ASD.</li> <li>34. My child's doctor helps me make decisions about my child's care.</li> <li>35. I do not trust the recommendations of my child's doctor.</li> <li>36. My child's doctor asks how I am doing.</li> <li>37. When I ask for information about my child's health, the doctor provides it.</li> </ol>

The FEASD scale had a satisfactory internal consistency and proved to be a valid measure. Family-centered care provided a strong theoretical framework for the items developed in the scale and fit well within the three factors on the scale. Family-centered care is a theory that is cited in educational and health care research as a best practice (Beatson, 2008; Dunst, 2002; Epley et al., 2010; King et al., 2004; Kuo et al., 2011; Moore et al., 2009; Rosenbaum et al., 1998; Tomasello et al., 2010; Trute, 2007). The FEASD scale is an important measurement tool of family support, and school, and health care quality for families of children with ASD, as it is the first instrument that aims to measure experiences in all three settings.

#### **Effects of Family and Health Care Provider Variables on FEASD Scale**

The second purpose of the study was to use the newly created scale to examine various demographic variables in the sample. Research questions three, four, five, six, and seven are discussed below.

The third research question examined the impact of race on the three factors in the FEASD. It was hypothesized that families of color would have a more negative experience in each of the three subscales of the FEASD, as documented by previous literature (De Valenzuela et al., 2006; Fierros & Conroy, 2002; Knapp et al., 2010; Mandell et al., 2010; Montes & Halterman, 2011; Ngui & Flores, 2006; Thomas et al., 2007; Zoints et al., 2003). The MANOVAs performed on the data showed that race does not predict the experiences of families on any of the FEASD scales.

To better understand the sample from the current study, the income levels of the families by race were examined more closely and compared to the US Census data

income by race. This information may explain the reason that the data did not show significant differences. In the current study, 22.2% of Black families reported earning \$100,000 or more annually, compared with 9.3% of Black families from the US Census data (2013). This suggests that the Black families who participated in this research study were more affluent than the Black population in the United States. Likewise, 14.3% of Hispanic families reported an annual household income of \$100,000 or more compared with the 11.7% reported by the US Census (2013). These data suggest that the sample in this study was not representative of the US population by race and annual household income. See Table 13 for the annual household income by race/ethnicity from the US Census (2012) compared with the sample included in this study.

Table 13  
*Annual Household Income by Race/Ethnicity*

	Asian	Black	Hispanic	White
<b>\$0 - \$24,999</b>				
FEASD Data	0.0%	18.5%	11.9%	10.4%
U.S. Census	19.6%	38.9%	31.7%	23%
<b>\$25,000- \$49,999</b>				
FEASD Data	6.7%	25.9%	16.7%	15.7%
U.S. Census	19.3%	28%	29.7%	25%
<b>\$50,000-\$74,999</b>				
FEASD Data	40.0%	14.8%	31.0%	18.4%
U.S. Census	16.9%	15.1%	17.6%	18.7%
<b>\$75,000-\$99,999</b>				
FEASD Data	33.3%	11.1%	21.4%	18.6%
U.S. Census	11.8%	8.7%	9.1%	12%
<b>\$100,000 and over</b>				
FEASD Data	6.7%	22.2%	14.3%	29.3%
U.S. Census	32.4%	9.3%	11.7%	21.4%

*Note.* The FEASD data sum for each race/ethnicity does not equal 100% because of respondents who did not answer the question.

The fourth research question examined the impact of income on the three factors in the FEASD. It was hypothesized that families with a higher annual household income would have a more positive experience in each of the three subscales of the FEASD, as documented by previous literature (Knapp et al., 2010; Mandell et al., 2005; Montes & Halterman, 2008; Morrier et al., 2008; Rhoades, Scarpa, & Salley, 2007). The MANOVAs performed on the data showed that income does predict the experiences of families in the Family Support variable. The questions in this subscale, include the following items: (1) There are family members that I trust to help care for my child; (2) My extended family (grandparents, uncles/aunts,

cousins, etc.) accepts my child; (3) When I have to leave the house I trust others in my family to watch my child; and (4) My extended family (grandparents, uncles/aunts, cousins, etc.) does not understand the challenges of raising a child with ASD. These items concern the level of family support that caregivers of children with ASD feel. Families who reported earning \$100,000-\$124,999 a year had a statistically significant higher mean score on the Family Support scale than families who earn less than \$25,000 a year. These results are similar to Kogan et al. (2008) who found that families of children with ASD were more impacted by income and receiving family support services than other families of children with other disabilities.

The fifth research question examined the impact of race of the physician on the experiences of children based on their racial identity. It was hypothesized that families with children of color who worked with a physician of color would have more positive experiences than families with children of color who work with a White physician. The MANOVAs performed on the data showed that the race of the physician does not predict the experiences of families. Previous research suggested a more positive outcome and experience for the patients with the same race/ethnicity as their physician as compared to patients with a different race/ethnicity as their physician (Cooper et al., 2003; Cooper-Patrick et al., 1999; Saha et al., 2003).

The sixth research question examined the impact of the type of specialist that diagnosed their child with ASD on the three components in the FEASD and the overall scale mean. It was hypothesized that families who had a pediatrician diagnose their child with ASD would have more positive experiences, as documented by previous literature (American Academy of Pediatrics, 2003). The items included in

the scale were written using family-centered care components. Since the American Academy of Pediatrics has endorsed family-centered care as a best practice, the researcher hypothesized that families who worked with a pediatrician would have more positive experiences.

The MANOVAs performed on the data showed that having a Pediatrician diagnose a child does predict the experiences of families on the Total FEASD Scale. The mean scores were significantly more positive for families who were cared for by a pediatrician than those families who were cared for by a psychologist. The results corroborate with Rhoades et al. (2007) who found pediatricians were more likely to contribute additional information about education-related support services, such as occupational therapy or social skills training, that help their children with ASD than other health care professionals.

Interestingly, the mean scores of the Health Care Quality Scale were not statistically different. Families who reported a psychologist as the diagnosing professional had the lowest mean score on the Health Care Quality Scale. One might hypothesize that the Health Care Quality scale would be significantly different, since the physician most often impacts health care quality. This finding suggests that the type of professional that diagnosed the child with ASD impacts a family's experiences overall in each of the three areas. Family-centered care stresses the importance of collaboration, communication, and respect; all of which are part of the FEASD Scale.

The seventh research question examined the impact of the education of the caregiver on the three components in the FEASD and the overall scale mean. It was hypothesized that caregivers with more education would have more positive

experiences in each of the three subscales of the FEASD, as documented by previous literature (Thomas et al., 2007). The MANOVAs performed on the data showed that education does not predict the experiences of families.

### **Limitations**

There are several limitations with the current study. First, the results should be cautiously generalizable since the household income levels and number of respondents from a racial/ethnic minority group were not representative of the United States population.

Second, due to the small number of some of the racial/ethnic groups, all families of color were collapsed into one racial/ethnic minority group. This reduced the ability to detect differences at more specified levels of the IVs. For example, there may be significant differences in all three scales between Asian families and Black families, but due to the low number of Asian families who participated in the study ( $n = 7$ ) this could not be explored.

Third, it is important to keep in mind that only families with access to the Internet would be informed about this study. Families who do not have Internet access would not be aware of the research study and subsequently would not be able to participate. Furthermore, the sample that participated in the Internet survey had the time and energy to devote to complete the online survey. Some families may not have completed the survey due to lack of child care, which could mean that the results are an overestimate of the experiences in schools, health care settings, and in families compared to the general ASD population. This sample is likely to be missing families who do not have disposable resources, lack connections to ASD support organizations,

and/or whose children have particular needs that would not allow them to complete an online survey.

Fourth, snowball sampling was employed to recruit respondents in this study. This method of recruitment is less desirable than random sampling, which would have randomly selected families of children with ASD to participate in the study.

Fifth, the survey was accessible to families who spoke English. Families with linguistic backgrounds other than English were excluded from participating in this study. While there are many challenges to translating an instrument into another language, the fact that this survey was only accessible to families who spoke English narrows the particular sample who participated in the study.

### **Future Research**

#### **Experiences to Obtain ASD Diagnosis**

This study aimed to examine various demographic factors in regard to experiences in schools, health care settings, and in their families. These three settings are connected to one another, as a diagnosis by a physician is often required for a child to be provided special education services. While this information offered insight into families who currently have a child diagnosed with ASD, it does not explain the challenges that families face while trying to obtain a diagnosis of ASD. Mandel et al. (2002) indicates a later diagnosis for families of color, thus examining the experiences of these families would be an important contribution to research. Either a quantitative or qualitative examination of the racial, cultural, and/or socioeconomic experiences that impede families from obtaining an ASD diagnosis would help in understanding how to provide support to these families.

## **Use of the FEASD**

As previously mentioned, differences between racial/ethnic minority groups could not be measured due to the sample size. Another study using the FEASD Scale should focus on obtaining responses from more families of color so that disaggregated analyses can be conducted. Also, it would be important to obtain a sample more representative in terms of income by race. Furthermore, adding a personal background question that inquired the age that the child was diagnosed with ASD, the types of services families receive, the annual out of pocket expenses to pay for services, and/or the severity of their child's disability could be examined further. It would also be important to develop and validate the scale in other languages.

## **Concluding Remarks**

The FEASD Scale is a validated scale to measure the experiences of families of children with ASD based on the results of principal components analysis and internal consistency reliability. The scale appears to measure the School Quality, Health Care Quality, and Family Support of families of children with ASD. Two of the findings were consistent with previous research (American Academy of Pediatrics, 2003, Knapp et al., 2010; Kogan et al., 2008; Mandell et al., 2010; Montes & Halterman, 2011; Morrier et al., 2008, Rhoades, et al., 2007) indicating that household income and the type of professional that diagnose a child with ASD impact a family's experiences. Although there were a number of noted limitations, this study provides a foundation to further develop the FEASD Scale, which may help to provide greater understanding of the challenges families of children with ASD encounter.

APPENDIX A

Letter to Experts for Feedback

Date

Dear Experts:

I invite you to help with the creation of the content for the Families Experiences with Autism Spectrum Disorder scale.

Read each item. Use the scales below to determine the relevance and clarity of each item. Please feel free to comment on items or suggest revisions as you feel are necessary.

<b>Relevance</b>	<b>1 = not relevant to ASD</b>	<b>2 = item needs some revision to be relevant to ASD</b>	<b>3 = item is very relevant</b>
<b>Clarity</b>	<b>1= item is not clear</b>	<b>2 = item needs some revision to be clear</b>	<b>3 = meaning very clear</b>

Adapted from Waltz and Bausell (1983)

<b>ITEMS</b>	<b>Relevance</b>	<b>Clarity</b>	<b>COMMENTS/SUGGESTIONS</b>
<b>Item 1</b>	<b>1 2 3</b>	<b>1 2 3</b>	
<b>Item 2</b>	<b>1 2 3</b>	<b>1 2 3</b>	
<b>Item 3</b>	<b>1 2 3</b>	<b>1 2 3</b>	

Thank you for your time and assistance with this process!

Sincerely,

Adam Moore, M.Ed.  
The University of Rhode Island  
Doctoral Student

### Expert Feedback Form

<b>Relevance</b>	<b>1 = not relevant to ASD</b>	<b>2 = item needs some revision to be relevant to ASD</b>	<b>3 = item is very relevant</b>
<b>Clarity</b>	<b>1= item is not clear</b>	<b>2 = item needs some revision to be clear</b>	<b>3 = meaning very clear</b>

ITEMS	Relevance	Clarity	COMMENTS/ SUGGESTIONS
1. The community in which I live is accepting of my child with ASD.	1 2 3	1 2 3	
2. I feel supported by my relatives.	1 2 3	1 2 3	
3. I am concerned that my child with ASD will not be able to participate in sports.	1 2 3	1 2 3	
4. There are family members I trust to help with caring for my child.	1 2 3	1 2 3	
5. My child has improved his/her skills at making friends from participating in ASD organizations.	1 2 3	1 2 3	
6. There are organizations in my community that support students with Autism Spectrum Disorder.	1 2 3	1 2 3	
7. The staff of ASD organizations does not connect me with other parents of children with ASD.	1 2 3	1 2 3	
8. I am treated like a partner in making decisions in my child's ASD organization.	1 2 3	1 2 3	
9. The community in which I live does not empathize with children with ASD.	1 2 3	1 2 3	
10. I pay a lot of money for my child to obtain services for ASD.	1 2 3	1 2 3	
11. The leaders of my church/religious organization are understanding of my child's needs.	1 2 3	1 2 3	
12. My extended family lovingly accepts my child.	1 2 3	1 2 3	
13. When I contact leaders in my local ASD organization they return my calls or emails.	1 2 3	1 2 3	

14. My family does not understand the challenges of raising a child with a disability.	1 2 3	1 2 3	
15. Religious services/activities include my child.	1 2 3	1 2 3	
16. I trust others in my family can help watch my child with ASD when I have to leave the house.	1 2 3	1 2 3	
17. I feel supported by organizations in my community.	1 2 3	1 2 3	
18. There are high quality free community programs for my child with ASD.	1 2 3	1 2 3	
19. Staff members of my local ASD organization are knowledgeable of ASD.	1 2 3	1 2 3	
20. The ASD organizations I am involved in have helpful information for my family.	1 2 3	1 2 3	
21. I am not confident in making recommendations about my child's education.	1 2 3	1 2 3	
22. My child's teacher is positive about my child's progress.	1 2 3	1 2 3	
23. My child's teacher finds ways to effectively include my child with ASD in classroom lessons.	1 2 3	1 2 3	
24. I had to battle with school staff to obtain a diagnosis of ASD for my child.	1 2 3	1 2 3	
25. My child's teacher is able to provide suggestions that support my child at home.	1 2 3	1 2 3	
26. My child is not included in activities in school.	1 2 3	1 2 3	
27. I am not comfortable asking for suggestions from my child's teacher.	1 2 3	1 2 3	
28. My child's teacher is willing to contact my child's doctor if I ask.	1 2 3	1 2 3	
29. My child's teacher advocates for what is best for my child.	1 2 3	1 2 3	
30. The staff at my child's school has made me an active partner in developing a plan for my child.	1 2 3	1 2 3	
31. My child's teacher is supportive of my family's choices for caring for my	1 2 3	1 2 3	

child with ASD.			
32. The teachers that work with my child are knowledgeable.	1 2 3	1 2 3	
33. My child's teacher respects me.	1 2 3	1 2 3	
34. I am comfortable asking for suggestions from my child's teacher.	1 2 3	1 2 3	
35. My child's teacher is disrespectful of my family's goals for my son/daughter.	1 2 3	1 2 3	
36. I am upset about the choice of supports in place at my child's school.	1 2 3	1 2 3	
37. I was an active team member in developing my child's Individualized Education Program (IEP).	1 2 3	1 2 3	
38. The staff members at my child's school treat me like a partner.	1 2 3	1 2 3	
39. My child's teacher has not provided enough academic support for my child.	1 2 3	1 2 3	
40. My child's school is accepting of children with disabilities.	1 2 3	1 2 3	
41. The leaders of my child's school do not effectively include children with Autism Spectrum Disorder.	1 2 3	1 2 3	
42. My child's teacher helps my son/daughter make friends at school.	1 2 3	1 2 3	
43. My child's teacher is not willing to collaborate with me.	1 2 3	1 2 3	
44. The school staff in my child's school help connect me to other organizations to help my child.	1 2 3	1 2 3	
45. My child's doctor does not refer my family to support services (such as family groups, children's groups, etc)	1 2 3	1 2 3	
46. My child's doctor provides resources to help my family navigate paying for services.	1 2 3	1 2 3	
47. My child's doctor values my perspective.	1 2 3	1 2 3	
48. My child's doctor does not ask me questions during office visits.	1 2 3	1 2 3	
49. My child's doctor collaborates with me in setting up programs to help my child.	1 2 3	1 2 3	

50. My child's doctor understands if I choose not to follow his or her advice.	1 2 3	1 2 3	
51. I am satisfied with my child's doctor.	1 2 3	1 2 3	
52. When I go to my child's doctor I feel like he/she listens to my concerns about my child.	1 2 3	1 2 3	
53. My child's doctor does not listen to me when I speak about my child's struggles.	1 2 3	1 2 3	
54. My child's doctor is willing to talk to the teachers at my child's school.	1 2 3	1 2 3	
55. My child's doctor is knowledgeable about ASD.	1 2 3	1 2 3	
56. My child's doctor provided me with helpful information on ASD.	1 2 3	1 2 3	
57. My child's doctor helps me make decisions about my child's care.	1 2 3	1 2 3	
58. I am dissatisfied with my child's doctor's knowledge of ASD.	1 2 3	1 2 3	
59. I do not trust the recommendations made by my child's doctor.	1 2 3	1 2 3	
60. My child's doctor often asks about how I am doing.	1 2 3	1 2 3	
61. My child's doctor shares information about my child's health when I ask.	1 2 3	1 2 3	
62. I am receptive to listening to advice given by my child's doctor.	1 2 3	1 2 3	

APPENDIX B

Letter to Families for Feedback

Date

Dear Families:

I invite you to help with the creation of the content for the Families Experiences with Autism Spectrum Disorder scale.

Read each item. Use the scales below to determine the relevance and clarity of each item. Please feel free to comment on items or suggest revisions as you feel are necessary.

<b>Relevance</b>	<b>1 = not relevant to ASD</b>	<b>2 = item needs some revision to be relevant to ASD</b>	<b>3 = item is very relevant</b>
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<b>ITEMS</b>	<b>Relevance</b>	<b>Clarity</b>	<b>COMMENTS/SUGGESTIONS</b>
<b>Item 1</b>	<b>1 2 3</b>	<b>1 2 3</b>	
<b>Item 2</b>	<b>1 2 3</b>	<b>1 2 3</b>	
<b>Item 3</b>	<b>1 2 3</b>	<b>1 2 3</b>	

Thank you for your time and assistance with this process!

Sincerely,

Adam Moore, M.Ed.  
The University of Rhode Island  
Doctoral Student

### Family Feedback Form

<b>Relevance</b>	<b>1 = not relevant to ASD</b>	<b>2 = item needs some revision to be relevant to ASD</b>	<b>3 = item is very relevant</b>
<b>Clarity</b>	<b>1= item is not clear</b>	<b>2 = item needs some revision to be clear</b>	<b>3 = meaning very clear</b>

ITEMS	Relevance	Clarity	COMMENTS/ SUGGESTIONS
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3. I am concerned that my child with ASD will not be able to participate in sports.	1 2 3	1 2 3	
4. There are family members I trust to help with caring for my child.	1 2 3	1 2 3	
5. My child has improved his/her skills at making friends from participating in ASD organizations.	1 2 3	1 2 3	
6. There are organizations in my community that support students with Autism Spectrum Disorder.	1 2 3	1 2 3	
7. The staff of ASD organizations does not connect me with other parents of children with ASD.	1 2 3	1 2 3	
8. I am treated like a partner in making decisions in my child's ASD organization.	1 2 3	1 2 3	
9. The community in which I live does not empathize with children with ASD.	1 2 3	1 2 3	
10. I pay a lot of money for my child to obtain services for ASD.	1 2 3	1 2 3	
11. The leaders of my church/religious organization are understanding of my child's needs.	1 2 3	1 2 3	
12. My extended family lovingly accepts my child.	1 2 3	1 2 3	
13. When I contact leaders in my local ASD organization they return my calls or emails.	1 2 3	1 2 3	

14. My family does not understand the challenges of raising a child with a disability.	1 2 3	1 2 3	
15. Religious services/activities include my child.	1 2 3	1 2 3	
16. I trust others in my family can help watch my child with ASD when I have to leave the house.	1 2 3	1 2 3	
17. I feel supported by organizations in my community.	1 2 3	1 2 3	
18. There are high quality free community programs for my child with ASD.	1 2 3	1 2 3	
19. Staff members of my local ASD organization are knowledgeable of ASD.	1 2 3	1 2 3	
20. The ASD organizations I am involved in have helpful information for my family.	1 2 3	1 2 3	
21. I am not confident in making recommendations about my child's education.	1 2 3	1 2 3	
22. My child's teacher is positive about my child's progress.	1 2 3	1 2 3	
23. My child's teacher finds ways to effectively include my child with ASD in classroom lessons.	1 2 3	1 2 3	
24. I had to battle with school staff to obtain a diagnosis of ASD for my child.	1 2 3	1 2 3	
25. My child's teacher is able to provide suggestions that support my child at home.	1 2 3	1 2 3	
26. My child is not included in activities in school.	1 2 3	1 2 3	
27. I am not comfortable asking for suggestions from my child's teacher.	1 2 3	1 2 3	
28. My child's teacher is willing to contact my child's doctor if I ask.	1 2 3	1 2 3	
29. My child's teacher advocates for what is best for my child.	1 2 3	1 2 3	
30. The staff at my child's school has made me an active partner in developing a plan for my child.	1 2 3	1 2 3	
31. My child's teacher is supportive of my family's choices for caring for my	1 2 3	1 2 3	

child with ASD.			
32. The teachers that work with my child are knowledgeable.	1 2 3	1 2 3	
33. My child's teacher respects me.	1 2 3	1 2 3	
34. I am comfortable asking for suggestions from my child's teacher.	1 2 3	1 2 3	
35. My child's teacher is disrespectful of my family's goals for my son/daughter.	1 2 3	1 2 3	
36. I am upset about the choice of supports in place at my child's school.	1 2 3	1 2 3	
37. I was an active team member in developing my child's Individualized Education Program (IEP).	1 2 3	1 2 3	
38. The staff members at my child's school treat me like a partner.	1 2 3	1 2 3	
39. My child's teacher has not provided enough academic support for my child.	1 2 3	1 2 3	
40. My child's school is accepting of children with disabilities.	1 2 3	1 2 3	
41. The leaders of my child's school do not effectively include children with Autism Spectrum Disorder.	1 2 3	1 2 3	
42. My child's teacher helps my son/daughter make friends at school.	1 2 3	1 2 3	
43. My child's teacher is not willing to collaborate with me.	1 2 3	1 2 3	
44. The school staff in my child's school help connect me to other organizations to help my child.	1 2 3	1 2 3	
45. My child's doctor does not refer my family to support services (such as family groups, children's groups, etc)	1 2 3	1 2 3	
46. My child's doctor provides resources to help my family navigate paying for services.	1 2 3	1 2 3	
47. My child's doctor values my perspective.	1 2 3	1 2 3	
48. My child's doctor does not ask me questions during office visits.	1 2 3	1 2 3	
49. My child's doctor collaborates with me in setting up programs to help my child.	1 2 3	1 2 3	

50. My child's doctor understands if I choose not to follow his or her advice.	1 2 3	1 2 3	
51. I am satisfied with my child's doctor.	1 2 3	1 2 3	
52. When I go to my child's doctor I feel like he/she listens to my concerns about my child.	1 2 3	1 2 3	
53. My child's doctor does not listen to me when I speak about my child's struggles.	1 2 3	1 2 3	
54. My child's doctor is willing to talk to the teachers at my child's school.	1 2 3	1 2 3	
55. My child's doctor is knowledgeable about ASD.	1 2 3	1 2 3	
56. My child's doctor provided me with helpful information on ASD.	1 2 3	1 2 3	
57. My child's doctor helps me make decisions about my child's care.	1 2 3	1 2 3	
58. I am dissatisfied with my child's doctor's knowledge of ASD.	1 2 3	1 2 3	
59. I do not trust the recommendations made by my child's doctor.	1 2 3	1 2 3	
60. My child's doctor often asks about how I am doing.	1 2 3	1 2 3	
61. My child's doctor shares information about my child's health when I ask.	1 2 3	1 2 3	
62. I am receptive to listening to advice given by my child's doctor.	1 2 3	1 2 3	

## APPENDIX C

### Letter to Professionals to Code Survey Items

Dear Professional,

I invite you to code the following items on the Family Experiences with Autism Spectrum Disorder (FEASD) Scale. In table 1, you will find 5 pre-determined codes. These codes have been developed from extensive review of research on family-centered care, a best-practice for working with families of children with special needs. For each item answer the following question, “What is the underlying theme of this statement?” Each of the pre-determined codes has been assigned a letter to make the process easier for you.

For example, if you feel that item 1, should be coded with “Level of Information Sharing &/or Seeking,” write the letter, “A” in the box marked “Code.”

If you feel that the item does not fit in any of the codes, please write in the code you feel best represents that particular item. In addition, if you have any additional comments that you feel would be helpful, please provide these comments in the box provided to the right of each item.

Thank you for your time and expertise with this project!

Sincerely,

Adam Moore, M.Ed.  
Doctoral Student  
The University of Rhode Island

TABLE 1

<b>LABEL</b>	<b>Code</b>	<b>Definition</b>
<b>A</b>	<b>Level of Information Sharing &amp;/or Seeking</b>	<b>The extent to which a professional communicates with a family member (through sharing and seeking information)</b>
<b>B</b>	<b>Level of Respectful &amp; Supportive Interactions</b>	<b>The extent to which a professional values or supports the family member or child</b>
<b>C</b>	<b>Level of Establishing Collaboration &amp;/or Partnerships</b>	<b>The extent to which a professional offers to collaborate or create a partnership with the family member or another professional</b>
<b>D</b>	<b>Level of Competency</b>	<b>The extent to which a professional or parent has the level of knowledge, skills, and follow-through in supporting a child with ASD</b>
<b>E</b>	<b>Level of Access to Services</b>	<b>The extent to which a family is able to involve their child with ASD in supports, interventions, or services</b>
<b>F</b>	<b>Other</b>	<b>Please write down the code you feel best represents this item</b>

## APPENDIX D

### Family Experiences with Autism Spectrum Disorders (FEASD) Scale

Directions: In answering all of the following questions, please apply each item to your OLDEST child diagnosed with Autism Spectrum Disorder (ASD).

1. What form of Autism Spectrum Disorder (ASD) does your child have?

Autism

Rett syndrome

Asperger syndrome

Childhood Disintegrative Disorder

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

Other (please specify)

#### PART 1: Experience Scale

Directions: In answering all of the following questions, please apply each item to your OLDEST child diagnosed with Autism Spectrum Disorder (ASD). Please select one option that reflects your level of agreement with the following statements. When asked about your child's teacher or doctor, please answer the questions about your child's current teacher and doctor.

**1 =strongly disagree, 2=disagree, 3=agree, 4=strongly agree, or NA**

2. The community where I live accepts my child.
3. There are family members that I trust to help care for my child.
4. In my town there are community organizations that include people with ASD.
5. I pay a lot of money to get ASD services for my child.
6. The leaders of my place of worship understand my child's needs.
7. My extended family (grandparents, uncles/aunts, cousins, etc.) accept my child.
8. There are high quality, free community programs for my child.
9. When I have to leave the house, I trust others in my family to watch my child.
10. In my place of worship my child is included in activities.
11. My extended family (grandparents, uncles/aunts, cousins, etc.) does not understand the challenges of raising a child with ASD.
12. My child's educational team does not accept my recommendations for education/treatment.
13. My child's teacher finds helpful ways to include my child in lessons.
14. My child's teacher provides suggestions that help my child at home.
15. I am not comfortable asking my child's teacher for suggestions.
16. My child's teacher advocates for what is best for my child.
17. The school staff makes me an active partner in developing plans for my child.
18. My child's teacher supports my treatment choices for my child.
19. My child's teacher is knowledgeable about ASD interventions.
20. My child's teacher respects me.

21. I am comfortable asking my child's teacher for suggestions.
22. I am unhappy about the supports my child receives in school.
23. I was an active team member in developing my child's Individualized Education Program (IEP).
24. At my child's school, the staff members treat me like a partner.
25. My child's teacher does not provide enough academic support for my child.
26. The staff members at my child's school do not effectively include children with ASD.
27. School staff help my child make friends.
28. My child's teacher is not willing to work with me.
29. School staff help connect me to other organizations to help my child.
30. My child's doctor does not refer my family to support services (such as family groups, children's groups, etc.).
31. My child's doctor directs me to resources to help my family pay for services.
32. My child's doctor values my point of view.
33. I am not satisfied with the questions my child's doctor asks during office visits.
34. My child's doctor listens to my concerns about my child.
35. My child's doctor is knowledgeable about ASD.
36. My child's doctor provides me with helpful information about ASD.
37. My child's doctor helps me make decisions about my child's care.
38. I do not trust the recommendations of my child's doctor.
39. My child's doctor asks how I am doing.
40. When I ask for information about my child's health, the doctor provides it.

## PART 2: Personal Background Information

Directions: Please answer the following questions by checking the option that best describes the background information about you and your OLDEST child diagnosed with ASD.

41. What is your child's gender?

- Female
- Male
- Other

42. What year was your child born?

43. What language do you mainly speak at home?

- English
- Spanish
- Other (please specify)

44. Please describe your child's race/ethnicity. (Check All that Apply)

- American Indian or Alaska Native
- Asian
- Black or African American
- Hispanic or Latino

Native Hawaiian  
Other Pacific Islander  
White  
Unknown

45. What is your relationship to the child?

Mother  
Father  
Grandmother  
Grandfather  
Sibling  
Other (please specify)

46. Please describe your race/ethnicity. (Check All that Apply)

American Indian or Alaska Native  
Asian  
Black or African American  
Hispanic or Latino  
Native Hawaiian  
Other Pacific Islander  
White  
Unknown  
Other (please specify)

47. What city/town do you currently live in?

48. What state do you currently live in?

49. What is your approximate household income?

50. What is the highest level of education you have completed?

51. What race or ethnicity would you classify the health care provider that diagnosed your child with ASD?

American Indian or Alaska Native  
Asian  
Black or African American  
Hispanic or Latino  
Native Hawaiian  
Other Pacific Islander  
White  
Unknown  
Other (please specify)

52. What type of professional diagnosed your child with ASD?

Pediatrician  
Neurologist  
Family Doctor  
Psychiatrist  
Psychologist  
Other (please specify)

## APPENDIX E

Informed Consent Template- Anonymous Research  
(Anonymous meaning no one on the research team  
will ever have access to any identifiers.)

The University of Rhode Island  
Department of Education  
Address: 705 Chafee Hall, Flagg Road,  
Kingston, RI 02881

Title of Project: The Development and Validation of the Family Experiences with  
Autism Spectrum Disorder (FEASD) Scale

### **PLEASE SAVE OR PRINT THIS FORM FOR YOUR RECORDS**

Dear Participant,

You have been invited to take part in the research project described below. If you have any questions, please feel free to call Mr. Adam Moore at (401) 874-4200 or Dr. Joanne Eichinger at (401) 874-7420, the people mainly responsible for this study.

The purpose of this study is to examine the experiences of primary caregivers with children with Autism Spectrum Disorder (ASD). The research will be studying these experiences from families across the United States. Responses to these items will involve filling out a survey about your experiences in raising a child with ASD, and accessing services, as well as some personal background questions. All of the anonymous data collected in this study will be kept on a password-protected computer in a locked office at the University of Rhode Island.

**YOU MUST BE AT LEAST 18 YEARS OLD** to be in this research project.

If you decide to take part in this study, your participation will involve filling out a survey pertaining to your experiences in raising a child with ASD, and accessing services, as well as some personal background questions. The survey should take you approximate 15 minutes to complete.

The possible risks or discomforts of the study are minimal, although you may feel some embarrassment answering questions about private matters.

Although there are no direct benefits of the study, your answers will help increase the knowledge regarding how to best meet the needs of families of children with ASD in education, health care and organizational settings.

Your part in this study is anonymous. That means that your answers to all questions are private. No one else can know if you participated in this study and no one else can

find out what your answers were. Scientific reports will be based on group data and will not identify you or any individual as being in this project.

The decision to participate in this research project is up to you. You do not have to participate and you can refuse to answer any question.

Participation in this study is not expected to be harmful or injurious to you. However, if this study causes you any injury, you should write or call Mr. Adam Moore at (401) 874-4200 or Dr. Joanne Eichinger at (401) 874-7420, at the University of Rhode Island.

If you have other concerns about this study or if you have questions about your rights as a research participant, you may contact the University of Rhode Island's Vice President for Research, 70 Lower College Road, Suite 2, URI, Kingston, RI, (401) 874-4328.

You are at least 18 years old. You have read the consent form and your questions have been answered to your satisfaction. Your filling out the survey implies your consent to participate in this study.

Thank you,

Adam Moore, M.Ed.  
Doctoral Student

## APPENDIX F

### Letter for Online Survey

Dear caregiver of a child with Autism Spectrum Disorder:

I invite you complete the following survey. I am a doctoral student at The University of Rhode Island who is designing a survey to measure families' experiences with having a child with Autism.

If you choose to be part of this short survey and choose to provide your name and contact email and/or phone number to the following website, you will be entered into a drawing to win:

- \$25.00 cash

If you would like your name entered into a drawing for completing the survey, please email your name and phone number to [ASDfamilySurvey@gmail.com](mailto:ASDfamilySurvey@gmail.com)

If you have questions or comments about this study, my supervisor, Dr. Joanne Eichinger or I would be happy to speak with you. Her number at the University of Rhode Island is (401) 874-7420 or you may email [ASDfamilySurvey@gmail.com](mailto:ASDfamilySurvey@gmail.com).

Thank in you advance, for your time to complete this survey! I hope that you take the 15 minutes required to complete the survey and let your voice be heard. As a parent with a child with a disability, you undoubtedly have experiences that would be valued in helping other families. Thank you for your time and help with this important project.

Best wishes,

Adam Moore, M.Ed.  
The University of Rhode Island  
Doctoral Student

## APPENDIX G

### Letter for Piloting FEASD

Dear Family/Professional,

Thank you for your willingness to pilot the Family Experiences with Autism Spectrum Disorder (FEASD) scale. I appreciate your willingness to provide feedback to me about this scale.

Please use the following form to provide your feedback about any item or demographic question on the survey. Your input will help make final adjustments to the scale before it is sent out for families to complete.

If you have questions or would like to talk to me, I can be reached at (401) 874-4200 or at the email this message is being generated from. Additionally if you would like to speak to my supervisor, Dr. Joanne Eichinger, she can be reached at (401) 874-7420. Thank you for your support and assistance with this study.

Sincerely,

Adam Moore, M.Ed.  
The University of Rhode Island  
Doctoral Student

## APPENDIX H

### Pre-notice Email to Autism Organizations about Survey

Dear \_\_\_\_\_:

A few days from now you will receive a request via email to post a short questionnaire for a dissertation study being conducted at the University of Rhode Island. The email asks your assistance in sending a message on your ASD listserve to families of children with ASD. This questionnaire aims to better understand the experiences of families with children with Autism Spectrum Disorder (ASD).

I would appreciate your help in reaching out to as many families as possible to take part in this short survey.

Organizations who agree to post the link to the survey on their website or contact families about this survey will be entered into a drawing for a \$100 donation.

Additionally, individual families who participate in the survey will be entered into a separate drawing for \$25.

If your organization supports families who do not have access to the Internet, paper surveys are available. The instructions sent in the email will ask families to call, toll-free, 1-866-733-4190 and provide their name, address, and a number so that study materials may be sent to them. Alternately, I can provide your organization with an electronic version of the survey that can be printed out and distributed to families who wish to complete paper surveys and either mailed or faxed back to me.

If you have questions or would like to talk to me, I can be reached at (401) 874-4200 or at the email this message is being generated from. Additionally if you would like to speak to my supervisor, Dr. Joanne Eichinger, she can be reached at (401) 874-7420.

Thank you in advance, for your consideration to post the link to the survey. Caregivers with children with Autism Spectrum Disorder undoubtedly have experiences that would be valuable in helping other families. Thank you for your time and help with this important project.

Best wishes,

Adam Moore, M.Ed.  
The University of Rhode Island  
Doctoral Student

APPENDIX I

Email to Autism Organizations to Post Information about Survey

Dear \_\_\_\_\_:

A few days ago you received an email from me contacting you about posting a link to a survey that aims to better understand the experiences of families with children with ASD.

Below is information that I would appreciate you post on your website for families so that they may participate in the survey.

If you have questions or would like to talk to me, I can be reached at (401) 874-4200 or at the email this message is being generated from. Additionally if you would like to speak to my supervisor, Dr. Joanne Eichinger, she can be reached at (401) 874-7420.

Thank you in advance, for your consideration to post the link to the survey.

Best wishes,

Adam Moore, M.Ed.  
The University of Rhode Island  
Doctoral Student

-----  
As caregivers of children with Autism Spectrum Disorder, you face many challenges.

**Let your voice be heard!**

Help the field of Autism research by taking 15 minutes to respond to this short survey AND be entered to win a \$25 cash prize!  
{INSERT LINK TO SURVEY MONKEY SURVEY FEASD SCALE}

## APPENDIX J

### Second Email to ASD Organizations who choose to Post Survey Link

Dear \_\_\_\_\_:

THANK YOU for your willingness to post the link to the Family Experiences with Autism Spectrum Disorder (FEASD) survey to your organization's website! This project could not be possible without the dedication of organizations like yours—your generosity is greatly appreciated! Your organization is being entered into a drawing for \$100 cash donation as a small token of appreciation!

Would you also be willing to provide me with the names of *other organizations* in your area that support families with children with ASD who may be interested in completing this survey?

If you have questions or would like to talk to me, I can be reached at (401) 874-4200. Additionally if you would like to speak to my supervisor, Dr. Joanne Eichinger, she can be reached at (401) 874-7420.

Thank you again for your support!

Best wishes,

Adam Moore, M.Ed.  
The University of Rhode Island  
Doctoral Student

## APPENDIX K

### Second Email to ASD Organizations who choose not to Post Survey Link

Dear \_\_\_\_\_:

Thank you for your consideration to post the link to the Family Experiences with Autism Spectrum Disorder (FEASD) Scale. The work that your organization does for families with children with ASD is extraordinary and should not be overlooked. As a passionate researcher in the field, I commend your efforts and understand that you cannot assist in all research projects.

If you reconsider posting information about this survey to your website or within your organization, please feel free to contact me at the email address or at (401) 874-4200.

Best wishes,

Adam Moore, M.Ed.  
The University of Rhode Island  
Doctoral Student

APPENDIX L

FEASD Scale Item Means and Standard Deviations

Item		Std.	
		Mean	Deviation
1	The community where I live accepts my child.	2.77	.75
2	There are family members that I trust to help care for my child.	2.93	1.05
3	In my town there are community organizations that include people with ASD.	2.55	.95
4	I pay a lot of money to get ASD services for my child.	1.90	1.09
5	The leaders of my place of worship understand my child's needs.	1.43	1.42
6	My extended family (grandparents, uncles/aunts, cousins, etc.) accept my child.	3.02	.89
7	There are high quality, free community programs for my child.	1.75	.86
8	When I have to leave the house, I trust others in my family to watch my child.	2.85	1.02
9	In my place of worship, my child is included in activities.	1.41	1.47
10	My extended family (grandparents, uncles/aunts, cousins, etc.) does not understand the challenges of raising a child with ASD.	1.88	.84
11	My child's educational team does not accept my recommendations for education/treatment.	2.33	1.06
12	My child's teacher finds helpful ways to include my child in lessons.	2.64	1.08
13	My child's teacher provides suggestions that help my child at home.	2.06	1.05
14	I am not comfortable asking my child's teacher for suggestions.	2.67	1.14
15	My child's teacher advocates for what is best for my child.	2.36	1.10

	Item	Std.	
		Mean	Deviation
16	The school staff makes me an active partner in developing plans for my child.	2.53	1.09
17	My child's teacher supports my treatment choices for my child.	2.45	1.18
18	My child's teacher is knowledgeable about ASD interventions.	2.23	1.12
19	My child's teacher respects me.	2.79	1.05
20	I am comfortable asking my child's teacher for suggestions.	2.62	1.07
21	I am unhappy about the supports my child receives in school.	2.24	1.10
22	I was an active team member in developing my child's Individualized Education Program (IEP).	3.08	1.14
23	At my child's school, the staff members treat me like a partner.	2.53	1.09
24	My child's teacher does not provide enough academic support for my child.	2.33	1.13
25	The staff members at my child's school do not effectively include children with ASD.	2.32	1.15
26	School staff help my child make friends.	2.07	1.02
27	My child's teacher is not willing to work with me.	2.79	1.07
28	School staff help connect me to other organizations to help my child.	1.75	.93
29	My child's doctor does not refer my family to support services (such as family groups, children's groups, etc.).	2.04	.97
30	My child's doctor directs me to resources to help my family pay for services.	1.75	.93
31	My child's doctor values my point of view.	3.01	.88
32	I am not satisfied with the questions my child's doctor asks during office visits.	2.64	1.02

Item	Std.	
	Mean	Deviation
33 My child's doctor listens to my concerns about my child.	3.14	.78
34 My child's doctor is knowledgeable about ASD.	2.65	.98
35 My child's doctor provides me with helpful information about ASD.	2.22	.99
36 My child's doctor helps me make decisions about my child's care.	2.53	1.00
37 I do not trust the recommendations of my child's doctor.	2.72	1.12
38 My child's doctor asks how I am doing.	2.42	1.00
39 When I ask for information about my child's health, the doctor provides it.	3.13	.81

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