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Understanding the Stressors of Low Socioeconomic Rural Parents of Autistic Children

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COLLEGE OF EDUCATION

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Abstract

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MEd, University of Rio Grande, 2004

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Doctoral Study Submitted in Partial Fulfillment

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Teacher Leadership

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Abstract

Parents of children with autism spectrum disorder (ASD) often exhibit high parental stress which may be caused by parent-child behaviors, child behaviors, and parent distress. Awareness and understanding of ASD is critical for parents and educators to connect students with support services and resources. The purpose of this bounded, descriptive case study was to identify perceived parental stressors and to determine the primary stressors of parents with low socioeconomic status who are raising a child with ASD in a rural area. The foundation of family systems theory framed this study. Ten parents raising a child with ASD were purposefully selected and volunteered to participate in this study. The quantitative data were collected using the Parental Stress Index-Short Form, a 36-item Likert scale with items related to parent-child dysfunctional relationships, parenting distress, and child behavior. Descriptive analysis determined which domain and items were most stressful and were the basis for developing 6 semistructured interview questions. Interview data were open-coded and analyzed thematically to identify the greatest stressors to parents. Based on these findings, it is recommended that school personnel coordinate an autism support group to include educators, parents of children with ASD, and professional service providers to share formal and informal supports within the school district and the community. These endeavors may contribute to positive social change by providing parents and educators access to resources and therapeutic and social supports, thus allowing students with ASD to receive appropriate and timely support and to reduce parental stress.

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Dedication

I would like to dedicate this doctoral research study to Sondra, who challenged me to determine what stressors parents raising a child with ASD experience. I would also like to dedicate this study to all parents who are raising a child with ASD and cope with stressors specific to this disorder, yet, still love their children unconditionally.

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I would like to acknowledge all of the individuals who have been with me through this whole journey of learning. First, I want to thank my husband Jon, and my children Elizabeth, KayLee, and Spenser. It is with your love, understanding, and support that I was able to continue during my times of frustration and remain focused on the importance of my study. I would also like to thank my parents Roy and Diana. Your sacrifices and unconditional love guided me throughout my life and allowed me to remain driven and to be an exceptional person who cares for others. Melissa, you have loved and supported me for 30 years and it is rare to find a best friend who shares your passion for education. Lastly, I want to thank Roberta. You have been there since day one of this journey, and it is with your wisdom and guidance that I transitioned from being an educator to an educator who changes lives.

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Section 1: Introduction to the Study

Introduction

The diagnosis of a child with autism spectrum disorder (ASD) elicits varied reactions from parents. However, parental stress was shown to be the primary response (Hays & Watson, 2013). Parental stress experienced by the parents of a child with ASD could be different and higher than the parental stress experienced by parents who have a typically developing child or a child diagnosed with another disability (Abbeduto et al., 2004; Orsmond et al., 2004; Pisula, 2007). Parental stress experienced in parents raising a child with ASD is thought to be an outcome of caring for a child with a developmental disability in which the parent's perception is that the child's attributes are difficult to manage (Abiden, 1990; Woodgate, Ateah, & Secco, 2008). Researchers have delineated between stressors experienced by parents who have children with ASD and those with other children. Children with ASD have specific core deficits, such as impairments in social communication and restrictive or repetitive behavior. Parents often feel more distressed when trying to meet associated demands (Bayat, 2007; Hays & Watson, 2013; Jovanova & Radojichik, 2013). Moreover, because ASD is a developmental disorder that continues for the lifespan of the child, the result is also cumulatively stressful (Berge, Patterson, & Reuter, 2006).

Researchers have found that parents are unprepared to parent children with ASD, which often is affected by the lack of awareness of accessible resources, the lack of knowledge about existing community resources, or the capacity to provide appropriate therapeutic and social supports (Bishop, Richler, Cain, & Lord, 2007; McCubbin &

Figley, 1983; Seligman & Darling, 2007). Multiple researchers have empirically shown the validity of higher stress in parents of children with ASD (Abbeduto et al., 2004; Hays & Watson, 2013; Holroyd, Brown, Wilkler, & Simmons, 1975; Seligman & Darling, 2007; Weiss, 2002).

A qualitative descriptive case study was used to identify perceived stressors in parent-child relationships in relation to their child's behavior and parenting difficulties. Parents who demonstrated stressors when raising a child with ASD were also identified within this study. The population under study was a low socioeconomic rural area county in Ohio. The selected school districts for this study included the 10 small school districts in the county. I included all 10 school districts because parents who participated in the study could have children attending a school within any of the 10 districts. Parents who live in low socioeconomic rural areas are often faced with commonplace stress concerns, which could intensify their parental stress experiences (Dumas, Wolf, Fisman, & Culligan, 2007; Plant & Sanders, 2007). Stressors such as poverty, unemployment, expected cultural and socioeconomic rules, incongruous services and supports to serve children with ASD within educational settings, medical health shortages, medically underserved families, lack of community support systems, and lack of awareness and understanding of ASD, all or in part, could be valid stress concerns when determining parent stress perceptions (Dumas et al., 2007; Plant & Sanders, 2007; Woodgate, Ateah, & Secco, 2008). The Ohio Department of Jobs and Family Services (2013) provided statistical information supporting evidence that poverty, physician and medical health shortages, medically underserved families, high unemployment, and lack of supports and

interventions as key critical stress variables for families in low socioeconomic rural Ohio. Currently, within this local area, there is only one support group, The Autism Project of Southern Ohio. This research study seeks to provide a better understanding of how parents perceive and demonstrate stress while raising a child with ASD within a low socioeconomic rural area. Expanded sections and subsections containing data about specific parental stressors are referenced in Section 2, the Literature Review.

Problem Statement

There is a lack of understanding regarding how the perceptions of stress by parents raising a child with ASD affect parent-child behaviors, child behaviors, and parent distress. Based on their perceptions of stress experiences, parents demonstrate significant stress when raising a child with ASD (Abbeduto et al., 2004; Hays & Watson, 2013; Woodgate, Ateah, & Secco, 2008). With the rise in incidence in ASD, demands for increased awareness and understanding of the disorder are a priority, not only by parents but also by individuals who educate the children (Boyd & Shaw, 2010). With increased understanding, awareness of stress factors would provide awareness to educators and the ability to connect students with possible support services and other resources. A lack of awareness or understanding of ASD within the research site could contribute to the fact that the research area is medically underserved and has a medical health shortage, therefore, limiting the ability of parents to receive appropriate and timely identification and support. Often, children who live in low socioeconomic rural areas are under-identified because of disparities in access to diagnostics and other supports in the communities, resulting in children being educationally underserved (Durkin et al., 2010;

Palmer, Walker, Mandell, Bayles, & Miller, 2009; Palmer, Blanchard, Jaen, & Mandell, 2005).

Nature of Study

This qualitative descriptive case study was used to explore the demonstrated stress of low socioeconomic rural parents of children with ASD based on their perceptions of stress. Ten parents who were raising a child with ASD were invited to participate in the study. Each parent represented one unit of analysis, or case, for this study. The data collection consisted of the PSI-SF for quantitative data and a semistructured interview for the qualitative data. The PSI-SF consisted of three domains, parental distress, parent-child dysfunctional interaction, and the data collected were used to determine the stressors demonstrated by the parents within each of the three domains. The semistructured interview questions were used to collect qualitative data about parental perceptions of parent-child relationships, child behaviors, and parental stress when raising a child with ASD. Specific details of the data collection and analysis are addressed in Section 3 of this study.

Research Questions

The first research question relates specifically with the data collected using the PSI-SF. The following research questions deal specifically with the interview questions and align with the three sections of the PSI-SF: parental distress, parent-child dysfunctional interaction, and the difficult child:

1. What stressors do low socioeconomic rural parents of children with ASD demonstrate as measured by the PSI?

(a) parental distress subdomain and items,

(b) parent-child dysfunctional interaction subdomain and items, or

(c) difficult child subdomain and items.

2. How do low socioeconomic rural parents of children with ASD perceive parental stress?

    (a) How do low socioeconomic rural parents of children with ASD perceive their parent-child relationships?

    (b) How do low socioeconomic rural parents of children with ASD perceive their child's behavior?

    (c) What parenting difficulties do low socioeconomic rural parents of children with ASD experience?

Purpose of the Study

The purpose of this study was to identify what stressors parents demonstrate based on their perceived stress experienced by raising a child with ASD, specifically within a low socioeconomic rural area. A limited number of studies regarding parental stress in parents raising a child with ASD in low socioeconomic rural areas have been conducted by researchers (Durkin et al., 2010). Therefore, the specific contributors to stress warrant study due to the lack of current research and the unique population.

This qualitative case study had a two-fold focus: (a) to identify the stressors parents' experience and (b) their perceptions of potential stress in raising a child with ASD. A qualitative case study research design allows researchers to use real-life parenting experiences, such as investigating parenting stress concepts and events (Yin,

2014). Parenting concepts and events to be investigated in this study were perceived causes of stress from their parent-child relationships, the child's behaviors, and parent difficulties and their perceptions (Abidin, 1995).

Theoretical Framework

The theoretical framework for this study was grounded in the basic components of family systems theory (Bowen, 1979), which includes boundaries, family rules, and family role organization. Family systems theory was one of the first theories used to research the functioning of family systems. Family systems theory, also known as Bowen theory, focused on how individual subsystems of the family can be directly affected by change (Bowen, 1979). In family systems theory, the structure of the family includes characteristics of the nature of belonging, cultural and ideological style, interactions, and functionality (Allen, 2007; O'Gorman, 2012), which are placed within the family interactional system (Allen, 2007). Family systems theory includes both individual behavior and dyadic dynamics within the family (George, 2009; Seligman & Darling, 1997). The justification for using the theoretical foundation of family systems theory in this study was to explore how the family system functions when the changes exhibited by a child with ASD create stress for parents living in low socioeconomic rural areas. This study might provide additional insights for parents regarding how parental stress affects their daily lives (Dickstien, Siefer, & Albus, 2009; George & Sullivan, 2008). In family systems theory, any alteration to the family system may cause an imbalance of the whole family system (Dickstien et al., 2009; George & Sullivan, 2008; Seligman & Darling, 1997). Family systems must sustain a delicate balance in relationship patterns to maintain

family function and assuage family dysfunction (Allen, 2007; O'Gorman, 2012). The basics of family systems theory include other systems that interact with the family (i.e., friends, extended family, community, and society) and other service agencies such as schools and medical professionals (Cowan, Pape, & Mehta, 2009; Morgan, 1988).

Parental stress variables can present themselves as one or more of the following three basic characteristics found within family systems theory:

- boundaries (i.e., open, closed, and moderate),
- family rules, or
- family role organization (Bowen, 1979).

The first basic characteristic of family systems theory as related to this study is *boundaries*. Boundaries within the family system are divided into three subtypes: *closed*, *open*, and *moderate* (Kantor & Lehr, 1976). The explanations of family systems theory boundaries describe how lifestyle, culture, and family function within the local area of study and influence how they respond to parental stress. Characteristics of closed boundaries within families include privacy as a valued concept, values regarding roles are rigid, allegiance is to the family, and change is difficult and threatening (Kantor & Lehr 1976; Konstanatareas & Papageorgiou, 2006; Kormanik & Rocco, 2009).

The first of the boundaries, closed boundaries, affect the family system by presenting a guarded and rigid family, which does not change anything within the system in response to stress (Kormanik & Rocco, 2009; O'Gorman, 2012; Olson, Russell, & Sprenkle, 1980). Closed boundaries include rigid beliefs, such as, the father in the role of the patriarch whose job is to assign the workload to the mother, often causing the mother

to feel overburdened by excess work (Olson, Russell, & Sprenkle, 1980; Umberson, Williams, Powers, Chen & Campbell, 2005). The rigid parents may have a difficult time raising a child with ASD and adapting to the challenging behaviors because the members of the family are unwilling to lessen the burdens on each other (Duarte et al., 2005; Lyons, Leon, Roecker-Phelps, & Dunleavy, 2010; Olson, Russell, & Sprenkle, 1980).

On the other end of the boundary continuum are open boundaries. Open boundaries operate within the chaotic versus rigid family system (Allen, 2007; Kormanik & Rocco, 2009). Families that embrace open boundaries are characterized as families that have limited privacy, allow the entry of extended family members, friends, and strangers with ease, use spontaneity versus planning, have no clear-cut decision making, display inconsistent emotional expression, and respond to change with chaos and the family coming apart. Open boundaries are practiced by chaotic families, which may be characterized by instability and continual change that can exacerbate existing stress (Becvar & Becvar, 2003; Smith et al., 2008; Turnbull & Turnbull, 1986). In chaotic families, behaviors may be characterized by frequent role changes, the absence of a family leader, and the practice of using inconsistent rules (Becvar & Becvar, 2003; Crittenden & Dallos, 2009; Turnbull & Turnbull 1986).

The family system that practices the characteristics of a moderate boundary family obtains a balance of both open and closed boundary family characteristics (Becvar & Becvar, 2003; Turnbull & Turnbull 1986). Moderate boundary family systems have achieved balance and are characterized as able to provide easy access to family space and freedom to exchange with the outside, are able to explore outside communities and tend

to have strong connections, have well-defined rules that are flexible in nature, and encourage a balanced closeness while accessing resources when a stressful change occurs (Becvar & Becvar, 2003; George, 2009; Turnbull & Turnbull 1986).

For a family to function in balance, it must stay within the moderate boundaries and avoid the extremes of open and closed boundaries. family systems theory is applicable to this study because often the subjective cultural rules and stressors that can occur from living in a low socioeconomic rural area can influence how the family boundaries are set and used (Brown, 2013; McGoldrick, 1995). It is within these open and closed boundaries that parents can exhibit extreme stress.

A second characteristic of family systems theory is family rules. Families must live with stability and to do so, they must develop rules about how to live together (Allen, 2007; Finch & Finch, 2012; Krauss & Jacobs, 1990). Rules should typically be repetitive, predictable, and stable to solve problems and to ensure cohesiveness and stability within the family system (Allen, 2007; Cook & Oltzenbruns, 1989; Satir, 1988). In families where a child has a diagnosis of ASD, family rules and roles frequently change (Houser & Seligman, 1991; Mak et al., 2007; Myhill & Jekel, 2008). Based on the specific needs of the child, these changes are due to the high frequency of needs (Houser & Seligman, 1991; Mak et al., 2007; Myhill & Jekel, 2008). For example, the role of one parent may differ from the role of the other parent based on the stress within the family and the needs of the child that specific day. To handle the constantly changing environment, the family must learn how to adapt, communicate, and negotiate family rules to maintain family balance (Brown, 2013; Houser & Sieligman,1991; Imber-Black & Roberts, 1992).

A third characteristic of family systems theory is role organization within the family (Allen, 2007; George & Soloman, 2009). Role organization and its expectations within a family are often influenced by culture, ethnic background, familial experiences from childhood to adulthood, lifestyle, and family size and composition (Allen, 2007; Cowan, Pape, & Meheta, 2009; George & Soloman, 2009). The workable arrangement of roles is determined by functional level (Allen, 2007; George, 2009). Ideally, roles within families are both clear and flexible in nature but are affected and influenced by cultural aspects (Allen, 2007; Bowen, 1966; Bretherton & Munholland, 2008). The challenge is that the family tasks must be divided and carried out (Simon, Sterlin, & Wynne, 1985; Walsh & McGoldrick, 1991). For example, following a death of a family member, roles may need to be reassigned or shared, with role behavior apportioned to various family members (Walsh & McGoldrick, 1991). When parents are raising a child with ASD, the family role may change dramatically due to the varying needs of the child and the cultural or belief systems practiced by the parents (Shapiro & Accardo, 2008; Siman-Tov & Kaniel, 2011).

Operational Definitions

The definitions of the terms used in this study are listed and referenced below:

Autism spectrum disorders: A group of developmental disabilities that are characterized by impairments in communication and social interactions (APA-DSM-5, 2013).

Boundaries: Boundaries, as they pertain to family systems theory, are lines of demarcation determined by members of the system that enclose the system and establish

those who are members of the system (Minuchin, 1974). The permeability of a boundary (i.e., the ability of others to enter the system and for members to leave it) determines the degree of openness in that system.

Bounded system: The case selected for the study has boundaries, often by time or place and it has interrelated parents that form a whole. The case can be studied as both bounded and a system (Creswell, 2003).

Parental stress: A relationship between the parent and the environment in which the parent appraises the demands of being a parent as exceeding one's resources, leaving the parent to feel he or she has difficulty filling the role (Abidin, 1990).

Roles: Social expectations and norms within the family unit regarding an individual's position and behavior within a group as they pertain to family systems theory (Simon, Steirlin, & Wynne, 1985).

Rules: Prescriptions for and proscriptions against certain behaviors of all or some family members relating to appropriate role performance as they pertain to family systems theory (Krauss & Jacobs, 1990).

Assumptions

Several assumptions in parental stress research were important to this study. The first assumption is that the participants would commit to two separate meetings to complete data collection. Participants completed the items on the PSI-SF. Another assumption was that participants would provide honest answers to the questions asked during the semi-structured interviews. Last, it was assumed that participants would voice

their discomfort or request a counselor when answering the PSI-SF or the semistructured interview questions.

Limitations

Several limitations restricted this qualitative descriptive case study. First, the number of units of analysis used in the study was small due to the sensitive nature of the study. The small sample size makes it difficult to transfer findings to larger populations (Creswell, 2008). Second, although a qualitative interview was used to gather data, the data could not be verified independently and were taken at face value. Because of this limitation, there are several biases that might have occurred on the part of the participant, such as, selective memory, telescoping, attribution, or exaggeration (Brutus et al., 2013). Third, because the primary purpose of this study was to determine the stressors parents experience and parental stress perceptions, the specifics of the family such as dynamics, supports, employment, mental state, the size of the family, marital state, and the overall level of the family's needs were not researched. Fourth, because of specific documentation and recordkeeping within the 10 school districts in the research site, about the number of children with diagnosis of ASD, the number of children who were included in the regular education classroom, and the credentials of the teachers who were teaching children with ASD, this information was not available for inclusion in this study. Finally, the inclusion age for this study was 3 to 18 years. As children mature, their ASD symptomology and severity can lessen (Autism Society, 2014); therefore, it is assumed parents will describe their stress levels and severity in relation to their child's current age.

Scope and Delimitations

The scope of this study was a low socioeconomic rural school district in Ohio. The sample was delimited to parents raising a child with ASD in the PK-12th grade setting. The selection criteria delimited the sample to parents who were married, divorced, or single, and who lived in a school district in which the study was conducted. Parent participants must have lived in Ohio for a minimum of 5 years and must have had a child with a diagnosis of ASD between the ages of 3 and 18 years. Data collection and analysis was delimited to the three subscales of the PSI-SF. The rationale for this study was to explore a small sample of parents who were raising a child with ASD, to examine their stress perceptions using the three subscales of the PSI-SF, and to identify the common themes of stress among the parents.

The Significance of the Study

The larger educational setting of professionals who educate ASD students could benefit from the findings of this study. The current study's results could assist other ASD educators who find themselves in a similar locale. A primary reason this study was necessary is that parents in different contexts experience a unique set of stressors and to provide competent services, educators must know those parents' stressors.

This study could be a step toward positive social change in how educators relate to, work with, and support the parents of ASD children. If educators are knowledgeable and empathetic, it may be possible to relieve parental stress. This goal would require that administrators target assistance for teachers who teach children with ASD while collecting and tracking data about the academic progress of the child-parent unit.

Furthermore, this focus might arm policymakers who could lobby for and provide the resources necessary to reduce ASD parents' particular areas of stress.

Transition Statement

Section 1 of this study provided in-depth descriptions of the local problem, purpose, nature, and significance of the study. Research questions, theoretical framework, and key definitions were identified as well as how positive social change could be achieved as a significant overall contribution. Section 2 focuses on prior and current research, which shows the challenges of parental stress perceptions/factors and the effects of low socioeconomic rural culture. Section 3 includes information about the research design, methodology, research questions, study context, the basis of the research including data analysis, the instruments used to gather research data, and last, the validity and reliability of the research. Section 4 addresses the components used in gathering and reporting relevant research including the process of data gathering and reports the findings of the study. Section 5 includes the results of this doctoral study and interpretation with a brief overview of all aspects of the study. Included are implications for social change, recommendations for action, further study, reflection, and a concluding statement

Section 2: Literature Review

Introduction

The literature review for this study consists of empirical research that examines variables related to parental stress perceptions as experienced by parents raising a child with ASD. Parenting stress was examined within the contexts of parent-child relationships, child behaviors, and parenting difficulties. The first section of the literature review includes theories of parenting stress and provides a framework for autism spectrum disorder. The framework consists of the current diagnostic criteria for ASD, the history of autism, and historical and current theories of cause. This framework serves as informational text based on historical and current literature. The second section of the literature review includes parental stress perceptions as related to parent-child relationship variables. The third section of this literature review includes parental stress perceptions as related to child behavior variables. The fourth section of this literature review includes parental stress perceptions related to parental difficulties. The last section of this literature review is methodological evidence of parental stress perceptions related to research articles used for this study.

The literature consisted of information retrieved from the Walden University Library databases. The databases used for this study were Educational Resource Information Center, Psych Info, Teacher Reference Center, ProQuest, ERIC, and Google. Other resources that were applicable to the literature review were websites (e.g., Centers for Disease Control, APA, ODHHS, Mayo Clinic, ODJFS, OCALI, Autism Speaks, Autism Cures, Autism Society of America, and statistical websites. The search terms

used for these sites included *parental stress and ASD*, *family systems theory*, *poverty*, *low socioeconomic rural areas*, *ASD cause*, *ASD history*, and *ASD treatment options*.

Theories of Parenting Stress

In 1995, the publication of Abidin's PSI (Abidin, 1995) as a measuring tool for parental stress was integral in understanding the significance of parenting stress. The psychological feeling of stress results from the perception that the necessities of parenting supersede an individual's resources. The extreme duties with which a parent must engage when raising a child with a developmental disability such as ASD can encompass limitations in financial, physical, and personal resources and, as a result, induce stress. Parenting stress can also develop into problems in parental health, negative feelings as a parent and, ultimately, dysfunctional parenting (Abidin, 1995).

According to Abidin (1995), three major domains can be viewed as antecedents to parental stress: parental distress, difficult child characteristics, and dysfunctional parent-child interactions. The shortened form of the PSI also allows for the combination of these three domains into the total stress domain. Any of these domains can result in stress to parents. The parents' perceptions of distress and of difficult child characteristics can lead to dysfunctional parent-child interactions in which the parent can take on an impaired sense of parenting competence, parental role stress and conflict in relation to the child's other parent, a lack of social support, the presence of mental health issues, and additional stress from the other roles expected in the parent's life (Abidin, 1995).

Parental stress in relation to having a child with ASD has been a topic of empirical study in recent years. Four recent studies were conducted (Little, 2002;

Tomanik et al., 2004; Hastings et al., 2005; and Lecavalier et al., 2006). Each study examined the stress levels of parents raising children with ASD in various scenarios. The outcome for each of these studies was the same; parents who are raising a child with ASD experience higher stress than parents raising a typically developing child.

Autism Spectrum Disorder

The American Psychiatric Association's (APA, 2013) *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition-Text Revision* was published in March 2013 and offered a revised category and criteria for the diagnosis of autism. The differential diagnosis from the DSM-5 (APA, 2013) described four main categories of autism spectrum disorder (ASD). These categories were: (a) autistic disorder (autism), (b) Asperger syndrome, (c) pervasive developmental disorder (atypical autism), and (d) child disintegrative disorder.

The Mayo Clinic (2012) included a definition of autistic disorder (autism). Autistic disorder, although varied among individuals, shows common similarities within three crucial areas: social interaction, language, and behavior. Autistic disorder can become apparent as early as infancy. Deficits in social skills included symptoms such as consistent episodes when individuals failed to respond to their name, having poor eye contact, appearing not to hear someone at times, resistance to cuddling and holding, an unawareness of others' feelings, and a preference to play alone or retreat into his or her own world. Deficits in language skills included delayed speech (i.e., acquisition after age two); losing previously acquired abilities such as saying words and sentences; limited, or absence of, eye contact; abnormal speech tone or rhythm; inability to initiate or continue

a conversation; engaging in repeated words or phrases verbatim without understanding how to use them. Deficits in behavior patterns included consistent episodes where individuals performed repetitive movements such as rocking, spinning, or hand-flapping; developed specific routines or rituals; became disturbed if interrupted during routines or rituals; moved continually; was fascinated by parts of an object (such as spinning the wheels on a car); and had an unusual sensitivity to light, sound, and touch, but could be oblivious to pain. With maturation, often individuals with autism became more engaged with others and exhibited fewer behaviors. Children with ASD have intelligence ranging from lower than normal to high intelligence. A smaller number of children who have developed exceptional skills in a specific area such as math, art, or music were called autistic savants (Mayo Clinic, 2012).

The Mayo Clinic (2012) provided a description of Asperger's syndrome as a developmental disorder that affects a person's ability to socialize and communicate effectively with others. Often, children with this disorder show an all-absorbing interest in specific topics and exhibit varied levels of social awkwardness. Asperger's syndrome is typically found on the milder end of the autism spectrum. Individuals with Asperger's syndrome typically have not shown delays in the development of language but had difficulty with turn-taking conversations. The Mayo Clinic listed seven common symptoms of Asperger's syndrome:

- engaging in one-sided, long-winded conversations without noticing if the listener is listening or trying to change the subject;

- displaying unusual nonverbal communication including a lack of eye contact, few facial expressions, or awkward body postures and gestures;
- showing an intense obsession with one or two specific, narrow subjects, such as baseball statistics, train schedules, weather, or snakes;
- appearing not to understand, empathize with, or be sensitive to other's feelings;
- having a difficult time understanding other people or understanding humor;
- speaking in a voice that is monotonous, rigid, or unusually fast; and
- moving clumsily with poor coordination.

Pervasive developmental disorder (atypical autism), as defined by the Mayo Clinic (2012), was described as a disorder in which individuals share many of the same characteristics of autistic disorder (autism), but had not necessarily met all of the criteria. Childhood disintegrative disorder, as defined on the Mayo Clinic website (2012), was described as children who develop typically until the ages of two to four, but then exhibit a dramatic loss of previously acquired skills in two or more of five developmental areas, language, social skills, play, motor skills, and bowel/bladder control. Childhood disintegrative disorder is similar to autism under the condition that children lose significant skills in the areas of language, social play, and motor skills. The difference is that childhood disintegrative disorder occurs later than autism and involves a more dramatic loss of skills.

In addition to the currently defined ASD characteristics, the DSM-5 reflected new criteria to aid in the diagnosis of ASD, levels of severity, and support intensity (APA,

2013). Researchers have shown that the severity of ASD symptoms is the strongest and most consistent predictor of parental stress (Lyons et al., 2010). Lecavalier, Leone, and Wiltz (2006) examined caregiver stress when having a child with ASD. The results indicated that conduct problems and adaptive problems were the primary sources of stress. The DSM-5 outlined three levels of ASD severity and support intensity (APA, 2013). At level one, the individual required support; at level two, the individual required substantial support and at level three, the individual required very substantial support (APA, 2013).

Level one support criteria showed that without supports in place, deficits in social communication caused noticeable impairments. The impairments included difficulty initiating social interactions and demonstrating clear examples of atypical or unsuccessful responses to social overtures from others. In addition, the individual appeared to have decreased participation in social interactions, engaged in rituals and repetitive behaviors (RRBs), and had significant interference with functioning in one or more contexts (APA, 2013).

Level two support criteria showed that with supports in place the individual resisted attempts by others to interrupt RRBs or become redirected from a fixated interest. Characteristics include marked deficits in verbal and nonverbal social communication skills and apparent social impairments, even with supports in place; limited initiation of social interactions; and reduced or abnormal response to social overtures from others. With substantial supports in place, RRBs and/or preoccupations or fixated interests appeared frequently enough to be obvious to the casual observer and

interfered with functioning in a variety of contexts. Apparent distress or frustration by the individual is evident when RRBs are interrupted, and it can be difficult to redirect an individual from fixated interests (APA, 2013).

Level three support criteria showed that with very substantial supports the individual exhibited severe deficits in verbal and nonverbal social communication skills causing severe impairments in functioning. Individuals in need of level three support vary in areas such as limited initiation of social interactions and minimal response to social overtures from others. Preoccupations, fixated rituals, and/or repetitive behaviors markedly interfered with functioning in all spheres. Marked distress occurs when rituals or routines are interrupted, and it is difficult to redirect individuals from fixed interests (APA, 2013).

The History of Autism Spectrum Disorder

The first descriptions of autism were used by Drs. Bleuler, Kanner, and Asperger (Lyons & Fitzgerald, 2007). In 1908, Dr. Bleuler, a Swiss Psychiatrist, coined the term *autistic* to describe the symptoms of individuals with schizophrenia. In 1943, Dr. Kanner described *early infantile autism* in 11 children in his seminal paper *Autistic Disturbances of Affective Contact* (Kanner, 1943). Each child had the same symptoms of impairments in social interaction; anguish for changes; good memory; belated echolalia; over-sensitivity to certain stimuli, especially sound; food problems; limitations in spontaneous activity; good intellectual potential; and often coming from talented families (Lyons & Fitzgerald, 2007). In 1944, Dr. Asperger coined the term *autistic psychopathy* to describe four children in his thesis *Autistic Psychopathy in Childhood* (Lyons & Fitzgerald, 2007).

Dr. Asperger had described children who had similar traits to the ones identified by Kanner but had other traits that set them apart. He developed the term Asperger syndrome for these children. In addition to having the traits described by Kanner, they were also very clumsy and spoke in an adult-like manner (Lyons & Fitzgerald, 2007).

Dr. Bettelheim, a professor of child development, was perhaps the best-known theorist from the 1940s to 1970s about autism (Rudy, 2006; Rutter, 2005). In the 1960s, when autism was considered rare, the belief was that autism was an intellectual disorder that was handicapping (Rutter, 2005). A renowned expert on child development, Bettelheim shared the belief with Dr. Freud that all psychological issues were a direct result of childhood trauma (Rudy, 2006). Bettelheim theorized that autism was caused by poor parenting and believed that children with autism failed to develop normal empathy because their parents did not provide them with enough stimulation (Reynolds & Dombeck, 2011). He coined the term *refrigerator mothers* to describe unaffectionate mothers who had not given sufficient affection to their child, causing the child to develop autism (Reynolds & Dombeck, 2011; Rudy, 2006). Bettelheim (1967) stated, "belief of the precipitating factor in infantile autism is the parents' wish that the child should not exist" (p. 125) and the "extreme negative feelings felt by the mother sets the autistic process in motion" (p. 127). Bettelheim's claims were eventually determined to be unfounded and incorrect by Dr. Rimland, who debunked refrigerator mothers by the early 1970s (Cure Autism Now, 2005; Rudy, 2006).

Theories of Cause for ASD

Throughout the years, many causal theories, historical and current, have been used to describe beliefs and attitudes about the diagnosis of ASD. When autism was formally identified, it was considered a psychoanalytic disorder (Reynolds & Dombeck, 2011). Because it was a time when the psychoanalytic philosophy was prominent, the typical treatment for autism was talk therapy (Reynolds & Dombeck, 2011). During this time, autism was thought to occur in 4 to 5 out of 10,000 children (Ratajczak, 2011).

The theoretical causes of ASD have changed since entering the 21st century and clinicians have new ideas about the possible causes including the three most studied, vaccines, environmental factors, parental age, and finally the most probable cause, genetic factors (National Institute of Mental Health [NIMH], 2011). The correlation between vaccines and autism was prevalent in past research because vaccines were considered the primary causal factor for ASD in children 18 months and older (Grier, 2007; Lewine et al., 1999; NIMH, 2011). Parents reported that their children developed normally until they received vaccinations at 18 months (Lewine et al., 1999; NIMH, 2011). The preservative thimerosal was implicated as the causal factor in the increase in the prevalence of ASD (Grier et al., 2007). The research claimed that the mercury content in thimerosal caused autism because thimerosal contained 49% ethylmercury. In documented cases of mercury poisoning, the individual exhibited all of the signs and biological symptoms of an autistic disorder (Grier et al. 2007, NIMH, 2011). However, researchers rejected thimerosal as the theoretical cause when the prevalence of autism

continued to elevate even though thimerosal was removed in 2000 and only trace amounts could be found in vaccinations (Schechter & Grether, 2008).

Research in the last decade has produced data that show that environmental factors could possibly be a cause of ASD prevalence (NIMH, 2011). Environmental factors are anything from outside of the body that affects health (NIMH, 2011). Scientists are studying a process called epigenetics, which could show how certain environmental factors may affect certain genes (NIMH, 2011; Rutter, 2005). One such environmental factor primarily studied is the link of parental age to ASD. Specifically, the increase in the age of parents (Croen, Najjar, Fireman, & Grether, 2007). Croen et al. (2007) studied single birth children born from 1989-2002 and confirmed results that showed a 10-year increase in the maternal age was associated with a 38% increase in the odds ratio for autism. In a 10-year increase in paternal age, the increased odds of having a child with autism was 22% (Croen et al., 2007). In 2010, Shelton, Tancredi, and Herta-Picciotto discovered the trend of delayed birth, over the last decade, contributed to a 4.6% increase in the incidence of ASD.

The best-established causal factor for ASD is a genetic liability (Rutter, 2005). Scientific researchers were focusing on how various genes interact with each other and show evidence that there are as many as 12 or more genes on various chromosomes that may be related to different degrees of ASD (NICHD, 2011). The National Association of Mental Illness (NAMI) reported twin studies were the largest defender of the gene theory (Rutter, 2005). Rutter explained that identical twins had a 60% chance for both children having ASD, whereas, fraternal twins showed a 5% chance of prevalence. In 2011, The

NIMH showed the prevalence of a child having ASD if the child's identical twin had ASD is 9 of 10 births or 90%. Family studies of ASD have shown that typical siblings of a child with an ASD diagnosis have a 2-8% chance of also having a diagnosis of ASD (NICHD, 2011). Clinicians still do not have a definitive cause for autism, and there are no objective diagnostic tests; therefore, a clinical diagnosis is based on criteria from the DSM and individual behavior (Ratajczak, 2011).

Parental Perceptions and Parental Stress

Research conducted about parental stress, as experienced by families who have a child with ASD, has shown that stress is significant and the severity of the stress can be influenced by parental perceptions of parent-child relationships, child behaviors, and parenting difficulties (Abiden, 1990; Lyons et al., 2010; Woodgate, Ateah, & Secco, 2008). For this section of the chapter, parental perceptions of parent-child relationships will be described in the context of parents' dissatisfaction with interactions with their child and the degree to which parents find their child unacceptable (Abidin, 1990; Haskett, Ahern, Ward, & Allaire, 2006). Parental perceptions of child behaviors will be described in the context of parents' perceptions of their child's self-regulatory abilities (Abidin, 1990; Haskett et al., 2006). Parental perceptions of parenting difficulties will be described in the context of distress resulting from personal factors and from life restrictions due to the demands of raising a child with ASD (Abidin, 1990; Haskett et al., 2006).

Parental Perceptions of Parent-Child Relationship Stress

This section includes perceived parental stressors in which parent-child interactions are found to be unacceptable and disappointing to a parent. Perceived stress is viewed in the context of ASD diagnosis and social interactions.

ASD diagnosis and parenting stress. The diagnosis of ASD can cause great stress on parents, often resulting in parents exhibiting grief, denial, and anger (Rarity, 2007). Parents can become dissatisfied with their child interaction pre-diagnosis due to behavioral issues, communication difficulties, increased parental responsibility, and overall familial strain (Honey et al., 2005; McConachie, 2005; Rogers, 2008). The initial diagnosis of a child with ASD is a complex and thorough investigation by a multidisciplinary team of health professionals. Clinicians gather data about the child's developmental history from the parents and data findings from clinical observations and assessments (Bruey, 2004; Jordan, 2001; Moh & Magiati, 2011). The diagnosis wait time is a significant stressor for parents because often there was a long delay between the time parents expressed their concerns and the time their child was actually diagnosed (Bruey, 2004). Parents typically consult an average of 4.5 professionals before they are given a diagnosis of ASD for their child (Goin-Kochel et al., 2006). During this time, parents can feel anxiety, helplessness, uncertainty, panic, distress, and social isolation (Siman-Tov et al., 2011).

Once a diagnosis is obtained, parents can experience high levels of grief, denial, and anger (Rubens, 2009). Grief is often the first emotion parents feel after receiving the diagnosis of ASD for their child, and it can manifest as episodic or ongoing (Rubens,

2009). For parents of children with ASD, the loss of the idea of a perfect child can be triggered at any time by an experience or during developmental milestones (Rarity, 2007). Parents must relive the grief of knowing their child is different, which can raise their stress levels (Rarity, 2007). After the initial diagnosis, parents can feel very overwhelmed and resort to denial as a way to help them deal with the change in their reality and the seriousness of the diagnosis (Rarity, 2007; Rubens, 2009). Even though parents have experienced the challenges of ASD exhibited by their child prior to the diagnosis, they may deny or refuse the new diagnosis (Rubens, 2009). Anger is a common emotion in parents who have a child with a diagnosis of ASD because parents feel pain, fear, humiliation, disappointment, and self-doubt, which results in resentment and blame of others (Exkhorn, 2005). Because ASD is a lifelong disorder, the stress that stems from the diagnosis of ASD affects the parents' relationship with their child and stress results (Rarity, 2007, Rubens, 2009).

Social interactions and parenting stress. Parents are greatly affected by the effects of stress on their social lives when raising a child with ASD, which can lead to unhealthy parent-child interactions (Haskett et al., 2006). The responsibility of the parent revolves around filling the needs of their child, which in turn, causes extreme frustration and isolation for the parent (Datz, 2006; Doherty, 2008; Gray, 2002; Moes, 1995). The outcome of the parental frustration can relate to a number of negative characteristics on the part of the parent such as low levels of parental warmth and reciprocity, and the use of harsh discipline (Haskett et al., 2006; Rogers, 1993; Shiflet & Windsor, 2002).

Maladaptive behaviors such as sleep issues, not being able to do things as a family, extreme parenting demands, taking a child with ASD into the community, excessive stereotypical behaviors, and socializing issues make parents feel ostracized from others (Gray, 2002; Hartley et al., 2012). A study conducted by Cassidy, Truesdale-Kennedy, and Slevin (2008) explored the examination of the parent's perception of the child with ASD and the effects of the challenges on the family. Additional social functioning restrictions perceived by the parents in the study were not being able to take their child to other people's homes, not being able to obtain a consistent babysitter for their child, conflicts with their child, sleep deprivation, and frustration with parent-child interactions (Cassidy et al., 2008; Kanner, 1943; Konstantareas & Stewart, 2006; Kroeger, Shultz, & Newsome, 2007).

Higgins, Bailey, and Pearce (2005) noted the biggest concern for parents when engaged in social functioning was having the community judge their child's behavior. When their child exhibited misbehavior or typical autistic behavior, parents believed they were judged based on their poor behavior management of their child while in public. The effects of social stigma and judgment of parents can have a significant effect on the parents' interaction with their child and can influence their child's social adjustment **(**Hartley et al., 2012).

Parental Perceptions of Child Behavior Stress

This section includes perceived parental stressors in the context of child behaviors, specifically, the parental perception of their child's self-regulatory abilities.

Stressors to be addressed are behavioral concerns and severity, treatment options, and support systems.

Behavioral concerns/severity of symptoms and parental stress. Behavioral concerns are a significant source of stress for parents raising a child with ASD and have been shown to elevate levels of anxiety and depression in parents (Benson & Karloff, 2009; Honey et al., 2005; Johnson et al., 2006; Rogers, 2008). Behavior problems exhibited by children with ASD (e.g., unpredictable aggression toward themselves and others, tantrums, self-stimulating behaviors, toileting and sleeping concerns, high levels of anxiety, mood swings, difficulty in making transitions, hyperirritability, rigidity, constant vocalizations, and echolalia or the lack of speech) were challenging behaviors the parents experienced daily resulting in parenting stress (Duarte et al., 2005; Labosh, 2005; Marcus et al., 2005; Rogers, 2008). The parents' level of stress is often determined by the severity of the behavior exhibited by the child. Therefore, the more severe the child's behavior, the more severe the stress in the parent (Bromley et al., 2004; Johnson et al., 2006; Rogers, 2008).

Because of the behavioral symptomology of a child with ASD, parents may have increased parental responsibilities such as, the pressure to plan activities to avoid occurring or escalating behavior, difficulty in knowing exactly what their child wants due to the inability to functionally communicate with their child, the burden of not knowing the ability of their child in certain circumstances, therefore, determining exactly what their child can handle in situations without a meltdown or tantrum is emotionally stressful

(Benson & Karlof, 2009; Erguner-Tekinalp & Akkok, 2004; Johnson et al., 2006; Rogers, 2008).

In addition, parents may need to engage in daily living skill behaviors, which can exacerbate their stress (Benson & Karlof, 2009). Toileting behavior can be a big challenge between parents and the child (Benson & Karloff, 2009). Children with ASD may have challenging and/or lifelong struggles with bowel or bladder issues, which can result in excessive changing of the child by the parent. An additional stressor for parents can be their child's sleeping pattern (Bebko et al., 1987; Benson & Karlof, 2009; Rogers, 2008). If the child has sleep concerns such as interrupted sleep patterns or insomnia the parent can suffer from little to no sleep, therefore, exacerbating their exhaustion and stress (Bebko et al., 1987; Benson & Karlof, 2009; Rogers, 2008). Due to these behavior concerns, parents often must create rigid routines, schedules, or find creative ways to prevent behaviors or cope with them afterward, leading to an increased need for physical and emotional supports (Benson & Karlof, 2009; Johnson et al., 2006; Marcus et al., 2005; Rogers, 2008).

Selecting treatment options and parental stress. Once a child is diagnosed with ASD, parents face the reality of treatment options based on what is available (Oswald, Ollendick, & Scahill, 2009). As a result of needing to choose from multiple options, parents feel overwhelmed about which treatment to use with their child (Cotton et al., 2010). Children with a diagnosis of ASD can have many specific needs that require many therapies and interventions. Parents can experience feelings of stress in addition to the stress of choosing therapies, including, quantity of time dedicated to providing care to

their child, a limited amount of personal time, overwhelming amounts of paperwork, and costs of treatments (Linares-Gonzalez, 2006; Johnson et al., 2006; Rogers, 2008). All of these stressors can affect the quality of relationships parents have with their child. However, the primary goal of parents is to alleviate the challenging symptomology of their child's ASD (Cotton et al., 2010; Myers & Plauche-Johnson, 2007).

Research has shown that specialized and supportive educational programs and interventions combined with therapies such as speech therapy, occupational therapy, and physical therapy, social skills supports, and behavioral interventions are the most effective treatments for a child with ASD (Myers & Plauche-Johnson, 2007). In recent years, researchers have added complementary and alternative medical treatments for children with ASD that include mind-body medicine such as yoga and music therapy, biologically-based practices, which include vitamin therapy, chiropractic manipulation, craniosacral massage, therapeutic touch and massage therapies, auditory integration, and energy medicine, which includes transcranial magnetic stimulation. Parents are electing to use alternative and complementary treatments with their children although they are not as well studied because of fears of side effects related to dietary and pharmacological drugs used in more traditional settings (Cohen & Kemper, 2005; Lew & Hyman, 2009; Swedo, 2012). Parents are stressed by having to choose treatment options. An additional stressor is the considerable amount of time and effort needed to support their ASD child (Altiere & von Kluge, 2009).

Social supports and parental stress. Parents of children with ASD may experience feelings of isolation or ostracism by members of the community or even

extended members of their family, due to their child's aberrant, disruptive, or problematic behavior (Datz, 2006; Doherty, 2008; Hartley et al., 2012). Family and community members may attribute the child's behavior to a lack of discipline or poor parenting and may refuse to help care for the child (Datz, 2006; Doherty, 2008; Grey, 2002; Hartley et al., 2012). The parent perceives that his or her extreme stress is a result of the behavior of the child and can feel hopeless (Deater-Deckard, 2004; Seligman & Darling, 2007). For parents under stress, social and community support could be a significant resource and serve as a protective factor contributing to the adjustment of parents and children with ASD (Altiere & von Kluge, 2009; Armstrong et al., 2005; Bromley et al., 2004; Tehee et al., 2009).

According to Payne (2005), support systems are "the friends, family, and backup resources that were accessed in times of need. Parents use support systems to relieve them temporarily from emotional, mental, financial, or time constraints (Payne, 2005). Social support refers to the individual's perception of cooperation and assistance as available to them by close or significant persons (Siman-Tov & Kaniel, 2011). Social support can be divided into two types of support, informal and formal (Seligman & Darling, 2007). Informal support is the type of support parents initially attempt to access and includes friends, extended family members, neighbors, and others who are not part of a formal organization and typically do not require the exchange of money. Formal supports are services that are provided by formal organizations or agencies (Siman-Tov & Kaniel, 2011; Seligman & Darling, 2007). The parent's perception of the adequacy of support contributes to the decrease of parental stress. Perception of the adequacy of social

support is thought to be influenced by the intensity, durability, reciprocity, and frequency of parent-caregiver contact (Abidin, 1990; Seligman & Darling, 2007).

Parental Perceptions of Parenting Difficulties

This section includes perceived parental stressors that stem from personal factors and life restrictions. Perceived stressors are in the context of parenting competence, financial strain, and marital satisfaction.

Parenting competence and parental stress. The complex and demanding duties of being the parent of a child with ASD can result in the parenting perception of the child's needs exceeding the parental resources needed to provide adequate care (Abidin, 1995; Johnson et al., 2006). Parents can develop feelings of low-efficacy and helplessness when parenting, which can decrease parenting satisfaction and ultimately interfere with their ability to parent (Bromley et al., 2004; Johnson et al., 2006; Rubens, 2009). Research has shown that parenting competence is lower for parents of a child with ASD compared to children with other types of disabilities (Abbott, 2013; Tobing & Glenwick, 2002). Parental perceptions of insufficient parenting competence can be viewed by parents as their ability to handle parenting responsibilities without feeling like they are "trapped" and being able to competently parent a child who has limited communication and social and behavioral deficits (Abbott, 2013; Abbuduto et al., 2004; Atwood, 2007). The unrelenting daily needs of a child with ASD can deeply affect and drain a parent psychologically and emotionally as they try to determine the unmet needs of their child, often leading to guilt, depression, and isolation (Benson & Karloff, 2009; Erguner-Teknalps & Akkok, 2004; Rogers, 2008). Often, the feeling of guilt can lead

parents to overcompensate, which leaves them physically and mentally exhausted (Siman-Tov & Kaniel, 2011).

Financial strain and parental stress. Financial strain experienced by parents of children with ASD can be perceived as a significant cause of parental distress, often leading to economic hardship (Abidin, 1995; Ganz, 2007; Hutton & Caton, 2005). The lifetime estimates of direct and indirect costs for an individual with ASD were reported to be upwards of 3 million dollars (Datz, 2006; Ganz, 2007). Direct costs include costs for physicians, outpatient services, clinic services, dental care, prescription medications, complementary and alternative therapies, behavioral therapies, hospital and emergency services, allied health equipment and supplies, home health services, medically-related travel, child care, respite care and family care, home and car modifications, related services, and other costs (Datz, 2006; Ganz, 2007; Lee, Anderson, Horowotz, & August, 2009).

In addition to the monetary strain, parents are also bound by time restraints in which they may need to wait or be put on a waiting list to receive specialized services or to obtain a meeting for their child. Parents are often faced with the emotional stress of feeling as if they must invest in any new concept or idea as a way to provide the best care for their child. This is commonly known as *stress spending* (Labosh, 2005). Stress spending is the phenomenon in which parents will spend money, above their means, to buy any new toy or gadget that would keep their child engaged or to pay exorbitant amounts to send their child to a special school or camp in hopes of decreasing their challenging behaviors or symptomology (Labosh, 2005).

The indirect costs that typically affect parents of children with ASD are related to their productivity at work or employment status (Labosh, 2005). Parents may need to refuse employment offers, reduce their work hours, resign, or become terminated all to make sure that their child is receiving the care they need (Ganz, 2007). The conflict in the work/home paradigm often occurs when the parent needs to be more engaged at home causing the work role to be compromised (Beck, Hastings, Daley, & Stevenson, 2004). Research has shown that parents, especially mothers, must adjust their work day to coordinate with their child's doctor appointments, therapies, and meetings often leading to increased absenteeism, which could lead to termination of employment (Abbott, 2013; Beck, Glidden, & Schoolcraft, 2003; Beck, Hastings, Daley, & Stevenson, 2004; Quine & Pahl, 1991). Mothers of children with ASD are estimated to have higher unemployment rates. Ganz (2007) reported that mothers have an estimated unemployment rate of 60% compared to the 20% estimated for fathers.

Economic hardship is the typical result of the financial strain experienced by parents who are raising a child with ASD. Although economic hardship is a factor for parents who have the means to provide financially for their child, it is especially devastating for parents who are low-income who typically end up in poverty (Ganz, 2007; Hutton & Caton, 2005). Because of the financial and employment stress felt by parents raising a child with ASD, poverty becomes a reality for families (Balfe & Tatum, 2010; Kogan et al., 2013; Piper-Terry, 2010). Poverty can be defined specifically by two main situations, situational and generational poverty (Payne, 2005). Payne wrote that situational poverty happens when a specific or particular event occurs causing a lack of

resources. The attitudes of parents who experienced situational poverty were ones of pride and refusal to accept help or charity (Payne, 2005, 2009; Shipler, 2004). As discussed previously, the cost of raising a child with ASD is tremendous, and many parents who are financially stable may find themselves in situational poverty (Kogen et al., 2013).

The second form of poverty that affects families is generational poverty. Generational poverty occurs when poverty had been evident for at least two generations and often families who fall into the low-income SES are members of generational poverty (Payne, 2009). Generational poverty includes hidden rules, individual cultural practices, and belief systems. Parents often do not even realize they are in poverty because it is relative, and if everyone else in their lives is living in poverty, poverty itself is vague (Payne, 2009).

The cultural beliefs practiced by families in generational poverty include specific family patterns (Biddle, 2001). Payne (2006, 2009) wrote that generational poverty is about survival. Therefore, taking care of the functional, emotional, and educational needs of the child with ASD is not necessarily the most important concern of the parents (Payne, 2005; Payne, DeVol, & Dreussi-Smith, 2001). Researchers have shown that economic pressure, especially in families in poverty, has negative dynamics such as ineffective problem solving, ineffective communication, conditional affection, limited flexibility, rigid values, and cultural family rituals (George, 2009; O'Gorman, 2012; Touliatos, Perlmutter, & Strauss, 1990). In generational poverty, parents experience

parental distress but it may be entwined with stressors allowed in the generational poverty culture (Payne, 2006, 2009).

Marital satisfaction and parental stress. Raising a child with ASD places significant stress on the marriage dyad (Hartley et al., 2012; Siman-Tov & Kaniel, 2011). The feelings of disconnect, isolation, blame, fair division of parenting roles, negative or non-emotional interactions, and lack of communication can lead to parental distress which, in turn, affects the marriage stability and satisfaction (Rogers, 2008). Marital dissatisfaction is a likely result of parental stress, especially when parents engage in a family life that revolves around the child with ASD (Hartley et al., 2012). A breakdown in effective and open communication between parents can result in blaming, where each parent blames the other for what they are not doing (Atwood, 2007; Hartley et al., 2010). The result of blaming is parental distress because each parent believes he or she is underappreciated by his or her spouse (Tani et al., 2012). Due to the lack of appropriate communication, the separation of roles emerges, and the longer spouses are not able to spend time together or share in each other's lives, the more likely the marriage cannot be sustained (Rogers, 2008). Not unlike the way parents and children are linked in mutually influential ways, the well-being and life circumstances of one spouse affects the other (Elder, Johnson, & Crosnoe, 2003). Once the married couple begins to experience the division of roles, mothers and fathers begin to experience parental distress differently (Knafl & Zoeller, 2000; Rogers, 2008). Mothers tend to become more reactive to their child's behavior, resulting in increased anxiety and depression; whereas, fathers tend to react to their wife's mood rather than the child's behavior (Berge, Patterson, & Rueter,

2006). The stressors felt by parents can be carried over to the intimate parts of the marriage. As the father begins to withdraw from the relationship and become more defensive, the intimate bonds begin to decrease (Hartley et al., 2012). If the bonds of intimacy decrease significantly, the satisfaction of the marriage may dramatically decrease, increasing the odds that the marriage will end in divorce; the divorce rate in families in which a child has a diagnosis of ASD is higher than families who have children without a disability (Hartley et al., 2012). The reported estimated divorce rate for parents of children with ASD is 80%, however, previous estimates of the divorce rate in parents whom children with ASD have been grossly inflated and have not taken into consideration the restrictions of the parents in the studies (Hartley et al., 2012).

Methodological Evidence of Parental Stress

In this section, qualitative, quantitative, and mixed methods research are used to show empirically how raising a child with ASD affects parental stress. The following supports the gap in research about how varied contributors to stress affect perceived stress felt by parents and support the evidence found in this literature review.

Qualitative Evidence of Parental Stress Contributors

Altiere and von Kludge (2009) explored the struggles and successes of 52 parents (i.e., 26 married couples) of children with autism. The age of the children with autism ranged from 3-16. However, more than half of the children were aged 7 years or younger. Parents were questioned using a semi-structured interview as a way to provide a detailed qualitative analysis of the difficulties that face parents of children with autism. The prompts used for the semi-structured interview were: (a) Tell the story of the birth of

your child with autism and how you found out your child had autism, (b) What do you believe caused your child's autism? and (c) Are there any valuable learning experiences you have gained from raising a child with autism? The interviewer only asked clarifying questions and followed the lead of the speaker. A grounded theory approach was used to collect and analyze data as a way to create a new theory instead of attempting to verify a pre-existing one. Narratives of the parents' challenges encountered when raising their child were subdivided into five categories, development, questioning, devastation, solutions, and growth.

Over a decade, Grey (2006) conducted a longitudinal qualitative study about the social experiences of families of children with autism and how they coped with the stress of parenting a child with ASD. An ethnographic method was used for the study that emphasized in-depth semi-structured interviews and observations of 28 parents (i.e., 19 mothers and 9 fathers) of children with autism. The interviews included questions concerning the child's medical history, the child's present symptomology, the effects of the child's problems on the parent's well-being, the effects of autism on the parent's social life, parental coping skills, and the parent's expectations for the future. The results show that over time the level of parental distress declined as parents reported that their child had improved to a point in which they could cope with the behavior, the parents adaption to the situation of having a child with ASD had significantly advanced, and when the family life became more routine, the child had improved over time and had become less disruptive.

Myers, Mackintosh, and Goin-Kochel, (2009) explored how children with ASD have affected the lives of their parents in five clusters: stress; child's behavior; parent's personal well-being, work, marital relationship; whole family; and social isolation. There were 493 parents of children on the autism spectrum who participated in the study. Of the children 295 (59.8%) had a diagnosis of autism, 116 (23.5%) had a diagnosis of Asperger syndrome, and 82 (16.6%) had a diagnosis of PDD-NOS. Data were collected through a web-based question: "How has your child in the autism spectrum affected your life and your family's life? Qualitative coded themes were subdivided into the five clusters. The stress cluster showed 71% (n = 350) of the parents' statements expressed extreme stress. The child's behavior and the demands of the child's therapy and care cluster showed that parents had five negative themes including difficulty dealing with the child's behavior problems, time demands for care and therapies, sleep problems, exhaustion, and struggles with schools and services.

The effects on the parents' personal well-being, work lives, and marital relationships cluster showed three negative themes; these were marital or couple strain, difficult emotions (i.e., grief, depression, or blame), and mothers/and or father's career/employment. The fourth cluster, effects on the family as a whole, including siblings and extended family, had four negative themes: effects on siblings, financial strain, the feeling that autism became the center of their lives and strained relationships with extended family members. The last cluster, social isolation, showed parents who responded to this cluster responded negatively about how their lives had been restricted and their social contacts reduced.

Quantitative Evidence of Parental Stress Contributors

Durkin et al., (2010) conducted a study designed to evaluate the hypothesis that the prevalence of ASD among children within the United States is possibly associated with socioeconomic status (SES). They used a cross-sectional study implemented with data from the Autism and Developmental Disabilities Monitoring Network (ADDM), a multiple source surveillance system, to determine the number of eight-year-olds with ASD among defined populations. A population-based cross-sectional design in which data from 12 ADDM participating sites located in Alabama, Arkansas, Colorado, Georgia, Maryland, Missouri, North Carolina, New Jersey, Pennsylvania, South Carolina, and Wisconsin were used to gain abstracted data from records from multiple educational and medical sources. The purpose was to find the number of children who would meet the ASD case definition; clinicians then determined if the ASD case definition was met. The ADDM relies on information for children who have access to diagnostic services for developmental disabilities. Data showed that children in higher SES showed a mean diagnostic age of 58 months versus low-income children who were diagnosed typically 2.7 months later, possibly due to the lack of access to diagnosticians. The prevalence of a relationship between ASD and SES was computed using prevalence ratios with medium SES serving as the reference category and Cochran-Armitage trends tests. The study did include a race variable and found that Hispanic and African American children only showed prevalence within the low SES category because more of these children live in poverty versus prevalence in other overall groups. The conclusion of the study ascertained that the bias that children of higher SES are more likely to obtain a diagnosis

before a low SES child could actually be related to *diagnostic bias* in which clinicians are more likely to give a diagnosis to educated or higher SES families. The SES gradient found in this study implies there are significant SES disparities in access to diagnostic and other services for children with autism in communities across the US. It also implies that the current estimate of ASD prevalence may actually be substantially undercounted, with children of low and medium SES being under-identified and under-served relative to those with higher SES.

Hoffman, Sweeney, Hodge, Wagner, and Looney, (2009) explored the stress levels of mothers of children with ASD and mothers of typically developing children using the PSI (Abidin, 1995). Mothers were recruited by trained research assistants at two local universities, a community college, community organizations, and a variety of businesses. A total of 341 mothers of typically developing children participated and 104 mothers of children with ASD. The PSI is divided into the parent domain and child domain. The child domain consists of six subscales: distractibility/hyperactivity, adaptability, reinforces parent, demandingness, mood, and acceptability. The parent domain consists of seven subscales: competence, attachment, health, role restriction, depression, and spouse-related stress. In the child domain, sample *t*-tests were used and mothers with children who have ASD reported higher stress ($M = 147.9$, $SD = 25.7$) than parents who have typically developing children ($M = 94.79$, $SD = 21.7$), $t(420) = 20.87$, $p = .001$.

Tehee, Honan, and Hevey, (2009) explored experiences of parents whose children have ASD and the influences of accessed support and the link between the involvement

of mothers and fathers on parenting stress. Participants were 42 parents (i.e., 23 mothers and 19 fathers) living in Ireland. The mean ages of the mothers were 40.9 years (*SD* = 5.7) and 44.9 years (*SD* = 7.2) for fathers. The mean age of the 22 children was 9.3 years (*SD* = 4.5). Social support was measured by the Support Questionnaire (SQ) developed by the researchers, and the Perceived Stress Scale-10 item (PSS-10; Cohen, Kamarck, & Mermelstein, 1983) was used along with the Family Stress and Coping Questionnaire (FSCQ; Minnes & Nachsen, 2003) to measure caregiving stress and coping and the Involvement and Responsibility Questionnaire (IRQ; Konstanareas & Homatidis, 1992) to measure parental responsibilities. Statistical significance showed a strong inverse relationship between social support and parenting stress ($r = -.54$, $p = .025$) and mothers perceived significantly higher levels of stress than fathers did (Kruskal-Wallis test, X2 = 9.243, $df = 1$, $p = 0.002$). Similarly, mothers reported significantly higher levels of stress and coping than fathers did in relation to caregiving (Kruskal-Wallis test, X2 = 13.872, df = 1, p = 0.001).

Mixed Methods Evidence of Parental Stress Contributors

Meirsschaut, Roeyers, and Warreyn (2010) investigated how mothers perceive the effects of their young child with ASD on their personal life and family life. Comparisons were also made of the parenting cognitions of mothers toward their child with ASD and their child who is typically developing. Seventeen mothers with a typically developing child and a child with ASD participated in the study and were recruited through local rehabilitation facilities. The children ranged in age from 46 to 84 months (M9sd) = 68.94 (11.76). The researcher chose to have the typically developing child be younger than the

sibling with ASD (29-83 months, (M9sd) = 50(15.23)). The measurement instruments used were the Maternal Efficacy Scale (Teti & Gefland, 1991), the Maternal Agency Questionnaire (Kuhn & Carter, 2006), and the Nimeegse, Ouderlijke Stress Index (NOSI; De Brock, Vermulst, Gerris, & Abidin, 1992), which is the Dutch version of the PSI (Abidin, 1983). The data were analyzed using qualitative and quantitative analysis. In the qualitative section, themes included how ASD affects the family's whole life, the lack of understanding from the environment of what ASD is and the affect it has on the family, the inaccessible caregiving system due to long waiting lists for services, coping strategies that have been developed by the mothers, and concerns and questions regarding the future and their parenting. Mothers showed higher stress with having a child with ASD because of difficulties with needing to have their normal family life interrupted, needing to have a structured and planned life, having a life that is less flexible or spontaneous than normal families, job and career adjustments, lack of understanding from family members and environment, isolation from relatives, marital strain, long waiting lists that restrict the accessibility of the caregiving system, putting all of their time and energy into doing everything they can for their child, finding balance between the needs of their child and being a normal family, and concerns for their child's future.

The quantitative analysis was used to compare the mothers' cognitions about her ASD child and a typically developing child. Mothers reported a lower sense of self-efficacy about parenting their child with ASD (M9SD) = 29 (4.83) than parenting their typically developing child (M(SD) = 32.29 (3.79)) ($F(1,16)$ 11.2, $p < .01$). The analyses also revealed that mother's feel more guilt toward the typically developing child (n = 13)

than toward the child with ASD (n = 8) (X2 (1)) = 3.11, p = .10). Higher levels of stress and depressive symptoms were reported with the child with ASD (M9SD) = 32.31 (10.36) than the typically developing child (n = 2/13).

Section 3: Research Method

Introduction

Parents of children with a diagnosis of ASD experienced higher levels of parenting stress (Dumas et al., 2007; Plant & Sanders, 2007; Woodgate, Ateah & Secco, 2008). Parental perceptions of parental-child interactions, child behavior, and parenting difficulties are all antecedents to parental stress that can result in impairment of parental role function and implementation of parental tasks (Abidin, 1990). In 10 low socioeconomic rural school districts found at the research site in Ohio, there is a lack of understanding of the contributors to stress for parents who have a child with ASD because there is a lack of current research. A qualitative research design is the most appropriate design for this study because in order to tailor support for parents, teachers, and administrators there need to be more specific details about how these stressors manifest themselves in this particular community. Therefore, a qualitative research design was needed for this study as a tool to allow for the research of the complex phenomenon of parental stress within the context of raising a child with a diagnosis of ASD. The result of the qualitative inquiry was to gain an in-depth understanding of the perceptions of parental stress when raising a child with ASD in a low socioeconomic rural area. The qualitative descriptive case study was an ideal design for this study because it allows data to be collected using quantitative and qualitative tools resulting in a holistic understanding of the phenomenon.

Research Design

A qualitative design with a descriptive case study approach emerged as the most appropriate methodological tool for this study. The qualitative research design is used to explore a social or human problem and allows the researcher to build complex, holistic pictures (Creswell, 2013). The qualitative design consists of multiple characteristics that align with the rationale of this study, including data collection occurring within a natural setting, the researcher being used as a significant instrument in data collection, data are descriptive and reported in words rather than numbers, the focus of qualitative research is the participants' perceptions and their meanings, and the use of inductive reasoning when analyzing data (Creswell, 2013).

The qualitative study of inquiry or approach was used as a guide for the procedures of the study (Creswell, 2013). The most appropriate inquiry for this study was the descriptive case study approach because both qualitative and quantitative measures were used to collect data. The analysis included descriptive statistics, which were used to describe the severity of stress data obtained from subdomains of the quantitative Parental Stress Index-SF and coding and thematic analysis for the qualitative semi-structured interview data (Yin, 2014). The case study approach permitted the research data collected to be based on both qualitative and quantitative evidence, which could be triangulated to lead to a credible understanding of the case (Yin, 2014). According to Yin (2014), a case study is an empirical inquiry that investigates a contemporary phenomenon, or case, in-depth and within a real-world context. The case study approach of qualitative research design is an exploration of the bounded system through detailed, in-depth data collection

involving multiple sources of information rich in content (Creswell, 2008; Yin, 2014). For this study, the bounded system was low socioeconomic rural parents who were raising children with ASD. Yin (2014) recommended extensive data collection using representatives of holistic analysis including documentation, archival records, interviews, direct observation, participant observations, and physical artifacts. For the purpose of this study, the quantitative instrument, the PSI-SF, and the associated qualitative semi-structured interview were used to collect data from participants. Each participant was considered a single case (Abidin, 1995).

Yin (2014) contended that the bounded system could be studied in one of three ways depending on the purpose of the study: an exploratory case study, explanatory case study, or descriptive case study. An exploratory case study typically is used to define the framework of a future study in that field. In addition, data collection is commenced prior to the final description of hypotheses and study questions. An explanatory case study, in contrast, is pursued to define how and/or why an experience occurs. The purpose of an explanatory case study is to suggest evidence of possible cause and effect relationships. Finally, the descriptive case study allows the researcher to simplify large amounts of statistical data and describe what the data show for each case. Descriptive statistics present quantitative descriptions in a manageable way and unlike inferential statistics, descriptive statistics do not try to reach conclusions that extend beyond the immediate data alone (Creswell, 2013). A descriptive case study, when used for the intent of educational research, is one that uses thick, rich descriptions to present a detailed account of the phenomenon under study. These studies are useful in presenting basic information

about areas of education in which little research has been done. For this study, a descriptive case study was chosen to provide research about the bounded system with the intention of developing a deeper understanding of parental stress contributors to educational professionals in low socioeconomic rural areas in Ohio.

Other qualitative approaches were considered and then determined to be less effective for this study, including phenomenology, biography, grounded theory, and ethnography. A phenomenology study seeks to explore the lived experiences of the phenomenon by multiple individuals (Creswell, 2008). Phenomenology determines what the experience means to people who have lived it and provides qualitative analysis of narrative data (Creswell, 2008). An important aspect of this study is to examine the perceptions of parental stress, as measured by the quantitative tool, PSI-SF. A quantitative tool may not be used in a phenomenological study, therefore; it was not the most effective approach to this study. A biography study is about an individual and his or her experiences as told to the researcher or found in documents and archival material (Creswell, 2008). Components of the biography study include collecting extensive information about the subject, as well as the historical and contextual material as it relates to the larger picture (Creswell, 2008). Because extensive research was not used when collecting data, the biography study was determined to be a less effective approach to this study. In grounded theory, the researcher discovers a theory and individuals take action or engage in a process as a response to a phenomenon (Creswell, 2008). When utilizing the grounded theory approach, the researcher initially collects 20-30 interviews and makes multiple visits to the field in order to ensure saturation (Creswell, 2008). Ten

interviews were used for this study; therefore, due to the sensitive and rare population within a low socioeconomic rural area, grounded theory was determined to be less effective for this study. Last, an ethnographic study is grounded in the description and interpretation of a cultural or social group or system (Creswell, 2008). Ethnography examines a group's behaviors or customs and is typically written in book-length form. Cultural rules about a group are gathered through observations and interviews that last a minimum of six months (Creswell, 2008). Because data collection for this study was not extensive, at least a minimum of six months, ethnography was determined to be less effective for this study.

A quantitative research design was considered and determined to be less effective for this study. Quantitative research methods are typically universal and are expressed in the form of variables (Creswell, 2008; Neuman, 2003). Usual measurements include formulas for finding means, median, and mode of a data set, data in the form of numbers, and specific data and findings from quantitative research in the form of pie charts, graphs, and tables (Creswell, 2008; Robson, 2002). Quantitative research is typically characterized by the use of surveys or experiments and provides a quantitative or numeric description of trends, attitudes, or opinions of the population by studying a sample of that population (Creswell, 2008). Based on the sample results, a researcher could make generalizations or claims about the population (Creswell, 2003). Since the sample size for this study was small, due to the sensitive and rare nature of the population to be studied, the statistical significance and generalizability to a larger population would not have produced an effective outcome. A quantitative design would also have been less effective

for this study because there was no need for inferential statistics, experiments, or determination of correlation or cause and effect due to the exploratory nature of the study.

A mixed methods research design was considered and determined to be less effective for this study. Creswell (2008) defined the mixed methods approach as collecting and analyzing both forms of data from the qualitative and quantitative research paradigms and mixing them as a way to help one strategy inform the other to provide an understanding of the research problem. Mixing may occur at several stages of research including data collection, data analysis, data interpretation, or a combination (Creswell, 2008, Teddlie & Tashakkori, 2009). The strategies of inquiry in a mixed methods approach involve using concurrent or sequential data collection as a way to better understand the research problem. Although the use of qualitative inquiry would have been appropriate for this study, as described above, the quantitative paradigm would not have been effective, therefore, making the use of mixed methods a less effective design.

Research Questions

The first research question deals specifically with the data collected with the PSI-SF. The following research questions deal specifically with the interview questions and align with the three subdomains of the PSI-SF: parental distress, parent-child dysfunctional interaction, and the difficult child.

1. What stressors do low socioeconomic rural parents of children with ASD demonstrate as measured by the PSI?

    (a) parental distress subdomain and items,

(b) parent-child dysfunctional interaction subdomain and items, and

(c) difficult child subdomain and items.

2. How do low socioeconomic rural parents of children with ASD perceive parental stress?

(a) How do low socioeconomic rural parents of children with ASD perceive their parent-child relationships?

(b) How do low socioeconomic rural parents of children with ASD perceive their child's behavior?

(c) What parenting difficulties do low socioeconomic parents of children with ASD experience?

These two main questions relate directly to the data collection and result reporting process. The first research question was answered using the Parental Stress Index-SF (Table 1). The results reported were the descriptive statistics collected with that instrument (see Table 1). The second research question and its sub-questions were answered using a combination of the PSI-SF data and the semi-structured interviews. Specifically, the PSI-SF data were used to generate questions and guide follow-up questioning during the semi-structured interview. The specific data collection and analysis of the PSI-SF and semi-structured interview are explained further in a later segment of this section. The PSI-SF data were used as a way to determine which of the specific stressors were most severe in this population (Research Questions 1a, 1b, and 1c)

and, thus, focus attention on those stressors during the semi-structured interviews to learn more about them (Research Questions 2a, 2b, and 2c).

Table 1.

Research Questions and Results to be Reported

Number	Research Questions	Results to be Reported and Goal
RQ 1	What stressors do low socioeconomic rural parents of children with ASD demonstrate as measured by the three PSI subdomains and their items? (a) Subdomain parental distress? (b) Average in subdomain parent-child dysfunctional interaction? (c) In subdomain difficult child?	Report: The three subdomain average scores for each participant. Goal: Determine which *subdomains* are the most stressful for this sample and should be given the most weight in the interviews. Report: Within each subdomain, for each specific PSI-SF item, the averages of 3.0 or greater and modes of 3 or greater on the survey scale of 1-5. Goal: Determine which items are the most stressful for this sample, and should be given the most weight in the interviews.
RQ 2	How do low socioeconomic rural parents of children with ASD perceive parental stress? (a) How do low socioeconomic rural parents of children with ASD perceive their parent-child relationships? (b) How do low socioeconomic rural parents of children with ASD perceive their child's behavior? (c) What parenting difficulties do low socioeconomic parents of children with ASD experience?	Report: For each subdomain research question all themes and subthemes that emerge from all of the participants' interviews. Goal: To understand the most stressful aspects of the parents' lives.

Note: see Table 2 for subdomains and individual items

Table 2.

Research Question 1 and Sub-questions 1a, 1b, and 1c with related PSI-SF Subdomain Items

Question	Research Question 1 Subquestions 1a, 1b, and 1c with related PSI-SF Subdomain Items
RQ 1a.	How do low socioeconomic rural parents of children with ASD perceive their parent-child relationships? Parental distress domain 1. I often have the feeling that I cannot handle things well. 2. I find myself giving up more of my life to meet my children's needs than I ever expected. 3. I feel trapped by my responsibility as a parent. 4. Since having this child, I have been unable to do new and different things. 5. Since having a child, I feel I am almost never able to do the things I like to do. 6. I am unhappy with the last purchase of clothing I made for myself. 7. There are quite a few things that that bother me about my life. 8. Having a child caused more problems than I expected in my relationship with my spouse/parenting partner. 9. I feel alone and without friends. 10. When I go to a party, I usually expect not to enjoy myself. 11. I am not as interested in people as I used to be. 12. I do not enjoy things I used to.
RQ 1b.	How do low socioeconomic rural parents of children with ASD perceive their child's behavior? Parent-child dysfunctional interaction domain 13. My child rarely does things for me that make me feel good. 14. When I do things for my child, I get the feeling that my efforts are not appreciated very much. 15. My child smiles at me much less than I expected. 16. Sometimes I feel my child does not like me and doesn't want to be close to me. 17. My child is very emotional and gets upset easily. 18. My child doesn't seem to learn as quickly as most children. 19. My child doesn't seem to smile as much as most children. 20. My child is not able to do as much as I expected. 21. It takes a long time, and it is very hard for my child to get used to new things. 22. I feel that I am: a very good parent, a better than average parent, an average parent, a person who has some trouble being a parent, not very good at being a parent. 23. I expected to have closer and warmer feelings for my child than I do, and this bothers me. 24. Sometimes my child does things that bother me just to be mean.
RQ 1c.	What parenting difficulties do low socioeconomic parents of children with ASD experience? Difficult child domain 25. My child seems to cry or fuss more than other children. 26. My child generally wakes up in a bad mood. 27. I feel that my child is moody and easily upset. 28. Compared to the average child, my child has a great deal of difficulty in getting use to change in schedules or changes around the house. 29. My child reacts very strongly when something happens my child doesn't like. 30. When playing, my child doesn't often giggle or laugh. 31. My child's sleeping or eating schedule was much harder to establish than I expected. 32. I have found that getting my child to something or stop doing something is: much harder than I expected, somewhat harder than I expected, about as hard as I expected, somewhat easier than I expected, much easier than I expected. 33. Think carefully and count the number of things which your child does that bothers you. 34. There are some things my child does that really bothers me a lot. 35. My child's behavior is more of a problem than I expected. 36. My child makes more demands on me than most children.

The semi-structured interviews and follow-up questions were used as a way to have the parents provide additional specific details about the stressors they noted within the PSI-SF subdomains. In Section 4, the reporting of results included two sections: (a)

PSI-SF data with descriptive statistics and (b) interview questions generated by the PSI-SF data and semi-structured interview qualitative results.

First, to answer Research Questions 1a, 1b, and 1c (Table 1), two data sets were reported: subdomains' mean T-scores and each subdomains' survey item means and modes (See Appendix c). Using the PSI-SF data, the first data set was mean T-scores for all participants for each of the three subdomains (see Table 2) to indicate their relative stress for the population as a whole. To clarify, there was one mean T-score per subdomain with three means. The second set of data reported was a mean and a mode for each of the 36 items on the PSI-SF (See Appendix C). These were used to indicate which items should be included in the semi-structured interview based on the most stressful items in this sample (highest means per item) and for the most people in this sample (most common rating/mode). The second part of the research question 1 results documented the interview questions generated by the PSI-SF data analyses in the first section of the results.

The second section of the results for Research Question 2 documented the themes that emerged from the semi-structured interviews. Results were organized in terms of the three subdomains. To summarize, the organization of Section 4 followed the structure in Table 1 where each research question addresses all three subdomains of research questions 1 a, b, and c descriptive statistics section and a resulting interview questions section, and then Research Questions 2 a, b, c, qualitative results organized by the three subdomains (See Table 2).

Context of Study

This study occurred in a low socioeconomic rural setting in Ohio. Because parents of children with ASD were the target group to be studied, they were accessed from the local autism support group located in the research area. The research site was one low socioeconomic status (SES) county in Ohio in which there were 10 school districts (ODJFS, 2013; Ohio County Profiles, 2013). School districts in the SES area were considered schools that provide education to high numbers of children in poverty (ODJFS, 2013, Ohio County Profile, 2013). The effects of poverty and SES on parents of children with ASD were significant to this study because they could contribute to the parents' perceptions of stress and/or how they demonstrate stress. Low SES was determined from school districts in the county reporting statistics that showed 37% of their students under age 18 lived in poverty. Additionally, many children experienced very low food security, which was described as a condition arising from a lack of money and other resources to acquire sufficient food intake due to limited resources.

The population of the research site was reported as 78,477. Of that population, the unemployment rate was 11.1%, and the per capita income was $28,000. In addition to the high unemployment rate, 36% of the population depended on additional income supports, which were not included in the workforce or the unemployment rate, such as, temporary assistance for needy families, supplemental security income, disability, and unemployment (Felmlee, 1995; Mak et al., 2007; ODJFS, 2013; Pines, 1997).

In addition to poverty and a low SES, the research area was also considered a medical health shortage and severely medically underserved area in the state of Ohio

(The Autism Taskforce, 2007. The Ohio Department of Health, Healthy Ohio Report (2008), defined a primary care health professional shortage as a population underserved for primary medical care and without a sufficient number of providers in the areas with higher population. They further reported a shortage as population/physician ratios were 3500:1 (ODH). Because of being medically underserved, the research site was considered a significant county in Ohio for under-identification of children with ASD (The Ohio Autism Taskforce, 2007). For the research site, the most recent under-identification rate for ASD was 35% (The Ohio Autism Taskforce, 2007).

Ethical Protections of Participants

This case study complied with the institutional review board (IRB) as regulated and required by Walden University. Specifically, this concerned the approval for using human subjects. To begin research with human subjects, I needed to complete an IRB application specifying how I would protect the human rights of participants in this study. This application needed to be approved by the IRB.

To obtain volunteers for this study, I contacted the president of the local autism support group, The Autism Project of Southern Ohio, to seek permission to recruit participants who attended the monthly meeting. The local autism support group was the largest gathering of parents who had children with ASD in my research area. Therefore, I expected to recruit approximately 10 participants from the group. Once in contact with the president of the autism support group, I explained the purpose of the study, for example “the purpose of the study is to identify what stressors parents perceive they have when raising a child with ASD and once they tell me their perceived stressors I can

identify how they demonstrate their stress." I explained why I chose the site to recruit parents by saying "the autism support group will allow me to recruit approximately 10 parents who are raising a child with ASD because the meeting consists of the largest group of parents who are raising a child with ASD from all over the county." I told the president I would need approximately 5-10 minutes to recruit participants and asked when my presence at the meeting (i.e., before, after, or during) would be considered the least disruptive to the parents.

In a meeting with the president, I explained the measurement tools: the PSI-SF and semi-structured interviews. I explained how they would be used to collect data and that the time commitments included two separate meeting dates and total time of 30 minutes the first day, and 60 minutes the second day. I explained that the expected benefits of the study were to help educators have a better understanding of the stress parents experience when raising a child with ASD, and how I proposed to disseminate the findings. I protected the rights of the parent in terms of anonymity and informed the parents of their rights to stop or withdraw from the study at any time. I provided a flyer asking for volunteers for the study. The flyer included a brief explanation of the study and instruments used for data collection and my contact information. Last, I asked the president of the autism support group to sign the letter of cooperation.

Once given verbal permission by the president of the Autism Project of Southern Ohio and IRB, I addressed the members of the autism support group using the same format I used when seeking permission from the president of the autism support group. At the end of my presentation, I passed out flyers that requested volunteer parents to

participate in my study. The flyer contained an overview of the study, ethical protection of the participants, and participants' expectations. Also, included on the flyer was my contact information using my cell phone number and an email address. I informed parents that if they were interested in volunteering, to please speak with me after the meeting or contact me within two weeks via my cell phone or by email. If the parent chose to volunteer for the study, then we chose a mutually agreed upon location and scheduled a date to begin data collection.

Ethical protections of live participants is a prerequisite when collecting, analyzing, and disseminating research data. To guarantee protection, I strictly adhered to the steps outlined below.

Step One: Introductions and Procedures for Participant Consent

On the first day of data collection, I set the participants at ease with polite conversation before I shared the consent form, and then I reviewed the consent materials carefully and thoroughly using the stated plan. I introduced myself, thanked them for participating in the study, and spoke with them in dialogue that would make the participants feel at ease, such as, "Tell me your favorite thing about your child." Next, I provided an informed consent form to the participants. I verbally reviewed the form in participant-friendly language, such as, "You do not need to do this if you do not want or if you start and want to stop that is okay, too." I informed participants that the data collection would occur over two separate meetings. In addition, their participation was voluntary, and no compensation was awarded for participation. I reviewed the purpose, procedures, and the benefits of the study. Participants had the option of obtaining a copy

of their consent form. If they chose to have a copy, I provided two identical consent forms to be signed; one copy was given to the parent. After the participant had signed the consent form, I placed the form in an envelope marked with a number 1-10. The number was assigned sequentially based on the order of the meetings for data collection (e.g., the meetings with the first participant were number 1). Using numbers rather than names ensured confidentiality and anonymity of participants. The marked envelope was sealed after the second meeting and once all forms and data collection instruments had been completed by participants. These documents are now stored in a locked cabinet at my home.

Step Two: Confidentiality

A separate but identical confidentiality form was presented to each participant of the study. Before signing, I reviewed the conditions of the form with each participant and answered any additional questions about confidentiality. Once signed, the confidentiality form was placed in the corresponding numbered envelope.

Step Three: Data Collection

Data collection occurred in two separate meetings. During the first meeting, consent and confidentiality were discussed and signed. Once the consent and confidentiality forms were signed, I began the quantitative data collection phase of the study providing the PSI-SF to be completed by a parent. Data collection was completed in a mutually agreed upon setting. I instructed the participant to answer all of the questions if he or she possibly could, but that he or she could, of course, choose not to answer a question if he or she preferred not to do so. However, if he or she chose not to

answer a question, his or her data were not used for the study. Average completion time of the consent form, confidentiality form, and the PSI-SF was approximately 30 minutes.

During the second meeting, parents were asked the interview questions with follow-up questions. Questions proceeded in the order of the subdomains from the PSI-SF. Questions were asked by the interviewer in the same order for all participants using an interview protocol. Follow-up questioning suggestions were listed on the protocol but varied according to the participant's answers. The questions were presented in the order in which they were written. A list of sample questions that pertain to the stressors (Appendix B) was provided for the IRB to view. A sample interview protocol question based on the survey item could be, "Give me two examples when your child had a tantrum, but you believe most other children would not have."

Participants were informed that an audio recording of the semi-structured interview would occur to assist me in later transcription. The time commitment for the semi-structured interview was approximately 60 minutes. Since the nature of the questions from this instrument could cause emotional harm, I had telephone numbers of local counselors available for participants. During the interviews, I adhered to the protocol and guidelines outlined in the data collection process, refrained from sharing personal experiences, and deleted off the record information from the analysis. Once the interview was completed, I turned the recording device off and placed the interview protocol with notes into the corresponding numbered envelope.

Step Four: Data Containment

I am the exclusive owner of the collected and analyzed data from the study. The data are kept in a locked cabinet in my home, in which only I have the key, and will be destroyed by shredding at the end of five years. Participants were informed of this during the initial recruitment and again during the informed consent.

Step Five: Protecting Participants' Identity

Participants were given a numbered code that was used in writing the findings. Given the sensitive nature of the study, numbered codes were used instead of pseudonyms. When writing the research, I did not use words that were biased against persons because of gender, sexual orientation, racial or ethnic group, disability, or age. I used the three guidelines suggested by the American Psychological Association 6th edition (2013) and presented unbiased language at the level of specificity, used language that was sensitive to labels, and acknowledged the participant in the study.

Step Six: Truthfulness of Data Reporting

I did not suppress, falsify, or invent findings to meet my needs or the needs of the audience. I anticipated the repercussions of conducting research with parents who had children with a diagnosis of ASD. I did not misuse the results to the advantage of any group.

Step Seven: Responsible Dissemination

When disseminating, I released the details of the research with the qualitative study design so readers could determine the credibility of the study for themselves. The research was released to members of the support group and with permission, posted on

the autism group's website. The information released to the support group and on the website was written in the form of a reader-friendly narrative brochure. The information was disseminated to school districts in the form of a traditional research report.

Role of Researcher

My role as a researcher remained the same before and after data collection and analysis, as a special education professional in which I serviced children with disabilities and their families. Currently, I am on an educational sabbatical. Most recently, I coordinated preschool special education services for children and their families in a county adjacent to the county in which I lived and in which research was conducted. I had direct contact with parents who had children with a diagnosis of ASD when serving as the district representative who conducted the suspected disabilities meetings, IEP meetings, and liaison to parents who needed added support for their children newly diagnosed with ASD. Although I held this position in a different county from the county in which I conducted research, the special education rules, programming, and services were the same in both counties.

My prior experience with parents, who had children with ASD, in the county in which I conducted research, was when I was an early childhood intervention specialist, teaching preschool children with disabilities. I had experienced instances in which parents of children with ASD were overly stressed by situations that related to the lack of understanding by educational professionals, employers, and medical personnel. My compassion for parents of children with ASD and my desire to help others in my

community to understand the most stressful situations needing the most immediate assistance has prompted my interest in creating positive social change.

Data collection was not affected by my most recent position because my parental relationships were not applicable since they occurred outside of the research site. Data collection within the research site was not duly affected because my experiences interacting with parents who had children with ASD coupled with my professional experiences of how to conduct non-judgmental and unbiased meetings with parents allowed me to remove my personal biases and assumptions when conducting data collection.

Criteria for Participant Selection

Setting and Sample

This study used a purposeful sampling frame to obtain participants. The sample size for this study consisted of 10 parents who were raising a child with ASD in a low socioeconomic rural Ohio area. A small sample size was chosen for this descriptive case study because the population to be studied was rare and sensitive. A small sample size was permissible when using the case study design approach (Yin, 2014). By using a sample size, there will be a broad enough sample for diversity in answers and the parents will be allowed an opportunity to reply and explain in sufficient depth during the semi-structured interview (Yin, 2014).

Participants

Participants for this study were parents of a child with a diagnosis of ASD. Participants were voluntarily recruited from the autism support group located within the

research area. The inclusion and exclusion criteria for participation in the study were as follows:

Inclusion criteria.

- The participant could be single, married, divorced, or a cohabitating parent of a child with a diagnosis of ASD.
- The participants' child needed to be between the ages of 3-18 and attend one of the 10 school districts within the research site area.
- The participant needed to have lived within the research site area for a minimum of five years.
- The participants' child with the diagnosis of ASD needed to have lived in the same home as the parent for a minimum of 3 years and needed to be between the ages of 3-18.
- The parent must accommodate two separate meetings for data collection.

Exclusion criteria.

The participants must:

- have had a child with a current diagnosis of ASD not be in the process of being diagnosed, and the child must not have had a diagnosis of additional disabilities and
- only have one child with a confirmed diagnosis of ASD living in the home.

Data Collection Procedures

Data collection occurred face-to-face with purposefully selected volunteers from the local autism support group within the research site area over a period of two separate

meetings. The data collection site was a mutually agreed upon location that was most convenient for the participant. When deciding upon the mutually agreed upon location, the participant was asked to consider a location that was free from distractions and had limited noise, as the semi-structured interview was audio recorded. At this first meeting, the consent forms were signed prior to collecting data. The steps to ensure the ethical protection of the participant outlined earlier in this section were implemented, and consent and confidentiality forms were signed prior to any data being collected.

During the first meeting, the consent and confidentiality forms were signed. Then the quantitative data were collected using the Parental Stress Index-Short Form (PSI-SF) instrument. Participants read statements and circled values from 1 to 5, with 5 being the most stressful, indicating how stressful the statement's content was for that participant. The time commitment for the first data collection meeting was approximately 30 minutes.

During the second meeting, the qualitative data were collected using the semi-structured interview consisting of the same interview questions for every participant and follow-up questions for clarity of the interview questions. The interviews were audio recorded. The time commitment for the second data collection meeting was approximately 60 minutes.

Parental Stress Index-Short Form

The PSI-SF is a self-reported Likert scale that measures origin and types of stress directly related to the parenting role (Abidin, 1995). The PSI-SF is the abbreviated version of the full-length PSI. The PSI-SF consists of 36 statements. Parents respond to each statement using a five-point Likert-type scale to indicate the level of stress for each

stressor (Abidin, 1995). The scale selections include strongly agree (5 = SA), agree (4 = A), not sure (3 = NS), disagree (2 = D), and strongly disagree (1 = SD). The PSI-SF is divided into three subscales: (a) parental distress, (b) parent-child dysfunctional interaction, and (c) difficult child (see Table 2).

According to Haskett (2006), internal consistency reliability for the composite total stress instrument was reported by the author as .91. Stability of the instrument was assessed by test-retest after a six-month interval and yielded an alpha of .84 for the total stress (p. 673). The PSI-SF has been validated by independent research efforts.

The coefficient alpha reliability is based on the normative sample range of .78 to .88 for the child domain subscales and .75 to .87 for the parent domain subscales. The reliability coefficients of the two domains (each with three subscales) and the total stress scale were .96 or greater, indicating a high degree of internal consistency for these measures. Test-retest reliability coefficients, obtained through several studies, ranged from .55 to .82 for the child domain, from .69 to .91 for the parent domain and from .65 to .96 for the total stress score. Validity has been investigated in studies that focus on at-risk children, attachment, ADHD, child abuse, forensic contexts, medical treatment adherence, substance abuse, parental depression, and others. The estimated length of time to complete the PSI-SF is 15 minutes.

The Ohio Help Me Grow, PSI-SF Guidance Document (2013) summarizes the PSI-SF processes needed to complete the instrument and score calculation. This tool takes approximately 10-15 minutes to complete and is written at a fifth-grade reading level. I provided the parent with one PSI-SF item booklet and a pen with which to write. I

explained that they should circle their ratings for each item. If they changed their mind, they Xed their first circle and circled their chosen response number.

According to the handbook for the survey, one is to calculate raw scores first. To calculate each subscale, I summed the responses for that subscale. For example, for subscale parental distress, I totaled scores for items 1-12 and entered the total in the box labeled "PD." For the subscale parent-child dysfunctional interaction, I totaled scores for items 13-24 and entered the total in the box labeled "P-CDI." For the subscale difficult child, I totaled scores for items 25-36 and entered the total in the box labeled "DC" for difficult child.

The three raw scores for the three subdomains (a) parental distress, (b) parent-child dysfunctional interaction, and (c) difficult child were each separately transformed into T-scores on a scale of 0-100 with a mean of 50. The survey PSI-SF instruction booklet includes a T-score conversion table to use. The conversion to the T-score table is located in Appendix E of this dissertation.

The T-scores standardize the raw scores and make possible meaningful, comparable means of all participant scores for each subscale. Therefore, all of the participants' T-scores for the difficult child subdomains were summed and divided by the number of participants—10. This was done for each of the three subdomains, so there was a standardized average T-score that was used to indicate which subdomains were more or less stressful for this sample of participants. These subdomain average T-scores were used to determine how much emphasis to place on each subdomain while writing the qualitative interview questions. For example, if the difficult child subdomain had an

average T-score of 98 while the other two subdomains were 40 and 50 respectively, then the interview focused heavily on the difficult child domain. In contrast, if all three subdomains were 77, 78, 74, then the interview focused equally on all three subdomains.

To make further use of these data to inform the construction of the interviews, the analysis also examined the items themselves within each subdomain. I used data tables (Appendix C) to determine the mean by averaging participants' raw ratings for each item and the mode counting the most common responses for each item. Thus, for each item, the data analyses reported the mode and the mean. The items that were stressful for most of the group determined when an item should be included in the interview questions. This was so that the interview questions were about the most stressful items for the most number of people in the group.

Semi–Structured Interview

The interview questions were identical for all participants and consisted of approximately six to eight questions based on the survey results. For example, if the Difficult Child group T-score was 86 and the others were 65 and 77, it would be logical to say that 86 gets three questions, 77, two questions, and 65 gets one question for a total of 6 questions. In contrast, if they were all fairly equal; such as 78, 75, 75; there might only be 6 questions; 2 each. These six would be the main questions that were written and asked of everyone.

The follow-up questions occurred at the time of the interview, were based on the individual responses of each participant, and were written into the protocol at the time of the interview. For example, if one of the interview questions was: "Why do you believe

your child loves you less than your other children?" then a follow-up question could be "So, you said you believe your child does not hug you enough. Tell me more about that." At this time, I also used clarifying questions as a way to validate the information I was receiving from parents. I tested my interpretations of the parent's response by repeating his or her response in my own words to him or her to clarify (Creswell, 2013). For example, "So, what I hear you saying is that your child hugs his brother, his teacher, and grandma. So, how do you react?" Alternatively, I could ask for confirmation that I was correct by saying, "So when he refuses to hug you it makes you sad after all the effort you put into helping him. Is that right?"

The primary interview questions were memorized to minimize losing eye contact with the interviewee, which could help to maintain rapport with the participant. While I based my analysis on the audiotape and paid attention to the participant as much as possible, at the beginning of each interview, I informed the participant that I would also be taking notes during the interview session. In particular, I made notes about participants' responses that I wanted to ask follow-up questions or when I needed some clarification. Once the data collection process was complete, I thanked the participant for taking part in the study and offered a copy of his or her results and a copy of the overall research results once the research was completed.

Data Analysis Plan

The data collected for this study were analyzed on two levels. The first level of analysis was for the quantitative data collected using the 36-item self-report instrument, the PSI-SF (Abidin, 1995). The second level of analysis was the qualitative data collected

from the audio-recorded semi-structured interview. The analysis of the PSI-SF data occurred after the first meeting with participants, and the analysis of the semi-structured interview occurred after the second meeting with participants.

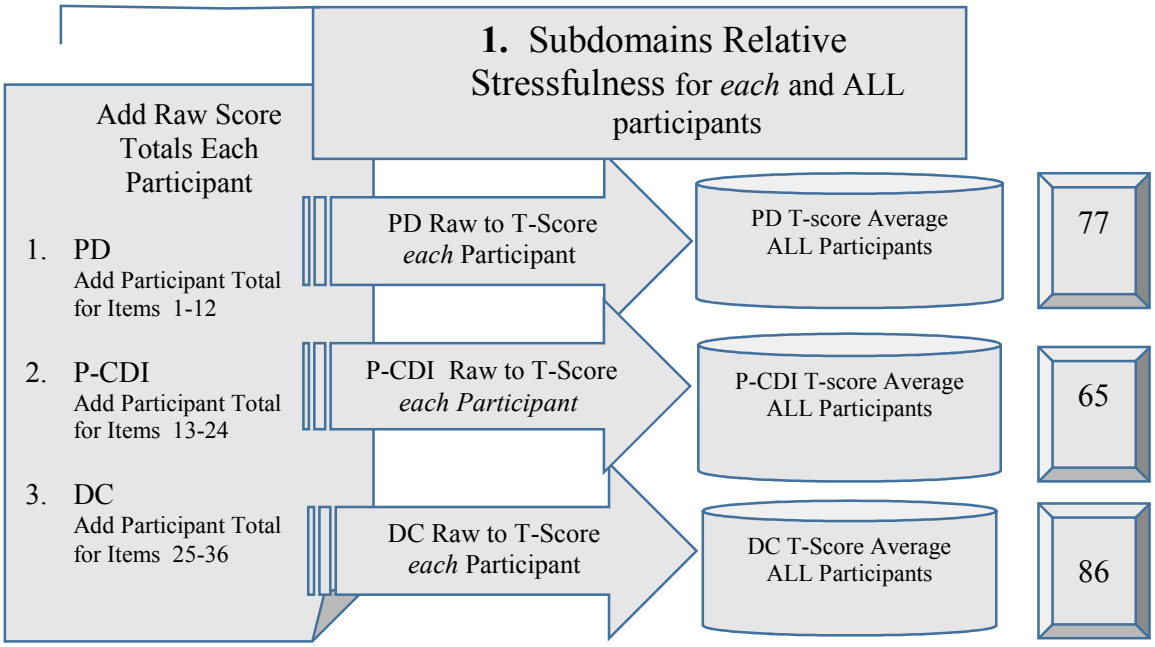
Descriptive Statistics Analysis

Using the illustration in Figure 1, I explained the two sub-steps within the process of data analyses for the survey data. The data calculated from the PSI-SF data were to inform the interview questions. That is, the most stressful subdomains and the most stressful items for this sample of participants were used in the actual interview questions.

The process was depicted in Figure 1 as subdomain analysis (labeled Step 1) and item analyses (labeled Step 2). In Step 1, each participant's data were totaled as a raw score. Then the raw score was converted to a T-score using the conversion table in Appendix E. As in the example, if for the Difficult Child subdomain a participant's raw score in the DC column of the table was 53, his or her T-score column value would be 80, and these would be entered into the bottom rows of tables in Appendix E. When all participants T-scores are in the bottom row of the Difficult Child subdomain data table, the mean would be calculated and entered into the bottom right-hand corner box with bold around it. In the example in Figure 1, the Difficult Child subdomain has a T-score of 86. As the mean is 50 for a T-score, this 86 would indicate a significant amount of stress for the sample parents in the subdomain of Difficult Child, and indeed is the area of greatest stress in the example in Figure 1.

The Difficult Child subdomain then was the area where more of the interview questions originated. As such, I moved to Step 2 of item analysis to determine which

items should be in the interview because they were most stressful for the most number of people. In the data tables in Appendix E all rating data were organized in a frequency table by item and participant. The mean and mode for each item's raw score were calculated to indicate the most stressful items (mean) for most of the participants (mode).



DC Questions 25-36	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Mode	Mean.
My child seems to cry or fuss more than other children.	1	2	2	2	2	2	5	5	5	5	2	3.1
My child generally wakes up in a bad mood.	5	5	5	5	5	5	5	4	4	5	5	4.8
I feel that my child is moody and easily upset.	5	5	5	5	0	0	5	5	0	0	5	3.5

Figure 1. Path of the data analysis process.

The means were considered first, and the five highest were given consideration for the interview. The number five was relative to the six to eight questions possible on the semi-structured interview. Any subdomain could not have more than three questions, but considering the top five allowed the researcher some flexibility, as well as the

opportunity to combine aspects of multiple questions. After the first five means were identified, within those five, the modes of four or five were considered to ensure that the most common answers were also the most stressful. Finally, the frequency tables were also referred to when making final decisions about questions, as in the first example in the table, a mode of one can sometimes have the remaining scores, as a five might not be a low score for four of the six participants indicating it might be important for the interviews. In general, the highest means and modes were chosen. Final decisions were made based on relative differences in the T-score means; 92, 55, 60 would need to be assigned different numbers of questions from each scale such as 6 questions, 2 questions, and 2 questions.

Semi-Structured Interview

The second instrument that was used in this study to collect qualitative data was a semi-structured interview. The interview was administered in the second meeting with the participants and was audio recorded for easier transcription later. The interview questions were determined and generated prior to the second meeting based on the participant scores on the three subdomains of the PSI-SF.

Once all scores were collected, totaled, and averaged, I compared the results of the PSI-SF domains in terms of the severity of stress averages. Once compared, I used the data to generate interview questions based on which items in each subscale showed the highest stress by participants. For example if “difficult child” had an average score for all participants of 1.9 of 2 while the other two subdomains were 1.1 and .2, it would show

me that “difficult child” was the most stressful for these participants. Thus, I would place the most emphasis on “difficult child” questions.

To follow with the example above, if “difficult child” was the most stressful for the parents, then I developed questions in that subscale. For example, if for item 30 in “difficult child” there were frequencies of seven two-scores and three one-scores for the item, then it would be part of the questions for the semi-structured interview. If all participants had an issue with that item, and seven of them had severe stress with that item, it should be included in the semi-structured interview questions.

Qualitative Analysis

The analyses of the qualitative data collected from the audiotaped semi-structured interview were included using information from the data and a reflexive journal to complete thematic analysis. Thematic analysis for the semi-structured interview consisted of the following steps.

Step One: Organizing

I organized and prepared my data by transcribing the audio-recorded semi-structured interview into a word-for-word narrative text. I also summarized any notes pertaining to the participants’ responses to the interview protocols that were written during the interview. Once data were transcribed into a Microsoft Word document, each participant’s analysis was placed in a digital folder that corresponded with an assigned corresponding number. For example, Joe was assigned the number 404. Therefore, his folder was named 404 and his protocol, interview transcription, and all related documents such as notes or coding schemes were included in this folder.

Step Two: Reading and Reflecting

I read all of the narrative texts to gain a general sense of the information and to reflect on the overall meaning while focusing on participants' general ideas, the tone of their ideas, and general impression of their overall depth. I made notes in the margins including reflexive notes and memos as I reviewed the information. I was not thinking about the substance of the information but its underlying meaning as a way to begin the initial sorting process.

Step Three: Identifying and Coding with Types of Topic Clusters

After reading several cases, I wrote a list of possible topics that were similar from each case to develop clusters. Clusters were labeled "major topics," "unique topics," and "outliers." I took my list of topics and created code abbreviations. For example, I put these codes next to the applicable segments of the text, such as, "Mdown" next to text in which parents described their child having a "meltdown behavior." As I initially coded the data, I determined whether new categories emerged and if so, I added them to my working list.

Step Four: Review and Refine Coding

Once I had a completed list of coded categories, I reviewed my existing categories and began to reduce my total list by finding the most descriptive word per category. For example, I might have reviewed "meltdown," "screaming" and "losing it" and changed them all to "tantruming" as a more descriptive word. Once reduced, I classified them into major codes and decided upon the final abbreviated choice, such as CMAB (child

maladaptive behavior). When necessary, I reviewed my codes and recoded my existing data as a way to refine categories.

Step Five: Generate Codes

I repeated steps 1-4 for each participant's interview to generate codes (Denzin & Lincoln, 2005). Every participant had a unique set of circumstances that required coding him or her individually section-by-section one person at a time. Pragmatically, this process helped me keep each individual participant clear in my mind and not begin to confuse them as I might if I coded all of question 1, then all of question 2, and so on. Codes were compared across participants to uncover commonalities and the variety of stressors that parents demonstrated.

The procedure I used for dealing with discrepant cases in analysis was based on suggestions by Freeman et al. (2007). When reviewing codes, I conducted a systematic search of all data to determine if any codes were misapplied to a section of the interview. If a code was misapplied, I considered it a discrepant case. I considered the information in the larger analysis to describe the pattern better, to find any other discrepant cases, and to decide what to do to resolve the discrepancy. Options included simply removing the case from the coded list, generating a new code if it was significant enough to warrant it, or revising the original code to include the discrepant case. These decisions were noted, shared, and reviewed by my methodologist to improve credibility. This was also when I did peer debriefing as discussed below.

Step Six: Recode

I used the coding scheme developed in the above five sections to recode clean versions of the transcripts one participant at a time. I reported the coding scheme in the results in terms of how many instances codes from the existing coding scheme were applied and how many times the coding scheme needed to be changed. The final coding scheme was included in the results.

Validity

Yin (2014) stated that a qualitative case study should be subjected to the same four tests of validity: construct validity, internal validity, external validity, and reliability. Each of these measures should be applied throughout the design, data collection, and data analysis of the case study. Yin claimed that the quality of the case study would be enhanced, and the weaknesses of the study diminished because of validity.

Construct validity is an assessment of how well ideas and theories are transferred into actual measures (Yin, 2014). Construct validity determines if the theoretical concept matched to the measurement instrument is important to have construct validity because when talking about theory, the words used are representative of concepts (Yin, 2014). The construct validity of this study consists of the theoretical concept of family systems theory (Bowen, 1979), which matches the PSI-SF and semi-structured interviews. An additional strategy that used to enhance construct validity was the linking of the research questions to the PSI-SF and a semi-structured interview. The strategy to enhance internal validity for this study was data triangulation. This study was triangulated using the PSI-SF, the semi-structured interview, and a peer debriefer. Creswell (2013) supported

triangulation by stating that when qualitative researchers locate evidence to document a code or theme in different sources of data, they are triangulating information and improving the validity of their findings.

Peer debriefing occurred at the end of step five, generating codes. As the researcher, I provided two interview transcripts and my coding scheme to my peer debriefer to review before we met. The interviews were free of any identifying markers, including redacting interview transcripts that included any identifying marks. At the meeting, I explained each of my codes with the debriefer, and he indicated the code's clarity, fit with the data he reviewed, and any suggestions for change to the code. The peer debriefer was someone who the researcher knew, was a special education professional with expertise in ASD, and had engaged in qualitative research as part of a master's thesis or doctoral dissertation. The resulting coding scheme was reported in the results.

After the peer debriefer session, I applied the codes once more to clean interviews and then counted how many were mismatched. The final test for a study suggested by Yin (2014) is reliability. This demonstrated how reliable my coding scheme was, that is, how often a section of data would be coded the same way if the analyses were done again. To improve the reliability of my coding, I determined the best code for the mismatches, thus, improved the reliability and validity of the data analyses.

The reliability of the survey data was sufficient and reported earlier in this document. Also noted earlier for the semi-structured interview, to improve reliability I adhered to the strict protocol of uniform questions and follow-up questions that were

generated from the PSI-SF subdomains. To decrease the likelihood of bias during the interview, I had an interview protocol, memorized the questions, and adhered to the questions written when conducting the interview (Coleman & Briggs 2005; Yin, 2014).

Summary

Section 3 described the qualitative case study design in this study including the rationale for the design, methodology, participant descriptions, researcher's role, data collection instruments, data collection, and analysis. Also included in this section were the instruments used to gather the data from the PSI-SF and semi-structured interviews. Last, the ethical protection of participants was discussed along with the reliability and validity of the study. Section 4 describes the data and how they were collected and organized. The analyzed data are presented, and the findings discussed. Last, the reliability and validity of data in this study are addressed. Section 5 provides interpretation of the study, the conclusions that were reached from the study data, and any final recommendations for further study.

Section 4: Results

Introduction

Data Collection

Participants in the study included 10 parents of children who have a diagnosis of ASD and who lived within the low socioeconomic rural research site in Ohio. Participants were chosen using purposeful sampling. Represented in this study were single, married, divorced, and cohabitating parents of a child with a diagnosis of ASD between the ages of 3-18 who attended one of the 10 school districts within the research site and had lived within the research site for a minimum of five years. Initially, I recruited participants from the local autism support group during their monthly meeting in May of 2015. The premise of the study was discussed, and a volunteer flyer with my contact information was provided to those in attendance.

Quantitative and qualitative data were collected for this descriptive case study during two separate meetings. The first data collected were from the quantitative PSI-SF (Abidin, 1995). The generated descriptive statistics from the collected quantitative data was used as the determinant of how many and the types of questions asked during the second data collection qualitative semi-structured interview.

Data collection began the week after the presentation. It took three weeks to accomplish the first meeting with each participant. The first meeting consisted of explaining informed consent, confidentiality, number assignment to ensure anonymity, and completing the quantitative measurement tool (PSI-SF; Abidin, 1995). Participants were given exact copies of informed consent and confidentiality forms for their records.

Afterward, I answered any questions, explained what would happen during the second meeting, and engaged in trust building conversations. The third week of recruitment was an influx of parents willing to participate. Many of these participants explained they were contacting me because they had heard from another participant that I was "okay" and "could be trusted." I expected to have some difficulty since I lived in the research area and was very familiar with the cultural rules of the area; however, I was surprised at the amount of mistrust.

The quantitative data collection included participants completing the PSI-SF (Abidin), a self-reported, 36-item, Likert scale, which measures origin and types of parental stress. Participants read statements and circled values 1-5 with 5 = Strongly Agree; 4 = Agree; 3 = Not Sure; 2 = Disagree; 1 = Strongly Disagree. The PSI-SF is divided into three subdomains, and each of the 10 participants' PSI-SF scores were tabulated using the raw score to T-score conversions using a table provided with the survey materials. Also recorded were the mean and mode for each of the 36 items. Descriptive statistics were calculated in which the mean and mode for each item's raw score was calculated to indicate the most stressful items (mean) for most of the participants (mode).

Completed data were recorded in frequency tables 3, 4, and 5 by item and participant (see Appendix C). The tabulated T-score averages for each subdomain determined the most significant subdomain, thus, determining how many questions came from each subdomain. The average T-score mean was 50; therefore, any score above 50 showed significant stress. The most significant stress subdomain was Parent Distress with

a score of 77.3. The second most significant was Difficult Child with a score of 68.2. The third most significant was Parent-Child Dysfunctional Interaction with a score of 67.6. To continue with the qualitative data collection phase, I needed to determine which questions would be included in the semi-structured interviews. The determination of which questions and how many questions to be included in the interview protocol were derived using the five highest mean averages from each item per subdomain and then further determined by the mode average in terms of the 10 participants. The top five items per each subdomain and the accompanied mean on a 5 point scale and mode out of 10 participants are displayed in Table 3, Table 4, and Table 5.

Table 3

Top Five Items for the Parental Distress Subdomain

Items	Mean	Mode
I find myself giving up more of my life to meet my children's needs than I ever expected.	4.5	4 and 5
There are quite a few things that bother me about my life.	4.2	4
Having a child caused more problems than I expected in my relationship with my spouse/parenting partner	4.2	4
I am unhappy with the last purchase of clothing I made for myself.	3.9	4
Since having this child, I feel I am almost never able to do the things I like to do	3.7	4 and 5

Note. Items taken from *The Parental Stress Index-Short Form (4th ed.)*, by R. Abidin, 1995, reprinted with permission. Participant size is 10 and items were rated using a 5-point Likert scale.

Table 4

Top Five *Items for the Difficult Child Subdomain*

Items	Mean	Mode
My child reacts very strongly when something happens that my child doesn't like.	4.4	4
My child makes more demands on me than most children.	4.3	5
I found that getting my child to do something or stop doing something is: ___ harder than I expected.	4.2	4 and 5
There are some things my child does that really bothers me a lot.	4.0	4 and 5
Compared to the average child my child has a great deal of difficulty in getting used to change in schedules or changes around the house.	3.9	5

Note. Items taken from *The Parental Stress Index-Short Form (4th ed.)*, by R. Abidin, 1995, reprinted with permission. Participant size is 10 and items were rated using a 5 pint Likert scale.

Table 5

Top Five Items for the Parent-Child Dysfunctional Interaction Subdomain

Items	Mean	Mode
My child is very emotional and gets upset easily.	4.3	5
It takes a long time, and it is very hard for my child to get used to new things.	4.2	4
My child doesn't seem to learn as quickly as most children.	3.5	5
My child doesn't seem to smile as much as most children.	3.5	2
My child is unable to do as much as I expected.	3.5	2

Note. Items taken from *The Parental Stress Index-Short Form (4th ed.)*, by R. Abidin, 1995, reprinted with permission. Participant size is 10 and items were rated using a 5-point Likert scale.

The range of questions possible for the semi-structured interview was within six to eight. Any subdomain cannot have more than three questions and considering the top five items from the survey in the tables allowed flexibility and the opportunity to combine aspects of multiple questions. The numbers of questions from each scale were three from parental distress, two from difficult child, and one from parent-child dysfunctional interaction. The semi-structured interview questions are listed below and on the interview protocol (Appendix B). The six questions I created for the interview by domain are displayed in Table 6.

Table 6

Semi-Structured Interview Questions by Domain

Interview Questions	Domain
Why do you believe you find yourself giving up more of your life to meet the needs of your child?	Parental distress
How does rarely being able to do the things you like to do bother you in your life?	Parental distress
How has having a child with ASD caused more problems than you expected in your spouse/parenting partner relationships?	Parental distress
Why do you believe your child reacts very strongly when something they do not like happens, such as getting used to changes in schedules or changes around the house?	Difficult child
Why do you believe your child makes more demands on you than another child would make on their parent?	Difficult child
Why do you believe your child is very emotional and gets upset easily?	Parent-child dysfunctional interaction

Note. Questions generated based on items from the *Parental Stress Index-Short Form (4th ed.)*, R. Abidin, (1995).

The second instrument was used to collect qualitative data in the form of an individual semi-structured interview. After generating interview questions, participants were called to schedule the last data collection meeting. All 10 participant interviews were scheduled for the following week. Each interview occurred at a mutually chosen location, and it was explained the interview would be audio-recorded for later transcription. The interview consisted of asking the established questions with spontaneous follow-up questions to enhance answers or provide clarity. Although there was room in the protocol for memos or notes, I had the sense that giving my full attention to the speaker allowed them to feel more at ease, so I gave up writing notes on protocols. The participants were aware that afterward the transcriptions would be kept in a secure location to protect their privacy.

Data Recordings

Interviews were transcribed by listening to audio recordings and typing individual interviews. At the end of each transcription, accuracy was checked by listening to the recording and reading the transcription simultaneously and then the transcription was placed into an electronic file labeled with the participant's corresponding number for easier access later. I used the transcriptions to create a reflexive journal to help with the sorting and coding process of qualitative data.

Tracking Systems

The system used to keep track of data included using a personal calendar, address book, color-coded stickers on the front of each participant's numbered manila envelope, a reflexive journal, and word documents used to record data in list form, data form, or table

form. The calendar was used to keep track of the meeting schedule in which participants were identified by number. The addresses/phone numbers were recorded in the address book and identified by number. Once participants were assigned a number and corresponding manila envelope, I affixed two color-coded labels, one on the left and one on the right of each envelope. The label on the left had a handwritten checklist that included initials for the words "informed consent (IC)," "confidentiality form (CF)," and written words "PSI-SF" and "table."

After reading aloud the informed consent and obtaining initials showing that they understood informed consent, the confidentiality form was read (participants also received an exact copy). Last, I explained how to answer the items using the 5 point Likert scale and protocol for changing their answer choice, which was to "X" out the incorrect answer before circling the new response. When the process was completed, I put the participants' paperwork inside the envelope, closed the fastener, and checked the corresponding boxes to indicate they were completed.

The "table" box was checked once the participants' data were recorded on the frequency tables, added, and converted to raw T-scores. When data were recorded for all 10 participants, the descriptive analysis section was completed. To ensure all of the numbers were tabulated correctly, I used an adding machine to recheck for accuracy.

The label on the right side of the envelope included a checklist reading "semi-structured interview" and "transcription." Once the semi-structured interview was complete and the audio recording transcribed, I checked each of these boxes showing that the data collection process was complete. The use of labels during the data collection

process allowed for a visual form of tracking to ensure each part of the data collection was complete before beginning data analysis.

The audio-recorded interviews were transcribed using Microsoft Word and placed in the designated digital folder labeled as 1, 2, and so forth based on the participant's corresponding number. When all interviews were transcribed, I created a reflexive journal in which each participant's number was followed by an itemized list of a transcription presented in bullet form for easier access. The reflexive journal allowed a clear representation of participants' stressors and was organized by subdomain.

Interview answers from the first three questions were bulleted under the title Parental Distress, then the next two under Difficult Child, and the last under Parent-Child Dysfunctional Behavior categories. The reflexive journal allowed for "clean" representation of interviews leaving out any additional or stray information that was not relevant to the purpose of the study. Participants used names and identifying markers during the original transcripts, and the reflexive journal allowed the removal of these markers. Participants were referred to as "parent" and the child as "child." The reflexive journal allowed for easier and more precise qualitative coding and analysis.

Findings

The purpose of this study was to identify what stressors parents demonstrated based on their perceived stress experienced by raising a child with ASD, specifically within a low socioeconomic rural area. Using a qualitative research design, specifically a descriptive case study approach, was an ideal design because of using both quantitative and qualitative tools, which allowed for a holistic understanding of the phenomenon. The

quantitative data tool, The Parental Stress Index-SF (Abidin, 1995), yielded descriptive statistics that were used to define the severity of stress obtained from the three subdomains. The qualitative tool, a semi-structured interview in which the questions were derived from the descriptive statistics produced from the PSI-SF analysis, yielded perceptions of parental stress in the words of participants and their meanings.

Research Questions

Research questions were developed and used to guide the inquiry of this study. The findings were based on the resulting data as they directly related to the research questions. Within this section, each research question will be addressed and associated with the findings of this study.

Research Question 1

What stressors do low socioeconomic rural parents of children with ASD demonstrate as measured by the PSI?

a. parental distress subdomain and items,
b. parent-child dysfunctional interaction subdomain and items, and
c. difficult child subdomain and items.

The stressors demonstrated by low socioeconomic rural parents of children with ASD were measured by the PSI-SF. Participants answered 36 self-report items, divided into 3 subdomains, using a 5-point Likert scale. Participants read statements and circled values 1-5 with 5 = Strongly Agree; 4 = Agree; 3 = Not Sure; 2 = Disagree; 1 = Strongly Disagree. The three subdomains (i.e., parental distress, difficult child, and parent-child dysfunctional interaction) were analyzed using descriptive statistics to determine which

stress items/domains parents demonstrated most significantly. Appendix D includes frequency tables 3, 4, and 5 showing the participants' individual scoring for each PSI-SF subdomain item. The raw score means and respective T-scores for the parental distress subdomain, parent-child dysfunctional interaction, and difficult child subdomains are displayed in Table 13.

Parental distress subdomain. The parental distress subdomain was determined to be the subdomain that contained the most stressful items for participants. The average T-score mean for the PSI-SF was 50 and the parental stress subdomain received an average T-score mean of 77.3. Therefore, the parental distress subdomain was identified as the most significant cause of stress for parents. The mean average and corresponding mode of parental distress items are displayed in Table 7. The mean was averaged using the raw scores and indicated which item was most stressful overall. The mode was tabulated using the raw scores and indicated which item was most often listed as stressful for participants. The table items were listed from highest to lowest for mean averages and included the corresponding mode.

Table 7

Parental Distress Subdomain, Mean Averages, and Modes

Items	Mean	Mode
I find myself giving up more of my life to meet my children's needs than I ever expected.	4.5	4/5*
There are quite a few things that bother me about my life.	4.2	4
Having a child caused more problems than expected in my relationship with my spouse/parenting partner.	4.2	4
I am unhappy with the last purchase of clothing I made for myself.	3.9	4
Since having this child, I have unable to do new and different things.	3.7	4
I am not as interested in people as I used to be.	3.7	5
Since having a child, I feel I am almost never able to do things I like to do.	3.6	2/4/5*
I do not enjoy things I used to do.	3.5	4
I often have the feeling that I cannot handle things well.	3.4	4
I feel alone and without friends.	3.3	2
I feel trapped by my responsibility as a parent.	3.2	5
When I go to a party, I usually expect not to enjoy myself.	2.9	2

Note. Items are taken from the *Parental Stress Index-Short Form (4th ed.)*, R. Abidin (1995). Reprinted with permission. *Indicates more than one mode existed.

The parent-child dysfunctional interaction subdomain. The parent-child dysfunctional interaction subdomain was determined to be the subdomain that contained the least stressful items for participants. The parent-child dysfunctional interaction subdomain received an average T-score mean of 67.6. The mean average and corresponding mode of parent-child dysfunctional interaction items are displayed in Table 8. As with the previous subdomain, the mean was averaged using the raw scores and indicates which item was most stressful overall. The mode was tabulated using the raw scores that indicated which item was most stressful for participants. Items in the table are listed from highest to lowest mean average and include the corresponding mode.

Table 8

Parent-Child Dysfunctional Interaction Subdomain, Mean Averages, and Modes

Items	Mean	Mode
My child is very emotional and gets upset easily.	4.3	5
It takes a long time, and it is very hard for my child to get used to things.	4.2	4
My child doesn't seem to learn as quickly as most children.	3.5	5
My child doesn't seem to smile as much as most children.	3.5	2
My child is not able to do as much as I expected.	3.5	2
When I do things for my child, I get the feeling that my efforts are not appreciated very much.	3.1	2
Sometimes I feel my child does not like me and doesn't want to be close to me.	2.9	1 and 4
Sometimes my child does things that bother me just to be mean.	2.9	2
My child smiles at me less than expected.	2.8	2
My child rarely does things for me that make me feel good.	2.2	1
I feel that I am: a very good parent, a better than average parent, an average parent, a person who has some trouble being a parent, not a very good parent.	2.1	1
I expected to have closer and warmer feelings for my child than I do, and this bothers me.	2.1	1

Note. Items are taken from the *Parental Stress Index-Short Form (4th ed.)*, R. Abidin (1995). Reprinted with permission

The difficult child subdomain. The difficult child subdomain fell between the most and least stressful subdomains. The difficult child subdomain received an average T-score mean of 68.2. The mean average and corresponding mode of difficult child items are displayed in Table 9. Like the parent distress and parent-child dysfunctional interaction domains, the difficult child mean was averaged using the raw score averages to indicate which item was most stressful overall, and the mode was tabulated using the raw scores indicating items most stressful for participants. Items are listed from highest to lowest mean average and the corresponding mode.

Table 9

Difficult Child Subdomain, Mean Averages, and Modes

Items	Mean	Mode
My child reacts very strongly when something happens my child doesn't like.	4.4	4
My child makes more demands on me than most children.	4.3	5
I have found that getting my child to do something or stop doing something is: __ harder than I expected.	4.2	4 and 5
There are some things my child does that really bothers me a lot.	4	4 and 5
Compared to the average child, my child has a great deal of difficulty in getting used to changes around the house.	3.9	5
I feel my child is moody and easily upset.	3.7	4
My child's sleeping or eating schedule was much harder to establish than I expected.	3.6	4
My child's behavior is more of a problem than I expected.	3.1	4
My child seems to cry or fuss more than other children.	3	2
Think carefully and count the number of things my child does that really bothers me a lot.	2.8	3
When playing, my child doesn't often giggle or laugh.	2.3	2
My child generally wakes up in a good mood.	2.2	2

Note. Items are taken from the *Parental Stress Index-Short Form (4th ed.)*, R. Abidin (1995). Reprinted with permission

Table 10

Raw and T-scores per the PD, PCDI, and DC Subdomains

Subdomain	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
PD raw score	34	32	50	33	50	41	47	58	51	45
T-score	62	60	80	61	80	70	76	88	85	71
PDCI raw score	29	26	43	36	48	32	49	43	22	39
T-score	59	56	76	67	81	60	83	72	51	71
DC raw score	44	34	48	52	33	38	46	38	38	49
T-score	70	58	74	79	64	63	72	63	63	76

Note. P1, P2, etc. represent participant 1, participant, 2…PD = Parental Distress, PCDI = Parent Child Dysfunctional Interaction, DC = Difficult Child.

Research Question 2

How do low socioeconomic rural parents of children with ASD perceive parental stress?

a. How do low socioeconomic rural parents of children with ASD perceive their parent-child relationships?

b. How do low socioeconomic rural parents of children with ASD perceive their child's behavior?

c. What parenting difficulties do low socioeconomic parents of children with ASD experience?

Six interview questions were generated to determine how low socioeconomic rural parents of children with ASD perceived stress. Questions were developed using the three PSI-SF subdomains in which descriptive statistics determined which domain would produce what number of questions. Results determined the Parental Distress domain would produce three questions; Difficult Child Domain would produce two questions; and Parent-Child Dysfunctional Interaction would produce one question. Relative to the research question 2 sub-questions, Parental Distress is equivalent to parenting difficulties, Difficult Child is equivalent to child behavior, and Parent-Child Dysfunctional Interaction is equivalent to parent-child relationships. These equivalencies to the research question 2 subquestions are referred to as the subdomains within this section.

The main interview questions were asked of every participant, but follow-up questions were specific to the individual. Interviews were transcribed, and coding was completed using the six steps outlined in the methodology section of the proposal. Five recodes were conducted to complete the final coding scheme. The initial coding included creating a list of major topics, unique topics, and outliers. The second coding included grouping initial codes into “like” groups. The third, fourth, and fifth recoding were completed by re-reading transcripts and reviewing codes as a way to refine codes and compile the final coding scheme. A complete list of the final coding scheme, which included 26 final codes and corresponding abbreviations, are found in Appendix D. Each of the subdomains was coded using the same 26 categories. Although each subdomain

had its own variations of stress categories, it was permissible for the stress category codes to occur in more than one domain. Table 11 displays final codes and corresponding examples of the codes.

Table 11

Qualitative Coding Scheme Explanations

Code	Explanations
Maladaptive child behavior (MCB)	Tantruming, Meltdown, Aggressive Behavior (self/others)
Parental respite (PR)	Parent needs a "break" for themselves.
Increased parental response (IPR)	Parent feels they are constantly in "need" by child.
Predictable environment (PE)	Child must have a routine or scheduled environment.
Unpredictable child behavior (UCB)	Parent does not know what will "trigger" child behavior.
Parental isolation (PI)	Parent has given up their personal activities. Parents feel they cannot go anywhere or engage in relationships because of the child's needs or demands.
Perceived misbehavior-others (PM-O)	Child's ASD behavior is considered "misbehavior" by others.
Economic distress (ED)	Includes financial distress, unemployment, or threats to employment when parent has to be absent to care for child's needs.
Marital disconnection (MD)	Spouse feels distanced from each other while attending to the needs of their child. A feeling of "not getting as much time together." Includes breakdown of marriage/partnership and divorce.
Defensive spousal relationships (DSR)	Spousal relationship becomes defensive when having to address the needs of the child with ASD.
Parental explanations-others (PE-O)	Parents feel the need to explain the behavior/needs of their child to others.
Insufficient supports available (ISA)	Parent feels there are no supports in the community to assist with child's needs or the parent's needs.
Professional mistrust (PM)	Parent feels they were unable to trust the professionals diagnosing and providing services to the child/family.
Parental self-expectations (PSE)	Parent feels they are responsible for all aspects of the child including demands, needs, love, support, explanations, and handling situations all fall on their shoulders.
Unfair parent role division (UPR)	Parent feels their role is more challenging/takes on more responsibility or unfair than their spouse.
Sibling equality guilt (SEG)	Parent feels they are ignoring the sibling or not paying as much attention to their other children because of the needs or demands of their child with ASD.
Unknown behavior response techniques (UBRT)	Because of the unpredictability of behavior, parents are unsure of how to discipline or provide consequences for their child.
Inappropriate self-regulation (ISR)	Child unable self-regulate once maladaptive behavior begins or escalates.
ASD management skills (AMS)	Parent unsure or tries management of ASD behaviors on a case-by-case/day-by-day strategy.
Ineffective coping skills-parent (ICS-P)	Parent feels helpless that child is unable to control behaviors or is nonverbal or incontinent.
Ineffective coping skills-child (ICS-C)	Child responses to changes in environment or family are not appropriate.
Sensory over-stimulation behavior (SOSB)	Child's behavior is related to an excess or limitation of sensory input.
Self-guilt (SG)	Parent feels guilty when they become frustrated or angry when handling situations that involve their child with ASD. They also can feel guilty for leaving the child to do something for themselves.
Fear of child protection (FCP)	Parent has fear for the protection of their child when they are not around, including at school and daycare.
Repetitious behavior (RB)	Parent has to engage in or handle situations in which the child exhibits repetitious behavior.
Child protection (CP)	Parent wants to protect child lifelong (i.e. not putting them in a group home).

The final coding scheme and explanations were developed and the codes re-applied to individually to clean interview transcripts. Because the interview questions were developed from a specific subdomain, I was able to code clean copies of the transcripts and record which stress perception codes emerged from which subdomain. The coded stress themes were not always specific to one particular domain, and some were found within all three domains. The next sections show the stress perception codes as relevant to parent-child relationships, child behavior, and parenting difficulties subdomains.

Parent-child relationship perceptions. Parental child relationship perceptions were those in which parent-child interactions were found to be disappointing and unacceptable to the parent. The parental perception stress codes addressing parent-child relationships are displayed in table 12.

Table 12

Parent Child Relationship Stress Codes

Codes	Abbreviations
Ineffective coping skills-child	(ICP-C)
Child protection	(CP)
Inappropriate self-regulation	(ISR)
ASD management skills	(AMS)
Ineffective coping skills-parent	(ICS-P)
Predictable environment	(PE)
Unpredictable child behavior	(UCB)
Increased parental response	(IPR)
Perceived misbehavior-others	(PM-O)
Sibling equality guilt	(SEG)
Unknown behavior response tactics	(UBRT)

Note. Explanation of these codes are found in table 14.

Child behavior parental perceptions. Child behavior perceptions were contextual to parental perceptions of their child's behavioral actions and the impact on

parenting. The parental perceptions stress codes for child behavior are displayed in table 13.

Table 13

Child Behavior Stress Codes

Codes	Abbreviations
Predictable Environment	(PE)
Unpredictable Child Behavior	(UCB)
Ineffective Coping Skills-Child	(ICS-C)
ASD Management Skills	(AMS)
Maladaptive Child Behavior	(MCB)
Parental Self-Expectations	(PSE)
Ineffective Coping Skills-Parent	(ICS-P)
Repetitious Behavior	(RB)
Insufficient Supports Available	(ISA)
Professional Mistrust	(PM)
Unknown Behavior Response Techniques	(UBRT)
Inappropriate Self-Regulation	(ISA)
Child Protection	(CP)
Parent Isolation	(PI)
Economic Distress	(ED)
Parental Explanation-Others	(PE-O)
Unfair Parent Role Division	(UPRD)
Sibling Equality Guilt	(SEG)
Sensory Over-Stimulation Behavior	(SOSB)

Note. Explanations of these codes are found in table 14.

Parenting Difficulties. Parenting difficulties perceptions are those that stem from personal factors and life restrictions. The parenting difficulties perception stress codes are displayed in table 14.

Table 14

Parenting Difficulties Stress Codes

Codes	Abbreviations
Parental Response	(IPR)
Defensive Spousal Relationship	(DSR)
Parental Respite	(PR)
Parent Isolation	(PI)
ASD Management Skills	(AMS)
Marital Disconnection	(MD)
Child Protection	(CP)
Parent Self-Expectations	(PSE)
Unfair Parent Role Division	(UPRD)
Unpredictable Child Behavior	(UCB)
Parental Explanation-Others	(PE-O)
Maladaptive Child Behavior	(MCB)
Perceived Misbehavior-Others	(PM-O)
Insufficient Supports Available	(ISA)
Ineffective Coping Skills-Parent	(ICS-P)
Self-Guilt	(SG)
Professional Mistrust	(PM)
Unknown Behavior Response Tactics	(UBRT)
Inappropriate Self-Regulation	(ISR)
Ineffective Coping Skills-Child	(ICS-C)
Sensory Over Stimulation Behavior	(SOSB)
Fear of Child Protection	(FCP)
Repetitious Behavior	(RB)
Predictable Environment	(PE)
Economic Distress	(ED)
Sibling Equality Guilt	(SEG)

Note. Explanations of these codes are found in table 14.

When compared, the parenting difficulties stress perception subdomain was found to have produced the highest number of codes, 26 out of 26, whereas, the child behavior subdomain produced 19 of the 26 codes, and the parent-child relationship subdomain produces the least with 11 out of 26. This comparison of stress perception codes by subdomain shows that parents perceived more stress in parenting difficulties, followed by child behavior and lastly parent-child relationships. Table 15 displays, when compared, the common stress codes amongst all three of the stress perception subdomains, parent-child relationships, child behavior, and parenting difficulties.

Table 15

Common Stress Codes amongst Stress Perception Subdomains

Parent-Child Relationships	Child Behavior	Parenting Difficulties
Predictable Environment	X	X
ASD Management Skills	X	X
Ineffective Coping Skills-Parent	X	X
Unknown Behavior Response Tactics	X	X
Sibling Equality Guilt	X	X

Note. Explanations of stress categories are found in table 14.

Comparing the frequency of the resulting 26 stress codes is crucial to understanding which perceived stressor was determined to be the highest, middle, and lowest source of stress. The frequency table in which the stressors were applied and how frequent they occur per subdomain are displayed in Table 16.

Table 16

Frequency of Codes per Subdomain

Codes	PD	CB	PCR
Maladaptive child behavior	3	4	1
Parental respite	7	0	0
Increased parental response	9	0	1
Predictable environment	1	8	2
Unpredictable child behavior	4	6	2
Parental isolation	7	1	0
Perceived misbehavior-others	3	0	1
Economic distress	1	1	0
Marital disconnection	6	0	0
Defensive spousal relationships	8	0	0
Parental explanations-others	4	1	0
Insufficient supports available	3	2	0
Professional mistrust	2	2	0
Parental self-expectations	5	3	0
Unfair parent role division	5	1	0
Sibling equality guilt	1	1	1
Unknown behavior response tactics	2	2	1
Inappropriate self-regulation	2	2	4
ASD management skills	7	5	4
Ineffective coping skills-parent	3	3	4
Ineffective coping skills-child	2	6	10
Sensory over-stimulation behavior	2	1	2
Self-guilt	3	2	2
Fear of child protection	2	0	2
Repetitious behavior	2	3	0
Child protection	6	2	5

Note. PD = Parenting Difficulties, CB = Child Behavior, PCR = Parent-Child Relationships.

Determining the frequency of stress codes helped determine the highest, middle, and lowest forms of stress for parents within the parenting difficulties subdomain, child behavior domain, and parent-child relationships domain.

Parenting Difficulties

Some of the highest perceived stressors exhibited by parents within the parenting difficulties subdomain were increased parental response in which nine out of 10 parents exhibited, defensive spousal relationships in which eight out of 10 parents exhibited, and parental isolation in which seven out of 10 parents exhibited. Some stress sources found to be of medium stress to parents were unfair role division in which five out of 10 parents exhibited, parental self-expectations in which five out of 10 parents exhibited, and parental explanations to others in which four out of 10 parents exhibited. Lastly, some stressors found to be the lowest stress source for parents were unknown behavioral response tactics in which two out of 10 parents exhibited, and predictable environment in which one out of ten parents exhibited.

Child Behavior

Within the subdomain of child behavior, some of the highest perceived stressors exhibited by parents were a predictable environment in which eight of 10 parents exhibited, ineffective coping skills-child in which six out of 10 parents exhibited, and unpredictable child behavior in which six out of 10 parents exhibited. Some of the stress sources found to cause medium stress in parents include ASD management skills in which five out 10 parents exhibited, child maladaptive behavior in which four out of 10 parents exhibited, and parental expectations in which three of 10 parents exhibited.

Lastly, some of the stressors causing the least amount of stress were insufficient supports available in which two out of 10 parents exhibited, unfair parent role division in which one out of 10 parents exhibited, and marital disconnection in which zero out of 10 parents exhibited.

Parent-Child Relationships

The parent-child relationships subdomain had the least amount of code frequencies among the three. The highest perceived stressor was ineffective coping skills-child, and all 10 parents exhibited this stressor. The stressors that caused medium stress for parents were child behavior in which five out of 10 parents exhibited, ineffective coping skills in which four out of 10 parents exhibited. The lowest stressors exhibited by parents from this subdomain include sibling equality guilt in which one out of 10 parents exhibited, parental explanations to others, parental respite, and insufficient supports available in which zero out of 10 parents exhibited.

To determine which of the 26 stressors were considered highest stress, medium stress, and lowest stress across all three subdomains, I added the frequency of stressors (see Table 19) across all three subdomains. Stressors with a total score of 0-5 were considered low stressors, stressors with a total score of 6-10 were considered medium stressors, and stressors with a total score of 10 or higher were considered highest stressors. The lowest, medium, and highest stressors are displayed in Table 17.

Table 17.

Lowest, Medium, and Highest Stressors across Subdomains

Lowest	Medium	Highest
Economic distress	Unfair parent role division	Predictable Environment
Sibling equality guilt	Self-guilt	Unpredictable child behavior
Perceived misbehavior-others	Increased parental response	ASD management skills
Professional mistrust	Maladaptive child behavior	Ineffective coping skills-parent
Fear of child protection	Parent isolation	Ineffective coping skills-child
Repetitive behavior	Marital disconnection	Child protection
Sensory over-stimulation	Defensive spousal relationship	
Behavior	Inappropriate self-regulation	
Unknown behavior response	Parental self-explanation	
Tactics	Parent respite	
Insufficient supports available		
Parental explanation-others		

Note. Stressors totaled across three subdomains, Parental Distress, Child Behavior, and Parent-Child Relationships.

Discrepant Cases

In alignment with the qualitative analysis outlined in the methodology section of this study, a systematic search of data was conducted to identify any discrepant cases. During the search, there were two codes that were misapplied, ASD appearance bias (AAB), and absence religious service attendance (ARSA). To resolve the discrepancy I considered the information in the larger analysis to better describe the pattern and decided to revise the original code to include the discrepant cases. I included the discrepant code, ASD appearance bias, with the original code of parental explanation-others (PE-O). It fit with the original code because the larger analysis determined parents needed to explain to others why their child was exhibiting ASD-related behavior, such as meltdowns, when the child does not “look disabled.” The second misapplied code of absence of religious service attendance was included with the original code of parental isolation.

Related Stressor Themes

Several common stressor themes emerged during the development of this study, specifically during the interview process. Among the many stressors experienced by parents raising a child with ASD, four common themes emerged consistently throughout the interviews. Although the severity of child ASD symptomology varied from mild to severe, four common stressors presented as significant for the majority of participating parents. The four common stressors were parental respite, marital disconnection, child unpredictable behavior, and parent isolation. Each of these themes is addressed in this section with supporting excerpts from interview transcripts. A complete list of stressors and clearly provided explanations of each are displayed in Table 14.

Parental Respite

During the interview process of this study, the absence of parental respite was a common theme among parent participants. Parents related their stress to the inability to have time for themselves due to the needs or demands of their child. The ability to find someone to watch or "babysit" their child was the common reason the parents believed they did not have respite for themselves.

Often, the child's aggressive behaviors, unpredictable behaviors, toileting issues, excessive energy, outbursts, and parental fear for the safety of the child were the reasons given by others to the parent as reasons for not wanting to watch or "babysit" their child. Parents also stated that even family members would not watch their child for many of the reasons previously provided. Examples taken from interviews include excerpts from parents #8, #2, #5, and #4.

Parent #8:

> Basically, I cannot do anything for myself because no one wants to babysit for him. I can leave him at childcare during certain hours of the day but after those hours there is no one to watch him. No one wants to watch him. He is urinary and bowel incontinent, is nonverbal, and unless you know him very well it is really hard for people to know what his wants and needs are because they cannot read him. I am very protective. I wouldn't leave him with just anybody because his is nonverbal and he couldn't tell me if someone hurt him or is mistreating him.

Parent #2:

That has probably been the biggest thing that is "me" time. Because we really don't have a lot of that, but like I said, my mom has really been the only person who can handle my child so she does help us when she can. But we have difficulty finding babysitters. He just doesn't do well with other people, he is just uncomfortable, and we don't want to leave him in an uncomfortable situation

Parent #5:

> Not really. I mean, there are sometimes I wish I had someone to watch him for a while just so I could think and just do stuff. So I could go out and stuff but it is just one of those things. He's really attached to me, and he cries and no one wants to watch him when he cries and they think he is really wild and hyperactive.

Parent #4:

> I can't get a babysitter for him if I want to do anything. If I don't get someone to watch him like his father or someone else, then I just don't get to do it. Because

> there are things he just won't do like go to church on Sundays. There is no special needs class so he can't be around all of those people. So I feel like I am giving up some of my spiritual time because he cannot be there. Finding a sitter, it's pretty much stayed consistent (since he was little). It is harder now to find someone because he is so big. He is sixteen years old, and his body has changed, you now. When people would watch him when he was a little boy and now if it's a girl watching him he has physical reactions and you know what I mean. So it is not as easy to get someone to watch him. So yeah, it has changed a little since he has gotten older.

Many of the parent participants expressed during their interview that even if they had someone to watch their child, they would still feel uncomfortable because of the fear of someone harming their child. Hence, the fear becomes an additional stressor so parents would rather be with their child even if they sacrifice time for themselves.

Marital Breakdown/Disconnection

Another common theme among the parent participants from this study was the breakdown of their marriage relationship or a disconnection with their spouse. Parents believed that the demands of their child were so high that the relationship with their spouse becomes disconnected. Examples of marital breakdown or marital disconnections expressed during the interviews included a breakdown in spousal time shared, paternal denial of diagnosis, maternal responsibility, spousal resentment, and divorce. Examples taken from the interview transcripts included excerpts from parents #4, #9, #7, #8, #2, #5, and #3.

Parent #4:

> Well, I'm divorced. I don't think; I think for the most part there is so much denial there that his dad doesn't take him anywhere outside of the home. When he has him, he doesn't take him outside of the home anywhere, like Walmart, or the grocery store or out to eat. He will take him to a drive through and then take him home. It did cause so much stress that we did get a divorce so because he couldn't deal with the fact that his child was different.

Parent #9:

> The tension between me and my husband has caused some problems. He loses his temper a little more because he gets stressed. So sometimes I have had to tell my husband to go out of the room…walk away. You gotta go calm down cause once the child sees you lose control then you are going to cause them to rage more. My child will cry at the drop of a hat and so if dad raised his voice or looks at her wrong she is crying. It has caused me and him not to have. . . we don't get time for each other anymore like we used to. But it has caused a lot of problems between me and him. We fight more than we used to. We don't fight over financial. We don't fight over the house. We don't fight over money or the job or anything. It is always our kids.

Parent #7:

> It is difficult you know. (Husband's name) and him butts heads a lot. Ya know, I've been around a lot longer. . . . Ya know, (husband) and I have only been solidly nine years this time. The (child) is almost 17, so I've learnt how to choose

the battles easier than (husband) does and I understand (child's) quirks all the time. The (husband) don't know why because (child) is 16 and a half--why things aren't changing. The (husband) will get really frustrated, and that causes a lot of problems with us. It gets to where he wants to bust his ass and then (child) retaliates back, and it just becomes a big blow up in our house. It is like pinning him against me in the house. I mean, it brings us against each other the three of us and ya know it's hard. Like I said, about once every two months is gets real heated at our house, and it gets very very stressful here. It's like, you know, if you (husband) don't like how things are here there's the door, and I've said it more than once.

Parent #8:

I don't have a spouse or partner, and I haven't since before he was a year old. That is why we separated because I discovered he was going to be abusive toward the baby and I wasn't dealing with that. So that was the end of that relationship. Yeah, I wasn't going to put up with anyone being mean to my kid. He didn't understand anything about my child, but it is his loss.

Parent #2:

I feel that moms have maternal thing going on that dads just do not get the patience. The (husband) had a higher expectation for his son to be able to do. And I feel like I just have to remind my husband a lot that it is not a typical child. That there are some things we have to do that you can't freak out because of what he is doing and scream STOP! All that is going to do is escalate the situation. Maybe

it's because I'm with him more, but I don't know. Like I said, I think moms just have the maternal, more of a bond or understanding or patience. I don't know how to explain it, but I think that has been our hardest thing in our partnership is my frustration at his lack of patience. I think he envies the patience that I have. He's told me before that that is something he doesn't understand and something he wished he had so it makes it hard on him because he sees it too. What has probably been the biggest thing that is us time, umm, because we really don't have a lot of that.

Parent #5:

I think it has a lot of challenges like my husband when he found out (child) had autism and stuff he really didn't understand it. He was denying it and fighting me with it and didn't want to do the therapies and stuff. It was really challenging cause (husband) thought it meant (child) was stupid and that everyone would call his son stupid. He was like flipping out and saying he's not stupid, and I'd just tell him that he was just had challenges that need to be met. He also got mad at me because I baby him and stuff and I always let him do stuff and stuff like that. We always get in fights about this and that too.

Parent #3

My husband at the time, his dad, didn't want to accept that he (child) had anything wrong with him. He didn't want to have nothing to do with special needs preschool or any of the testing at Children's (hospital). He didn't go with me. He didn't accept it. The (child) would prance around that way you know how they

> walk and stuff, and he would say make him stop that! Eventually, you know he. . . we got a divorce because he wanted to punish him (child) for things he didn't understand you know, and he didn't understand at all and he hasn't seen his dad since he was 13. He's out of his life.

Many of the parents expressed how the disconnection of their marriage or relationships was due to the lack of spousal interaction. It can be ventured to say that many of the disconnections could relate to how each spouse or partner views their child and how to cope with the stressors that accompany an ASD diagnosis. Spouses who have divorced or whose relationships no longer exist tended to blame the breakdown of the relationship or divorce specifically on the other spouse or partner.

Child Unpredictable Behavior

Parents communicated during the interview that not predicting their child's behaviors or reactions to situations was a stressor that was two-fold, first, stress from not predicting their child's actions or reactions to situations and, second, parental distress when their child does not understand the parent's behavior.

Trying to decipher what triggered their child's behavior and how to react caused many parents stress, especially in how to provide a solution to the behavior or a consequence. The majority of parents expressed that dealing with behavior was a case-by-case situation, and they lived their lives a day at a time. Some expressed that they did not know what to do while others had some solutions that were used in the hopes of ending the behavior. Excerpts from parents #2 and #4 are examples of the stress parents experience when their child exhibits unpredictable behavior.

Parent #2:

> The smallest thing can send us into a meltdown, which essentially can ruin our day. So if it's stopping to put on fireman boots while I am in the middle of dishes when I would expect to say "No, just wait a minute." I have to stop and address it to avoid a total meltdown. The biggest thing with our son is the repetition. He wants you to repeat everything he does so whether it is you saying something or lining his cars up if it is putting his shoes and socks on a certain way. It's just, if you do not play into his repetition, it sends him into a spiral, and it takes a really long time to bring him down. That also causes him to be mean to his brother. Handling behavior is just one case at a time. It's sometimes just asking him to stop, sometimes it is moving him on to something else, sometimes I have to move his brother on to something else. Sometimes it's as easy as him going to his room and taking a rest. We are really big on that. . go take a rest. It is just however I can do it.

Parent #4:

> Basically, (dealing with behavior) it is a lot of hit or miss. I had to, you know, I was really a pushover when he was little. Then one day I had to say "no you're not going to act like that, because if you act like that you are going to be in time out." Or "you're going to be on your bed, or you're just going to be in trouble." I did have some advice from a pediatrician when he was seven or eight years old. She said, 'Treat him as you treat (her other child). If you are going to put her in time out, put him in time out. If you are going to spank her, then you need to

> spank him.' It seems to have really worked because, you know, he knows that he had consequences the same as she did. So it is just a little bit different but I do try to treat them the same, but it is frustrating. He has learned that when he gets angry, I mean really really angry, sometimes, I have to. . . I get up. . . I say, "You are not going to do that, and you're going to act like you got some sense." "You're going to stop smacking" and if he continues to do it, I actually put him in the shower because that calms him. So I do that, or I make him go sit on his bed, which he doesn't like. . . but I do make him do that.

Another aspect of stress experienced by the parent participants in relation to unpredictable child behavior was the distress of knowing their child could not understand the parents' reaction, which ignited unpredictable behavior from their child. Excerpts are from parents #10, #4, and #2.

Parent #10:

> I have to stay at home with him and if we go to the store, for example, the last time we took him shopping. We went to Kmart, and he picked out a video game supposedly. I mean, he recognized it was a game, but as far as X-box or Play Station he didn't recognize that and all he knew was that it was a SpongeBob video game. So I sidetracked him, gave him a video game…not a video game, a movie, because we used to buy him a five-dollar movie. Then it went from a five-dollar video to sixty dollar dinosaurs. The video game at Kmart, I sidetracked him and gave him something else, and he found it (video game) again in a different game version. I think the one he found first was Play Station. I hid that and then

he found the exact same game for the X-box same picture on it and, of course, we couldn't buy it. Of course, he started screaming from the electronics all the way to the parking lot. He screamed bloody murder and ever since then we don't take him to the store.

Parent #4

He's one of those kids who have to live by a schedule. If he does not have that schedule, he cannot function. He gets very agitated like, for instance, like when the lights go out, and his iPad is not charged, he likes to lose his mind. He can't understand why the light has went out; he can't understand why his iPad won't work. I always have to be sure to have a charger in the car and that I have an iPad, my iPad, backed up charged because he cannot function. He throws a fit. He paces. He smacks himself. He just loses his mind. Well, sometimes he hits me. I mean not as much as he did when he was little and sometimes he gets so angry that he starts hitting and pinching. Of course, that is painful but it is mainly that, you know, I see him in such distress that it is painful for me. I don't want him to have those kind of reactions, you know. It is just very difficult to watch.

Parent #2

I don't know why he does it (unpredictable behavior). I wish I did. I think the biggest question with ASD is. . . how can we alleviate this? I mean, I know why I think he does it because I see it happen. It's hard to bring him back down when he gets worked up like that. It is not a typical, okay, "just walk away and let them have their meltdown," "in a couple of minutes he will be over it." He's going to

> keep going until he gets more and more frustrated until we find a way. That's like what I said before. It could be anything. It could be talking to him. It could be hugs, and sometimes he doesn't want to be touched. Sometimes he wants to go to his bed. Sometimes he wants to be alone. So it's every day.

Parent Isolation

Parent isolation was a common stress theme for parents as relayed during the interview. Parents related that due to the high needs and challenges of a child with ASD they found themselves isolated from their family members, friends, and community. While caring for the needs and behaviors of their child, parents also have to deal with the stress of being unable to attend family gatherings or trips into the community. This leads to an overwhelming feeling of isolation. The following excerpts from interviews showed how isolation affected the parent participants.

Parent #1

> I feel like my child's life is more important than mine. I feel like I need to be there to give him guidance because he is not completely aware of things that are right or wrong. Where I am an adult, I feel like things are right there before I go on with my own my life if that makes sense? Probably (given up) some of my hobbies like singing or I used to sing different places. Giving up things like clothing or getting my nails done or getting my hair done or going out to lunch with a girlfriend. Heck, even going out for date nights with my husband.

Parent #4

> I have to do that (give up my life) because my son has autism and is nonverbal. He has to have all of my extra time. To be able to figure what he wants to eat, what he wants to do, a lot of extra stresses. With the aggression, outbursts and the pacing, we are not able to do a lot of the things normal families go and do. So it's a little more, so it's a lot more stressful to live in his world, basically.

Parent #7

> We didn't go anywhere, no family, no relatives. It was his behavior people didn't understand. They would say if you just bust his ass once and a while things wouldn't be like that. It was, always, you know, you are going to let him sit in the car—are you serious? And I am like, yeah, I am so serious cause I am so not fighting that fight, ya know. There were things I'd fight and things I wouldn't. I choose the battles, and ya know, he has always been closed door. He doesn't like people. He doesn't like going places. He doesn't like Walmart, I mean, doesn't like to go to restaurants.

The feelings of isolation for parents of children with ASD span many different facets of their lives. Many things parents of typical children take for granted such as going to Walmart or being able to have their hair and nails done can seem like an impossibility for parents of children with ASD. The inability to do minor activities outside of their homes creates isolation which can contribute to other areas of stress in their lives.

Evidence of Quality

The evidence of quality for this study was adhered to by following the outlined data collection and analysis procedures as described in Section 3, the methodology. Further evidence of quality was measured using data triangulation, as suggested by Yin (2014) in which the quantitative data, qualitative data, and a peer debriefer were used to ensure validity and reliability of this study. The data collection and analysis of the quantitative and qualitative data were presented in Section 4.

To complete the triangulation, a peer debriefer was contacted and established. The peer debriefer was provided with two transcripts free of any identifying markers and a copy of the final coding scale with explanations, which are displayed in Table 1. The transcripts are divided by subdomain in which questions 1-3 are reflective of the PSI-SF subdomain of Parental Distress, questions 3 and 4 are relative to the Difficult Child subdomain and question 6 is relative to Parent-Child Dysfunctional Interaction. A meeting was scheduled to discuss the debriefing session further. During the meeting, the codes were explained, including the clarity and the fit with the data to be reviewed. The peer debriefer did not offer any changes to the existing coding schemes and determined them to be appropriate. After the peer debriefing session, I applied the codes once again to clean interviews and then made a comparison to the transcripts coded by the peer debriefer. Since the peer debriefer did not have any suggestions for changing the codes, I looked for sections of the coding for differences in coding. When comparing the transcript coded by the peer debriefer to the transcript I coded, there were minor coding differences. When the transcripts were compared side by side, the peer debriefer chose to

include four more codes to his transcription than I did. When my transcript was compared to his transcript, I used one specific code he did not use in his transcription. A representation of the coding comparison for transcript one is displayed in Table 18. Transcript two was coded using the same transcription process as transcript one. When transcription was compared side by side, the peer debriefer used four codes I did not use when I transcribed, and I used three transcription codes that were not used by the peer debriefer. The representation of the coding comparison for transcript two is displayed in Table 19.

Table 21

Peer Debriefer/Researcher Comparison Results—Transcript One

Subdomain	Peer Debriefer Codes	Researcher Code
Parental distress	MCB	MCB
	IPR	IPR
	UBRT	**
	SOSB	SOSB
	UCB	**
	AMS	AMS
	PR	PR
	DSR	DSR
	RB	RB
	UD	UD
	PSE	PSE
Difficult child	ISA	ISA
	UBRT	UBRT
	ICS-P	**
	IPR	IPR
	MD	MD
	AMS	AMS
	SEG	SEG
	UCB	UCB
	**	PM
Parent-child	ICS-C	**
Dysfunctional interaction	SOSB	SOSB
	RB	RB
	PE	PE

Note: ** reflects a code not used by the peer debrifer or researcher once transcripts were compared.

Table 19

Peer Debriefer/Researcher Comparison Results—Transcript Two

Subdomain	Peer Debriefer Codes	Researcher Code
Parental Distress	PR	PR
	PI	PI
	SG	SG
	PSE	PSE
	SOSB	SOSB
	UCB	UCB
	ED	**
	ICS-P	ICS-P
	FCP	**
	PM	PM
	DSR	DSR
	MD	MD
	**	UPRD
	**	PE-O
	CP	CP
Difficult child	PE	PE
	PR	PR
	UCB	**
	PI	PI
	**	UBRT
Parent-child	ICS-C	ICS-C
Dysfunctional interaction	AMS	AMS
	FCP	FCP
	SEG	SEG
	PE-O	**

Note: **Reflects a code not used by the peer debriefer or researcher once transcripts were compared.

Section 5: Discussions, Conclusions, and Recommendations

Overview

There is a lack of understanding by educational professionals regarding the stress parents experience when raising a child with a diagnosis of ASD in a low socioeconomic rural area (Boyd & Shaw, 2010). Low socioeconomic rural parents of children with a diagnosis of autism spectrum disorder experience significantly higher stress levels based on their stress perceptions of parent-child behaviors, child behaviors, and parent distress (Abbeduto et al., 2004; Hays & Watson, 2013; Woodgate, Ateah, & Secco, 2008).

The purpose of this study was to identify what stressors low socioeconomic rural parents demonstrate based on their perceived stress experienced by raising a child with ASD. I sought to gain knowledge and firsthand information from parents regarding perceived stressors experienced when raising a child with ASD. Therefore, I focused on finding the stressors they demonstrated, the severity of the stressors, and their perceptions of parental stress in relation to parent-child relationships, child behavior, and parenting difficulties.

To obtain evidence of the stressors a bounded descriptive case study using purposeful sampling was conducted. Participants were recruited from the Autism Project of Southern Ohio, autism support group in the research area. The data collection was face-to-face and occurred over two separate meetings. The first meeting consisted of obtaining data using the quantitative measurement instrument, The Parental Stress Index-Short Form. The second meeting consisted of gathering qualitative data using a semi-structured interview.

Parents provided evidence of which stressors they demonstrated based on their perceived stress when raising a child with ASD, specifically within a low socioeconomic rural area. The evidence consisted of 26 different stressors that parents demonstrated based on their parental stress perceptions. The stressors were relative to the three subdomains of parenting difficulties, child behavior, and parent-child interactions. The 26 stressors are identified and explanations provided in Table 11. For educators to understand the severity of the stressors in addition to the types of stressors experienced by parents raising a child with ASD, a list of the 26 demonstrated stressors and their severity, high, medium, or low, as reported by parents are displayed in Table 20.

Table 20

Demonstrated Stressors and Level of Severity

Stressor	High	Medium	Low
Maladaptive child behavior		X	
Parental respite		X	
Increased parental response		X	
Predictable environment	X		
Unpredictable child behavior	X		
Parental isolation		X	
Perceived misbehavior-others			X
Economic distress			X
Marital disconnection		X	
Defensive spousal relationships		X	
Parental explanations-others			X
Insufficient supports available			X
Professional mistrust			X
Parental self-expectations		X	
Unfair parent role division		X	
Sibling equality guilt			X
Unknown behavior response tactics			X
Inappropriate self-regulation		X	
ASD management skills	X		
Ineffective coping skills-parent	X		
Ineffective coping skills-child	X		
Sensory over-stimulation behavior			X
Self-guilt		X	
Fear of child protection			X
Repetitious behavior			X
Child protection		X	

Essentially, educators strive to provide the most appropriate education for all children including appropriate services and resources to parents (Myers, Plauche-Johnson, 2007). Therefore, the outcome of this study showed how stress impacts parents of children with ASD, specifically the stressors demonstrated by parents based on their stress perceptions. Parents who participated in this study said, in summary, their children needed to have additional supports from school to help lessen the stress experienced by parents due to the limited support resources within the community.

Interpretation of Findings

Research Question 1

What stressors do low socioeconomic rural parents of children with ASD demonstrate as measured by the PSI?

a. parental distress subdomain and items,

b. parent-child dysfunctional interaction subdomain and items, and

c. difficult child subdomain and items.

The PSI-SF measurement tool was key to finding the significance of parental stress and how stress was demonstrated to parents. The PSI-SF divides 36 items into three subdomains each containing 12 items (Abidin, 1995). Participants scored each item using a Likert scale with 5 = Strongly Agree; 4 = Agree; 3 = Not Sure; 2 = Disagree; 1 = Strongly Disagree. After initial recruitment of participants, which occurred on May 9, 2015, a challenge related to the theoretical framework for this study occurred.

Although several parents expressed interest in participating in the study, they did not follow through. I had anticipated this due to the cultural norms of a low socioeconomic rural Appalachian area. The theoretical framework for this study, family systems theory (Bowen, 1979), supported my anticipation in which allowing a "stranger" into the participant's cultural ideology of privacy, mistrust of others, and family allegiance could affect the functionality of the family system. Although 10 participants were needed to conduct the study, it took 3 weeks to recruit 10 participants willing to schedule the first meeting.

The stressors that socioeconomic rural parents with ASD experience was determined by subdomain and individual items within that subdomain. Findings from the PSI-SF show that of the three subdomains, Parental Distress was the highest subdomain for stress followed by Difficult Child and last, Parent-Child Dysfunctional Interaction.

Items from the PSI-SF are rated by a 5-point Likert scale, in which, 5 = Strongly Agree; 4 = Agree; 3 = Not Sure; 2 = Disagree; 1 = Strongly Disagree. Items that show a rating of three or higher on the scale show the most stress for the sample. Items within each subdomain that received a rating of 3 or higher are displayed in tables 21, 22, and 23.

Table 21

Parental Distress Items Rated by Parents with a 3, 4, or 5

Item	3	4	5
I often have the feeling that I cannot handle things well.	0	4	2
I find myself giving up more of my life to meet my children's needs than I ever expected.	0	5	4
I feel trapped by my responsibility as a parent.	0	1	4
Since having this child, I have been unable to do new and different things.	0	4	3
Since having a child, I feel I am almost never able to do the things I like to do.	1	3	3
I am unhappy with the last purchase of clothing I made for myself.	1	3	4
There are quite a few things that that bother me about my life.	0	3	4
Having a child caused more problems than I expected in my relationship with my spouse/parenting partner.	1	6	3
I feel alone and without friends.	0	2	3
When I go to a party, I usually expect not to enjoy myself.	1	2	2
I am not as interested in people as I used to be.	1	2	5
I do not enjoy things I used to.	0	5	2

Note. Ratings are from 10 participants. A rating of 5 = strongly agree, 4 = agree and 3 = not sure.

The rating of items with a score of 3 showed that the item could or could not have caused stress to the parent. The rating of a 4 showed that the item caused stress for the parent. The rating of an item with 5 showed that the item caused significant stress for the parent. Complete ratings per item and raw score to T-score conversions for this subdomain are found in Appendix D. The T-score for the overall subdomain was 77.3

which showed the Parental Distress subdomain contained the most significant stress items.

Based on the scoring of the Parental Distress subdomain, the first three questions for the semi-structured interview were developed and generated. The three questions generated were:

1. Why do you believe you find yourself giving up more of your life to meet the needs of your child?
2. How does rarely being able to do the things you like to do bother you in your life?
3. How has having a child with ASD caused more problems than you expected in your spouse/parenting partner relationships?

Table 22

Parent-Child Dysfunctional Interaction Items Rated by Parents with 3, 4, 5

Item	3	4	5
My child rarely does things for me that make me feel good.	0	1	1
When I do things for my child, I get the feeling that my efforts are not appreciated very much.	0	1	3
My child smiles at me much less than I expected.	0	2	1
Sometimes I feel my child does not like me and doesn't want to be close to me.	0	3	2
My child is very emotional and gets upset easily.	0	2	4
My child doesn't seem to learn as quickly as most children.	0	2	4
My child doesn't seem to smile as much as most children.	0		3
My child is not able to do as much as I expected	1		3
It takes a long time, and it is very hard for my child to get used to new things.	0		4
I feel that I am: a very good parent, a better than average parent, an average parent, a person who has some trouble being a parent, not very good at being a parent.	1		1
I expected to have closer and warmer feelings for my child than I do, and this bothers me.	0	2	0
Sometimes my child does things that bother me just to be mean.	1	2	2

Note. Ratings are from 10 participants. A rating of 5 = strongly agree, 4 = agree and 3 = not sure.

The rating of items with a score of 3 showed that the item could or could not have caused stress to the parent. The rating of a 4 showed that the item caused stress for the

parent. The rating of an item with 5 showed that the item caused significant stress for the parent. Complete ratings per item and raw score to T-score conversions for this subdomain are found in Appendix D. The T-score for the overall Parent-Child Dysfunctional Interaction subdomain was 67.6, which means this subdomain item caused the least stress for parents, therefore, it was the least significant for the stress of all three subdomains.

Because this subdomain showed the fewest stress items, only one question was taken from this subdomain for the interview and was the last question asked during the interview. Why do you believe your child is very emotional and gets upset easily?

Table 23

Difficult Child Items Rated by Parents with 3, 4, 5

Items	3	4	5
My child seems to cry or fuss more than other children.	1	2	2
My child generally wakes up in a bad mood.	0	1	0
I feel that my child is moody and easily upset.	0	6	2
Compared to the average child, my child has a great deal of difficulty in getting use to change in schedules or changes around the house.	0	2	5
My child reacts very strongly when something happens my child doesn't like.	0	6	4
When playing, my child doesn't often giggle or laugh.	0	3	1
My child's sleeping or eating schedule was much harder to establish than I expected.	2	5	2
I have found that getting my child to something or stop doing something is: much harder than I expected, somewhat harder than I expected, about as hard as I expected, somewhat easier than I expected, much easier than I expected.	5	4	4
Think carefully and count the number of things which your child does that bothers you.	0	0	2
There are some things my child does that really bothers me a lot.	1	4	4
My child's behavior is more of a problem than I expected.	2	4	2
My child makes more demands on me than most children.	2	3	5

Note. Ratings are from 10 participants. A rating of 5 = strongly agree, 4 = agree and 3 = not sure

The rating of items with a score of 3 showed that the item could or could not have caused stress to the parent. The rating of a 4 showed that the item caused stress for the parent. The rating of an item with 5 showed that the item caused significant stress for the parent. Complete ratings per item and raw score to T-score conversions for this subdomain are found in Appendix C. The T-score for the overall Difficult Child

subdomain was 68.2 which showed this domain is less stressful than the Parental Distress subdomain but more stressful than the Parent-Child Dysfunctional Interaction subdomain.

Based on the T-scores of the Difficult Child subdomain, two questions were generated for the interview. These questions were:

1. Why do you believe your child reacts very strongly when something they do not like happens, such as getting used to changes in schedules or changes around the house?
2. Why do you believe your child makes more demands on you than another child would make on his or her parent?

All questions were chosen per each subdomain based on the T-scores, item means, and modes as provided by all 10 participants. The T-score was determined for each of the subdomains which showed the relative stress for the population as a whole. The mean was used to determine the highest mean per item and the mode determined the most common rating. The questions were generated as three questions from the highest T-score subdomain, two questions from the second highest T-score subdomain, and one question from the lowest T-score subdomain. The top five means and modes were then determined, and the interview questions were generated. The stressor items from the PSI-SF, which were assigned a score of 3, 4, or 5, showed similarities with stressors found within the research literature, such as parents having difficulties in their marriage/relationship (Hartley et al., 2012), feeling depressed due to the inability to handle all of the stress related to ASD symptomology (Benson & Karloff, 2009; Siman-Tov & Kaniel, 2011), and feeling pressure to spend money they do not have on toys or

gadgets in hopes of their child learning a new activity (Ganz, 2007; Labosh, 2005). The similarities are displayed in Table 24.

Table 24

Similarities between PSI-SF Stressors and the Research Literature

Stressor	Similar to Research
Parental Distress	
I often have the feeling that I cannot handle things well.	Yes
I find myself giving up more of my life to meet my children's needs than I ever expected.	Yes
I feel trapped by my responsibility as a parent.	Yes
Since having this child, I have been unable to do new and different things.	Yes
Since having a child, I feel I am almost never able to do the things I like to do.	Yes
I am unhappy with the last purchase of clothing I made for myself.	No
There are quite a few things that that bother me about my life.	Yes
Having a child caused more problems than I expected in my relationship with my spouse/parenting partner.	Yes
I feel alone and without friends.	Yes
When I go to a party, I usually expect not to enjoy myself.	No
I am not as interested in people as I used to be.	Yes
I do not enjoy things I used to.	Yes
Parent-Child Dysfunctional Interaction	
My child rarely does things for me that make me feel good.	No
When I do things for my child, I get the feeling that my efforts are not appreciated very much.	Yes
My child smiles at me much less than I expected.	Yes
Sometimes I feel my child does not like me and doesn't want to be close to me.	Yes
My child is very emotional and gets upset easily.	Yes
My child doesn't seem to learn as quickly as most children.	Yes
My child doesn't seem to smile as much as most children.	Yes
My child is not able to do as much as I expected.	Yes
It takes a long time, and it is very hard for my child to get used to new things.	Yes
I expected to have closer and warmer feelings for my child than I do, and this bothers me.	Yes
Sometimes my child does things that bother me just to be mean.	No
Difficult Child	Yes
My child seems to cry or fuss more than other children.	Yes
My child generally wakes up in a bad mood.	Yes
I feel that my child is moody and easily upset.	Yes
Compared to the average child, my child has a great deal of difficulty in getting use to change in schedules or changes around the house.	Yes
My child reacts very strongly when something happens my child doesn't like.	Yes
When playing, my child doesn't often giggle or laugh.	Yes
My child's sleeping or eating schedule was much harder to establish than I expected.	Yes
There are some things my child does that really bothers me a lot.	Yes
My child's behavior is more of a problem than I expected.	Yes
My child makes more demands on me than most children.	Yes

Research Question 2

How do low socioeconomic rural parents of children with ASD perceive parental stress?

a. How do low socioeconomic rural parents of children with ASD perceive their parent-child relationships?

b. How do low socioeconomic rural parents of children with ASD perceive their child's behavior?
c. What parenting difficulties do low socioeconomic rural parents of children with ASD experience?

Low socioeconomic rural parents of children with ASD were asked to answer six face-to-face semi-structured interview questions that were generated from the PSI-SF. I included follow-up questions as necessary and individual to each parent as a way to dig deeper and clarify. Parents perceived their parent-child relationships as less stressful than their child's behavior and most stressful was parenting difficulties.

When completing the initial sorting process, several stress categories for sub-questions a, b, and c emerged when determining how to create major themes for the individual transcripts. During the interview process, I noticed that parents would answer the main questions and follow-up questions; however, many answers also included information that would be relevant to another one of the interview questions. Parents were allowed to speak freely and then would be redirected to the question at hand by using a follow-up question.

Many themes emerged from the interview and interview transcription process. Some were specific to parent-child relationships, some were specific to child behavior, some were specific to parenting difficulties, and some were applicable to all three. These stressors were considered in the coding process and eventually some would become the basis of final codes.

Parent-child relationships contained the least stressors of all three domains; however, some important perceived stressors did emerge during the interview process. Some of these important stressors are displayed in Table 25.

Table 25

Parent Child Relationship Stressors

Perceived Stressors of Relationship Dysfunctions
Parental frustration.
Guilt over being angry or frustrated at their child.
Child's maladaptive behaviors causing stress (e.g. pacing, finger flicking, hand and arm flapping, stimming on objects, aggressive behavior).
Parent thinks child feels out of control and does not know how to regulate own behavior.
Without parental intervention, the child does not know how to cope with everyday situations.
The parent does not know how to cope with everyday child interactions/behaviors.
Parents wanted to protect child by taking on extreme measures to ensure the child is safe, taken care of appropriately and be in control of all aspects of the child's life.

Parental perception of child behavior was a medium source of stress for parents that emerged during the interview process. Some of these important stressors are displayed in table 26.

Table 26

Child Behavior Stressors

Perceived Stressors of Child Behavior
Parent needed to provide a predictable and routine environment for the child to "keep peace."
Parent wanted to ensure the child did not engage in maladaptive behavior (e.g., melting down or acting aggressively).
Parent feeling isolated from other persons or activities in their lives while meeting the challenging and demanding needs of their child.
Parent having difficulty with the diagnostic process, wait time between receiving diagnosis and providing service.
Feeling frustrated that professionals including medical and educational are not helping their child in ways that could increase success on the part of the child.
Parents felt like they have to increase expectations when providing care and meeting challenges of the child.
A feeling of nonsupport from their spouse.
ASD management skills were a direct link to their ability to not cope with situations that arise that affect them and their child.
Parents found that having to go into their child's world and engage in activities such as ritualistic behavior or repetitious behavior caused exhaustion.
Parent had an overall feeling that the child's ASD is "taking over" their lives.
Parents felt economic distress due to the large amount of money spent on diapers/adult diapers/pull ups for their incontinent children.

Parenting difficulties subdomain was the subdomain in which parents expressed their stress perceptions to be the most significance. During the interviews, some important stress perceptions emerged. These stress perceptions are displayed in Table 27.

Table 27

Parenting Difficulties Stressors

Perceived Parenting Difficulties
Parent worries who will watch, provide daycare, or babysit their child as to give the parent a break from the severe mental and emotional strain that accompanies meeting the demands of a child with ASD.
Parents had difficulties expressing to their spouse what needs to be done to assist in caring for the child. Resentment and a disconnected and defensive marital environment.
Feeling as if the parental role division is unfair and inappropriate.
Parent assuming more and more expectations on themselves which can lead to poor ASD management skills or ineffective coping skills.
Parent has a high feeling of guilt and is torn between providing the ongoing needs of his or her child and managing the other siblings.
Parent is afraid the sibling feels less important.
Having to continually explain or justify their child's typical ASD behavior to others, such as their spouse, other outside family members, medical professionals, educational professionals, and members of the community.

The findings of this study closely align to the larger body of literature that exists about parenting stress when raising a child with ASD including the theoretical framework, family systems theory (Bowen, 1979). The larger body of literature was comprised of prior research findings identifying stressors parents of children with ASD experience. I categorized these stressors as they aligned to the three subdomains of parent-child relationship stress, child behavior stress, and parenting difficulties.

The parent-child relationship stressors identified within the larger body of literature were identified as:

- ASD diagnosis and wait time (Bruey, 2004),
- severe punishment of child (Haskett, Ahern, Ward, & Allaire, 2006),
- inability to do things as a family (Cassidy et al., 2008),
- excessive stereotype behaviors (Duarte et al., 2005; Rogers, 2008),
- parent feels ostracized by others (Datz, 2006),
- inability to find a consistent babysitter (Doherty, 2008),

- community judgment (Higgins, Bailey, & Pierce, 2005), and
- parent viewed as having poor behavior management (Hartley et al., 2012).

The child behavior stressors found within the larger body of literature were:

- maladaptive behaviors (Hartley et al., 2012),
- pre-planning to avoid unwanted behaviors (Benson & Karloff, 2009),
- determining child's need when child is unable to functionally communicate (Benson & Karloff, 2009),
- determining the child's coping ability (Benson & Karloff, 2009),
- parent creating rigid or routine schedules (Benson & Karloff, 2009), and
- parent inability to attend, pay for, or have access to interventions/therapies (Linares-Gonzales, 2006).

The stressors within the larger body of literature that align with parenting difficulties were:

- lack of support system (Siman-Tov & Kaniel, 2011),
- parenting satisfaction/competence (Johnson et al., 2006),
- parents feeling "trapped" by ASD (Atwood, 2007; Abbott, 2013),
- parent physically/emotionally drained (Siman-Tov & Kaniel, 2011),
- financial strain/unemployment (Ganz, 2007),
- stress spending (Labosh, 2005),
- poverty/hardship (Kogen et al., 2013),
- marital dissatisfaction/divorce (Hartley et al., 2012).

The comparison of literature stressors, by subdomain and the alignment with study findings, is displayed in Table 28.

Table 28

Identification of Literature Stressors by Subdomain in Comparison to Study Findings

Literature Stressors	Literature Subdomain	Study Findings
ASD diagnosis and wait time	PCRS	Yes
Extreme parenting responsibilities	PCRS	Yes
Severe punishment of child	PCRS	Yes
Excessive stereotypical behavior	PCRS	No
Parent feels ostracized from others	PCRS	Yes
Inability to find a consistent babysitter	PCRS	Yes
Community judgement	PCRS	Yes
Parent viewed as poor behavior Management	PCRS	Yes
Maladaptive behaviors	CB	Yes
Inability to take child to others homes	CB	Yes
Unable to do things as a family	CB	Yes
Severe behavior issues with child	CB	Yes
Pre-planning to avoid unwanted behaviors	CB	Yes
Parent creating rigid routines/schedules	CB	Yes
Parent may not be able to choose, pay for, attend interventions/therapies	CB	Yes
Trying to determine needs due to inability functionally communicate		
Determining child's coping ability in situations	PD	Yes
Functionally communicate	PD	Yes
Determining child's coping ability in situations	PD	Yes
Lack of support system	PD	Yes
Parenting satisfaction/competence	PD	Yes
Parents can feel "trapped" by ASD Physically/emotionally	PD	Yes
Drain parent	PD	Yes
Financial strain/unemployment	PD	Yes
Lack of understanding by employer	PD	Yes
Stress spending	PD	No
Poverty/hardship	PD	Yes
Marital dissatisfaction/divorce	PD	Yes

Note. Literature subdomains are Parent-Child Relationship Stress (PCRS), Child Behavior (CB), and Parenting Difficulties (PD). Some stressors can appear in more than one subdomain. "Yes and "No" reflect if the stressor identified in the literature appears in the findings of the study. Findings of the Study stressors are listed and explained in Table 14.

The theoretical framework of family systems theory (Bowen, 1979) is grounded in family systems and how they function when change occurs. In FST, the structure of the family could include characteristics of belonging, cultural and ideological styles, interactions, and functionality which are placed within the family interactional system (Allen, 2007). When there is any alteration or change in the delicate balance in relationship patterns, such as stressors experienced by low socioeconomic rural parents of

children with ASD, the alteration can cause an imbalance of the whole family system (Allen, 2007; O'Gorman, 2012). Raising a child with ASD is a significant source of stress to the family, especially when the family lives in a low socioeconomic rural area (Brown, 2013; Hays & Watson, 2013). When parents need to cope with challenging and increasing demands of their child, it could easily be inferred that the family system experiences imbalance. The justification for the use of this theoretical framework was to explore how family systems function when changes exhibited by the child with ASD create stressors for parents. The connection of the study findings and conclusions to the theoretical framework were determined using the transcripts from the semi-structured interview. There are three basic characteristics in which stressors can occur, boundaries, family rules, and family role organization (Bowen, 1979).

Boundaries are divided into three separate subtypes, open, closed, and moderate (Bowen, 1979). The explanations of boundaries describe how lifestyle, culture, and family function in the local research area influence how parents respond to parental stress. The characteristics of open boundaries are when families respond to stress with chaos, limited privacy, accepting of family and strangers with ease, spontaneity instead of planning, no clear-cut decision making, instability, and constant change, which can exacerbate existing stress (Becvar & Becvar, 2003; Smith et al., 2008, Turnbull & Turnbull, 1986). The stress findings from the study that illicit an open boundary parental stress response are displayed in Table 29.

Table 29

Study Stress Findings that Illicit Open Boundary Characteristic Response

Stressors	Open Boundary Characteristics
Maladaptive child behavior Unpredictable child behavior Unknown behavior response techniques ASD management skills Ineffective coping skills-parent Self-guilt Repetitious behavior Ineffective coping skills-child	Chaotic environment, instability, no clear-cut decision making, spontaneity versus planning, inconsistent emotional expression, limited privacy, frequent role changes

Note. Open boundary characteristics, (Becvar & Becvar, 2003).

The characteristics of closed boundaries affect the family system in that families are rigid, guarded, and private (Kormanik & Rocco, 2009, O'Gorman, 2012). Closed boundary families practice a patriarchal system in which the father assigns the workload, typically to the mother (Umberson, Williams, Powers, Chen, & Campbell, 2005). Rigid parents have difficulty raising children because they are unwilling or unable to adapt to challenging behaviors or lessen the burdens for others (Duerte et al., 2005; Lyons, Leon, Roecker-Phelps, & Dunleavy, 2010). The stress findings from this study that elicited a closed boundary response are displayed in Table 30.

Table 30

Study Stress Findings that Illicit Closed Boundary Characteristic Response

Stressors	Closed Boundary Characteristics
Maladaptive child behavior Child protection Fear of child protection Ineffective coping skills-parent Ineffective coping skills-child ASD management skills Unfair parent role division Defensive spousal relationship Professional mistrust Economic distress	Guarded, rigid, value privacy, patriarchal workload assignment, overburdened mother, inability to adapt to challenging behaviors, unwilling to lessen others' burden (family members)

Note. Closed boundary characteristics (Becvar & Becvar, 2003).

The last boundary, moderate boundaries, characterized family systems that have achieved balance (Brown, 2013). They are able to exchange with others with ease, explore outside communities, and have strong connections, well-defined flexible rules, and access resources when a stressful change occurs (Brown, 2013; McGoldrick, 1995).

When engaging in the data collection process for this study, specifically during the interview process, participants shared how the stressors of living in a poverty area and raising a child with ASD impacted their family systems. It is with this information that I was able to infer that moderate boundary characteristics were not used in response to stress.

The second characteristic of FST in which stressors can occur was in response to family rules (Allen, 2007; Finch & Finch, 2012). To maintain stability, families must develop rules about how to live together. Based on the specific needs of the child with ASD the environment can be in continual change (Brown, 2013). To maintain family balance and handle the continually changing environment, families must learn how to adapt, communicate, and negotiate family rules (Brown, 2013). When conducting the semi-structured interview, parents made reference to their struggle with creating and following family rules. They stated that the inability to create and consistently follow rules created extreme stress. During the semi-structured interview, parents described specific situations in which they experienced extreme stress due to their lack of ability to create and consistently follow rules. The stressors that elicit stress due to the inability for parents to create and consistently follow rules were: ASD management skills (how to respond to behavior and practice discipline), predictable environment (following through

with schedules and routines), fair division of parenting roles (one parent is doing more than the other), and marital disconnection (not keeping weekly “dates”).

The last FST characteristic in which stressors can occur was in response to role organizations within the family (Allen, 2007). Role organization and the expectations within the family are often influenced by culture, ethnic background, familial experiences, lifestyle, and family size/composition (Cowen, 2007; George & Soloman, 2009). Family roles should be ideally clear and flexible, but the symptomology demands of ASD and other influences such as cultural aspects can shape the roles. During the semi-structured interview, parents identified stressors that were aligned with the ability or inability of the family to create clear-cut role organizations. The stressors that elicit stress due to the inability for families to create stable role organization were: defensive spousal relationships, economic distress, parental isolation, sibling equality guilt, unfair parent role division, and increased parental response.

The practical applications of the findings of this study are to share with the support group the results of the study to help them request services or supports that will ease some of their stress. For example, asking for additional childcare services or providing parents with contact information to services and supports within their community. The format of dissemination should clearly show the purpose of the study as well as the results and implications for the use of the information. Educators should understand the purpose of the study and take steps to apply the new information in a way to positively benefit parents and families of children with ASD and provide more appropriate services and supports to children and families.

Implications of Social Change

This study served as a catalyst for social change by identifying the stressors experienced by parents who are raising a child with ASD in a low SES rural area and how those stressors, when applied to individual families, could lead to teacher leaders assisting in finding and implementing supports to relieve parental stress. Challenges expressed by parents, based on the findings of this study, were that parents of children within a low SES rural area were unaware of or had limited information about formal and informal supports available to them. Parents indicated that formal supports, such as finding competent professionals who did not accurately diagnose children with ASD or having to wait for services and informal supports, such as limited childcare resources negatively impacted the family functionality and the possibility that their child would be educationally underserved.

Once teacher leaders assist parents in identifying their stressors, educators can begin the process of developing supports, and lastly, show parents how to access and implement supports. With supports in place, social change can occur in the everyday lives of students and parents.

Recommendation for Action

It may be beneficial if educational professionals stay consciously aware of the needs of the families as a unit and extension of the child's education (Boyd & Shaw, 2010). The parenting stress findings from this study can provide educators with the knowledge of the stressors parents experience when trying to cope with the child's demands, abilities, and educational needs with limited support. A large part of the

problem stems from the lack of formal and informal supports and then the limited knowledge families have to access the existing ones. This dilemma creates parents who demonstrate their stress based on perceptions, which includes the perception of not having supports to assist with raising their child. Many parents expressed that they are the only ones who provide support for the specific needs of their children creating frustration and often breakdown within the parents' own life. My recommendations are:

- For educators to create and provide a parent needs assessment to be completed by parents of children with ASD twice per year (fall/spring). Educators could become aware of the needs of their parents, which in turn impacts how services, supports, and resources are provided to students. Keeping and tracking the individual needs can help teachers develop ways to target specific goals and objectives for the child. Once educators have tracked the needs of their parents they can research and compile a list of formal and informal supports within the school district and within the community. Examples could be directories of medical health professionals, community autism support groups, autism support websites, childcare programs that accept children with disabilities, and afterschool programs.
- Discuss with the school superintendent and school board members during monthly board meetings about how to find funding to support families. An example could be to create a small "parent library" in which parents can take pamphlets or have access to magazines and literature about autism.

- Provide parents with phone numbers and emails to state agencies, such as OCALI in Ohio, which provide support to parents who have children with ASD.

I will disseminate the study findings in two separate ways. I will create a reader friendly brochure, which will be disseminated to the autism support group and, with permission, added to their website. The second dissemination will occur in the form of a traditional research report and provided to the school districts along with the narrative brochure. The dissemination of the information could promote awareness of the stress parents experience when raising a child with ASD and be used as a stepping stone to creating better educational services for children and as an extension, families.

Recommendations for Further Study

Further research is needed to examine how parents perceive parental stress when raising a child with ASD. The findings of this study have showed there was a need for further research. One recommendation for further study could include examining how parental stress specifically impacts fathers in low SES rural areas and how to provide support. The research from this study showed mothers feel fathers do not cope well or are not understanding of how ASD affects their child. There have been limited research studies about fathers and children with ASD, but further study specifically addressing coping and how to provide support is recommended. I would recommend a replication of this research study design in which the bounded descriptive case study occurs in low SES rural areas similar to the research area of this study. Since coping is not specific to the Parental Stress Index, I would recommend the use of a coping scale that caters to parents

of children with disabilities, such as, the Coping Health Inventory for Parents (McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1983). I would use the PSI-SF and CHIP as the quantitative tools in which I would generate the semi-structured interviews. An additional study could be to explore which stressors are highest in creating marital defensive relationships. I would recommend a modified replication of this research design in which a bounded descriptive case study is used to occur within a similar low SES rural research site. I would not use the PSI-SF but the Locke and Wallace Marital Adjustment Scale (Locke & Wallace, 1959). One last study could include finding strategies that could work for parents when they are dealing with unpredictable behaviors or maladaptive behaviors, specifically ones that are quick and effective. Parents in this study reported that often they were at a loss in how to consistently handle the unpredictable and maladaptive behaviors of their child. Although there are research studies about different "techniques" in handling these behaviors, I think making techniques that are applicable for parents who live in low socioeconomic rural areas is necessary. The necessity is that when creating techniques for rural and low socioeconomic techniques, the culture, and familial needs should be considered. Again, I recommend a modified replication of this study by using the bounded descriptive case study design within a low SES rural research site. There are many adaptive and behavior scales that cover a range of ages and abilities. The Vineland Adaptive Behavior Scales (Sparrow, Cicchetti, & Balla, 2005) measures adaptive and maladaptive behavior for typical and special needs of children and adults. These recommendations for study would

be extensions of this study and would continue to help "solve" the problem of parental stress as experienced by parents of children with ASD.

Reflection

This research study has been a journey of passion, not only for the child who has a diagnosis of ASD, but also the parent. The purpose of the study was to determine how parents in a low socioeconomic rural area perceived stress when raising a child with ASD. Once engaged with parents, I found it was not just about the stress they feel or how they cope, it was about how they love their children so much that the stress is secondary to providing for their child no matter what. I found parents who are sacrificing almost all things in their lives just to ensure their child has the attention, care, support, and love that is required by any child. I found these parents to be strong in character and willing to face the adversities of educators, medical professionals, and community members not understanding their needs and feeling inadequate to advocate for them. Some parent participants expressed they tend to believe what they are told about their child's educational needs by educators without question and at face value. They also said they believed they were not a part of the child's education and their input was not "valued." The truth is they know their child; therefore, their input should be heard and valued. It was a challenge at first making the initial contact with parents because I was a stranger and they are very protective of their child, family, and family practices. Like many rural areas, I was prepared for this mistrust. However, once I had made contact with one parent, the reputation that I was "okay" and could be trusted spread among parents. I would complete my data collection with parents and then would have a cup of coffee as

they talked with me about their child or if we knew the same people within our small town. Within my small southern rural community it is considered a rule of "hospitality" to stay for a cup of coffee or tea when coming to someone's home. The denial of this "rule" can be viewed as rude or unappreciative of the person inviting you into his or her home. I knew that my biases or preconceived notions would not affect my data because I am familiar with the rural culture and knew once I was accepted they would be open and honest to a fault. They spoke freely, and I listened recording their responses. Ultimately, every parent expressed gratitude to me for conducting this study and hoped it really helped not only in our educational systems but also within our community. I found a greater understanding and empathy for these parents and their strength.

Concluding Statement

This research was intended to provide educators with an understanding of stressors parents experience when raising a child with ASD in a low socioeconomic rural area. With the rise of ASD incidence, it is a necessity for teacher leaders to have an increased understanding of ASD as a disorder, as well as, the impact ASD stress has on parents in poverty. The many stressors parents experience when raising a child with ASD, such as economic disparities, lack of respite, mistrust of professionals, and insufficiency of available supports were identified in this research study. Often, parents believe they are "all alone" when trying to cope with the stressors of having a child with ASD. Without the understanding of the stressors parents' experience, there can be a disconnection between educators and parents. The supports educators are already providing to the student and the actual supports and resources parents may need to access

to compliment the learning of their child can be limited. There are many stressors that parents experience that can limit that connection with their child's teacher. It is my hope that the development and conclusion of this study will provide teacher leaders the opportunity to understand the parental stress parents of children with ASD experience. It is my belief that once educators become aware of the stressors, they can internalize the stressors, become empathetic to the plight of the parent, and work to ensure children are not underserved due to a lack of services or supports.

References

Abbeduto, L., Seltzer, M., Shattuck, P., Krauss, M., Orsmond, G., & Murphy, M. (2004). Psychological well-being and coping in mothers of youths with Down syndrome, autism, and Fragile X syndrome. *American Journal of Mental Retardation*, 109, 237-254. doi:10.1352/0895-8017(2004)109,237:PWACIM.2.0.CO;2

Abidin, R. (1990). Introduction to the special issue: The stresses of parenting. *Journal of Clinical Child Psychology*, *19*(4), 298-301. doi:10.1207/s15374424jccp1904_1

Abidin, R. (1995). *Parenting stress index* (4th ed.). Charlottesville, VA: Pediatric Psychology Press.

Abbott, A. (2013). Love in the time of autism. *Psychology Today*. Retrieved September 16, 2013 from www.psychologytoday.com/articles/201306/love-in-the-time-autism

Allen, M. (2007). The dance inside ME. *PsycCRITIQUES, 53*(42), article 3. doi:10.1037/a0013360

Altiere, M., & von Kludge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies, 18*, 83-92. doi:10.10007/s10826-008-9209-y

American Psychiatric Association. (2013). *Diagnostic and statistical manual of disorders* (5th ed.). Washington, DC: American Psychiatric Association.

Armstrong, M., Birnie-Lefcovitch, S., & Unger, M. (2005). Pathways between social support, family wellbeing, quality of parenting, and child resilience: What we know. *Journal of Child and Family Studies, 14*, 269-270. doi:10.1007/s10826-005-5054-4

Atwood, T. (2007). *The complete guide to Asperger's syndrome*. London, UK: Jessica Kingsley Publishers.

Autism Society of America. (2011). *Autism statistics*. Retrieved: August, 2013 from http://www.autism-society.org

Balfe, M., & Tantum, D. (2010). A descriptive social and health profile of a community of adults and adolescents with Asperger's syndrome. BMC *Research Notes*, 21, 300. doi:10.1186/1756-0500-3-300

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51, 702-714. doi:10.1111/j.1365-2788.2007.00960.x

Bebko, J., Konstantareas, M., & Springer, J. (1987). Parent and professional evaluations of family stress associated with characteristics of autism. *Journal of Autism and Developmental Disorders*, 17, 565-576.

Beck, A., Hastings, R., Daley, D., & Stevenson, J. (2004). Pro-social behavior and behavior problems independently predict maternal stress. *Journal of Intellectual and Developmental Disabilities*, *29*(4), 339-349. doi:10.1080/13668250400014509

Becvar, D., & Becvar, R. (2003). *Family therapy: A systemic integration* (5th ed.). Boston, MA: Allyn & Bacon.

Benson, P., & Karloff, K. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39, 350-362.

Berge, J., Patterson, J., & Reuter, M. (2006). Marital satisfaction and mental health of couples with children chronic health conditions. *Families, Systems, & Health*, *24*(3), 267-285. doi:10.1037/1091-7527.24.3.267

Bettelheim, B. (1967). *The empty fortress infantile autism and the birth of self.* New York, NY: The Free Press.

Biddle, B. (Ed). (2001). *Social class, poverty, and education: Policy and practice*. New York, NY: RoutledgeFalmer.

Bishop, S., Richler, J., Cain, A., & Lord, C. (2007). Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal on Mental Retardation, 112*(6) 450-461 doi:10.1352/0895-8017(2007)112%5B450:POPNII%5D2.0.CO;2

Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry, 7*, 345-374. doi:10.1016/s0010-440x(66)80065-2

Bowen, M. (1979). *Family therapy in clinical practice.* New York, NY: Jason Aronson.

Boyd, B. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism & Other Developmental Disabilities, 17*(4), 208. doi:10.1177/10883576020170040301

Boyd, B., & Shaw, E. (2010). Autism in the classroom: a group of students changing in population and presentation. *Preventing School Failure*, *54*(4), 211-219. doi:10.1080/10459981003744552

Bretherton, I., & Munholland, K. (2008). Internal working models in attachment relationships. In J. Cassidy & P. Shaver (Eds.), *Handbook of attachment: Theory, research, and clinical application* (2nd ed., pp. 102-127). New York, NY: Guilford Press.

Bromley, J., Hare, D., Davison, K., & Emerson, E. (2004). Mother supporting children with autism spectrum disorders: Social support, mental health status, and satisfaction with services. *Autism*, 8, 409-423. doi:10.1177/1362361304047224

Brown, J. (2013). Bowen family systems theory and practice: Illustration and critique. Retrieved: January 29, 2013 from http://www.familysystemstraining.com/papers/bowen-illustration-and-critique.html

Bruey, C. (2004). *Demystifying autism spectrum disorders: A guide to diagnosis for parents and professionals*. Bethesda, MD: Woodbine House.

Brutus, S., Aguinis, H., & Wassmer, U. (2013). Self-reported limitations and future decisions in scholarly reports: Analysis. *Journal of Management*, 39, 48.

Cassidy, A., Truesdale-Kennedy, M., & Slevin, E. (2008). Preschoolers with autism spectrum conditions: The impact on families and the supports/ available to them. *Early Child Development and Care, 178*(2) 115-128. doi:10.1080/0300443071491721

Centers for Disease Control and Prevention (2012). *Data and statistics, autism spectrum disorders-NCBDD*. Retrieved January 15, 2012 Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA model in a community setting. *Journal of Developmental Behavior Pediatrics, 27*(2), S145-S155.

Cohen, S. Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*(4), 385-96.

Cohen, M., & Kemper, K. (2005). Complementary therapies in pediatrics: A legal perspective. *Pediatrics*, 115, 774.

Coleman, M., & Briggs, A. (2005*).* Research methods in educational leadership and management. *Educational Management Research and Practice*. London, UK: Sage.

Cook, A., & Oltjenbruns, K. (1989). *Dying and grieving: Lifespan & family perspective*. New York, NY: Holt, Rinehart, and Winston.

Cotton, S., & Richdale, A. (2010). Sleep patterns and behavior in typically developing children and children with autism, Down syndrome, Prader-Willie syndrome, non-specific intellectual disability, and autism spectrum disorder. *Research in Autism Spectrum Disorder*, 4, 490-500. doi:10.1016/j.rasd.2009.11.006

Cowen, S., Pape, C., & Meheta, N (2009). Adult attachment, couple attachment, and children's adaptation to school: An integrated attachment template and family risk

model. *Attachment & Human Development*, *11*(1), 29-46. doi:10.1080/1461673080250022

Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.

Creswell, J. (2003). *Research design: Quantitative, qualitative, and mixed methods approach* (2nd ed.). Thousand Oaks CA: Sage.

Creswell, J. (2005*). Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (2nd ed.). Upper Saddle River, NJ: Pearson Education.

Creswell, J. (2007). *Qualitative inquiry and research method: Choosing among the five approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. (2008). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.

Creswell, J. (2013). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (4th ed.). Upper Saddle River, NJ: Pearson Education.

Creswell, J., & Plano, V. (2011). *The mixed methods reader*. Thousand Oaks, CA: Sage.

Creswell, J., Plano-Clarke, V., Guttmann, M., & Hanson, E. (2003). Advanced mixed methods research design. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research,* (p. 209-240). Thousand Oaks, CA: Sage.

Crittenden, P., & Dallos, R. (2009). All in the family: Integrating attachment and family systems theories. *Clinical Child Psychology and Psychiatry*, *14*(3), 389-409.

Croen, L., Najjar, D., Fireman, B., & Grether, J. (2007). Maternal and paternal age and risk of autism spectrum disorders. *Archived Pediatric Adolescent Medicine*, 161, 334-340. doi:10.1001/achpedi.161.4.334

Cure Autism Now, (2005). *Refrigerator mothers*. Retrieved: June, 2014 from http://www.autismspeaks.org

Datz, T. (2006). *Autism has high costs to U.S. society*. Press release, April 25, 2006. Harvard School of Public Health. Retrieved August 23, 2013 from: http://www.hsph.harvard.edu/news/press-releases/2006-releases/press0425006.html

De Brock, A., Vermulst, A., Gerris, J., & Abidin, R. (1992). *Nijmeegse Ouderlijke Stress Index, handleiding experimentele versie* [Nijmegen Parenting Stress Index, manual experimental version]. Lisse: Unpublished manuscript.

Deater-Deckard. (2004). *Parenting stress*. New Haven, CT: Yale University Press.

Denzin, N., & Lincoln, Y. (Eds.) (2005). *Handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.

Dickstein, S., Seifer, R., & Albus, K. (2009). Maternal adult attachment representation across relationship domains and infant outcomes: The importance of family and couple functioning. *Attachment & Human Development*, *11*(1), 5-27. doi:10.1080/14616730802500164

Doherty, S. (2008). Day-to-day struggles of autistic children affect entire family. *The Capitol Times*. Retrieved September 1, 2013 from http://host.madison.com/ct/news/local/health_med_fit/article_c42f9884-2c8c-11df-be20-001cc4c002e0.html

Duarte, C., Boldin, I., Yazigi, l., & Monney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, 9, 416-427. doi:10.1177/1362361305056081

Dumas, J., Wolf, L., Fisman, S., & Culligan, A. (2007). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality*, 2, 97-110. doi:10.1080/09362839109524770

Durkin, M., Maenner, M., Meaney, Levy, S., DiGuiseppi, C., Nicholas, J., . . . Shieve, L. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLOS ONE, 5*(7) e11551. doi:10.1371/journalphone.0011551.

Erguner-Tekinalp, B., & Akkok, F. (2004). The effects of a coping skills training program on the coping skills, hopelessness, and stress levels of mothers of children with autism. *International Journal for the Advancement of Counseling*, 26, 257-269.

Exkhorn, K. (2005). *The autism sourcebook: Everything you need to know about diagnosis, treatment, coping, and healing*. New York, NY: Harper Collins.

Felmlee, D. (1995). Fatal attractions: Affection and disaffection in intimate relationships. *Journal of Social and Personal Relationships,* 12, 295-311. doi:10.1177/0265407595122009

Finch, D., & Finch, K. (2012). *Yes, you are supposed to hug me now: Best practices for neurologically-mixed marriages and other harrowing relationships*. Talk presented by AANE in Waltham, MA. December 1, 2012.

Freeman, M., deMarrais, K., Preissle, J., Roulston, K., & St. Pierre, E. A. (2007). Standards of evidence in qualitative research: An incitement to discourse. *Educational Researcher*, 36, 25-32. doi:10.3102/0013189X06298009

Ganz, M. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatric and Adolescent Medicine*, *161*(4), 343-349. doi:10.1001/archpedi.161.4.343

George, C. (2009). Couple relationships and the family system: Commentary from a behavioral systems perspective. *Attachment & Human Development*, *11*(1), 103-110. doi:10.100/14616730802564293

George, C., & Soloman, J. (2008). The care giving system: A behavioral systems approach to parenting. In J. Cassidy & P. Shaver (Eds.), *Handbook of attachment: Theory, research, and clinical application* (2nd ed., pp. 833-856) New York, NY: Guilford Press.

Grier, D., Sykes, L., & Grier, M. (2007). A review of Thimerosal (Merthiolate) and its ethylmercury breakdown product: Specific historical considerations regarding safety and effectiveness. *Journal of Toxicology and Environmental Health. Part B. Critical Review*, 10, 575-596.

Glidden, L., & Schoolcraft, S. (2003). Depression: Its trajectory and correlates in mothers rearing children with intellectual disabilities. *Journal of Intellectual Ability Research*, *47*(4-5), 250-263.

Goin-Kochel, R., MacKintosh, V., & Myers, B. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism*, *10*(5), 439-451. doi:10.1177/1362361306066601

Gray, D. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*, 27, 215-222. doi:10.1080/1366825021000008639

Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with developmental disorder. *Autism*, 11, 489-501. doi:10.1177/1362361307083258

Harris, S. (1983). The family of the autistic child: A behavioral-systems view. *Clinical Psychology Review*, 4, 227-239. doi:10.1016/0272-7358(84)90001-1

Hartley, S., Barker, E., Baker, J., Seltzer, M., & Greenberg, J. (2012). Marital satisfaction and life circumstances of grown children with autism across 7 years. *Journal of Family Psychology*, *26*(5), 688-697. doi:10.1037/a0029354

Haskett, M., Ahern, L., Ward, C., & Alliare, J. (2006). Factor structure and validity of parenting stress index—short form. *Journal of Clinical Child and Adolescent Psychology*, *35*(2), 302-312.

Hastings, R., Kovshoff, H., Ward, N., Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, *35*(5), 635-644. doi:10.1007/s10803-005-0007-8

Hays, S., & Watson, S. (2013). The impact of parenting stress: A meta-analysis of studies the comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism Developmental Disorder*, 43, 629-642 doi:10.1007/s10803-012-1604-y

Help Me Grow. (2013). *PSI-SF guidance document*. Retrieved November 2014 from www.helpmegrow.ohio.gov/professional

Higgins, D., Bailey, S., & Pearce, J. (2005). Factors associated with functioning style and coping strategies of families with a child with autism spectrum disorder. *Autism*, 9(2) 125-137.

Hoffman, C., Sweeney, D., Hodge, D., Lopez-Wagner, M., & Looney, L. (2009). Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism & Other Developmental Disabilities*, *24*(3), 178-187.

Holroyd, J., Brown, N., Wilker, L., & Simmons, J. (1975). Stress in families of institutionalized and non-institutionalized autistic children. *Journal of Community Psychology*, 3, 26-31. doi:10.1002/1520-6629(197501)3:1%3C26:AID-JCOP2290030105%3E3.0.CO;2-Y

Hopson, B. (1986). Transition: Understanding and managing personal change. In: *Psychology for Social Workers* (D. M. Herbert), 141-165. Basingstoke, UK: MacMillan Press.

Honey, E., Hastings, R., & McConachie, H. (2005). Use of the questionnaire on resources and stress (QRS-F) with parents of young children with autism. *Autism*, 9, 246-255. doi:10.1177/1362361305053256

Houser, R., & Seligman, M. (1991). A comparison of stress and coping by fathers of adolescents without mental retardation. *Research in Developmental Disabilities*, 12, 251-260. doi:10.1016/0891-4222(91)90011-G

Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. *Autism, 1*(2), 135-162. doi:10.1177/1362361397012003

Howlin, P. (2000). Assessment instruments for Asperger syndrome. *Child Psychology and Psychiatry Review*, *5*(3), 120-129. doi: 10.1111/1475-3588.00298.

Hutton, A., & Caron, S. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities*, *20*(3), 180-189.

Interactive Autism Network, IAN Stats. (2014). *Quick state stats*. Retrieved: May 26, 2014 from http://www. dashboard.ianexchange.org/quickstats.aspx?AI=OH

Imber-Black, E., & Roberts, J. (1992). *Rituals for our times: Celebrating, healing, and changing our lives and our relationships*. New York, NY: Harper Collins.

Johnson C., & Myers, S. (2006). American Academy of Pediatrics Council on Children with Disabilities. Identification and evaluation of children with autism spectrum disorders. *Pediatrics,* 120, 1183-215.

Jordan, R. (2001). Multidisciplinary work for children with autism. *Educational and Child Psychology, 18*(2), 5-106.

Jovanova, C., & Radojichik, D. (2013). Parents of children with developmental disabilities: Stress and support. *Journal of Special Education and Rehabilitation, 14*(1-2), 7-19 doi:10.2478/v10215-011-0029-z

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child,* 2, 217-250.

Kantor, D., & Lehr, W. (1976). *Inside the family*. New York, NY: Harper Row.

Kogan, M., Blumburg, S., Scheive, L., Boyle, C., Perrin, J., Ghandor, M., Signgh, G., Strickland, B., Terevathan, E., & VanDyck, P. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the United States. *Pediatrics*, 124, 1-9.

Konstantareas, M., & Papageorgiou, T. (2006). Effects of temperament, symptom severity, and level of functioning on maternal stress in Greek children and youth with ASD. *Autism*, 10, 593-607. doi:10.1177/1362361306068511

Konstantareas, M., & Stewart, K. (2006). Affective regulation and temperament in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *36*(2), 143-154.

Kormanik, M., & Rocco, T. (2009). Internal versus external control of reinforcement: A review of the locus of control construct. *Human Resource Development Review*, *8*(4), 463-485.

Krauss, M., Seltzer, M., & Jacobson, H. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research,* 50, 883-893.

Kroeger, K., Schultz, J., & Newsom, C. (2007). A comparison of two group-delivered social skills programs for young children with autism. *Journal of Autism and Developmental Disorders*, 37, 808-817. doi:10.1007/s10803-006-0207x

.Labosh, K. (2005). Stress: Take a load off! Autism, stress & ways to keep your wheels on. *Autism Advocate, 38*(2).

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behavior problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, *50*(3), 172-183. doi:10.1111/j.1365-2788.00732.x

Lee, C., Anderson, J., Horowitz, J., & August, G. (2009). Family income and parenting: The role of parental depression and social support. *Family Relations, 58*(4), 417-430, Oct. 2009. doi:10.111/j1741-3729.2009.00563.x

Levy, S., & Hyman, S. (2009). Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child Adolescent Psychiatry Clinical North America*, *17*(4), 803-ix. doi:10.1016/i.chc.2008.06.004

Lewine, J., Andrews, R., Chez, M., Patil, A., Devinsky, O., Smith, A, . . . Orrison, W. (1999). Magnetoencephalographic patterns of epileptiform activity in children with regressive autism spectrum disorders. *Pediatrics*, 104, 405-418. doi:10.1542/peds.104.3.405

Lewis, O. (1959). *Five families: Mexican case studies in the culture of poverty.* New York, NY: Basic Books.

Lewis, O. (1966). *LaVida: A Puerto Rican family in a culture of poverty—San Juan and New York.* New York, NY: Radom House.

Linares-Gonzalez. L. (2006). *A supportive training program for parents of autistic children.* (Doctoral Dissertation). Retrieved from ProQuest.

Little, L. (2002). Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorders. *Pediatric Nursing*, 28, 565-570.

Locke, H., & Wallace, K. (1959). Short marital adjustment and prediction tests: Their reliability and validity. *Marriage and Family Living*, 21, 251-255.

Lyons, A., Leon, S., Roecker-Phelps, C., & Dunleavy, A. (2010). The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child Family Studies*, 19, 516-524. doi:10.1007/s10826-009-9323-5.

Lyons, V., & Fitzgerald, M. (2007). Asperger (1906-1980) and Kanner (1894-1981), the two pioneers of autism. *Journal of Autism and Developmental Disorders*, *37*(10), 2022-2023.

Mak, W., Ho, W., Y, A., & Law, R. (2007). Sense of coherence, parenting attitudes and stress among mothers of children with autism in Hong Kong. *Journal of Applied Research in Intellectual Disabilities*, 20, 157-167.

Marcus, L., Kunce, L., & Shopler, E. (2005). *Working with families*. In F. R. Volkman, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp. 1055-1086). Hoboken, NJ: John Wiley & Sons.

Mayo Foundation for Medical Education and Research. (n.d.). Retrieved December 1, 2011 from www.mayoclinic.com

McConachie, H., Randle, V., & LeCouteur, A. (2005). A controlled trial of a training course for parents of children with suspected autism spectrum disorder. *Journal of Pediatrics*, 147, 335-340.

McCubbin, H., & Figley, C. (1983). *Stress and family*. New York, NY: Brunner/Mazel.

McCubbin, H., McCubbin, M., Patterson, J., Cauble, A., Wilson, L. & Warwick, W. (1983). CHIP-Coping Health Inventory for Parents: An Assessment of Parental Coping Patterns in the Care of the Chronically Ill Child. *Journal of Marriage and the Family*, 359-370.

McGoldrick, M. (1995). *You can go home again*. New York, NY: Norton.

Meirsschaut, M., Roeyers, H., & Warreyn, P. (2010). Parenting in families with a child with autism spectrum disorder and a typically developing child: Mother's experiences and cognitions. *Research in Autism Spectrum Disorders, 4*(1), 661-666.

Merriam, S. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.

Minnes, P., & Nachshen, J. S. (2003). The family stress and coping interview for families of individuals with developmental disabilities: A lifespan perspective on family adjustment. *Journal of Intellectual Disability Research*, 47, 285-290.

Minuchin, S., (1974). *Families and family therapy*. Cambridge, MA: Harvard University Press.

Moes, D., Koegal, R., Schreibman, L., & Loos, L. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports,* 71, 1271-1274.

Moh, T., & Magiati, I. (2011). Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6, 293-303. doi:10.1016/j.rasd.2011.05.011

Morgan, S. (1988). The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism and Developmental Disorders*, 18, 263-280. doi:10.1007/BF02211952

Myers, B., Mackintosh, V., & Goin-Kochel, R. (2009). "My greatest joy and my greatest heartache": Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3, 670-684.

Myers, S., & Plauche-Johnson, C. (2007). Management of children with autism spectrum disorder. *Pediatrics*, 120, 1162.

Myhill, G., & Jekel, D. (2008). *Asperger marriage: Viewing partnerships through a different lens.* Retrieved from Naswma.org/associations/8381/files/FCE_ AspergerMarriage.pdf

National Institute of Health and Human Development, (2011). Autism overview: What we know. *US Department of Health and Human Services*. Rockville, MD: National Institutes of Health. Retrieved from http://www.nichd.nih.gov/

National Institute of Mental Health. (2011). *What is autism spectrum disorder.* Retrieved December, 2013 from http://www.nimh.nih.gov

Neff, L., & Karney, B. (2009). Stress and reactivity to daily relationship experiences: How stress hinders adaptive processes in marriage. *Journal of Personality and Social Psychology, 97*(3), 435-450.

Ohio Center for Autism and Low Incidence. (2012). Retrieved from http://www.ocali. org/

Ohio Department of Jobs and Family Services. (2013). *Data and statistics*. Retrieved June 15, 2014 from http://www.odh.ohio.gov

O'Gorman, S. (2012). Attachment theory, family systems theory, and the child presenting with significant behavioral concerns. *Journal of Systemic Therapies*, *31*(3), 1-16. doi:10.1521/jsy4.2012.31.3.1

Ohio Autism Taskforce. (2007). *Progress and status report*. Retrieved June 15, 2014 from http://www.autismohio.org

Ohio County Profiles. (2013). *Statistical and demographic data*. Retrieved June 2014 from http://www.jfs.ohio.gov/County/County_Directory.pdf

Ohio Department of Health. (2008). *Healthy Ohio report.* Retrieved November 2014 from http://www.odh.ohio.gov

Olson, D., Portner, J., & Lavee, Y. (1985). *FACES III manual*. St. Paul, MN: University of Minnesota.

Olson, D., Russel, C., & Sprenkle, D. (1980). Circumplex model of marital and family systems II: Empirical studies and clinical intervention. In J. P. Vincent (Ed.), *Advances in family intervention assessment and theory* (Vol. 1, pp. 129-179). Greenwich, CT: Jai Press.

Orsmond, G., Wyngaarden-Krauss, M., & Seltzer, M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34*(3) 245-256 doi:10.1023/B: JADD.0000029547.96610.d

Palmer, R., Walker, T., Mandell, D., Bayles, B., & Miller, C. (2009). Explaining low rates of autism among Hispanic schoolchildren in Texas. *American Journal of Public Health*, 100, 270-272.

Palmer, R., Blanchard, S., Jaen, C., & Mandell, D. (2005). The association between school district resources and identification of children with autistic disorder. *America Journal of Public Health*, *95*(1), 125-130.

Patton, M. (1990). *Quantitative research and evaluation methods* (2nd ed). Newbury Park, CA: Sage.

Payne, R. (2005). *A framework for understanding poverty* (4th revised ed.). Highlands, TX: aha! Process.

Payne, R. (2006). *A framework for understanding poverty* (5th revised ed.). Highlands, TX: aha! Process.

Payne, R. (2009). Moving from idle class to situational poverty, from stability to instability: What you can do to help your students and parents during the present economic downturn. *Instructional Leader*, *22*(3).

Payne, R., & Ehlig, B. (1999). *What every church member should know about poverty*. Highland, TX: aha! Process.

Payne, R., Devol, P., Smith-Drussi, T. (2001). *Bridges out of poverty: Strategies for professionals and communities*. Highland, TX: aha! Process.

Patterson, J. (2005). Weaving gold out of straw: Meaning-making in families who have children with chronic illnesses. In W, Pinsoff & J. Lebow (Eds.), *Family psychology: The art of the science* (pp. 521-548). New York, NY: Oxford University Press.

Pines, A. (1997). Fatal attractions or wise unconscious choices: A relationship between causes for entering and breaking intimate relationships. *Personal Relationship Issues*, 4, 1-6.

Piper-Terry, M. (2010). *Autism and families: Stress, divorce, and economic considerations. A review of the literature*. Retrieved September 9, 2013 from vaxtruth.org

Pisula, E. (2007). A comparative study of stress profiles in mothers of children with autism and those with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, 20, 274-278. doi:10.1111/j.1468-3148

Plant, K., & Sanders, M. (2007), Predictors of caregiver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51, 109-124.

Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transactional model of coping. *Journal of Community and Applied Social Psychology*, 1, 57-70.

Rarity, J. C. (2007). *Nonfinite grief in families with children on the autism spectrum*. (Doctoral Dissertation). Retrieved from ProQuest Information and Learning Company.

Ratajczak, H. (2011). Theoretical aspects of autism: Causes—A review. *Journal of Immunotoxicology*, *8*(1), 68-79. doi:10.3109/1547691x.2010.545086

Reynolds, T., & Dombeck, M. (2011). Historical/contemporary theories of cause and genetic contributions. *Mental Health Care*. Ritchie, J., Lewis, J., & Elam, G. (2003). Designing and selecting samples. In Jane Ritchie and Jane Lewis (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp. 77-108). Thousand Oaks, CA: Sage.

Robson, C. (2002). *Real world research* (2nd ed.). Hoboken, NJ: Blackwell Publishing.

Rogers, M. (2008). Can marital satisfaction of parents raising children with autism be predicted by child and parental stress? Alliant International University, San Diego, CA, ProQuest, UMI Dissertation Publishing. 3305380.

Rubens, J. (2009). *Effects of contextual influences on stress level for caregivers of children diagnosed with autism*. (Doctoral Dissertation). Retrieved from ProQuest

LLC. 6).

Rudy, L. (2006) *Refrigerator mothers*. Retrieved August 14, 2013 from http://www. autism.about.com/od/causesofautism/p/refrigerator.htm.

Rutter, M. (2005) Genetic influences and autism. In: *Handbook of autism* (3rd ed.). (Ed. F. Volkmar), New York, NY: Wiley.

Satir, V. (1998). *The new people making*. Mountain View, CA: Science and Behavior Books.

Schechter, R., & Grether, J. (2008). Continuing increases in autism reported to California's developmental services system: Mercury in retrograde, *Archived, General Psychiatry*, 65, 19-24. doi:10.1001/archgenpsychiatry.2007.1

Scioto County Jobs and Family Services. (2012). *Job and family services profile*. Retrieved June 15, 2014 from http://www.jfs.ohio?County/County_Directory.pdf

Seligman, M., & Darling, R. (2007). *Ordinary families, special children* (2nd ed.). New York, NY: Guilford Press.

Shapiro, E. (1994). *Grief as a family process: A developmental approach to clinical practice*. New York, NY: Guilford Press.

Shapiro, B., & Accardo, P. (2008). *Autism frontiers: Clinical issues and innovations*. Baltimore, MD: Paul H. Brooks Publishing.

Shelton, J., Tancredi, D., & Hertz-Picciotto, I. (2010). Independent and dependent contributions of advanced maternal and paternal ages to autism risk. *Autism*, 3, 30-39. doi:10.1002/aur.135

Shiflet, K., & Winser, A. (2002). *Parenting style and parenting stress among children*

with executive and self-regulatory problems. Poster presented at the Biennial Conference on Human Development, Charlotte, NC.

Shipler, D. (2004). *The working poor*. New York, NY: Vintage Books.

Simon, F., Sterlin, H., & Wynne, L. (1985). *The language of family therapy: A systemic vocabulary and sourcebook*. New York, NY: Family Process Press.

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

Smith, T., Polloway, E., Patton, J., & Dowdy, C. (2008). *Teaching students in inclusive settings* (5th ed.). Needham Heights, MA: Allyn & Bacon.

Smith, L., Hong, J., Seltzer, M., Greenberg, J., Almeida, D., & Bishop, S. (2010). Daily experiences for mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40, 168-178. doi:10.1007/ s10803-009-0844-y

Smith, L., Seltzer, M., Tager-Flusberg, H., Greenburg, J., & Carter, A. (2008). A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders*, 38, 876-889. doi:10.1007/s10803-007-0461-6

Swedo, S. (2012). *Advances in the treatment of autism spectrum disorders. National Institute of Health, Department of Health and Human Services*. Retrieved March 5, 2012 from http://www.nih.gov

Tani, M., Kani, C., Ota, H., Yamada, T., Watanabe, H., Yokoi, H., Iwananmi, A. (2011).

Mental and behavioral symptoms of persons with Asperger's syndrome: Relationships with social isolation and handicaps. *Research in Autism Spectrum Disorder*, 6, 907-912. doi:10.1016/j.rasd.2011.12.004

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Thousand Oaks, CA: Sage.

Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to parents of individuals with autism spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22, 34-42. doi:10.1111/j1468-3148.2008.00437.x

Teti, D., & Gefland, D. (1991). Behavioral competence among mothers of infants in the first year: The mediational role of maternal self-efficacy. *Child Development*, *62*(5), 918-929.

Tobing, L., & Glenwick, D. (2002). Relation of the childhood autism rating scale-parent version to diagnosis, stress, and age. *Research in Developmental Disabilities*, 23, 211-223.

Tomanik, S., Harris, G., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, *29*(1), 16-26.

Touliatos, J., Perlmutter, B., & Straus, M. (1990). *Handbook of family measurement techniques*. Newbury Park, CA: Sage.

Turnbull, A., & Turnbull, H. (1986). *Families, professionals, and exceptionality: A special partnership.* Columbus, OH: Merrill Publishing.

Turnbull, A., Turnbull, R., Erwin, E., & Soodak, L. (2006). *Families, professionals, and Exceptionality: Positive outcomes through partnerships and trust* (5th ed.). Upper Saddle River, NJ: Pearson/Merrill/Prentice Hall.

Umberson, D., Williams, K., Powers, D., Chen, M., & Campbell, A. (2005). As good as it gets? A life-course perspective on marital quality. *Social Forces*, 84, 493-511. doi:10.1353/sof.2005.0131

United States Department of Education. Students, Scioto County Schools. (2009). Retrieved from http://education.ohio.gov

Walsh, F. (1993). *Normal family processes* (2nd ed.). New York, NY: Guilford Press.

Walsh, F. (2006). *Strengthening family resilience*. New York, NY: Guilford Press.

Walsh, F., & McGoldrick, M. (Eds.) (1991). *Living beyond loss: Death in the family*. New York, NY: W. W. Norton & Co.

Watson, S., Coons, K., & Hays, S. (2012). *Autism and fetal alcohol spectrum disorder Part 1: A comparison of parenting stress.* (Manuscript submitted for publication).

Weiss, M. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115-130. doi:10.1177/1362361302006001009

White, S., Oswald, D., Ollendick, T., & Scahill, I. (2009). Anxiety in children and adolescents with autism spectrum disorder. *Clinical Psychology Review*, 29, 216-229. doi:10.3109/08039489309103324

Woodgate, R., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, *18*(8), 1075-1083.

Yin, R. (2009). *Case study research: Design and method*. Newberry Park, CA: Sage.

Yin, R. (2014). *Case study research: Design and method* (5th ed.). Newberry Park, CA: Sage.

Appendix A: Parental Stress Index—Short Form

Record/Profile Form

Richard R. Abidin, EdD

Instructions:

On the inside of this form, write your name, gender, date of birth, ethnic group, and marital status; today's date; and your child's name, gender, and date of birth. This questionnaire contains 36 statements.

Read each statement carefully. For each statement, please focus on the child you are most concerned about and circle the response that best represents your opinion. **Answer all questions about the same child.**

Circle SA if you strongly agree with the statement.

Circle A if you agree with the statement.

Circle NS if you are not sure.

Circle D if you disagree with the statement.

Circle SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies. SA (A) NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. **Your first reaction to each question should be your answer.**

Circle only one response for each statement, and respond to all statements. **Do not erase!** If you need to change an answer, mark an "X" through the incorrect answer and circle the correct response. For example:

I enjoy going to the movies. SA A NS (X) (SD)

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PSI-4 SHORT FORM

Answer Sheet

Name _____ Gender _____ Date of birth ____/____/____

Ethnic group _____ Marital status _____ Today's date ____/____/____

Child's name _____ Child's gender _____ Child's date of birth ____/____/____

SA = Strongly Agree **A = Agree** **NS = Not Sure** **D = Disagree** **SD = Strongly Disagree**

1. I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD
2. I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD
3. I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
4. Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
5. Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
6. I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
7. There are quite a few things that bother me about my life.	SA	A	NS	D	SD
8. Having a child has caused more problems than I expected in my relationship with my spouse/parenting partner.	SA	A	NS	D	SD
9. I feel alone and without friends.	SA	A	NS	D	SD
10. When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
11. I am not as interested in people as I used to be.	SA	A	NS	D	SD
12. I don't enjoy things as I used to.	SA	A	NS	D	SD
13. My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
14. When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
15. My child smiles at me much less than I expected.	SA	A	NS	D	SD
16. Sometimes I feel my child doesn't like me and doesn't want to be close to me.	SA	A	NS	D	SD
17. My child is very emotional and gets upset easily.	SA	A	NS	D	SD
18. My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
19. My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
20. My child is not able to do as much as I expected.	SA	A	NS	D	SD
21. It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD
22. I feel that I am: (Choose a response from the choices below.)	1	2	3	4	5
23. I expected to have closer and warmer feelings for my child than I do, and this bothers me.	SA	A	NS	D	SD
24. Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD

1. a very good parent.
2. a better-than-average parent.
3. an average parent.
4. a person who has some trouble being a parent.
5. not very good at being a parent.

SA = Strongly Agree **A** = Agree **NS** = Not Sure **D** = Disagree **SD** = Strongly Disagree

25. My child seems to cry or fuss more often than most children. ..... SA A NS D SD
26. My child generally wakes up in a bad mood. ..... SA A NS D SD
27. I feel that my child is very moody and easily upset. ..... SA A NS D SD
28. Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house. ..... SA A NS D SD
29. My child reacts very strongly when something happens that my child doesn't like. .. SA A NS D SD
30. When playing, my child doesn't often giggle or laugh. ..... SA A NS D SD
31. My child's sleeping or eating schedule was much harder to establish than I expected. SA A NS D SD
32. I have found that getting my child to do something or stop doing something is: (Choose a response from the choices below.)..... 1 2 3 4 5

    1. much harder than I expected.
    2. somewhat harder than I expected.
    3. about as hard as I expected.
    4. somewhat easier than I expected.
    5. much easier than I expected.

33. Think carefully and count the number of things which your child does that bothers you. For example, dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. (Choose a response from the choices below.)..... 1 2 3 4 5

    1. 1-3
    2. 4-5
    3. 6-7
    4. 8-9
    5. 10+

34. There are some things my child does that really bother me a lot. ..... SA A NS D SD
35. My child's behavior is more of a problem than I expected. ..... SA A NS D SD
36. My child makes more demands on me than most children. ..... SA A NS D SD

Appendix B: Sample Semistructured Interview Protocol Questions

Interview Protocol
Doctoral Study Walden University
Time of Interview:
Date:
Interviewer: Wendi Dunham, Doctoral Candidate at Walden University
Interviewee:

Brief Description of Study: This study seeks to discover the contributors of stress for parents who are raising a child with ASD in low socioeconomic rural areas.

Questions

1. Why do you believe you find yourself giving up more of your life to meet the needs of your child?

2. How does rarely being able to do the things you like to do bother you in your life?

3. How has having a child with ASD caused more problems than you expected in your spouse/parenting partner relationships?

4. Why do you believe your child reacts very strongly when something they do not like happens, such as getting used to changes in schedules or changes around the house?

5. Why do you believe your child makes more demands on you than another child would make on their parent

6. Why do you believe your child is very emotional and gets upset easily?

Thank you for participating in this study! Your privacy is a priority, and your information will remain private and confidential.

Appendix C: Scoring Tables

Table C1.

Subscale Parental Distress Scores, Frequencies and Averages/Modes

Questions 1-12	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Mode	Mean
I often have the feeling that I cannot handle things well.	2	2	4	2	4	4	4	5	5	2	4	3.4
I find myself giving up more of my life to meet my children's needs than I ever expected.	4	4	5	4	4	5	4	5	5	5	4/5	4.5
I feel trapped by my responsibility as a parent.	1	2	4	1	2	2	5	5	5	5	5	3.2
Since having this child, I have been unable to do new and different things.	4	2	4	2	2	4	4	5	5	5	4	3.7
Since having a child, I feel I am almost never able to do the things I like to do.	4	2	2	3	4	2	4	5	5	5	2/4/5	3.6
I am unhappy with the last purchase of clothing I made for myself.	4	4	5	3	5	4	5	5	2	2	4	3.9
There are quite a few things that bother me about my life.	2	4	5	5	5	4	4	5	4	4	4	4.2
Having a child caused more problems than I expected in my relationship with my spouse/parenting partner.	5	4	4	4	4	4	5	3	5	4	4	4.2
I feel alone and without friends.	2	2	4	2	5	2	4	5	5	2	2	3.3
When I go to a party, I usually expect not to enjoy myself.	2	1	4	3	5	2	2	5	1	4	2	2.9
I am not as interested in people as I used to be.	2	4	5	2	5	4	2	5	5	3	5	3.7
I do not enjoy things I used to.	2	1	4	2	5	4	4	5	4	4	4	3.5
Total Raw Scores	34	32	50	33	50	41	47	58	51	45		
Raw Score to T-score conversion	62	60	80	61	80	70	76	88	85	71		77.3

Table C2.

Subscale Parent-Child Dysfunctional Interaction Scores, Frequencies of Scores and Averages/Modes

Questions 13-24	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Mode	Mean
My child rarely does things for me that make me feel good.	1	1	2	1	4	2	3	5	1	2	1	2.2
When I do things for my child, I get the feeling that my efforts are not appreciated very much.	2	2	5	2	2	2	5	5	2	4	2	3.1
My child smiles at me much less than I expected.	2	1	4	2	4	2	4	5	2	2	2	2.8
Sometimes I feel my child does not like me and doesn't want to be close to me.	1	2	4	2	5	4	5	1	4	1	¼	2.9
My child is very emotional and gets upset easily.	4	5	5	5	4	4	5	4	2	5	5	4.3
My child doesn't seem to learn as quickly as most children.	4	1	4	5	2	2	5	5	2	5	5	3.5
My child doesn't seem to smile as much as most children.	2	2	4	5	5	4	4	5	2	2	2	3.5
My child is not able to do as much as I expected.	5	4	2	2	5	2	4	5	2	4	2	3.5
It takes a long time and it is very hard for my child to get used to new things.	4	4	4	5	5	4	4	5	2	5	4	4.2
I feel that I am: a very good parent, a better than average parent, an average parent, a person who has some trouble being a parent, not very good at being a parent.	1	1	3	1	4	2	2	1	1	5	1	2.1
I expected to have closer and warmer feelings for my child than I do, and this bothers me.	1	1	2	1	4	2	4	1	1	1	1	2.1
Sometimes my child does things that bother me just to be mean.	2	2	4	5	4	2	5	1	1	3	2	2.9
Total Raw Scores	29	26	43	36	48	32	49	43	22	39		
Raw Score to T-score conversion	59	56	76	67	81	60	83	72	51	71		67.6

Table C3.

Subscale Difficult Child Scores, Frequencies of Scores and Averages/Modes

Questions 25-36	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Mode	Mean
My child seems to cry or fuss more than other children.	4	3	2	5	2	2	4	1	2	5	2	3
My child generally wakes up in a bad mood.	2	2	4	2	2	4	2	1	2	2	2	2.2
I feel that my child is moody and easily upset.	4	5	4	4	2	4	4	1	5	4	4	3.7
Compared to the average child, my child has a great deal of difficulty in getting use to change in schedules or changes around the house.	4	2	5	5	2	4	2	5	5	5	5	3.9
My child reacts very strongly when something happens my child doesn't like.	4	5	5	5	4	4	4	5	4	4	4	4.4
When playing, my child doesn't often giggle or laugh.	2	1	4	5	2	2	4	4	2	1	2	2.7
My child's sleeping or eating schedule was much harder to establish than I expected.	4	4	4	5	2	4	5	2	2	4	4	3.6
I have found that getting my child to something or stop doing something is: ____ harder than I expected.	5	4	5	5	4	3	4	5	3	4	4/5	4.2
Think carefully and count the number of things that your child does that bothers you.	3	1	3	1	5	1	3	3	3	5	3	2.8
There are some things my child does that really bothers me a lot.	4	2	4	5	2	4	5	5	4	5	4/5	4
My child's behavior is more of a problem than I expected.	4	2	4	5	1	2	4	1	3	5	4	3.1
My child makes more demands on me than most children.	4	3	4	5	5	4	5	5	3	5	5	4.3
Total Raw Scores	44	34	48	52	33	38	46	38	38	49		
Raw Score to T-score conversion	70	58	74	79	64	63	72	63	63	76		68.2

Appendix D: Raw Score to T-Score Conversions for the PSI-SF

T-Score	PD	P-CDI	DC	TS	T-Score
≤ 100					≤ 100
99					99
98					98
97					97
96					96
95					95
94		60			94
93		59			93
92		58		180	92
91		57		177-179	91
90		56		175-176	90
89	60	55		172-174	89
88	59			170-171	88
87	58	54	60	167-169	87
86	57	53	59	165-166	86
85	56	52	58	163-164	85
84	55	51	57	160-162	84
83	54	50	56	158-159	83
82	53	49		155-157	82
81	52		55	153-154	81
80	51	48	54	151-152	80
79	50	47	53	148-150	79
78	49	46	52	146-147	78
77		45	51	143-145	77
76	48	44	50	141-142	76
75	47	43	49	138-140	75
74	46			136-137	74
73	45	42	48	134-135	73
72	44	41	47	131-133	72
71	43	40	46	129-130	71
70	42	39	45	126-128	70
69	41	38	44	124-125	69
68	40	37	43	121-123	68
67	39			119-120	67
66	38	36	42	117-118	66
65	37	35	41	114-116	65
64	36	34	40	112-113	64
63		33	39	109-111	63
62	35	32	38	107-108	62
61	34		37	105-106	61
60	33	31	36	102-104	60
59	32	30		100-101	59
58	31	29	35	97-99	58
57	30	28	34	95-96	57
56	29	27	33	92-94	56
55	28	26	32	90-91	55
54	27		31	88-89	54
53	26	25	30	85-87	53
52	25	24		83-84	52
51	24	23	29	80-82	51
50	23	22	28	78-79	50
49		21	27	76-77	49
48	22	20	26	73-75	48
47	21		25	71-72	47
46	20	19	24	68-70	46
45	19	18	23	66-67	45
44	18	17		63-65	44
43		16	22	61-62	43

T-Score	PD	P-CDI	DC	TS	T-Score
42	17	15	21	59-60	42
41	16	14	20	56-58	41
40	15		19	54-55	40
39	14	13	18	51-53	39
38	13	12	17	49-50	38
37	12			46-48	37
36			16	44-45	36
35			15	42-43	35
34			14	39-41	34
33			13	37-38	33
32			12	36	32
31					31
30					30
29					29
28					28
27					27
26					26
25					25
24					24
23					23
22					22
21					21
20					20
19					19
18					18

Note. n = 1,055-1,056. PD = Parental Distress, P-CDI = Parent-Child Dysfunctional Interaction, DC = Difficult Child, TS = Total Stress.

.

Appendix E: Final Codes and Abbreviations

Final Coding Scheme	Abbreviations
Maladaptive child behavior	MCB
Parental respite	PR
Increased parental response	IPR
Predictable environment	PE
Unpredictable child behavior	UCB
Parental isolation	PI
Perceived misbehavior-others	PM-O
Economic distress	ED
Marital disconnection	MD
Defensive spousal relationships	DSR
Parental explanations-others	PE-O
Insufficient supports available	ISA
Professional mistrust	PM
Parental self-expectations	PSE
Unfair parent role division	UPRD
Sibling equality guilt	SEG
Unknown behavior response tactics	UBRT
Inappropriate self-regulation	ISR
ASD management skills	AMS
Ineffective coping skills-parent	ICS-P
Ineffective coping skills-child	ICS-C
Sensory over-stimulation behavior	SOSB
Self-guilt	SG
Fear of child protection	FCP
Repetitious behavior	RB
Child protection	CP