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The Lived Experiences of Low Income Parents of Children with Autism

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This is to certify that the doctoral dissertation by

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Walden University
2017

Abstract

Lived Experiences of Low-Income Parents Raising Children With Autism

by

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MA, Mercer University School of Medicine, 2002

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

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Abstract

Previous studies indicated that parents raising children with autism (CWA) experience higher rates of stress; however, no qualitative studies have addressed low-income parents' lived experiences of raising CWA. The purpose of this hermeneutic phenomenological study was to understand the challenges that low-income parents of CWA face daily within the framework of family systems theory and biopsychosocial theory. Research questions focused on the impact of income and the core symptoms of autism (social deficits, communication deficits, and repetitive behaviors) on marital and interpersonal relationships. Semistructured interviews with 13 parents were conducted, and transcripts were analyzed for themes using a 4-step process. Results indicated some negative impacts on parents' marital, social, and professional relationships. Themes included higher levels of stress and depression, decreased social interaction, less personal and professional satisfaction, and lower levels of marital satisfaction. Findings may be used to increase empathy and understanding of parents' challenges and improve access to resources and services required for CWA and their parents to enhance their quality of life.

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Dedication

This dissertation is dedicated to my family for their patience while I completed my academic journey. Without your support and encouragement, I would not have made it to the end so “Thank you all!” Family members include but are not limited to my husband, Michael Sullivan, my daughters, sons-in-law, and granddaughter, Steven, Amber, Zaylee Mason, and Daniel, Ashley and Caroline Garrett; my mother, Mary Ann Langford; my mother-in-law, Diana Glover; my brother, Chuck Langford, Jr.; my aunts, uncles, cousins, nieces, nephews, and numerous friends and coworkers who have supported me through the years in this quest. A special thanks to my esteemed colleagues, Dr. Juanita Sibayan, Dr. Susan Ruiz, Dr. Michelle Saari, and Dr. Heather Chapman for your support throughout our educational journey together. Although they were not able to see my goal come to fruition, I also thank Charles Langford, Sr. (Daddy), William Carlton, and Ella Mae Langford (my paternal grandparents), and Thomas and Belle Paul (my maternal grandparents) for their love and support. Most of all, I thank God for giving me the strength, motivation, and determination to achieve this goal.

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Chapter 1: Introduction to the Study

Parents of children diagnosed with autism (PCWA) face unique stressors (Anderson, 2010; Bebko, Konstantareas, & Springer, 1987; Cappe, Wolff, Bobet, & Adrien, 2011; Davis & Carter, 2008; Mount & Dillon, 2014) that separate them from parents raising children with other developmental disorders (Hall, Neely-Barnes, Graff, Krcek, Roberts, & Hankins, 2012; Neely-Barnes & Dia, 2008; Wang, Trancredi, & Thomas, 2011). Most of the support for children with disabilities comes from their families, which includes parents and siblings, as well as grandparents, in many cases (Neely-Barnes & Dia, 2008). Neely-Barnes and Dia (2008) reported both positive and negative experiences for parents raising children with autism. Although the disability affects the family in terms of time, emotional resources, and financial resources to help care for the child with autism (CWA), some parents believe their families have grown personally and spiritually and see their child with a disability as a reward (Neely-Barnes & Dia, 2008).

Anderson (2010) identified the top three areas of stressors for PCWA: (a) worrying about the child’s future, grieving the child’s diagnosis, and the difficulty of locating and securing appropriate services; (b) confusion when their child does not respond to their affection, does not maintain eye contact, and does not want to be held; and (c) the child’s problematic behaviors, which include tantrums, refusal to sleep, and extreme rigidity. Anderson pointed out that when these challenges are present, a parent is more likely to experience depression as he or she grieves for the child’s future and struggles to find and obtain resources to help provide the child with the best quality of life possible.

According to the Centers for Disease Control and Prevention (CDC, 2013), the three most commonly diagnosed developmental disabilities are (a) ADHD, which increased from 7.8% in 2003 to 11.0% in 2011; (b) cerebral palsy, which occurs in 1 of 303 children; and (c) autism, which occurs in 1 of 88 children. Intellectual disabilities (also known as mental retardation), which occur in 1 of 10 U.S. children between the ages of 6 and 21 years, ranked 7th out of the 10 developmental disabilities (CDC, 2013). The rate for autism is 1 in 68, indicating an increase in diagnoses in 2 years (CDC, 2015).

The *Diagnostic and Statistical Manual of Mental Disorders-5* (DSM-5; American Psychiatric Association [APA], 2013), listed three hallmarks of autism that include impairments in social interactions, communication deficits, and repetitive or stereotypical behaviors. Autism is one of seven neurodevelopmental disorders listed in the DSM-5 (APA, 2013). A plethora of research is available regarding parental stress and marital satisfaction for parents raising children with autism (Brobst, Clopton, & Hendrick, 2009; Chew, 2007; Duba, Hughey, Lara, & Burke, 2012; Eddy & Walker, 1999; Freedman, Kalb, Zablotsky, & Stuart, 2012; Grosso, 2011; Hartley, Baker, Baker, Seltzer, & Greenberg, 2012; Pisula & Kassakowska, 2010; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). However, few qualitative studies have specifically addressed the lived experiences of parents raising children with autism, particularly those without financial means to seek the resources their child may need to increase the child and the parent's quality of life. According to Parish, Thomas, Williams, and Crossman (2015), parents who are privately insured and raising CWA spend about 5 times more for out-of-pocket expenses compared to families who are publicly insured. Parents typically spend about $9.70 per $1000 on medications, outpatient services, and dental care (Parish et al., 2015). Lavelle et al. (2014) reported the bulk of the cost for autism on a national level was $8,610 per child per year to cover special education expenses; $3,020 per year was spent on medical expenses. As of 2011, the cost for autism on a national level was $137 billion per year, but that cost has increased to $2.3 billion per year currently as the rates of autism have increased (Lavelle et al., 2014). For CWA who are between ages 3 and 17, the cost is more than $17,000 per year, which can place a financial burden on parents (Lavelle et al., 2014).

In a qualitative study of PCWA in rural areas of Canada, Hoogsteen and Woodgate (2013) found that autism was practically invisible to community members as a disorder because the child typically looked and talked like most other children until the child demonstrated disruptive behaviors, such as tantrums, meltdowns, and yelling. At this point, community members often attributed the behaviors to a “bad” child or poor parenting (Hoogsteen & Woodgate, 2013). Limited qualitative research is available on the lived experiences of low-income parents raising CWA. The present qualitative study was conducted to gain a better understanding of the lived experiences of these parents and the phenomenon of raising CWA with limited financial resources, as well as the impact autism has on the marital and family relationship. The CDC (2013) has attempted to raise public awareness of autism spectrum disorders (ASDs) since 2008. The aim of the current study was to raise awareness of the challenges that low-income PCWA face daily in their quest to obtain services needed to provide their children with the best quality of life possible. Findings may encourage professionals to develop effective programs to assist these families. The interview questions were used to explore the lived experiences of parenting a child with autism when financial resources are limited. The participants' responses provided a better understanding for readers of what low-income PCWA experience daily, which resources parents found most conducive to promoting a better quality of life for their child, and how child-related stressors affected their family. The goal of this study was to promote social change by increasing public awareness, providing first-hand information to professionals of resources low-income PCWA need, and promoting empathy for these parents and their children.

One of the hallmarks of autism is the presence of a severe communication deficit. Communication is defined as a mutual exchange of information between two or more people to express ideas, thoughts, opinions, and feelings, as well as words, sounds, signs, or behaviors, and is essential throughout a person's lifespan not only to meet individual needs, but also to achieve goals (Autism Society, 2013). Communication is essential for mutual understanding and requires the knowledge and the use of language or acquisition of spoken language (Dahlgren & Sandberg, 2008; Ingersoll, 2010). Dahlgren and Sandberg (2008) pointed out that CWA have delayed development in referential communication skills, which prevents them from adapting to the listener's needs. In addition, CWA are unable to understand the other person's perspective and may also experience linguistic factors that can cause a delay, an absence of spoken language, or difficulties in comprehension (Dahlgren & Sandberg, 2008). This may increase parental stress. In one of the first studies that compared parental stress with the symptoms of autism, Bebko et al. (1987) found that parents rated cognitive and communication deficits as the most stressful symptoms of autism. When a child is unable to use meaningful language to communicate with others, he or she resorts to nonverbal forms of communication, which can present a challenge for parents as they struggle to decipher the child's needs (Bebko et al., 1987).

Researchers are increasingly aware that raising a child with developmental disabilities (CDD) can produce even more stress for parents when they face additional stressors, particularly communication deficits, compared to parents raising typically developing children (TDC) (Anderson, 2010; Bebko et al., 1987; Daniels et al., 2008; Davis & Carter, 2008; Moore & Vandivere, 2000). Additional stressors may include problems with sensory, motor, emotional, behavioral, or cognitive functioning associated with their child's disability (Brobst et al., 2009; Davis & Carter, 2008; Weiss & Lunsky, 2011). Mount and Dillon (2014) found that parenting an adolescent child with autism presented unique parenting stresses. These stressors compromise marital quality and overall marital satisfaction and lead to a conflictual marriage for parents of a developmentally disabled child; even when the couple is satisfied with their marriage, they are often negative about the quality of their marriage (Parker, Mandleco, Roper, Freeborn, & Dyches, 2011). However, some researchers (Bayat, 2007; Hartley et al., 2012) pointed out that families of CWA can be quite resilient and parents can be quite satisfied with their marriage. Hartley et al. (2012) found that a higher household income, as well as the closeness of the mother–child relationship, determines higher levels of marital satisfaction for PCWA.

Previous quantitative studies have indicated that PCWA experience unique stressors when raising children with autism, which include behaviors such as physical, impulsive, and verbal outbursts; food-related issues; social perceptual issues; lack of spontaneity for parents; inflexibility; views from other people about their child's behaviors or autism; and communication difficulties with the child (Mount and Dillon, 2014). Participants in Mount and Dillon's (2014) study reported that these difficulties also have an impact on relationships with partners, others in the family (e.g., siblings and other relatives), and communication with CWA. These difficulties can lead to parental feelings of frustration, guilt, regret, uncertainty, and fatigue as parents struggle to cope with the ASD diagnosis (Mount and Dillon, 2014).

Very few qualitative researchers have addressed the lived experiences of lower income parents raising children with autism and the impact that a lack of finances has on parental stress and the marital relationship. One qualitative study (Hoogsteen and Woodgate, 2013) focused on the lived experiences of parents raising children with autism in a rural area, but the purpose was to promote autism awareness to the community members to enhance an overall understanding of the struggles parents raising children in rural areas face. A total of 26 Canadian families participated in the study, most whom were Caucasian, and of the participating children, only 21% were nonverbal (Hoogsteen and Woodgate, 2013).

Falk, Norris, and Quinn (2014) found that significant factors affecting parental mental health included a lack of socioeconomic support and parental cognitions, more so than autism symptom severity and maladaptive behaviors, as reported in previous studies. Falk et al. also pointed out that more attention had been given to mothers than to fathers in previous research. According to Falk et al., results from their study indicated that a mother's age was a strong predictor of increased anxiety; in addition, child aggression toward adults led to higher levels of depression, along with a perceived lack of social support and an externalized parental locus of control. For fathers, satisfaction with parenting led to higher levels of depression, father's age led to higher levels of stress, and the child's aggressive behavior led to elevated levels of anxiety. Falk et al. concluded that the severity of autism symptoms and the child's externalizing behaviors did not directly influence parental psychological distress; rather, the combination of the two variables, along with parental cognitions and perception of socioeconomic support, led to higher levels of distress across both genders.

Hoogsteen and Woodgate (2013) reported that parents felt autism was an invisible disorder to most people in their rural area because they received comments that their child looked normal; however, when their child had tantrums in public, those same community members contributed the child's behaviors to poor parenting or to an uncontrollable child. Socioeconomic status, particularly financial status of participants, was not addressed in this study. However, participants believed that because they lived in rural areas, resources to help them provide a better quality of life were absent, leaving them to raise their children without necessary resources and daily services that are present in more populated areas (Hoogsteen and Woodgate, 2013).

Hermansen and Miller (2008) conducted a qualitative study to better understand the lived experiences of mothers of children with ADHD undergoing chiropractic care. Similar to the experiences of PCWA, the ADHD child’s demands for frequent attention from parents or caretakers were often blamed on poor parenting (Hermansen & Miller, 2008). In addition, mothers reported higher levels of stress as they had to alter their schedules and daily activities because they never knew what may happen with their child. One mother reported that her entire family had adjusted due the child’s ADHD, particularly in terms of a regular daily routine and diet. One parent noted that when her child was unable to do something she wanted to do, it often took 2 hours for the child to calm down and she and the rest of her family had to learn to simply wait it out, although she did get frustrated at times (Hermansen & Miller, 2008).

A gap existed regarding the lived experiences of PWCA who have lower incomes. The present study addressed the accounts, beliefs, and lived experiences of parents, as well as their stress and marital satisfaction while raising CWA from a family systems perspective. Cridland, Jones, Stoyles, Caputi, and Magee (2015) pointed out that family systems theory should be incorporated when working with families who have a child with a disability such as autism because each member has a specific role within the family system, and roles may change as members assume more responsibility to care for the CWA.

Both qualitative and quantitative studies have indicated that parents who received an early diagnosis for their child (Baird, Cass, & Slonims, 2003; Neely-Barnes & Dia, 2008) and those who also received mental health treatment themselves were able to significantly reduce their overall stress levels (Benjak, Mavrinac, & Simetin, 2009; Mungo, Ruta, D'Arrigo, & Mazzone, 2007; Smith, Romski, Sevick, Adamson, & Bakeman, 2011). In addition, parents who received treatment experienced reduced marital stress, improved physical and mental health, better coping strategies, more effective communication with the CWA, and improved overall quality of their marital relationship (Davis & Carter, 2008; Smith et al., 2011). Although several qualitative studies have been completed, only one focused on the lived experiences of PCWA in rural areas, and none focused on the lived experiences of low-income PWCA. The present study addressed the lived experiences of PCWA with limited financial resources to gain insights as to how raising a CWA impacts a parent's mental health and marital relationship from the parent's perspective.

Background

Autism is considered a spectrum disorder because of its complexity and the varying degrees of characteristics that include "impairments in social interaction, imaginative ability, verbal and nonverbal communication skills, and a limited number of interests and activities that tend to be repetitive" (Tsai, 2003, p. 2). Individual symptoms range from a mild form in which only a few symptoms are displayed at school or in the neighborhood, to more severe forms in which symptoms are expressed in all areas of life (Tsai, 2003). Those who suffer from autism may also suffer from some degree of mental retardation (APA, 2013). CWA experience significant social impairments and have difficulty establishing friendships with others because they lack the ability to maintain eye contact and have difficulty understanding and recognizing facial expressions, body language, and gestures (APA, 2013). Younger CWA may not be as disturbed as older children are by their inability to develop friendships with others because they are often oblivious to those around them, including others who may be in distress.

CWA experience significant language problems that can range from delayed language development to a lack of spoken language (APA, 2013). According to APA (2013), even when a child with autism speaks, the child is frequently unable to participate fully in conversations with others because he or she experiences problems with speech, grammar, and comprehension. CWA are unable to participate fully in a meaningful conversation with others because they lack social imagination and are very spontaneous. Grammar usage is often quite immature and stereotypical in that CWA may repeat all or parts of a sentence they have heard before, including jingles and commercials. CWA may also demonstrate inappropriate speech skills, which include tone of voice, pitch, rate, and rhythm, and may incorrectly emphasize the wrong syllables. In many cases, these children are verbally engaged in idiosyncratic language and can only be understood by those with whom they are most familiar (Grandin, 1984). Due to problems with comprehension, CWA often have difficulty understanding questions and following directions, requiring simple and concrete one-step directions (Grandin, 1984).

Bolman (2006) reported that although the source is unknown, a statistic that has plagued parents has been the claim that the divorce rate is 80% for parents raising CWA.

According to a survey conducted by Harris Interactive (2008), parents of children with no special needs had a divorce rate of 39% (*n* = 866) whereas parents of those with autism had a divorce rate of 30% (*n* = 1,573). Based on these statistics, the rate of divorce is 25% lower in PCWA, and of the 475 families of CWA who were divorced, only one third believed raising a child with autism had anything to do with their divorce (Harris Interactive, 2008). Bolman agreed that although the statistic of 80% has been used repeatedly to identify the number of divorces occurring in families of CWA, no data are available to support this claim.

Freedman et al. (2012) assessed divorce rates of parents raising CWA and found that while raising CWA does create a significant amount of stress between partners, the rates of divorce for participants were no different from those of typical couples. Freedman et al. were unable to find empirical support for 80% divorce rate claim for PCWA after conducting a study using information from the Kennedy Krieger databank. Freedman et al.'s results were important because they indicated that parents raising CWA were no more prone to divorce than parents raising children without autism. Sobsey (2004) pointed out that a great deal of available research had indicated that parents raising CWA are doomed, but Sobsey found that there was no statistical difference in divorce rates of parents raising CWA compared to parents raising TDC. In addition, Sobsey found that of the PCWA who were divorced, marital problems predated the child's disability, indicating that divorce was not the result of the child's disability.

Bolman (2006) argued that communication is vital in family relationships. Factors that contribute to higher levels of stress among couples that can affect the entire family over time include communication challenges, misunderstood social cues, and a lack of emotional understanding (Bolman, 2006). Other stressors include obtaining a proper and accurate diagnosis, locating resources including adequate education by properly trained teachers to help the child, learning to manage autistic behaviors, and balancing the typical daily demands of any family, particularly those with CWA (Bolman, 2006).

Bolman (2006) found that while most fathers of children with autism went to work, mothers stayed home to take care of the child, which often led to financial challenges from having only one income. When the father returned home, he became frustrated with the mother's attempts to have him play with and interact with the child because the father had no idea how to play with a child with autism (Bolman, 2006). Bolman theorized that over time, frustration from this and other demands contributes to a collapse in the marital relationship for which couples typically do not seek counseling. The continuous buildup of stress may contribute to an increasing rate of divorce among families of CWA, more than how the couple functions as parents. A gap existed regarding the lived experiences of PWCA who have lower incomes. This study addressed the lived experiences of low-income parents raising CWA.

Problem Statement

Previous research supported the idea that parenting children can be stressful and expensive, particularly when raising children with special needs (Anderson, 2010; Brobst et al., 2009; Davis & Carter, 2008). Previous quantitative research focused on comparing the stressors of PCWA and PCDD with the stressors of parents of children without special needs and the toll on the marital relationship (Benson & Dewey, 2008; Daire, Munyon, Carlson, Kimemia, and Mitcham, 2011; Duba et al., 2012; Eddy & Walker, 1999; Hartley et al., 2010; Mungo, Ruta, D'Arrigo, & Mazzone, 2007; Parker et al., 2011; Pisula, 2007; Rao & Bidel, 2009; Schieve et al., 2007; Tehee, Honan, & Hevey, 2009).

Although it is apparent that autism requires extensive and expensive treatment and support, the problem remains that it is not known how low-income parents experience raising a child with communication deficits or how the low income and CWA affect the family system. Providing low-income parents the opportunity to share their feelings, express their concerns, and suggest possible solutions for coping with an uncommunicative child has the potential to enhance the understanding of professionals and other parents living with these difficult children. The present study addressed the lived experiences of raising a child with autism and the impact on low-income parents, as well as the family in general.

Purpose of the Study

The purpose of this study was to explore how raising a child with autism has impacted PCWA and their families. I analyzed the parents' perceived experiences to identify specific stressors they felt negatively impacted themselves, their CWA, their families, and their marital satisfaction and whether they perceived that their finances affected their child's care. Research supported the fact that parental stress levels are higher in those raising children with special needs (Moore & Vandivere, 2000), particularly those raising CWA (Anderson, 2010), but very little was known about the lived experiences of PCWA with limited finances.

According to the United States federal poverty guidelines (Healthcare Facility Regulation, 2015), a family of four is living in poverty if the annual income is $24,250 ($2,021 monthly) or less (see Appendix C). In the state of Georgia, a family of four is considered indigent if the annual income is $30,313 ($2,526 monthly), which is 25% above the federal poverty guideline. Because some people do not qualify as indigent but have lower incomes that challenge their ability to provide for their families, eligibility for participation was also defined by the U.S. Department of Education (2017) based on the size of the family unit and income tables for Medicaid and Peach Care for Kids as outlined in the Income Guidelines for Parents, Caregivers and Kids from the Georgians for a Healthy Future (2016). For example, a family of four with a child age 0 to 1 and an income of $50,926 or less was eligible to participate in this study; a family of four who had a child age 4 to 18 with autism and an income of $33,552 was eligible to participate.

In the current study, understanding the impact of poverty on parental stress and the ability to obtain necessary services may encourage health care providers to include parental needs in the diagnosis and treatment of CWA. Providers may suggest, develop, and provide affordable services to enhance parental coping skills and thereby strengthen the quality of marital and family relationships, which could lead to positive social change in terms of fewer divorces which could have a positive impact on the entire family and their overall level of functioning, including their interdependence on each other.

Research Questions

1. How do low income parents describe their daily lived experiences of raising a child with autism?

2. What effects does the CWA’s communication deficit have on parental stress, if any?
3. How do parents describe their relationships with family members and their social experiences outside the home?
4. How do parents indicate their child’s autism has impacted their marital relationship and family?

Theoretical Framework for the Study

Engel (1980), a cardiologist, introduced the biopsychosocial model as an alternative to traditional medical treatment for patients. The biopsychosocial model was used to examine the contribution of stress in parenting children and overall marital satisfaction. This model was chosen for this study because it focuses on parental physiological and psychological well-being from a holistic perspective, considering the effects of a person’s environment (socio) on his or her mental health (psycho) and the impact of those from a physiological (bio) perspective of the quality of overall health (Lakhan, 2006).

Gaining an understanding of what PCWA perceive to be their greatest stressors may provide insight that will guide professionals in developing treatment plans from a biopsychosocial perspective to also include the PCWA, as well as the CWA, which may reduce parental stress. A diagnosis of autism not only affects the child, but also affects the entire family as it presents unique challenges (Cridland et al., 2014). A CWA often requires assistance from family members for attending to daily basic self-care needs, communication, cognitive and emotional tasks, and mobility (Cridland et al., 2014).

Sudden mood changes can lead to challenging behaviors and can disrupt a regular daily schedule, thereby mandating a need for flexibility (Cridland et al., 2014). The sudden mood changes can also decrease spontaneity and social interactions (Cridland et al., 2014).

Hermansen and Miller (2008) applied the biopsychosocial model in their study of children with ADHD receiving chiropractic care. The authors pointed out that, like children with autism, children with ADHD are often labeled as problem children due to their behaviors, and ADHD, like autism, has a strong psychosocial component because not everyone accepts the diagnosis and parents are often seen as the blame for the behavioral problems in their children. As Engel's focus shifted from disease to health, Hermansen and Miller stated that social support, in conjunction with doctor-patient interactions, parental involvement, and the use of pharmacological or other treatments, could lead to improved overall health of the child and parent as symptoms of ADHD were decreased.

PCWA may experience stress at a more intense level than those with typically developing children but Freedman et al. (2012) reported that divorce rates for families raising children with autism are much lower than the reported 80%. Stress levels and possibly divorce rates may decrease among PCWA if specific measures are taken to provide parents with resources discussed in the current study to eliminate some of the stressors, improve marital satisfaction, and promote a happier and physically and psychologically healthier family members. Bayat (2007) suggested that families of CWA develop strengths that make them resilient. These strengths include connectedness and closeness, attributing a positive connotation and applying meaning to autism, and spiritual and personal growth. These factors can foster a healthier and happier marriage and illustrate the combination of factors that lead to the benefit of employing the biopsychosocial model when working with families of those with autism.

Singer, Ethridge, and Aldana (2007) reported that of 17 studies they reviewed, all focusing on the catastrophic effects of raising a CDD, there are treatments such as cognitive-behavioral therapy that can be used to teach parents effective strategies for handling their children’s negative behaviors. Cognitive-behavioral therapy is more effective in reducing parental stress when presented over an extended period, particularly for mothers, but may also be helpful for fathers (Singer, 2007). Previous studies focused on the biopsychosocial model when considering the impact on the family, but very few focused on family systems theory as an approach to working with families of children with autism (Cridland et al., 2014; Cridland et al., 2015). Family roles change as each member assumes increased responsibilities including assisting the CWA with daily living and basic care needs, meal preparation, toileting, and hygiene, as well as managing financial burdens (Cridland et al., 2015). Parents may work longer hours due to the financial costs of necessary services, including therapies, treatments, and educational services, to ensure the best quality of life for the CWA. When both parents work outside the home, Cridland et al. (2014) pointed out that older siblings often must take on a parent-like role as they assume responsibilities to care for the CWA until the parents return home. PCWA experience unique stressors that can impact their lives, but they can also impact the entire family as everyone works together to help the CWA. Gaining an understanding of perceived stressors for PCWA may provide necessary insights for professionals in terms of treatments, services, and other resources that will not only help the CWA, but the PCWA as well.

Nature of the Study

I chose a qualitative hermeneutic phenomenological method for this study instead of a quantitative method because I focused on the subjective experiences of individuals and groups (see Kafle, 2011) as participants shared their personal stories and perspectives of raising a CWA. This method provided a rich, clear view of participants' daily lived experiences that led to a better understanding of the impact autism has on families. This method also allowed any resurfacing themes to emerge in collected data; because responses were recorded, researcher biases were minimized.

This hermeneutic phenomenological study focused on understanding how the lived experiences of low-income parents raising children with autism impacted their overall stress and marital satisfaction. This specific method provided firsthand insights from the perspective of PCWA regarding their daily lived experiences and the role autism plays in their interpersonal relationships and overall family functioning. These personal perspectives provided insights regarding the biological effects of autism on the family, as well as adjustments families have made in their psychological and social functioning. This information, from a biopsychosocial perspective, could lead to social change for families of CWA, as well as the general population. The information from the current study provided a better understanding of how autism affected overall family functioning as viewed through the lens of family systems theory. The transcendental phenomenological design is further discussed in Chapter 3.

Creswell (2007) outlined eight verification steps to ensure reliability and validity to provide credibility in a qualitative study. These steps include the appropriateness of the research questions, researcher bias, and validity of the research and triangulations of the data. These processes are discussed in greater detail in Chapter 3.

Interview data was analyzed using a chart that focused on theme identification, exploratory analysis, open coding, text analysis, and qualitative research methods, the essential techniques used to identify themes for qualitative data (Ryan & Bernard, 2003). The resulting themes provided useful information about the participants' lived experiences regarding parental stress of raising children with autism, communication deficits between the parents and the child, and the role stress plays in marital satisfaction of the couple. The study results and emerging themes and analysis are discussed in Chapters 4 and 5.

Definitions of Terms

Autism: A complex neurodevelopmental disorder that consists of communication deficits, social impairments, and restricted or stereotypical behaviors, interests, or activities. These behaviors are present on a wide spectrum in children prior to 36 months of age (Karande, 2006).

Autism spectrum disorder (ASD): The wide range of developmental disorders that include impairments in the formation of (a) social interaction; (b) language, communication, and imaginative play; and (c) interests and activities (Muhle et al., 2004).

Childhood schizophrenia: A chronic, debilitating illness that involves hallucinations, delusions, and irrational behavior and thinking and has a profound effect on functioning ability, making it difficult to carry out daily routine tasks (Mayo Clinic, 2008).

Infantile autism: A syndrome appearing by 36 months that involves disordered language and cognitive skills; impaired social interactions; abnormal responses to sensory stimuli, events, and objects; poor eye contact; an insistence on sameness; an unusual capacity for rote memorization; repetitive and stereotypic behavior; and a normal physical appearance (Kemper & Bauman, 1998).

Pervasive developmental disorders (PDD): Disorders that result from delays in the development of socialization and communication skills (National Institute of Neurological Disorders and Stroke, 2009). Parents sometimes notice symptoms in infancy, although onset is typically at 3 years of age. Characteristics include difficulty using or understanding language, social difficulties, unusual play with toys, difficulty with changing routines, and repetitive body movements. Examples include Asperger's syndrome, childhood disintegrative disorder, and Rhett's syndrome (National Institute of Neurological Disorders and Stroke, 2009).

Assumptions

This study was based on the following assumptions: (a) participants were truthful in all their disclosures and (b) participants were able to articulate their emotional state and experiences.

Scope and Delimitations

Participants were recruited from online autism support groups in Georgia found on social media and from a local college. Flyers requesting participation in the study were sent electronically to each organization. Flyers were posted in strategic locations for a period of 3 weeks on a local college campus. The flyers included my contact information and an e-mail created specifically for this study. All participants had computer access and responded to flyers via e-mail, telephone, or private message through social media. I responded and e-mailed a disclosure statement of the purpose and topic of the study, along with an informed consent that explained the participant’s rights, an eligibility survey, and a brief demographic survey. These items were sent via e-mail to all participants electronically and upon return receipt and confirmation of the participant’s eligibility, interviews were scheduled.

I recruited 13 low-income parents of CWA who met the study’s inclusion criteria: (a) the participant had an annual income equivalent or below the federal poverty level or was within range specified by the U.S. Department of Education (2017), (b) the participant has lived with the CWA for a period of at least 1 year after the child was diagnosed with autism, and (c) the participant’s child had a definitive diagnosis of autism for a minimum of 1 year. Participants were all biological mothers, although the study was open to fathers of CWA. The exclusion criteria consisted of a participant who never lived with the other biological parent of the CWA or who did not otherwise meet the inclusion criteria.

Limitations

A limitation of this qualitative study was the inclusion of only mothers, seven of whom worked outside the home on at least a part-time basis, who assumed the primary role of caring for the child. I expected that more participants would be men. Future research addressing the perceptions, beliefs, and attitudes of fathers raising children with autism and the impact it has on their stress level in comparison to mothers, and their overall marital satisfaction would be interesting.

Significance of the Study

Although researchers have established assessment and treatment modalities for CWA, no qualitative studies have been conducted with low-income parents to explore their lived experiences of raising a child with autism from a biopsychosocial and family systems perspective. Contributions from the present study included gaining a better understanding of the lived experiences of raising a child with autism and the impact autism has on low-income parents, as well as the family in general. This understanding is vital for physicians and other professionals, especially mental health professionals such as psychologists and therapists who work directly with PCWA, who could contribute to enhancing the quality of life of these individuals. Speech therapists and teachers, who also work with CWA and their parents, may also find the results helpful.

When professionals are aware of the types and intensity of the stressors these parents face daily, particularly when communication problems exist between the parent and child, professionals can exercise more patience and understanding when working with the child and the parent, thereby causing the parents to feel more supported. Providing a list of low-cost resources to parents that includes marriage therapy, stress-management groups, or autism-support groups may decrease parents' stress and increase marital satisfaction, resulting in better overall family functioning. Findings may lead to positive social change by allowing physicians and other professionals, teachers, parents, and others to focus on supporting organizations and institutions already in place, as well as creating new ones that would significantly improve the quality of life for CWA and their parents who may become emotionally or physically overwhelmed.

In addition to focusing on the child, professionals must not forget the needs of the parents and must provide them with essential resources to lessen the stress of caring for their child as much as possible. If parents can reduce their individual stressors, this may lead to improved psychological well-being and may promote stronger and healthier marriages that will fortify the family system. The results from the current study also provide helpful information for researchers in future studies.

Summary

Researchers agreed that most parents experience daily stressors, such as juggling work, household chores, childcare, and finances, and many agree that PCWA have additional stressors that can have a negative impact on their marital relationship, if not handled appropriately (Benson & Dewey, 2008). Family systems theory suggests that the increased responsibilities of parents and siblings can lead to changes within the family system as roles change so everyone can focus more on assisting the CWA (Cridland et al., 2015). The purpose of this study was to explore the lived experiences of lower income PCWA and their ability to provide essential services, treatments, and other resources necessary for a higher quality of life for their child, while they strived to reduce their own stress levels and maintain a satisfactory marital relationship. Chapter 2 provides a review of relevant research and literature pertaining to the rising rates of autism, the increased awareness of autism, the intensity of the stressors that accompany CWA, and the impact stressors have on the overall quality of the marital relationship.

Chapter 2: Literature Review

Lower income PCWA may not receive the same, or the same level, of services and resources necessary to raise their children as PCWA with higher incomes. The inability to provide necessary resources for the CWA may affect the PCWAs' psychological well-being, as well as their marital relationship, after a diagnosis of autism has been received. This may present new and significant challenges for parents that may exacerbate parental stress and any dysfunction that may already exist in the marital relationship. This study addressed PWCAs' perceived experiences to determine specific stressors they felt negatively affected them, their CWA, their families, and their marital satisfaction, and the role limited finances played in their overall lived experiences.

When children are first diagnosed with autism, many parents feel alone and are not sure where to turn for assistance (Lord & McGee, 2001). Due to the specific and unique demands of caring for a CWA, some parents may be forced to choose between continued employment and quitting their job to stay at home to care for the CWA. A reduction of income could negatively affect family finances and increase tension between the couple (Benson & Dewey, 2008). Stressors may overwhelm parents to the point that some may experience physical and psychological health issues such as heart attack, digestion problems, ulcers, depression, anxiety, and other mental health issues that could lead to increased conflict with their spouse (Montes & Halterman, 2007; Mungo et al., 2007).

The present literature review is divided into three main sections. In the first section, literature on ASD is reviewed to give readers information about its origin, characteristics, and symptoms. In the second section, literature on parental stressors and marital satisfaction is reviewed to increase the reader's awareness of the unique stressors experienced by PCWA, as well as how these impacted overall marital satisfaction. In the third section, literature on the benefits of incorporating the biopsychosocial model and family systems theory when providing treatment is reviewed to describe how families of CWA are impacted from a biological, psychological, and social perspective. Treatment that focuses on the entire family leads to a better quality of life for the CWA, as well as for the entire family (Cridland, Jones, Magee, and Caputi, 2014).

Hall et al. (2012) found that PCWA suffered higher levels of stress and experienced less family resiliency when they failed to communicate with each other or when they failed to work together to problem solve or develop positive coping strategies. Results suggested that increased social support, positive appraisals, the ability to obtain more resources, and the ability to work together to problem solve and develop positive coping strategies helped couples enjoy higher levels of family resiliency (Hall et al., 2012). Hartley et al. (2012) found that despite an ASD diagnosis, married couples could support each other and cope with challenges associated with raising a child with autism, but marital discord could appear if fathers felt disconnected from their child.

Divorce rates among PCWA have been estimated to be up to 80% (Bolman, 2006.) Although researchers have been unsuccessful in locating a scientific study that supports this statistic, it has caused widespread concern among couples in the autism community. According to Freedman et al. (2012), couples who hear the statistic after learning their child has been diagnosed with autism often view autism and divorce as dual diagnoses. Although all couples experience stress in their daily lives, especially when raising children, PCWA experience additional stressors in obtaining a quick and definitive diagnosis that leads to the task of locating the most appropriate treatment for their child based on the child's specific needs (Benson & Dewey, 2008; Rao & Beidel, 2009).

Results from a survey conducted by Harris Interactive (2008) indicated that 1,136 children between the ages of 8 and 17 (91%) stated they knew their parents were stressed and could see it manifested in their behaviors. Of these participants, 39% felt sad and worried, 31% felt frustrated, 24% were annoyed, 21% felt helpless, 14% reported they were not bothered, 13% felt angry and scared, 8% felt alone, and 2% indicated other. Of participants, 34% indicated that their parents yelled when stressed, 30% indicated that parents argued with household members, and 18% reported their parents often told them they were too busy and "didn't have time."

The present study addressed the lived experiences of low-income PCWA to gain insights as to how raising a child with autism impacted a parent's mental health and marital relationship from the parent's perspective. Although several qualitative studies had been completed, only one focused on the lived experiences of parents of children with autism in rural areas. None focused on low-income parents raising children with autism and their lived experiences.

Literature Search Strategy

Research articles were obtained through searches in EBSCOhost, Medline, PsycINFO, ProQuest, SAGE, GALIELO, PsycARTICLES, SocIndex, and Dissertation

Abstracts International. Key search terms included *parental stress*, *marital satisfaction*, *communication*, *developmental disabilities*, *parental stress*, *poverty*, and *autism.*

History and Etiology of Autism Spectrum Disorder (ASD)

Autism is a major focal point for many researchers, yet it is also one of the most controversial topics in the field of psychology. Autism is defined as a complex behavioral syndrome with a neurodevelopmental origin that involves deficits in social interaction, language and communication, and bizarre or repetitive behaviors or mannerisms (Baird et al., 2003; Browndyke, 2002). Due to the complexity of symptoms, autism is classified as a spectrum disorder because symptoms can differ from child to child in terms of severity.

Bluler, a Swiss psychiatrist, first coined the word *autism* in 1911 while working with schizophrenic patients (as cited in Gerrard, 2006). Bluler used the word autism to refer to clients who appeared to escape from reality by turning inward and ignoring the world around them. The term referred to *split mind* and was not used in the United States until 1938 when Kanner applied the term to children who appeared to have some emotional disturbance that caused them to experience major learning difficulties (as cited in Gerrard, 2006). Kanner was credited with the description of autism in 1943 (as cited in Browndyke, 2002; Dumont-Mathieu & Fein, 2005; Sponheim, 1996) to describe behaviors observed in children as having “autistic disturbance of affective contact” (Kanner, 1943, p. 217). Kanner highlighted features such as obsessive and stereotypic behaviors accompanied by echolalia, a condition in which they repeat what others have said in person or from television or radio (National Institute on Deafness and Other Communication Disorders [NIDCD], 2009).

In 1943, Kanner examined the behaviors of 11 CWA studied for approximately five years. The children were between the ages of 2 and 11 years during these observations. Kanner noted that although there were differences, there were also common themes in behavior that included preferences to be alone, a lack of affection for parents and other caretakers, language difficulties, problems with food, preferences for structure and same order of objects, and fear of moving objects and objects that made noises (e.g., mixers, vacuums, swings, elevators, running water, and mechanical toys). Some children were thought to be mute because they did not respond in any way, particularly verbally, when spoken to and behaved as if they heard nothing around them. Some portrayed excellent rote memory and could memorize words to songs, poems, and stories whereas others appeared to be unable to make intelligent decisions or judgments. Temper tantrums were common during times of frustration. Repetitive or stereotypic behaviors included fascinations with spinning items (e.g., tops and balls) although most repetition in these cases pertained to language in the repetitive use of the same words, phrases, or sentences (Kanner, 1943).

Later, Asperger (as cited in Wing, 1981) applied the term autism to children who appeared to suffer from mental retardation that prevented them from learning in the same manner as their same-age peers. The term autistic has been used to describe those with childhood schizophrenia, infantile autism, infantile psychosis, Asperger’s syndrome, and Kanner’s syndrome. Mental retardation was not attributed to the diagnosis of autism until after Kanner’s (1943) studies.

According to Grinker (2007), autism was not categorized as a separate disorder until 1980 in the *Diagnostic and Statistical Manual of Mental Disorders*. Prior to 1980, Grinker explained the term was included in the publication of the *Diagnostic and Statistical Manual of Mental Disorders* in 1952 under the code 295.8, schizophrenic reaction, childhood type. Erikson (1950) described treatment of multiple case studies of schizophrenic children. Many of these children exhibited behavioral symptoms strikingly similar to autism as described in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (APA, 2013).

Autism was mentioned again in 1968 in the *Diagnostic and Statistical Manual of Mental Disorders, Second Edition* (APA, 1968) under the same code describing behavior of schizophrenic children as “autistic, atypical and withdrawn behavior; failure to develop identity separate from the mother’s; and general unevenness, gross immaturity and inadequacy or development. These developmental defects may result in mental retardation, which should also be diagnosed” (as cited in Grinker, 2007, p. 66). According to Grinker (2007), the 1980 APA manual included a separate diagnosis entitled “infantile autism.” Grinker described five areas of qualifications for the diagnosis of autism:

- Onset prior to 30 months of age;
- Pervasive lack of responsiveness to other people (autism);
- Gross deficits in language development;
- If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, and pronominal reversal; and

- Bizarre responses to various aspects of the environment, (e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects; absence of delusions, hallucinations, loosening of associations, and incoherence as in schizophrenia).

The characteristics of autism were further characterized in 1987 in the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised* as “autistic disorder.” According to Grinker (2007), a person had to meet criteria for at least eight of the 16 characteristics listed to be diagnosed with autism. The characteristics were divided into four principal areas. Area A included qualitative impairment in reciprocal social interaction. Area B included qualitative impairment in verbal and nonverbal communication and in imaginative activity. Area C included marked restricted repertoire of activities and interests as manifested by stereotyped body movements, persistent preoccupation with parts of objects, marked distress over changes in environment, unreasonable insistence on following routines in precise detail, a markedly restricted range of interests, and a preoccupation with one narrow interest. Area D focused on onset during infancy or early childhood, prior to or after 36 months. To receive a diagnosis, a person must meet at least two items from A, one from B, and one from C (Grinker, 2007).

Diagnoses of mental retardation declined between the years of 1985 and 1998 from 101.13 to 65.99 and prevalence rates for autism increased from 5.48 to 56.23 per 10,000 births (Shattuck, 2006). The category of developmental delay was introduced in 1997. Shattuck (2006) attributed the increase in autism to the diagnostic substitution of autism, mental retardation, and developmental-delay categories. According to the Autism Information Center of the U.S. Department of Health and Human Services (HHS) CDC (2007), Autism and Developmental Disabilities Monitoring Network, data released in 2007 indicated that about 1 in 150 8-year-old children in multiple areas of the United States had an ASD. The number of CWA was reported to be 1 in 166 (CDC, 2004; Wing, 1981). In 2009, the rate increased to 1 in 110 (CDC, 2009). In 2011, the CDC reported rates were 1 in 150; in 2012, the CDC (2012) reported the rate of autism had increased to 1 in 88 and today, the rates are 1 in 68 (CDC, 2015). Although beyond the scope of this paper, the etiologies of these changing rates are of great concern to parents and to researchers who will continue to seek answers through continued research.

The *Diagnostic and Statistical Manuel of Mental Disorders, 5th Edition* (APA; DSM-5, 2013) currently defines autism as “a disorder with qualitative impairments in social interactions, communication, and repetitive and stereotyped patterns of behavior” (p. 75). Children are often unable to establish or maintain eye contact and may engage in repetitive behaviors, such as hand flapping and rocking. In addition, there may be an absence of language or marked impairment in language abilities, if present at all (World Health Organization, 1992, F84.0).

Diagnostic guides in the *International Classification of Diseases* (*ICD-9*; WHO, 1992) are like those in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5*; APA, 2013) and cautions physicians and healthcare professionals that although all IQ levels can be associated with autism, mental retardation occurs frequently. This category includes autistic disorder, childhood autism, Kanner’s syndrome, and infantile psychosis. Physicians are challenged to consider specific developmental disorders of receptive language (F80.2) with secondary socioemotional problems; reactive attachment disorder (F94.1) or disinhibited-attachment disorder (F94.2); mental retardation (F70-F79) with some associated emotional/behavioral disorder; schizophrenia (F20.) of unusually early onset; and Rhett's Syndrome (F84.2).

The review of the literature revealed a variety of beliefs and theories about the cause of autism and the increased rates, including environmental factors, genetic factors, changes in diagnostic criteria, increased media coverage of autism causing more public awareness, increased education of professionals regarding autism and its features, and the understanding that children are being diagnosed at earlier ages.

Autism Etiology

Although no one single theory regarding the etiology of autism has been found to date, structural magnetic resonance imagining (MRI) brain studies have indicated that CWA have increased volume of the total brain with abnormalities in the cerebellum, frontal lobe, and limbic system, particularly in the amygdala and hippocampus regions (Karande, 2006). The amygdala is responsible for emotional and social behaviors (Adolphs et al., 1998). Individuals with lesions in this area may have difficultly recognizing emotional facial expressions. The function hippocampus functions in learning, sensory information processing, and the formation of new memories (Mulligan et al., 2009). The hippocampus is quite sensitive to disease and environmental factors and even the slightest lesion could cause an individual to have difficulty forming new memories and using old ones (Mulligan et al.).

Karande (2006) reported that elevated serotonin levels in the platelets have also been identified in 30% of CWA (Karande, 2006). Karande (2006) described the belief that autism forms when high serotonin levels in the blood enter the brain of a fetus and damage the neurocircuitry. Family studies and twin studies have indicated a 60% concordance for autism in monozygotic twins compared to zero percent in dizygotic twins, indicating that genetics play a significant role in the susceptibility to autism. Families with a history of diseases such as Fragile X (a mental retardation syndrome), tuberous sclerosis, phenylketonuria, and neurofibromatosis produce CWA more often than they produce others (Karande, 2006).

Two other areas of the brain that can lead to autism if damaged include Broca's area in the left hemisphere, which is responsible for the difficulty in finding desired words, and Wernicke's area, which can result in meaningless and unconnected speech (Gerrard, 2006). Lesions in Broca's area cause a person to lose their ability to use spoken or written language (Berker, Berker, & Smith, 1986). Lesions in Wernicke's area cause an inability to understand spoken language when listening, an inability to read or speak with meaning. If individuals can use spoken language, it is often meaningless babble (Berker et al., 1986).

Researchers agree that autism is a complex neurological disorder, although the underlying brain injury has yet to be identified. Many studies have linked autism to various parts of the brain (Rodier, Ingram, Tisdale, Nelson, & Romano, 1996). Rodier et al., 1996, reviewed autopsy data on brains and conducted a study on rats to determine how damage in the central nervous system affects neural-tube closure. They found that when these injuries occur during or just after neural-tube closure, there is a loss of neurons from the basal plate of the rhombencephalon, which leads the researchers to think that autism forms around the time of neural-tube closure (Rodier et al., 1996).

Researchers paid special attention to neonatal head circumferences and brain volume in the formation of autism (Courchesne et al., 2001). Researchers studied 60 autistic and 52 normal boys between the ages of 2 and 16 using an MRI. They reviewed clinical records and recorded neonatal head circumference and brain volume at birth. Results indicated that by the age of 2 to 4, 90% of boys with autism had larger than normal average brain volume and 37% met the criteria for developmental macrocephaly (large brain). They also found more white matter and 12% more gray matter in the cerebral cortex than normal. There was less gray matter and a smaller ratio of gray to white matter in the cerebellum of autistic boys (Courchesne et al., 2001).

Some researchers ascribe to the nongenetic theory as the causation for autism, for example, viral infections such as rubella. Of children born in 1964 during the rubella pandemic, 8–13% developed autism along with other birth defects. Prenatal, perinatal, or neonatal trauma has also been associated with autism (Browndyke, 2002).

Although no specific cause of autism has been identified, many researchers, including Rodgers (2009), believe that genetic and environmental factors are responsible. Many children appear to be born with ASD susceptibility. One theory that has been discarded is the belief that “bad parenting” causes ASD (Rodgers, 2009). Since 2000, an escalation of reports has linked Thimersol in the measles/mumps/rubella (MMR) vaccine to autism. As a result, many parents have elected not to immunize their children; which has caused a rise in measles, mumps, and rubella, according to a current news report. The CDC and the NIMH formed a committee in 2000 to examine evidence related to the theory that the MMR vaccine causes ASD. The committee found no link between the vaccine and ASD (Rodgers, 2009). Wing and Potter (2002) concurred with the CDC that there is no correlation between the MMR vaccine and autism. Instead, they attributed the current rise of autism to changing diagnostic criteria and increasing awareness and recognition of ASD.

Parental Concerns and Expectations of Child Development

Erickson identified the second stage of development (ages 18 months to 3 years old) as the toddler stage when the goal is autonomy versus shame. In this stage, children are building self-esteem and developing independence (autonomy). Children, who are taught right from wrong by caring and affectionate parents, develop pride rather than shame. It is also during this stage that children become defiant, stubborn, and engage in tantrums as they struggle to learn new tasks.

By the age of 3, typically developing children (TDC) should be able to feed themselves, walk from one place to another, talk, respond to others, be less dependent, and show some sense of power and control in their independence and with toileting habits (American Academy of Pediatrics, 2010). Although their physical growth and motor development may be slow during this period, their intellectual, social, and emotional development is in full force leading to drastic changes (American Academy of Pediatrics, 2010).

Some parents experience significant stress during this stage as they first notice some peculiarities in their children. For example, they may notice their child, who once babbled or talked, interacted socially with others, maintained eye contact, and returned affection, suddenly stopped doing those things. In addition, the child may have developed some unusual stereotypical behaviors.

According to Anderson (2010), parents of children with developmental disabilities (PCDD) grieve as they accept their child's diagnosis and try to cope with the symptoms and challenges to the best of their ability, while also seeking treatment and services to provide a better quality of life for their family. Providing a better quality of life often requires financial and personal sacrifices, as parents focus solely on their child instead of themselves and their own needs, causing other family needs to be neglected. Although PCDD illustrate higher stress levels than parents of those without disabilities, PCWA and behavior disorders report higher levels of stress with disorders such as Down syndrome, as well as PCDD, which lead to higher levels of depression and frustration regarding challenging behaviors (Anderson, 2010; Lessenberry & Rehfeldt, 2004).

There are three major reasons why PCWA experience elevated levels of stress (Anderson, 2010). First, in addition to grief and being concerned about the child's future, PCWA often struggle with the causation of autism and their contribution to the disorder. Second, from a social perspective, CWA may not like to be held and may not maintain eye contact or respond to kisses and hugs, forcing PCWA to learn to love the child in a manner conducive to the child. Finally, regardless of where the child falls on the autism spectrum, difficult behaviors are very common and often consist of tantrums, rigid rituals, and intense sleep problems, affecting the entire family and their daily functioning (Anderson, 2010; Brobst, Clopton, & Hendrick, 2009; Davis & Carter, 2008; Lessenberry & Rehfeldt, 2004; Weiss & Lunsky, 2011).

Ellis et al. (2012) pointed out it is common for children to develop behaviors that are habit like during their lifetime. Such habits include nail biting, thumb sucking, occasional hair pulling, teeth grinding (bruxism), head banging, and rocking or other rhythmic movements. However, if the behaviors are not severe and do not interfere with normal daily functioning or meet the criteria for stereotypic movement disorder (APA, 2013), many of these behaviors will be outgrown and will cease as the child ages. Ellis et al. recommend a mental health clinician be consulted to rule out underlying psychiatric conditions associated with general anxiety disorder, trichotillomania (an anxiety disorder that involves excessive hair pulling leaving bald spots), or bruxism (teeth grinding), which can cause considerable damage to teeth.

Self-injurious behaviors are of more concern because “severe head banging or hitting may lead to cuts, bleeding, infection, retinal detachment, and blindness” (APA, 2013; p. 131). Stereotypic movements, defined in APA (2013) include “hand waving, rocking, playing with hands, fiddling with fingers, twirling objects, head banging self-biting or hitting parts of one’s own body” (p. 131). Sometimes, individuals may even use objects intended for play (e.g., spinning tops, balls, wheels, etc.) to hit themselves or others that may cause injuries.

Repetitive behaviors can cause significant problems for families because they consume most of the individual’s time, especially when anxious and agitated, and if the parents or other family members try to intervene to stop the repetitive behaviors, the individual can become extremely disruptive (Boyd, Woodard, & Bodfish, 2011). Repetitive behaviors also cause "significant functional impairment for individuals with autism" because "they often interfere with the individual's ability to function in daily life" (Boyd et al., 2011, p. 1). Those with autism may experience the comorbidity of obsessive-compulsive disorder, a preference for sameness, unusual or intense interests, and repetitive movements associated with functional impairment (Boyd et al., 2011, p. 2). Researchers have reached consensus that behavior problems in children and adults with developmental disabilities are one of the most significant stressors for families (Hastings & Brown, 2002).

Parental Concerns

It is logical to believe that parents raising CWA experience higher levels of stress compared to parents who are raising children without special needs. Schieve et al. (2007) conducted a study comparing parent aggravation rates in parents raising children with autism spectrum disorders (ASD), parents raising children with developmental disorders other than ASD, parents raising children with other healthcare needs, and parents raising typically developing children. Parental aggravation rates were measured using the Aggravation in Parenting Scale, a scale derived from the Parenting Stress Index and the Childbearing Scale developed by Blumberg et al. A variety of variables were assessed, including the family's financial status which revealed that 35.6% to 52.6% participants had annual incomes of or below 200 percent of the Federal Poverty Level.

In a qualitative study, Schieve et al. (2007) found that two-thirds of CWA also required special services such as medical, mental health, and educational services. Medical services included prescription medications and physical therapy, while educational services included occupational, and speech therapy. Maladaptive behaviors and emotional problems often necessitated the use of mental health treatment, including counseling (Schieve et al., 2007). Schieve et al. reported that parental aggravation was directly associated with poverty, single-parenthood, and lower parental education. The study included 73,030 children aged 4 to 17 assigned into five groups.

1. Children with autism currently (*N* = 872).
2. Children with a report of ASD in the past but not currently (*N* = 438).
3. Children with special health care needs with developmental problems (*N* = 4158),
4. Children with special health care needs without developmental problems (*N* = 11,100, and
5. Children without special health care needs (*N* = 56,462).

Participants were grouped by age with 13.9% being 4-5; 48.7% being 6-11; and 37.4% being 12-17. A total of 81% of participants were males and race was divided into four categories as well: Hispanic = 19.6%; Non-Hispanic white – 66.6%; Non-Hispanic black = 8.3%; and Non-Hispanic multiracial or other = 5.5%. A total of 35.7% fell at or below 200% of the Federal Poverty Level.

Results also indicated that PCWA scored in the high aggravation range (55%) compared to parents of children with developmental needs other than autism (44%), parents of children with healthcare needs other than developmental needs (12%), and parents of children with no special needs (11%). The rate for PCWA, however, increased to 66% for parents whose children were recently diagnosed and needed special services and was 28% for those who did not require special services. Unique stressors are apparently associated with raising a child with autism who requires special services, compared to PCWA who require no special services (Schieve et al., 2007). The present study will specifically address the impact of lower income on PCWA in terms of finding and obtaining services that may ensure a higher quality of life for their child, as well as to develop an understand of how having a lower income impacts PCWA and the family as a system.

Parental Frustration With the Diagnostic Process

Parents of children with autism are often overwhelmed by the stress of raising a child with autism and want a diagnosis as soon as possible (Benson & Dewey, 2008). The American Academy of Pediatrics' Committee on Children with Disabilities (CCD; 2001) described the diagnostic process as quite complex because characteristics vary from one child to another and occur on a wide continuum from very mild peculiarities to severe developmental challenges. It can take up to 4 years to receive a diagnosis because there is no specific laboratory test to detect autism and because parent's generally first notice delays in speech development and social skills between the ages of 1 and 3.

The diagnostic and evaluative process can be quite emotional for parents, and may cause them to become angry or even depressed, requiring them to seek medical attention themselves. When physicians use a biopsychosocial model of treatment, they will be better able to understand sources of physical complaints of these parents as they inquire about psychosocial stressors parents encounter during the diagnostic and evaluation process. When physicians clearly understand the underlying stressors, they can refer the parent to appropriate community resources that will provide necessary assistance and support for parents.

Parents initially develop concerns about a child's developmental milestones when they notice problems with language, communication, and social skills (Rodgers, 2009). Parents may notice behaviors that seem restrictive, repetitive, or focused on stereotyped interests and activities (Karande, 2006). These behaviors exist on a wide spectrum and are apparent prior to the age of three (Karande, 2006). After a parent has developed concerns about their child's development, physicians are typically the first healthcare professionals to encounter a child with ASD when the child is under the age of five.

The CCD (2001) pointed out that when pediatricians suspect that a patient may have ASD, it is of the upmost importance that a diagnosis be made as soon as possible so a conducive treatment plan can be implemented to provide the best outcome for the child and family. The CCD (2001) concurred and stated that when an early diagnosis can be made, the referral process can be expedited and appropriate interventions can be implemented more quickly to promote positive long-term outcomes for the child and their families. Generally, parents are the first to develop concerns regarding their child's development. Many parents become concerned when a child around the age of 18 months begins to regress developmentally, when their vocabularies are not as extensive as their same-age peers or when they simply stop speaking altogether, and when they fail to respond to parental affection.

Those parents of children under the age of five do not typically focus on concerns regarding their child's social-skill deficits, but when they do, it should become a concern of major importance for the physician (CCD, 2001). When concerns include "abnormal eye contact, aloofness, failure to orient to name, failure to use gestures to point or show, lack of interactive play, and lack of interest in peers," physicians should be concerned. When these skills are of concern, in addition to concerns about delays or regression in language, physicians should immediately be prompted to recommend additional evaluations (CCD, 2001). Speech delays are common in a variety of disorders and are usually the most common developmental concern of parents during the toddler and preschool years (CCD, 2001). The first recommended step regarding the evaluation of speech is to determine if there is a delay in expressive language (speech) and in receptive language. When combined, these delays are typical characteristics of mental retardation, as well as hearing loss, and must be diagnosed independently of ASD (CCD, 2001).

When a parent becomes concerned about their child's developmental progress and the child is taken to a professional for help, 50% of those parents are told not to worry, although they continue to do so until they receive a definitive diagnosis (CCD, 2001). Until then, many families experience a great deal of stress as they attempt to locate resources on their own until a diagnosis is received (CCD, 2001). Parents who suspect autism in their child can easily become frustrated with the diagnostic process. Parents want and need the most accurate and reliable diagnosis as soon as possible, to begin early intervention and increase their child’s quality of life, as well as to improve overall family quality (Baird et al., 2003). According to the CCD, the time span between the first parental awareness of ASD and the actual definitive diagnosis of ASD is approximately 4 years. Many families are dissatisfied with the length of time involved in the diagnostic process (Shah, 2001). Many parents feel that if their concerns were taken more seriously, they and their children would receive assistance in a timelier manner from medical and mental health professionals (Shah, 2001).

Some parents take immediate action and schedule an appointment with a physician to determine why the child has regressed in developmental stages, but others may wait longer, perhaps thinking it is a temporary setback and the child will continue to progress like any other typical child their age after a certain period (Shah, 2001). Many parents become anxious and worried as they attempt to seek answers and to raise their child to the best of their ability. This anxiety is often compounded by inaccurate diagnoses, multiple visits to various healthcare professionals, and the amount of time that passes until a definitive diagnosis of autism is finally acquired (Baird et al., 2003; Shah, 2001). In one sense, a diagnosis of autism may provide some sense of relief to parents because it gives meaning to unusual behaviors, but in another sense, it increases the parents’ stress level (Shah, 2001).

An earlier diagnosis can result in earlier intervention and treatment and is universally believed to be essential in helping CWA and their parents facilitate the best quality of life possible (Lord & McGhee, 2001). The Early screenings, like those performed for vision and hearing, should be conducted with children to detect autism and to facilitate earlier interventions and to determine the most conducive treatment early (Committee on Children with Disabilities (CCD, 2001). In contrast, practitioners must have a clear understanding of what ASD means and how it is acquired. Parents experience an increase in stress during the diagnostic process and the longer it takes, the more stressful the parents become because they are left, oftentimes without additional resources to manage a child who exhibits behaviors quite different from other TDC in the family, or from those in the community (CCD, 2001).

Harrington, Rosen, Garnecho, and Patrick (2006) stated that “many health care providers are unaware of parental beliefs and treatments, both medical and complementary, that parents use for their child with ASD” (p. 156). These researchers believed that if medical professionals developed an understanding of the beliefs parents held regarding the diagnosis, cause, and use of medical and complimentary care, physicians would be better at providing more comprehensive care. Parents want their CWA to be diagnosed as early as possible because they believe that early intervention may improve the child’s long-term quality of life.

When a child between 3 and 5 years old receives an early diagnosis, and is referred for treatment, their prognosis of ASD is improved (Rhoades et al., 2007). ASD is not often diagnosed until ages three or four because medical professionals lack the training to provide evidence-based-treatment recommendations (Rhoades et al., 2007). These researchers conducted a study of 146 ASD caregivers who completed an online survey providing demographics, the diagnostic process, sources of information/support, and the need and availability of local services for ASDs. Results indicated the average

age of diagnosis to be 4 years and 10 months with a mode of Age 3. Although 40% of professionals provided additional information about ASD after diagnosis, only 15 to 34% provided advice regarding medical/educational programs and only 6% referred to an autism specialist; 18% percent provided no further information following the diagnosis.

Developmental pediatricians, rather than psychiatrists, primary-care physicians, neurologists, or psychologists, rendered a diagnosis at the earlier ages and were more likely to provide caregivers with additional information on autism (Rhoades et al., 2007). When practitioners fail to provide further information, parents are left to find answers on their own and often turn to videos, books, the Internet, conferences, and other parents who have CWA. To improve quality care, physicians should receive specialized training about ASD. Then, early screening, diagnosis, and information regarding empirically supported services can be discussed with the caregiver (Rhoades et al., 2007).

When ASD is not diagnosed until the age of six, as it is in many cases, families become frustrated with healthcare professionals, especially because some have expressed their concerns to professionals since their children were 2 years of age (Rhoades et al., 2007). Parents are often correct regarding their concerns over their children's development, and in many cases, symptoms can be seen prior to 12 months of age, which makes families aware of developmental difficulties long before a definitive diagnosis is made (Rhoades et al, 2007). Parents often become frustrated with medical professionals because, although they voice their concerns about potential causes of autism, healthcare professionals either ignore them or do not take them seriously (Baird et al., 2003).

Tidmarsh and Volkmar (2003) described the diagnostic process of ASD. First, a clinical assessment should be completed by a multidisciplinary team of specialists. The clinical assessment should be very thorough and should include a developmental history that includes information on pregnancy, birth, development, and the age at which the parent first became concerned about developmental regression. This history should include information about sleep and eating habits, especially any changes or food sensitivities. A family history is important in identifying neurodevelopmental disorders. It is also important to note the child's behaviors in the past and present, specifically any changes in behavior that have recently occurred. The physician should conduct a physical examination, paying attention to growth measurements, especially head circumference, and skin pigmentation. Depigmented markings are associated with tuberous sclerosis. If any abnormalities are found during the neurological examination, an electroencephalogram (EEG) and magnetic resonance imaging (MRI) are necessary.

When loss of language is of concern, children should engage in a sleep-deprived EEG to rule out Landau-Kleffner syndrome, a childhood disorder that causes a gradual or sudden loss of language (NIDCD, 2009). Other symptoms include an abnormal EEG, seizure activity, aphasia, and behaviors such as hyperactivity, depression, and aggression (NIDCD, 2009). The last step in the clinical assessment is an audiogram to rule out any possible hearing loss that might directly relate to the language delay (Tidmarch & Volkmar, 2003).

The two most widely used criteria for autism are found in the *ICD-9* (World Health Organization, 1992) and the *Diagnostic and Statistical Manual of Mental*

Disorders (APA, 2013). Although autism is behaviorally defined, professionals should be aware of various organic etiologies, which include prenatal complications (e.g., rubella, untreated tuberous sclerosis, phenylketonuria, and ingestion of anticonvulsants during pregnancy) and postnatal infections such as encephalitis (Baird et al., 2003). Healthcare providers should also be aware that specific medical causes are only found in 6% of people with autism. Epilepsy was one of the early characteristics that alerted healthcare professionals that autism is a neurobiological disorder. Prior to this, many thought children had autism because of “refrigerator moms.”

The term autism was coined by Kanner in 1946 but it was Bettelheim who coined the term “refrigerator mom,” a term applied to mothers of autistic children during the 1950s and 1960s (Waltz, 2002). Bettelheim believed autism resulted when mothers were cold and aloof from their children (as cited in Olney, 2000). During the 1950s, many believed autism was caused by mothers who did not provide enough affection or those who did not bond well with their young children (Rodgers, 2009).

In addition, to the clinical assessment, laboratory tests should be used to rule out Fragile X syndrome and a chromosome analysis (Tidmarsh & Volkmar, 2003). Genetic testing has become much used to determine any abnormalities of Chromosomes 7 and 15. Other laboratory tests can rule out immune deficiencies or metabolic problems. Recent research supported the influence of genetics in autism (Karande, 2006). Recent neuroimaging studies supported the idea that autism may be caused by atypical functioning in the central nervous system, particularly in the limbic system with the amygdale and the hippocampus.

Tidmarsh and Volkmar (2003) recommended that once the clinical and laboratory testing has been completed, clinicians conduct a diagnostic assessment using specific tools designed for detecting autism, such as the Childhood Autism Rating Scale-2nd edition (Schopler et al., 2010), the Autism Diagnostic Observation Schedule-Generic (Lord et al., 1989), and the Autism Diagnostic Interview-Revised (Rutter et al., 1994). No single clinical or diagnostic tool identifies autism and there is no medical test for ASD (CDC, 2007).

Professionals use a variety of diagnostic assessments to detect autism. Developmental testing to assess levels of intelligence and adaptive behavior should involve instruments such as the Wechsler Preschool and Primary Scale of Intelligence-Revised (Wechsler, 1989), the Wechsler Intelligence Scale for Children-3rd edition (Wechsler, 1991), the Stanford-Binet Intelligence Scale (Thorndike et al., 1986), and the Mullen Scales of Early Learning (Mullen, 1995). Those with low linguistic levels and autism may benefit from the Leiter International Performance Scale (Roid & Miller, 1997). For adaptive behavior, the most popular tool used is the Vineland Adaptive Behavior Scale (Sparrow et al., 2005).

Tidmarsh and Valkmar (2003) recommended that a speech and language assessment be included in the diagnostic assessment to assess a child’s communication skills. They pointed out that this assessment is essential because it determines whether the child has high-functioning autism or has a semantic-pragmatic language disorder. Some of the assessments that can be used include the Peabody Picture Vocabulary Test-Revised

(Dunn & Dunn, 1981) and the Reynell Developmental Language Scales (Edwards et al., 2011).

The next step in the diagnostic process is a functional evaluation (Tidmarsh & Volkmar, 2003). This includes a behavior assessment with questionnaires such as the Aberrant Behavior Checklist or the Nisonger Child Behavior Rating Form (Tassé et al., 1996), which can provide pretreatment and post treatment ratings to guide the intervention. Also included is a family assessment to learn about the family and the extended community and the child's overall environment. The family assessment also brings to light any stressor in the family in addition to coping with an ASD child. Once this is completed, social workers can become involved to provide support and community resources to fit a family's needs.

The increasing numbers of CWA have led many parents and professionals to question whether screening should take place as a standard precaution against PDD. Baird et al. (2003) pointed out the difference between screening, which they defined as "the prospective identification of unrecognized disorder by the application of specific tests or examinations" (p. 468) and surveillance, which refers to "the ongoing and systematic collection of data relevant to the identification of a disorder over time by an integrated health system" (p. 468). Baird et al. described surveillance as a "parent–professional partnership" that focuses on developmental and behavioral skills over time. The purpose of screening is to identify any possible abnormal neurodevelopmental disorders, such as language disorders, that might lead professionals to a specific condition or to a developmental delay.

The CDC (2007) stated that screening takes place in two steps. The first step is a developmental screening and surveillance The CDC recommended these screenings for all children at their 9-, 18-, 24- and 30-month well-child checkups. If a child is at risk for an ASD due to family history, more screening should occur. The second step of screening is the diagnostic comprehensive evaluation, which should be performed to distinguish between high-functioning autism and Asperger's syndrome (CDC, 2007). Screening tools can identify a child with developmental disorders or those with delays in specific areas such as cognitive development, language, or gross-motor skills. Screening cannot provide a definitive diagnosis and they cannot provide in-depth information about development in specific areas. In contrast to what some researchers believe, the CDC recommended screening and surveillance as the first step in the diagnostic process. They listed the comprehensive diagnostic assessment as the second step.

Baird et al. (2003) argued that screening is essential because early identification will ensure immediate medical treatment that can prevent disability such as phenylketonuria or sensori-neural deafness. The information obtained from the screening will also be beneficial to parents regarding the possibility of having another child with ASD. Baird et al. stated the risk of having a second child with ASD is 5% but the chances of having a child with more general problems in social communication or cognitive development is several times higher. The researchers argued that knowledge could allow the parents to make an informed decision about having other children. In addition, information from the screening would allow parents to implement behavioral techniques that will enhance the child's overall functioning over time.

Benefits of Unity Among Physicians and Psychologists

Healthcare providers agree that no single psychological test or medical test identifies autism; as a result, several tests and clinical interviews may be required before a definitive diagnosis of autism can be finalized. Parents become frustrated when they seek medical treatment from a physician but are then referred to a series of other professionals before a diagnosis is made. Goin-Kochel et al. (2006) surveyed 494 parents of children with PDD about their level of satisfaction with the diagnostic process. They found that educated parents and those from a higher socioeconomic status appeared to obtain an earlier diagnosis and enjoy more satisfaction with the diagnostic process than those from lower socioeconomic status or those who are less educated (Goin-Kochel et al., 2006).

Siklos and Kerns (2005) surveyed 56 Canadian PCWA regarding their experience and satisfaction with the diagnostic process. They found an elevated level of frustration among the parents because, on the average, parents saw 4.3 professionals and waited approximately 3 years after their initial visit to the doctor to receive a diagnosis. Siklos and Kerns concluded that parents are much happier with the diagnostic process when they see fewer professionals and when their children receive a diagnosis at a younger age.

When parents detect an abnormality in their child's development, they tend to feel helpless, but when they seek assistance from a doctor and are referred to one professional after another and do not receive a diagnosis for several more years, it is understandable that they would become frustrated. While they are awaiting a diagnosis, they are left to raise a child who is exhibiting behaviors uncharacteristic of same-aged peers. Unless professionals have provided the parent with suggestions on behavior management, stress management, and expectations regarding their child's progression or lack thereof, parents are left on their own to raise the child. The CCD (2001) instructed that management of ASD is as challenging as the diagnosis itself, because there is no proven cure. For this reason, professionals must work together as teams to ensure parents are given a diagnosis sooner, so earlier interventions can be implemented to decrease stress for the child and for the family.

Prior to the 1970s, treatment for ASD focused on treating the child and the family together, and the child separately at times, in psychotherapy. During the 1970s, the focus changed because professionals believed ASD was a neurobiological disorder of organic origin, so treatment focused more on behavioral, developmental, and educational strategies. The CCD (2001) pointed out, "there is no global consensus" that any one strategy is more effective than another. Current preferred treatments focus on overall functioning and include broad-based goals such as increasing communication, social, adaptive, behavioral, and academic skills, while decreasing maladaptive and repetitive behaviors. They also advocate focus on helping the family manage the stress of raising a child with ASD.

PCWA are often overwhelmed and feel helpless in how to help their children. The CCD (2001) recommended that, because pediatricians are often the first to encounter and diagnose children with ASD, they provide the support the parent needs to lessen their stress level. The physician should discuss any concerns of the parents on ASD from a medical standpoint, discussing the child's developmental milestones and future prognosis and consulting with parents on genetic counseling to deter the possible occurrence of ASD in siblings.

The physician should also discuss the homeopathic interventions that many have tried with ASD and the effects these remedies may have on the child based on the results from their physical examination. Some examples of such homeopathic remedies include: gluten and casein-free diets (Whiteley et al., 1999); removal of dairy products (Interactive Autism Network (IAN), 2008); and the use of vitamins and minerals (Pfeiffer, Norton, Nelson, & Shott, 2005). Whiteley et al. (1999) suggested the removal of gluten, an enzyme found in milk products, and gluten, a protein found in wheat, rye, and barley as a popular treatment during the 1960s. Likewise, IAN researchers (2008) suggested that 82% of autistic children on gluten- and casein-free diets showed an overall improvement in autistic behaviors and skills. Pfieffer et al. (2005) found the use of Vitamin B-6 and the mineral, magnesium, to yield inconclusive positive effects on autistic symptoms.

Estes et al. (2009) reported that PCWA could handle the daily stressors of life but experience more parent-related and psychological distress, primarily in managing autistic behaviors than parents of TDC. Although PCWA face a variety of problems and issues, Estes et al. suggested that it is often due to parents becoming overwhelmed managing problem behaviors of autism, therefore, the treatment should begin with therapists. Therapists can assist parents with parenting skills specific to autistic behaviors, stress management, organization, and individual emotional and marital needs that might result from raising a child with ASD (Estes at al., 2009).

Therapists and social workers could work together to encourage parents to engage in various support groups or to engage in social interactions with other parents of ASD children. Estes et al. (2009) acknowledged that divorce rates are high and suggested parents remain connected by engaging in regular respite (short-term, temporary breaks for caretakers). The Autism Treatment Acceleration Act, Senate Bill S. 819, (2009) provided enhanced treatments, services, support, and research for CWA and their families. Many PCWA are hopeful that these healthcare reforms will provide them with the funds to engage in respite, as well as to seek necessary treatments and other services that will improve their lives, as well as the life of their autistic child.

In the past, some insurance companies were free to deny treatments such as occupational, speech, and physical therapy for autistic children, but Blue Cross Blue Shield Insurance Company of North Carolina (2009) approved the services of speech, occupational and physical therapists in their *Medical Policy Manual*. These professionals work with the child and the parents directly and work with teachers, the school psychologist, and other school officials to provide the services needed, based on the child's individual educational and physical needs (NIMH, 2011).

In summary, because autism is a neurological disorder, pediatricians, family physicians, pediatric neurologists, and other healthcare professionals will want to work together to create the most conducive medical treatment program for the individual child. Team members should interact and work in conjunction to ensure the child, the family, and other professionals involved with the child are receiving the support they need to ensure the child's success academically, developmentally, physically, and socially.

Although it might not be feasible for each member of the team to sit down for a meeting on a continuous basis, it is essential that each member be personally aware of the child’s individual needs.

Stress and Its Relationship to Parental Resource Needs

ASD is a perplexing disorder that not only affects the child, but also affects the entire family, especially the couple raising the child. Parents want and need the most accurate and reliable diagnosis as quickly as possible to acquire the most conducive treatment for their child to ensure the highest quality of life possible and training for the parents to increase overall familial satisfaction (Bolman, 2006). In addition to stressors faced by most couples in general, couples raising CWA and other special needs (e.g., ADHD, cerebral palsy, etc.), are likely to experience stress more intensely and are more prone to negative outcomes than parents without special-needs children. This is especially the case, if the children are nonverbal and are unable to communicate with parents and other family members (Dunn et al., 2001; Wymbs et al., 2008).

In previous studies, PCWA ranked the need for financial assistance as their top stressor (Benson & Dewey, 2008). Other stressors included respite, family/spousal support, an accurate and timely diagnosis, knowledgeable professionals who provide helpful resources, day programs, and social and recreational opportunities for the child and the family. Fathers rated the need for in-home services significantly higher than did mothers (Benson & Dewey, 2008). Parents of children with more severe ASD experienced higher levels of stress than did others. Stress levels for parents of children recently diagnosed with ASD experienced significantly higher levels of stress compared to parents of children who were diagnosed with ASD for more than a year (Benson & Dewey, 2008).

Mori et al. (2009) conducted a study in Japan to determine levels of parental stress for parents raising children with another pervasive developmental disorder on the autism spectrum, Asperger's syndrome, compared to those parents raising children with high-functioning autism. Results indicated that of 193 families (*n* = 30 for Asperger's families and *n* = 163 for autism families), 67% of the Asperger's families and 57% of the autism families scored at or above the 90th percentile on the normal parental-stress scores on the Parenting Stress Index, Short Form. Results also indicated that although families of children with Asperger's syndrome reported significantly higher levels of stress than those of CWA, both groups experienced significant amounts of stress altogether (at or above the 90th percentile). Mori et al. also found higher levels of stress in parents who became concerned over their child's behavior at earlier ages, those families in which fathers were less involved, and families that had a history of psychiatric disorders. Families of adult children who were dependent on them also exhibited higher levels of stress unless they knew their child would receive long-term services from a residential-care facility or a hospital (Mori et al., 2009).

Although Mori et al. (2009) conducted their study in Japan, the participating families reported the same stressors as did American families when raising children with PDD. Some stressors included family resources and supports, particularly during the diagnostic process, social understanding and acceptance, financial issues, family cohesiveness, and changes in lifestyle, including decreased marital satisfaction and increased marital discord. Mori et al. pointed out characteristics among parents included lower self-esteem, lower locus of control, difficulty accepting their child's diagnosis, differences in parental expectations of the child, as well as differences in parental roles. In addition, parents had higher potentials for mental health problems, including depression. According to Mori et al., because many American families share the same concerns, this demonstrates a commonality of parental concerns and stressors when raising a child with a PDD.

Most parents understand that treatment is necessary but cost is often a major concern for them. Jennings (2005) indicated that some treatments are very expensive, which leads to financial issues and negatively affects stress. One treatment option is to place the child in an institutional environment where the child can enjoy the services of a personal assistant 24 hours per day, to ensure that all their needs are met. One parent may decide that institutionalizing their child is best choice, whereas the other parent may decide that the child is a part of the family and should be treated as such, staying in the home to be cared for as the other family members. This difference of opinion can cause significant conflict in the couple and the stressors involved can lead to mental and physical health problems in the parents.

CWA experience behaviors that negatively affect their educational and social performance. Parents are frequently summoned to schools for parent–teacher conferences, and to participate in IEP meetings. Many parents of newly diagnosed children are unfamiliar with the rights of CWA and feel alone and helpless when it comes to advocating for their children; many do not know to whom they can turn for help (Lord & McGee, 2001).

Some parents may be forced to choose between continuing or quitting jobs to stay home to care for their child. This could negatively affect family finances and thus increase tension between the couple (Benson & Dewey, 2008). Stressors may overwhelm parents and some may experience physical health issues such as heart attack, digestion problems, and ulcers; in addition, some may experience depression, anxiety, and other mental health issues that could lead to increased conflict with their spouse (Montes & Halterman, 2007; Mungo et al., 2007).

Differences in Parental Stress and Age of ASD Child

Researchers (e.g., Tehee et al., 2009) have reported significant differences in the stress level of parents that varied by the age of the child. For example, parents of children aged 11–14 reported receiving better quality of support than parents of children who were younger or older (Tehee et al., 2009). Parents of children aged 15–18 reported receiving significantly lower amounts of information/education than those with younger children. Tehee et al. pointed out that stress levels may differ between mothers and fathers and stated that some of the possible explanations included the fact that mothers tended to be more involved with the child as a caretaker, and their overall involvement might have increased their overall stress level. In addition to caring for the child, mothers also tended to assume responsibility for the household chores; the inequality of childrearing responsibilities negatively impacted temperament of the child. The culturally defined role of the mother to assume the bulk of domestic duties may contribute to the disparity in domestic and childcare differences between mothers and fathers. Fathers have more opportunities than do mothers to “escape” domestic duties. Thus, parents may experience elevated levels of stress due to the imbalance in caregiving roles (Tehee et al., 2009).

Schieve et al. (2007) conducted a survey to assess stress indicators when parenting a child with autism. Of the 78,305 children and corresponding parents (or other knowledgeable adults participating), 55% of PCWA scored in the high-aggravation range on the Aggravation in Parenting Scale (APS) compared to 44% of parents of children with other developmental disorders, 12% of parents of children with special healthcare needs without developmental disorders, and 11% of parents of children without special healthcare needs. Results indicated that parents experience a significant amount of unique stress when parenting a child with autism, compared to their counterparts. As Benjak et al. (2009) concluded, “Appropriate treatment and psycho-social support should be provided before the health of parents becomes seriously compromised” (p. 409).

Coping Differences for Fathers and Mothers of Children With ASD

Significant discrepancies exist between mothers and fathers of CWA in their need for external coping resources as well as their coping techniques (Tehee et al., 2009). Parents identified 12 sources of stress: (a) behavior, (b) the future, (c) education, (d) personal constraints, (e) child’s relationships with others, (f) needs of other family members, (g) lack of/delayed basic skills, (h) social aspects, (i) attaining support and services; language/dealing with sexuality (equally ranked); (j) disruption of home life and environment/diet/understanding child’s needs (equally ranked); (k) finance; and (i) transportation. The top 11 facilitators for stress relief included (a) school or school staff and services, (b) respite, (c) family, (d) spouse, (e) home help/home tuition, (f) health board/health workers and services, (g) support groups/other parents, (h) friends, (i) other children, (j) social life/recreation, and (k) the Autism Society.

Description of Communication Problems of Autism

Parents of typically developing children (TDC) can engage in reciprocal communication but parents of children with autism cannot because CWA are often focused on themselves and live in a private world with little to no socialization (NIDCD, 2009). Although some CWA cannot speak at all, others have excellent vocabularies and can speak about a subject in depth for extended periods.

The number of CWA who have little or no functional speech ranges from 25 to 61% (Schlosser & Wendt, 2008). Some CWA use repetitive or rigid language, constantly repeating words they have heard, known as echolalia. Those who are autistic savants may indulge in a very in-depth monologue about a subject of interest, although they are unable to engage in a typical two-way conversation with others. In addition, about 10% of CWA may also have exceptional talents or skills in an area such as mathematics, art, or music (Schlosser & Wendt).

In addition to language difficulties, many CWA possess poor nonverbal skills and often lack the ability to read facial expressions or body language, thereby exacerbating their communication problems with others (NIDCD, 2009). Others may be viewed as being uninterested, rude, or inattentive during a conversation because they are unable to use or understand gestures and facial expressions to engage in meaningful and reciprocal communication. As a result, CWA sometimes become frustrated as they attempt to express their needs to others and parents may also become frustrated as they struggle to interpret and fulfill their child’s needs.

A child’s ability to communicate varies significantly based on their intellectual and social development (NIDCD, 2009). Although some CWA are unable to use meaningful language to communicate with others, some children can speak but may experience language problems in using repetitive or rigid language or echolalia. Some may say things out of context or say things during the middle of a conversation that have no meaning to others, such as counting from one to five repeatedly. Instead of being able to state their needs, some may ask “Do you want a drink?” when they are thirsty, or when meeting others, including those with whom they are familiar, or may introduce themselves as though it is their first time meeting the person (NIDCD, 2009).

Some CWA have narrow interests or exceptional abilities, such as carrying on a lengthy, in-depth monologue about something in which they are interested, yet they are unable to participate in a two-way conversation with another person on the same topic. Some have excellent mathematics skills, whereas others might have exceptional music, art, or business-related skills. The 10% with exceptional skills are said to have “savant” skills (NIDCD, 2009).

Some CWA experience uneven language development such that they develop an extensive vocabulary in an area of interest, but lack vocabulary in other areas, or they may be able to read, but not comprehend words at very early ages. Because they often fail to respond to others, even when they hear their own name, some of these children are misidentified as having hearing problems (NIDCD, 2009).

Another problem area for CWA is poor nonverbal communication skills. In these instances, children are unable to use or understand facial gestures and body language. Because they avoid eye contact, others may think them being rude, uninterested, or inattentive. Due to the lack of communication skills, many children become frustrated when making their needs known; they often engage in verbal outbursts or other inappropriate behaviors (NIDCD, 2009). Although it is easy to understand how an inability to communicate effectively with others can frustrate a child who has ASD, one must wonder how their communication deficits affect the parents' overall stress level.

Social-Skills Deficits

Mothers and fathers of toddlers recently diagnosed with autism reported similar levels of stress from the child's behavior and social skill deficits, but fathers reported more stress in the parent–child relationship and social interaction than mothers (Davis & Carter, 2008). Mothers who reported higher levels of overall parenting stress also reported higher levels of stress from their child's lack of social relatedness, more stress in the parent–child relationship, and more parental distress. For mothers, self-regulating behaviors (e.g., eating, sleeping, and emotion regulation) were found to be most stressful. Although stressful for both parents, externalizing behaviors (e.g., aggression, delinquency, and hyperactivity) were more stressful to fathers than to mothers, perhaps because these behaviors are difficult to manage and are embarrassing in public (Liu, 2004).

Stress and Parental Health

Daniels et al. (2008) suggested a direct correlation between autism and a parent's hospitalization for depression, schizophrenia, or other mental disorders based on an analysis of birth and hospital records of 1,237 Swedish children born between 1977 and 2003 who were diagnosed with autism prior to the age of 10. When compared with 30,925 control subjects, parents with autistic children were twice as likely to have been hospitalized for a mental disorder compared to parents of children without autism. If researchers can determine if autism is more common in families with other psychiatric disorders, they can better focus on shared genetic and environmental factors (Daniels et al., 2008).

A study of 178 PCWA and 172 parents of nondisabled children in Croatia aimed to assess rates self-perceived health problems of parents (Benjak et al., 2009). Results indicated that PCWA perceived themselves as having poorer health with significant deterioration in the last year, compared to parents of children without disabilities. The largest difference was in psychological disorders when 11% of parents of autistic children reported specific or chronic conditions compared to 4.3% of parents of children without disabilities. There was no difference in the rates of physical health between groups. Of PCWA, 71% believe their own health, and their children's health and lives, would improve if four goals were met. First, they believed the public should be better educated about ASD; second, they believe measures should be taken to integrate children with ASD into educational settings and society in general; third, categorize ASD as a 100% disability so parents can obtain more services; and finally, introduce personal assistants to help and make mothers the legal caregiver. Of specific importance is the need to obtain an early diagnosis, followed by support and treatment, not just for the child, but for the parents as well. Immediate treatment of parents could significantly reduce stress and improve parental health and stability (Benjak et al., 2009).

Impact of Stress on Parental Social Life

Freedman, lead researcher for the Kenney Krieger IAN Project (Freedman et al., 2012), conducted three different surveys, collecting data from parents of autistic children to determine the effects of family stress related to autism. In their first report, they examined child-related behavior such as erratic sleep patterns. Their second report focused on family finances and parental education/career goals. Their third and final report examined relationships with others. Results indicated that 60% of parents reported that having a child with autism had an overall negative effect on their friendships. Parents indicated that many of their extended family, friends, and the public do not understand the needs of a child with autism, particularly when the child has a public tantrum. Parents also explained that because they must watch their child constantly when in the homes of friends and family, as well as in other social settings, they declined social invitations from others and chose to stay at home. This ended some of the relationships with friends and family, which, in turn, caused the PCWA to feel isolated. Some parents reported they have been asked to leave public settings (e.g., churches, restaurants, and playgroups) due to their child's behavior. Some adult observers have described CWA as "simply an unruly child who needs discipline."

Impact of Stress on Religious Practices, Employment, and Household Duties

A report from the IAN Project, based on a population-based, cross-sectional survey, (Freedman et al., 2012) also indicated that PCWA who were ages 3–5 were 70% less likely to attend weekly religious services than were parents of a child with ADHD. In addition, researchers were told that some of the parents had autistic traits themselves, especially in establishing social relationships. Like parents of TDC without autism, the IAN parents who participated in the research project indicated they faced many of the same stressors (e.g., balancing work, household chores, financial responsibilities, and family demands) as other couples. However, they felt that as PCWA, they also had additional challenges that caused significant stress (e.g., obtaining an accurate and quick diagnosis for their child, investigating various treatment options, finding providers, transporting children to and from appointments, interacting with insurance providers, and participating in school individualized-education-program (IEP) meetings).

Freedman et al. (2012) reported that 60% of mothers and 54% of fathers indicated that having a child with autism had a somewhat negative or very negative impact on the couple’s relationship. Researchers pointed out that having a child with a disability does not always produce a negative effect on the couple’s relationship. In fact, despite the additional stressors that many PCWA face, there was no indication that they differed in any way from other couples of TDC in spousal support, respect for each other, or commitment. More importantly, there was no support for the 80% divorce rate reported for PCWA. In addition to these extra tasks, PCWA also have the added emotional stress of learning that their child has a disability, which can have a direct impact on their health and their marital relationship (Freedman et al.).

In one of the few qualitative studies in this area, the authors reported that ASD can positively influence a family in terms of family functioning, including the development of psychological and emotional strength, improved communication skills and higher levels of empathy and patience (Cridland et al., 2014). Neely-Barnes and Dia (2008) point out that families are critical supports for children with disabilities although the disability can impact the entire family and the way family members cope with the disability can have a direct impact on relationships, particularly on marital and overall family functioning when it comes to parenting stress and depression.

Marriage and Divorce Statistics for U.S. Couples

Although the source in unknown, many researchers are aware of the common belief in the autism community that the divorce rate among PCWA is 80% (Freedman et al., 2012). However, a 2008 Easter Seals Survey, conducted by Harris Interactive, contradicted the 80% statistic, and found that PCWA were more likely to be married than were parents of children without special needs. Divorce rates were identified as 39% for parents of children without any special needs children compared to 27% of PCWA (Harris Interactive, 2008). A study by Siegel (2003) concluded that rates among PCWA were no different from rates of those with children without autism. During this study, Freedman et al. (2012) revealed the results of a study conducted for Kennedy Kreiger Institute (2010) in which the team completed the first analysis of 2007 data from the National Survey on Children’s Health to determine the number of parents who were married or divorced. Of the 77,911 children between ages 3 and 17, 64% with ASD were either the biological or adopted child of a two-parent family, compared to 65% of children without autism. Freedman was unable to locate the source of the 80% divorce-rate statistic (Freedman et al., 2012). Dawson of Autism Speaks acknowledged that parents of ASD children are under significant stress but believed Freedman's study is "good news" for parents and did not indicate that a high divorce can be assumed when raising a child with autism.

In a press release on May 19, 2012, Freedman, lead researcher, indicated that results from the study entitled the IAN Project at the Kennedy Kreiger Institute did not support the 80% statistic, "a figure that is almost doubled that of U.S. statistics for first marriages." According to Freedman et al., parents have often reported the 80% divorce-rate statistic. Freedman et al. believed the statistic further exacerbates the existing stress level of families of CWA, particularly when they are already feeling overwhelmed by having a child newly diagnosed with autism, and often view the statistic as a dual diagnosis (Kennedy Krieger Institute, 2010).

Although the issues described above may add stress for PCWA, the receipt of an earlier diagnosis may warrant earlier interventions that will not only help the child, but will also help the parents learn how to more effectively manage the symptoms of autism. This early diagnosis could help reduce parental-stress levels and thus lead to happier and psychologically healthier families, and may fortify the marital relationship (Baird, Cass, & Slonims, 2003; Schieve et al., 2007).

National statistics on marriage and divorce from the CDC's (2009) Vital Statistic Report indicated that in the District of Columbia and 44 U.S. states, marriage rates were 7.1 per 1,000 of the total population, and divorce rates were 3.5 per 1,000 total population. According to statistics from Real Relational Solutions (Baker, 2007), 59% of the American population is currently married. This number is down from 62% in 1990 and 72% in 1970. The percentage of overall divorces is 10%, up from 8% in 1990 and 6% in 1980. Seven percent of the population is widowed. Five and a half million unmarried American couples live together, 89% of which are male–female couples. The number of marriages in 2005 was 2,230,000 compared to 2,279,000 in 2004, despite a population increase of 2.9 million in the same period. The divorce rate for 2005 was 3.6 (per 1,000 people), which was the lowest rate since 1970 according to Real Relational Solutions (Baker, 2007). Interestingly, 82% of married couples celebrate their fifth anniversary, while only 33% celebrate their 25th, and only 5% celebrate their 50th anniversary. Baker (2007) reported that 50% of first marriages, 67% of second marriages, and 74% of third marriages end in divorce. A household economic study conducted by the National Center for Health Statistics (HCHS, 2009) indicated that divorce is influenced by the way couples resolve personal issues, in addition to laws that make it easier to get divorced.

Divorce is on the rise for couples in general due to "traditional reasons, as well as the starter marriage syndrome" (Gottman, 1997, p. 2). The two major reasons for divorce are high conflict in the first 5 to 7 years, and the loss of intimacy and connection during the first 10 to 12 years of marriage (Gottman, 1997).

Significant marital conflict can occur if parents disagree about keeping a child with autism at home rather than placing the child in an institutional setting (Jennings, 2005). Having a child with autism requires “an extraordinary level of support” (Jennings, 2005, p. 583), especially if the child is lower functioning and requires assistance throughout the day and night. If kept in the family home, caregivers quickly tire and, due to the amount of effort, sacrifice, and tolerance required to care for the child, a significant amount of family conflict may arise (Jennings, 2005). In addition, parents must decide if they will continue working, which then may lead to financial stress. The cost of highly structured and specialized treatment programs is often expensive and if finances are minimal, marital conflict intensifies even further (Jennings, 2005).

Effort to Keep Families Together

Due to the high rate of divorce among this group of parents, many organizations have developed a wide variety of studies that are currently available on the issues identified above, but only a few studies have examined the impact of stress on marital relationships and the actual rate of divorce among families with ASD children. In response to the previously mentioned 80% divorce rate, the National Association for Autism issued a plea via the internet asking PCWA to participate in a survey located on their website under a tab labeled, “Families First.” The survey consisted of five questions, one of which was the participant’s current marital status, and another asking if they were experiencing marital problems with the other parent of their autistic child. The information from this poll will be used, according to the site, to determine the resources needed for a marital-counseling program to be provided to PCWA to keep families together.

Bolman (2006) identified three stages of development and services needed to deter divorce among families of ASD children. First, Bolman suggested that receiving an accurate diagnosis as early as possible is key to obtaining early intervention. Not only does this reduce parental stress associated with the medical care of their child, but it also reduces emotional stress because parents are able to obtain services to help their child much more quickly. Second, having access to useful information is vital for parents to learn how to manage their child's ASD-related behaviors. Bolman pointed out that the misinformation that is currently available and the lack of knowledgeable professionals has contributed to parental stress and nationwide pandemonium. In addition, mothers sometimes take on the role of becoming the autism expert. Bolman suggested that moms and dads both take part in researching the disorder and equally participate in the child's daily care (e.g., attending IEP meetings at school and attending doctor visits and therapy appointments). The third area is adolescence and adulthood. According to Bolman, adolescence is especially difficult for PCWA because children become physically larger and are harder to manage as tantrums sometimes intensify, children develop sexually, and educational needs change to focus more on transitioning the child to function in the community rather than on academics. Other issues parents face during this time include what the child will do after high school for living arrangements, particularly in the event of both parents' deaths, especially if the grandparents are also deceased or are unable to assume the role of caretaker for the child. Other issues include guardianship and legal issues, and the child's participation in day, vocational, or other community programs. Bolman suggested that focusing on these issues might provide professionals with the tools to empower couples and prevent divorces in the future.

Despite all the stressors, if PCWA have access to resources to help the child, as well as themselves, it is possible that they can live healthier, happier, and more productive lives. PCWA are often so busy taking care of their child, they neglect their own needs and health (Jennings, 2005).

Biopsychosocial Theoretical Model

The biopsychosocial model developed by Engel, a cardiologist, internist, and psychoanalyst (Wise, 2001), has been useful in the diagnosis and treatment of autism because it is a holistic approach that examines the effects of biological, sociological, and psychological factors on one's overall health. The biopsychosocial model has changed the focus from disease to health by recognizing that factors from these perspectives can affect one's physical health (Lakhan, 2006). Physicians and mental health professionals can work together to treat the whole person. Using a holistic approach will greatly affect recovery from disease or illness, and promote better relationships between patients and their physicians (Lakhan, 2006). The biopsychosocial theory became popular as professionals focused on etiology and preventative factors associated with human health and disease (Dowling, 2005). Engel believed that physicians could learn about a patient's illness by using open-ended questions and an empathetic ear (as cited in Wise, 2001).

A mental health report from the United States Health and Human Services (HHS) Office of the Surgeon General (Satcher, 1999, C. 2) indicated the biopsychosocial model is especially useful in treating mental health issues because the exact cause of mental health disorders is currently unknown. The causes of health and disease are often seen as “an interplay or interaction” with biological, psychological, and social factors (Satcher, 1999, C. 2). When a patient has a mental disorder such as schizophrenia but also suffers from diabetes, both are viewed as an interaction of biological, psychological, and sociocultural factors. Treating autism from a biopsychosocial approach can be effective because the three main characteristics of autism are impairments in social interactions, limited or meaningless communication, and stereotypical or repetitive behaviors (Satcher, 1999).

The biopsychosocial model is successful in helping physicians understand disease and illness on multiple levels because it is a philosophical and a practical clinical guide (Borrell-Carrio et al., 2004). It covers all levels from molecular to societal. The model allows physicians to understand how a patient feels about a diagnosis and why they and their family members react as they do. This model builds trust between the patient and the physician, as it inspires empathy from the physician.

When physicians operate from a biopsychosocial perspective, they are more responsive to questions the patient or their family members have about the diagnosis (Borrell-Carrio et al., 2004). Instead of focusing on the diagnosis itself, they are more prone to communicate with the patient in a manner that inspires dialogue. This technique is particularly important for families of autistic children when there may be a lack of knowledge about the disorder. In this case, a physician would establish a positive working relationship with the family by providing education on the characteristics of the disorder, expectations, treatments, and available resources that will help the patient and the family. According to a parent survey, it is important to parents to receive accurate information about ASD and treatment options at the time of the diagnosis (Rhoades et al., 2007). In the current study, this topic is important because autism often causes a great deal of stress for parents as they struggle to manage their child while awaiting a definitive diagnosis and can also have a negative impact on the family dynamics overall. Understanding the biological impact of autism on families, including the psychological and social impact on the individual family members may help to inform others of the unique biopsychosocial experiences and the impact on overall family functioning (e.g., FST) as adjustments are made to accommodate the needs of the CWA.

Family Systems Theory

A family can be perceived as a system, meaning that one person has a direct impact on another, especially when one person is not functioning as well as others; therefore, families of CWA may benefit from family systems therapy that was introduced by Bowen in 1976 (Cridland et al. 2014, Cridland et al. 2015, Goepfert et al. 2015, Neely-Barnes & Dia, 2008). While therapy may not directly help the CWA, it can have a significant positive impact on other family members, as they continue to struggle with raising the CWA and accepting his or her limitations. As previously mentioned, the three major characteristics of autism include deficits in the areas of social interactions, communication, and repetitive behaviors and all three may have a direct impact on family members, especially PCWA who experience unique stressors as they cope to manage the symptoms of autism. The biopsychological model, developed by George Engle in 1977, is a good fit when treating PCWA and the family is a system where each person serves a role and when a person has a disability, it can mean that members within the family system may have to change their roles to accommodate the person with the disability (Goepfert, Mulé, von Hahn, Visco, & Siegel, 2015). What happens in a person's environment can have a significant impact on his or her physical and emotional well-being. Parents are reported to experience a host of medical (Borrell-Carrio et al., 2004) or psychological problems (Bayat, 2007; Benson & Dewey, 2008; Schieve, et al., 2007), including anxiety and depressive disorders (Bolman, 2006; Cappe, et al., 2011) as parents strive to understand and accommodate the specific needs of the CWA (Lakhan, 2006).

Due to the demanding characteristics of the symptoms of autism, parents often rely on professionals from the community to provide them with techniques to help manage their child's individual symptoms (Cridland et al., 2015). The parent's experience within the family system can be impacted by environmental, physical, or emotional factors with the potential for dysfunction as adjustments are made to accommodate the needs of the CWA (Lakhan, 2006). Each family member undertakes a unique role and set of responsibilities within the family. Parents have been reported to assume the bulk of household and caretaking responsibilities (Cridland et al., 2014), particularly when a child within the family has a chronic illness, or a disability such as autism (Cridland et al., 2014). In the same study, some parents transferred household responsibilities to others in the family to allow themselves more time to meet the demands of caring for the CWA (Cridland et al., 2014).

As family members of a CWA take on additional responsibilities and step into roles they may not ordinarily fulfill in a family, stress can run high and thus lead to higher levels of psychological problems, more emotional reactivity instead of problem-focused coping strategies, and more family conflict overall. This has been reported to be particularly the case for older sisters, who often assume additional responsibilities to help their parents in caring for the CWA (Cridland et al., 2015). In addition, families of CWA often must work with a variety of service providers (e.g., doctors, speech and occupational therapists, teachers, and other specialists) which can impose time demands and reduce the family's opportunity for social activities thus exacerbating feelings of frustration (Cridland et al.).

The way the family functions in response to the child's disability affects family outcomes overall (Neely-Barnes & Dia, 2008). Neely-Barnes and Dia (2008) stated that marital and family functioning is a much stronger predictor of parenting stress and depression than a child's disability. According to Cridland et al. (2015), applying Family Systems Theory to families who have a CWA is a perfect fit for treatment because the focus is on not only the interactions within the family or between family members and the CWA; the theory also focuses on the family's interaction with other systems (e.g., community, other families, schools and social groups). The Family Systems Theory recognizes the influence of the biopsychosocial model in that what happens in a person's environment can take a toll on a person's physical and psychological well-being and vice-versa (Lakhan, 2006).

Cridland et al. (2015) identified several concepts from Family Systems theory that would benefit families of CWA. The family as a system includes all individuals who depend on each other over time for comfort, nurturance, support, and emotional support. These individuals work in conjunction with each other to experience emotional closeness, cognitive engagement, physical health habits, social connectedness, communication, expectations, and interactions and can range from positive to negative. The individuals can interact with other systems or with subsystems within the family. In well-functioning family systems, boundaries are well defined but may be blurred or convoluted in poorly functioning families or in subsystems. In addition, role confusion may be present in terms of individual family members' responsibilities, which can lead to poorly regulated boundaries. An ambiguous loss can occur as one copes with having the CWA present physically but not psychologically. Resilience is also a factor in terms of challenging life circumstances including physical, psychological, emotional, and social resilience. According to Cridland et al. (2015), despite the traumatic news of the ASD diagnosis, traumatic growth occurs because family members also feel a sense of relief and validation, and over time, as they develop an understanding and acceptance of the CWA.

Because each member in the family plays a specific role, it is hypothesized that PCWA and their families may feel exceptionally challenged. PSWA not only attempt to manage typical issues that face all families (e.g., work, finances, interpersonal relationships with each other and those outside the family, time), but the additional challenges associated with autism. Such challenges include trying to acquire services from a variety of providers from the community to improve the quality of life for their

CWA, themselves, and their entire family. As a result, some PCWA may fall prey to physical (biological) illnesses (e.g., any illness related to depression or anxiety to include, but not limited to, stomach or digestive problems, ulcers, migraine headaches, other aches and pains, insomnia, fibromyalgia, etc.); as well as, mental (psychological) disorders (e.g., depression, anxiety disorders, marital or family problems, etc.). Adding to the strain, are social and financial issues (e.g., working with physicians, speech and occupational therapists, therapists who specifically work with the CWA to promote positive behaviors, teachers, and even extended family members) who may be involved with caring for the CWA. Addressing treatment from a biopsychosocial perspective when conducting family therapy may benefit all family members, regardless of the role they play when living with a CWA.

Summary

The entire family is affected when a child has been diagnosed with autism (Cridland, et al. 2014). Symptoms such as deficits in communication, poor social interactions, and stereotypical, or repetitive behaviors can also have a profound impact on all family members as each member must adjust their own personal, professional, and social lives to effectively meet the CWA's needs. Due to some of the behaviors such as having intense tantrums while in public or engaging in socially inappropriate behaviors or interactions with others can cause a family to make social and personal sacrifices of their own to accommodate the CWA. Such behaviors exacerbate the stress levels of the parents, as well as the other family members, and can also lead to increased psychological problems which can take a toll on a marriage, as well as on the family overall (Davis and Carter, 2008; Tehee, et al., 2009). Demands on time to accommodate financial requirements and time to seek support from community resources can also increase parental stress, especially when extended family members fail to understand the full impact of ASD and the adjustments that the entire family makes to accommodate the CWA (Benson and Dewey, 2008; Cridland et al. 2015; Schieve et al. 2007). These demands are often exacerbated when families experience poverty or have lower incomes as it presents more challenges in terms of acquiring services and resources for the CWA (Schieve, et al. (2007); Anderson, 2010).

Family Systems Theory (FST) incorporates the biopsychosocial model when it comes to treating families of CWA because what happens in one's environment can have a direct impact on one's mental and physical health. This directly applies to parents of CWA because they frequently must work in partnership with professionals in the medical and educational fields, in addition to their spouses, children, extended family members and the public to obtain necessary resources for their CWA and to educate those with limited knowledge of autism and its characteristics (Cridland et al., 2015). If providers working with CWA are aware of the struggles PCWA have identified from their daily lived experiences, perhaps treatment for CWA can also include parental concerns on a more frequent basis and improve the psychological well-being of parents, which may lead to improved marital relationships, as well as improve the overall quality of family functioning and other interpersonal relationships. Chapter 3 provides the research methodology for this qualitative study, the research design, the process of acquiring the sample population, data collection process, and how the data will be analyzed.

Chapter 3: Research Method

The purpose of the present study was to explore the lived experiences of low-income PCWA to determine how autism has affected their daily lives, as well as their marital and family relationships. Chapter 3 is divided into five major sections. The first section includes a discussion of the study design and rationale. In the second section, I describe the role of the researcher. The third section includes a description of the methodology used in the study. The fourth section includes a description of issues of trustworthiness. The fifth and concluding section includes a summary.

Research Design and Rationale

The research questions for this qualitative study were as follows:

1. How do low-income parents describe their daily lived experiences of raising a child with autism?
2. What effects does the CWA's communication deficit have on parental stress, if any?
3. How do parents describe their relationships with family members and their social experiences outside the home?
4. How do parents indicate their child's autism has impacted their marital relationship and family?

The central focus for this study was low-income parents' lived experiences of raising a child with autism. Low-income was defined based on family size and income per the U.S. federal poverty level provided by the Healthcare Facility Regulation Division/Office of Health Planning, Georgia Department of Community Health (2015) and the U.S. Department of Education (2016) based on the size of the family unit and income tables for Medicaid and Peach Care for Kids as outlined in the Income Guidelines for Parents, Caregivers and Kids from the Georgians for a Healthy Future (2016). For example, a family of four with a child ages 0 to 1 and an income of $51,048 or less was eligible to participate in this study; a family of four who has a child age 4 to 18 with autism and an income of $33,552 was eligible to participate. Parents raising children with autism experience unique stressors compared to other parents, including those raising children with other developmental disabilities, those with other health care needs, or typically developing children (Antshel & Joseph, 2006; Cappe et al., 2011; Ingersoll & Hambrick, 2011; Schieve et al., 2007). As symptoms can vary in severity, each CWA is different and parental experiences may also differ. Little information is available on the impact of autism on low-income parents and their marital satisfaction when raising CWA.

Hermeneutic Phenomenology

The qualitative phenomenological model was selected for this study to provide a deeper understanding of how the phenomenon of autism is experienced by parents with limited income and how it effects the family and the marital relationship. Experiential accounts provided by the participants provided a textural and structural description of the phenomenon of autism (see Creswell, 2013). The hermeneutic phenomenological method was chosen for this study to develop a comprehensive understanding of low-income parents raising children with autism from the participants’ perspectives (see Creswell, 2013).

Husserl (as cited in Kafle, 2011) introduced phenomenology as a method of combining philosophy with research. The focus was on consciousness in a philosophical sense, but Heidegger took phenomenology in another direction. Heidegger (as cited in Kafle, 2011) believed the focus should be more on existential and hermeneutic (interpretation) experiences. According to Kafle (2011), hermeneutic phenomenology focuses more on how a person experiences things through consciousness, which allows researchers to provide a rich textured description of lived experiences. Phenomenology as a discipline is a qualitative research method that focuses on people's perceptions of the world in which they live and what it means to them and how it provides meaning (Kafle, 2011).

Transcendental, Hermeneutic, and Existential Experiences

Husserl (as cited in Kafle, 2011) introduced transcendentalism as the original phenomenological form, which Husserl described as observing a person's experience of a phenomenon to discover reality. Husserl believed it was possible to avoid personal prejudices and opinions to capture the lived world of the participant as he or she experiences the phenomenon (Kafle, 2011). Heidegger disagreed with the idea of suspending personal opinions and turning to interpretive narratives for meaning and instead believed in the objective nature of things (Kafle, 2011). Heidegger believed the focus should be more on the subjective experiences of individuals or groups through real life stories. Heidegger believed that the description of interpretations was an interpretive process (Kafle, 2011). According to modern existentialism, introduced by Kierkegaard (1813-55), humans are a paradox, or a contradiction between mind and body (Kafle, 2011). Existential phenomenologists believe that a person's description of everyday experiences comes from the individual's perception not from the individual's consciousness (Kafle, 2011).

A hermeneutic phenomenological method was used in the present study to enhance the reader's understanding of low-income PCWA. This qualitative design was selected because it required an open dialogue, thereby providing critical firsthand insight of how the phenomenon of autism has directly impacted PCWA. Readers may develop a better understanding of autism and empathy for parents as parents report their daily experiences raising a child with autism and the challenges they face as they attempt to manage the defining characteristics of the disorder, which include social and communication deficits and behavioral challenges (see Creswell, 2007). Finances may impede the ability of the parent to acquire necessary services for the child, which may increase parental stress and impact marital satisfaction and overall family relationships, as well as career and social relationships (see Creswell, 2007; Schieve et al., 2007). Study participants provided experiential accounts, which were the basis of the textual and structural descriptions of the phenomenon of autism from which the essence of the phenomenon was identified (see Creswell, 2007).

Role of the Researcher

My role as the researcher in this study included recruiter, correspondent, interviewer, data coder, data entry clerk, analyst, and writer. Although each role had specific duties, the intention was to complete each phase as accurately as possible. My interest in the subject of autism was spurred by classroom experiences as a special education teacher in a middle school setting. I am no longer employed in that capacity; however, my quest to develop a deeper understanding of the phenomenon of autism has not dissipated. As a college instructor, I have taught several students who were eligible participants because I was no longer teaching them. I took every precaution to avoid any potential ethical issues at my place of employment when my previous students chose to participate in my study, and I made sure that they had already completed the classes that I taught to avoid any potential power differentials.

As a mother of typically developing twin daughters, I know that raising children can be challenging, but through my classroom experiences I became aware that raising a child with autism presents a unique set of challenges to parents that I did not have as a parent. I became aware of some of the challenges that these parents face daily, but I was also interested in their personal experiences and perspectives. I was also aware that due to the challenges that accompany the diagnosis, some parents may become socially isolated. Those who attempt to work outside the home or engage in social activities may find that the challenges are overwhelming and may become socially isolated as a result. I took every precaution to ensure privacy and confidentiality for each phase of the study for participants. Participants were low-income parents raising children with autism.

Although I did not have any personal connections with autism, I did have some professional experiences from the classroom and understood that some participants may have had similar experiences. To separate my experiences from those reported by participants, I bracketed my experiences to ensure that I analyzed only the opinions, experiences, and beliefs of the participants. To mitigate any personal biases, I focused solely on the participants and the responses generated during the interviews.

Methodology

Participant Selection Logic

Participants for this study consisted of a pilot subject and 13 participant parents (all mothers), raising school-age children with autism, all of whom were between the ages of 4 and 10. Saturation was not achieved prior to interviewing the 13th participant, so all 13 participants completed the interview. Participants who met inclusion criteria provided data for the study via the criterion-based sample method defined by Creswell (2007). Inclusion criteria for this study consisted of the following: (a) participant had an annual income equivalent to or below the federal poverty level according to the U.S. Department of Education based on the number of people in their family, (b) participant had lived with the CWA for at least 1 year after the child was diagnosed with autism, and (c) the participant's child had a definitive diagnosis of autism for a minimum of 1 year. Participants could have included the biological mother or father; however, only mothers participated. The exclusion criteria consisted of participants who had never lived with the other biological parent of the CWA or who did not otherwise meet the inclusion criteria.

The size of the sample in qualitative research does not have to be large if the researcher can achieve representativeness and generalizability from a small number of participants (Englander, 2012). Phenomenological research using the qualitative method "meets general scientific criterion as well as a statistically-based approach" (Englander, 2012, p. 20). At least three participants should be used, but to add depth Englander recommended between five and 20 participants; however, the more participants used, the more work for the researcher. Interviews were conducted until saturation occurred with the 13th interview. Saturation occurs when the same themes begin to emerge (Creswell, 2015). The goal of the study was to explore the phenomenon of the participants' lived experiences of raising a child with autism to enhance the understanding of those who have not been in this position (see Englander, 2012). The researcher's task is to present the reader with a "meaning-structure of the phenomenon in an eidetically constituted" manner by conducting interviews to become familiar with the phenomenon, not the participant, via the participant's description of his or her lived experiences (Englander, 2012, p. 22).

Instrumentation

I used semistructured interviews that were conducted either via telephone or in person. No historical or legal documents were used as sources of data for this study. Semistructured interviews have been deemed a sufficient data collection instrument for phenomenological research (Kafle, 2011).

The semi-structured interview was developed based on the current research of autism. The interview contained 12 open-ended questions and pre-planned prompts to allow flexibility and good interviewing techniques. The first three questions were designed to establish rapport and to increase the comfort level of participants. The first two questions were factual and focused on the child and the specific symptoms of autism and their severity. The third question demonstrated researcher empathy, promoted open dialogue, and established rapport. All interview questions were as literal as possible to decrease misunderstandings of the research question.

Pilot Study

A pilot study was conducted, prior to collecting any data for the study. By conducting a pilot study, I tested the reliability and validity of the research questions. Kim (2015) listed four ways in which pilot studies can be helpful to researchers. First, it can help researchers to identify any potential barriers related to the recruitment of participants. Second, it can also help researchers to ensure they are engaging with the participants in a culturally appropriate manner and from a phenomenological perspective. Third, it can ensure the researcher is setting aside any prejudgments (epoche) and finally, it provides the researcher with an opportunity to modify interview questions (Kim).

Pilot participants were recruited through a verbal request amongst friends and associates who have a child diagnosed with autism. I conducted the interview over the phone after the participant complete the electronic Eligibility Study; and Pilot Study Consent Form. Following the conclusion of the interview, the pilot participant was asked about the clarity of the questions and if she felt any questions were biased in any way. She was also asked for suggestions and additional questions or areas that the researcher may have not previously considered. Changes were made to questions as needed. Pilot participant results were not included in the final analysis.

Main Study

Procedures Sampling Strategy

I incorporated snowball sampling as suggested by Creswell (2013) for participants who were familiar with others who are also parents of children with autism who were willing to participate in my study. Recruitment flyers will be placed in strategic areas around a local college campus and sent electronically to administrators of several online autism support groups in Georgia that were found on social media (see Appendix D). The flyer consisted of a description of the study, the criteria for inclusion or exclusion, and contact information for the researcher. Two forms of recruitment flyers were made available, one form was placed on a college campus (Appendix D), and another recruitment flyer was sent to online forums (Appendix D). Both recruitment flyers are available in the appendices and described the inclusion criteria.

Data Collection

Once institutional approval had been received from Walden University and from the local college, Central Georgia Technical College, participants were recruited using flyers placed on campus and were e-mailed to the Georgia Autism Society, students, faculty, and staff at Central Georgia Technical College, and local support groups for parents of children with autism in Macon, Georgia. The flyers included a description of the purpose of the study, as well as the duration, the inclusion and exclusion criteria for participation and my contact information (phone number and an e-mail developed specifically for this study (Appendix D). Because an adequate number of participants were not available, participants were sought from LinkedIn and Facebook.

Participants who were interested in the study contacted me via telephone or e-mail and completed an Eligibility Survey either electronically or in person. If eligible for participation, an Informed Consent was completed either electronically or in person. Provisions were made to mail materials to participants who chose to conduct the interview over the phone but lacked access to a computer in which I would have mailed a self-addressed stamped envelope for the return of the Informed Consent form and upon return receipt, I would have contacted the participant by telephone to conduct a brief demographic survey (Appendix B), followed by the interview (Appendix A). All participants had access to computers or chose to meet in person so this step was not necessary and forms were e-mailed instead. Participants who chose to meet in person completed the Eligibility Survey and Informed Consent and after eligibility was determined, were immediately interviewed in a private classroom of the local college. The consent form included notification of the participant's right to withdrawal from the research at any time. No interviews were conducted until after consent forms had been signed and received by researcher at which time interviews were conducted in person or on the telephone.

Interviews

After each participant made initial contact with me via telephone or e-mail, and they had been deemed eligible to participate and agreed to participate in the study, I determined their preference as to how they wanted to conduct the one-hour interview, whether it be via telephone or in person and we arranged a time and date convenient for them. I made sure the participants understood that a public area was not considered a secure location for this type of interview. If they wished to do the interview over the telephone, I recommended the participants respond to the questions in a room by themselves where others could not overhear the conversation to maintain confidentiality and privacy for other family members. Participants who choose to meet in person were asked to meet in a private room of a local college convenient to their location arranged by me. I informed participants that the interview would need to be recorded using a digital voice recorder so a transcript could be created by me of their responses for accuracy.

Once a time and date has been scheduled, if the participant had chosen to meet in person, I collected the signed Informed Consent upon arrival. Participants who chose to participate over the telephone were not interviewed until after I had received the Informed Consent via e-mail and then the demographic survey was competed on the phone prior to the interview. During the interview, prior to introducing the interview questions, I permitted the participants to ask questions and addressed concerns and informed them of the possibility of a follow-up call to clarify any unclear responses. I explained that a transcript of the recording would allow me to correctly analyze their feedback. Upon completion of the interview, I answered any questions or addressed any concerns participants may have had during debriefing with the understanding that if needed, I would contact them with a follow-up telephone call after reviewing recorded responses should clarification be needed.

Debriefing Participants

Each participant was formally debriefed in a discussion with me following the interview to check in and discuss any questions or concerns that might have surfaced because of the interview questions (see Appendix A). I performed this same check in with each participant at the end of the data collection process to ensure that any issues were adequately addressed. All participants were e-mailed or provided with contact information for supportive counseling in their area.

Data Analysis

Semi-structured interviews were the sole data collection technique used to answer all research questions. I followed all procedures for coding data as specified by Billups (2015) and Creswell (2015). I began with one participant and followed through with all questions, thus reading and re-reading several times to ensure understanding and accuracy.

All qualitative data analysis involved the same basic four steps: (1) raw data management, (2) data reduction, (3) data interpretation and (4) data representation (Billups, 2015). The process for step 1 involved collecting raw data, organizing, reading through twice and making notes, identifying themes, attitudes, and behaviors, merging themes, and interpretation of the data. This process was repeated until I had effectively managed the raw data collected and organized into meaningful units of analysis (Billups, 2015). A review of the transcript yielded raw data that was unusable or irrelevant to the study (e.g., “Umm…” or “I cannot think of anything right now.”), which was deleted (Billups, 2015).

The second step focused on data reduction which required a variety of procedures and techniques. Procedures included visualizing, describing, classifying, interpreting data, as well as reading and making notes and then organizing or filing information for effective data management (Billups, 2015). According to Billups, categorizing data can lead to deeper immersion and can make it easier to detect emerging themes, specifically when chunking like information together. Winnowing, a technique recommended by Billups (2015) consists of developing initial categories and a set of codes used for clustering raw data that share similar meanings or qualities. The codes were kept in a list or book and may have to be refined two to three times or as needed (Billups, 2015)

The third step was data interpretation and themes. During this stage, chunks of related information had already been coded into groups according to similar meanings and thus themes emerged which could be interpreted to answer research questions (Billups, 2015).

The fourth and last step focused on reporting the data. Billups (2015) suggested telling the story in a narrative and chronological format that includes flashbacks and critical incidents, theatrics and themes that are illustrated through visual representations such as figures, charts, and tables.

The relationship between research questions and interview questions is detailed in Appendix A. All qualitative data collected during interviews was transcribed verbatim by me. I ensured that no personal identifiers were accidentally included during transcription to ensure confidentiality of all personal information gathered during the study. Interviews conducted using voice recordings were transcribed verbatim by me.

A table generated in Word was used to assess themes present in participant feedback. Another researcher trained in qualitative research was asked to review the methodology for themes to ensure none were overlooked. Although the goal was to interview a total of 13 participants, had saturation occurred prior to the goal, the study would have ceased and data analysis would have commenced.

Rich thick description was provided to sufficiently report information about what was done in all stages of the data collection and analysis so the reader will develop a solid understanding of the study and its strengths and weaknesses (Creswell, 2013).

Issues of Trustworthiness

In qualitative studies, trustworthiness requires the researcher to demonstrate credibility, dependability, transferability, and confirmability. Trustworthiness and authenticity are provided via multiple methods to include triangulation, thick description, audit trail, member checking, and reflexive journal. These methods provide documentation of the study's transferability, dependability, confirmability, and inter coder reliability.

Transferability

I summarized participant responses through a rich, thick description of the participant and the participants lived experience (Kafle, 2011) and identified major themes from the interviews.

Dependability

Triangulation and member checks were used to establish dependability and accuracy (Creswell, 2013). Triangulation was accomplished by using multiple participants. Credibility was established in the present study by using open-ended questions to maintain the quality of the research process. I focused on the four standards of the hermeneutic cycle which include credibility, transferability, dependability, and conformability during the interpretation and writing process (Kafle, 2011) by focusing on the "wholeness of the experience" and searching for themes to provide meaning to the phenomenon from the reported lived experiences (Simon & Goes, 2011). To maintain these four themes, Simon and Goes recommend the use of an audit trail to establish credibility, which is described as a description of steps taken throughout the entire research process, including the reporting of findings which will explain what was done during the investigation.

To ensure anonymity in the final published paper, Simon and Goes (2011) suggested that participants be assigned pseudonyms, which will allow them to report their experiences in their own words while maintaining confidentiality. Participants will be able to reveal their feelings and attitudes about the phenomenon using in-depth interviews (Simon & Goes). Member checking will ensure credibility by allowing the participant to review the transcript for accuracy (Creswell, 2013). The use of reflexive journaling through the research process will allow me to bracket my experiences to provide awareness of my own biases so they can be removed from my analysis (Creswell, 2013). The journal can also be used to record my thought processes throughout the study which will support the credibility and dependability of my interpretations.

Confirmability

For confirmability, the maintenance of raw data obtained throughout the study provided an audit trail that can used by others to verify trustworthiness and authenticity of my findings. Raw records include interviews, transcripts, my reflexive journal, all notes, drafts, and research obtained throughout the study. I also maintained the reflexive journal as described above.

Inter coder reliability was established by following the four steps for qualitative research (Creswell, 2015) which included defining categories and subcategories that were specific to the study goals that must be checked and rechecked (Billups, 2015). Intra coder reliability was established by a table created for each interview question which helped to identify emerging themes from participants and prevented duplication in the transcription process.

Dissemination of the Findings

Several stakeholders may wish to review the findings of the study. In the event, the participants would like to know more about how their experiences contributed to this research, I will send them an electronic copy of my summary. A copy of the findings will also be made available in the dissertation database at Walden University. I believe the findings can contribute to positive social change as readers develop more empathy and understanding of the phenomena of autism and the resources and services required for CWA and their parents to live a better quality of life.

Ethical Considerations

Approval was obtained from Walden University's IRB (2016.07.1 4 13:49:57-05'00'). All participants were assigned a random number to ensure confidentiality. An e-mail account will establish specifically for the study. All contacts were deleted after data has been collected, unless participants requested a copy of the findings in which case contacts were deleted after the information had been sent. Interview material and demographic materials were stored and locked in a file cabinet in the researcher's home office, which was also locked. No identifying information was kept with the electronic or raw data. The key associating the name with the code numbers was kept in a separate locked box in the researcher's locked home office. Only I had access to the data. All electronic files and information were stored on my laptop secured with a password known only to me, which was also be stored in a locked office located in the researcher's locked home office. Only I used this laptop; electronic information stored on this laptop was never viewed in a direct access area where information might have been compromised. Hard copies of the data will be kept for a minimum of five years and thereafter destroyed accordance with the APA standards.

The risk of this study was low and was limited to issues regarding confidentiality and the potential for psychological distress. The study was conducted only after I had obtained approval from Walden University Institution Review Board. Participants were instructed that the participation in this study was voluntary and that they may withdraw consent at any time. They were informed that they were free to refuse to answer any question they may not wish to answer.

If the participant reports they have experienced any physiological distress, discomfort, or unwanted feelings during their participation in this study, steps would have been taken to make sure the participation was referred to a specialist in their area to address their concerns immediately. As a precaution, all participants were provided with a list of local therapists and mental health agencies should they decide these services are needed in the future. This incident would have been reported to the Walden IRB immediately. Debriefing was conducted to determine if professional counseling was needed. Conditions concerning the issues confidentiality and any limits to this provision were addressed when participants were presented with consent forms. Participants were presented with consent forms, which they were required to read and sign and return prior to any consideration of participating in this study. Consent was a process of confidentially and the voluntarily nature of the study will was discussed at each interaction of the study with the participant.

Summary

Using a hermeneutic phenomenological research, this study examined the textural and structural descriptions regarding the phenomenon of the lived experiences of raising a child with autism (Cashin, 2003). Of interest were the reported parental stressors related to the symptoms of autism itself, particularly communication deficits, behaviors, and impaired social relationships for the CWA on the parents, as well as marital satisfaction and family relationships overall. Qualitative interviews were used to acquire relevant participant interview data. I composed the essence statement to depict what it means to raise a child with autism and the impact it has on the lower-income parent and family in general.

Organizations such as Autism Speaks, have attempted to enlighten the public using media (e.g., commercials on TV, ads on radio, magazines, and newspapers) about the symptoms and characteristics of autism to heighten awareness about the disorder overall. As a college instructor, I have had several previous students who have children diagnosed with autism, some of whom have been diagnosed for a while, but others who have a more recent diagnosis. By incorporating the lived experiences of those who participate in this study, I hope to bridge understanding between readers, as well as to promote empathy, for parents and the unique challenges they face when raising a CWA. Although there are a few studies available that provide some personal insight from parents regarding some of the stressors they face and the impact it has on them personally, low-income parents raising children with autism are a population who have not been richly studied. The findings of this study could prompt further research into the physical and mental well-being of these parents, as well as to bring unmet needs to the attention of professionals. This could lead to the development of future programs that would fulfill any needs mentioned by the parents, who could, in turn, help to increase the overall physical, psychological, and social well-being for all PCWA.

Chapter 3 was a description of the proposed study which began with a description of the research tradition and rationale. A description of the researcher’s role and the primary data collection method was then explained. A discussion of the methodology, including step-by-step procedures were then discussed. Lastly, a description was provided of the methods to be used for addressing issues of trustworthiness. Chapter 4 will provide a description of the pilot study and the impact it has on the main study, the setting in which the actual study was conducted, and the demographics and characteristics of the study. Lastly, the results of the study will be discussed.

Chapter 4: Results

The purpose of the current study was to explore the daily lived experiences of parents raising children with autism, specifically those who have low-incomes as it relates to their ability to acquire necessary services and treatments for their children. This study addressed a gap that exists in current studies in the United States regarding the lived experiences of raising a child with autism for parents who have lower incomes. A qualitative hermeneutic phenomenological study was used to understand the lived experiences, beliefs, and stressors of low-income parents raising children with autism to gain an understanding of the experience as the participant believes it exists (see Cashin, 2003; Kafle, 2011). I also addressed concerns such as household finances, employment outside the home, social interactions, and marital satisfaction and their impact on raising a child with autism from a family systems perspective. Individual interviews, which were driven by the research questions developed for this study, were used to obtain required data. This chapter provides a thorough description of the setting, data collection methods, data analysis, and the essence statement of the phenomenon (see Creswell, 2013).

Pilot Study

The pilot study was conducted with one individual who had prior knowledge of autism. After I described the research study and the steps that would be taken to conduct the interview, the individual granted consent and the interview was conducted via telephone using the same interview questions developed for this study. The participant was then asked to provide feedback regarding the questions' structure and relevance as well as the appropriateness of each question. From the pilot study interview, the participant determined that each of the questions was easy to understand, was relevant to the research topic, and did not cause the interviewee to feel distressed in any way. I determined that the interview questions could be used for this study without changing the questions or the interview process.

Setting

Fliers were posted with permission on a local college campus, as well as on several social media Facebook pages for autism support groups, although most of the participants in this study were recruited via friends through word of mouth. Three individuals elected to be interviewed in person and the remaining nine elected to be interviewed via telephone. Due to a technical malfunction with the digital recording, one of the nine telephone interviewees had to be interviewed twice. IRB approval was received to conduct the interviews in person or via telephone. Participants responded to a written request that was electronically sent to friends and acquaintances who then communicated to me through a minimum of three e-mails to provide consent. All participants were e-mailed an informed consent form, which they signed and e-mailed back to me. Once the consents were received, I scheduled a time for the telephone interview via text. At the appropriate times, I contacted each participant individually to conduct the interview. The three participants I met in person met with me in a private room of a local college library. All interviews were digitally recorded to ensure transcription accuracy. I did not have any further communications with participants or acquaintances who may have referred them to me. An e-mail specific to this study was set up and used for all electronic correspondence with those interested. Several interested individuals were rejected because they did not meet the criteria for the study. By using the fliers, I was better able to reach out to those who might be interested in participating in the study throughout the State of Georgia.

Demographics

Thirteen women met the criteria to be eligible to participate in this study; one participant had two children, age 4 and age 10, both of whom have autism, thus making a total of 14 children. All participants were referred to me via friends who had seen my flier on the college campus or on Facebook. Participants ranged in age from 25 to 52. Additional demographics are displayed in Table 1.

Table 1

Demographic Characteristics of Parents of Children With Autism

Characteristic		*n*	%
Gender			
	Female	13	100%
Age			
	20-29	2	15%
	30-39	9	69%
	40-49	1	.08%
	Above 50	1	.08%
Ethnicity			
	African American	4	31%
	Caucasian	9	69%
Education			
	HS/GED	4	31%
	Some but <2 yrs College	6	46%
	AA	2	15%
	MA	1	.08%
Employed			
	F/T	2	15%
	P/T	2	15%

	Both F/T & P/T	2	15%
	FMLA	1	.08%
	Not employed	6	46%
Annual Income			
	$10k or Below	2	15%
	$10,000-20,000	4	31%
	$20,001-$30,000	3	23%
	$30,001-$40,000	3	23%
	$40,001-$50,000	1	.08%
Child’s Age			
	4*	3	21%
	5	3	21%
	6	2	14%
	7	1	.07%
	8	1	.07%
	9	1	.07%
	10*	4	29%

*Parent has two children, both of whom fall into this age category.

Data Analysis

When conducting qualitative phenomenological research, the researcher is charged with the burden of ensuring validity and credibility (Creswell, 2013). According to Moustakas (1994), epoche, or bracketing, is a technique used in phenomenological research that allows the researcher to set aside his or her own experiences and view the information provided by participants with a fresh perspective. Prior to engaging in this dissertation process, I had very little exposure or knowledge of autism, other than having one student in a previous middle school classroom. The time I spent with this student challenged me to learn ways I could work effectively with the student during our time together. The experience piqued my interest because I had received no specific or formal training on autism and had to learn quickly how to interact with this student. Since that time, a cousin I do not see very often had a child with autism. During my classroom experience with the young man who led me to the topic for this dissertation, I found many challenges and tried many different techniques to work effectively with him, including taking a sign language class to communicate with him because he was nonverbal, and reading books on autism, one of which was written by the mother of a child with autism whom I later began corresponding with via social media. Because of my limited knowledge, I had no understanding of autism. However, after working with this student and observing my cousin's son during a family reunion, I used epoche to set aside my experiences and beliefs to better understand the daily lived experiences of the parents I interviewed who were raising children with autism. Because I had limited information on autism, I could listen with an open ear instead of comparing my experiences to the experiences of the participants. This deterred any attempt to include my opinions, beliefs, experiences, or biases as a researcher.

Horizontalization

According to Creswell (2007), horizontalization is the next step in phenomenological research. In this step, each statement is viewed with equal value, thereby providing a new horizon causing fresh ideas to emerge from the data (Creswell, 2007). I used a table for each individual research question to categorize participant responses. The table was divided into three columns. The first identified participants who were coded by their first and last initials, the second included their answer to the research question, and a third column was left blank so I could list emerging themes. There were 12 charts, one for each interview question, which allowed me to go back and identify themes that emerged from each individual answer and for each individual research question. Answers were examined for any similarities or distinctions for each individual participant. This process is called textual description and is used to describe the experiences of each participant.

Textural Description

Themes emerged as each participant shared her personal account of their daily experiences living with a child with autism (see Creswell, 2013). The textural description was necessary to understand the context in which the experience occurred as well as the perceptions and beliefs of the participant. To consider the relevance of these experiences to the phenomenon being studied, I compiled a comparative description between participants to examine how participants described their experiences. To fully describe the setting that the experience occurred in, I used a process known as imaginative variation (see Creswell, 2013).

Imaginative Variation

Moustakas (1994) defined imaginative variation as structured description and pointed out that this requires researchers to create a structured description of how the phenomenon was experienced. Each experience providing a unique perspective from the individual regarding the phenomenon, but it was necessary to examine how the participant experienced what was described from each response (Moustakas, 1994). To identify themes, I had to compare responses from everyone for each question. I then went back a second time to make sure no themes were missed and that each one reflected the phenomenon of the parent's lived experiences of raising a child with autism.

Discrepant Cases

There were 13 participants in this study. One interested person was disqualified because her income did not meet the criteria of the study, and one was disqualified because her child's age did not meet the specifications of the study. Of the 13 who participated, two conveyed significant stress compared to the other participants, both physically and mentally, as well as psychologically, and described their experiences as follows. One was more positive about her experiences with autism compared to the other participants. Examples of responses include the following:

> I feel like I failed him at times. I gained weight and lost weight. My teeth went bad…just deterioration of health overall. I've been in the psych ward twice and rehab twice. I'm better now though; I'm happy now actually. When I say all this

> stuff, I am describing prior to me getting out of my own funk because of this. I socially isolated myself. (CH, age 28, married, son, age 5.)

The second participant stated that it “delayed my career” because she had to stop working. She also became “very depressed” to the point of being hospitalized for being suicidal. Her thoughts at that time were “whoever can handle them, can have them.” She “lost” all of her friends and developed high blood pressure problems, along with diabetes, that led to hospitalization. In addition, because her husband would not acknowledge that anything was wrong with the children, her “marriage went downhill.”

> It hurt me because I am the mother and a mother just knows about her children. These were my first two kids but I have been around others raising children and I just knew. Mothers just know…. Physically, my blood pressure had gotten down but here, over the summer, my pressure has been high so I was in the hospital but after a few days, it went down again and then I went home. About three hours after I got home, my pressure shot back up. I just didn’t understand because this was new for me. It has happened three times. The first time it happened, the oldest was 6 and then when he was 8 and then last year when my little one was 3. **[How are you feeling now?]** It’s been stressful and has gotten more stressful after the incident last summer with my mom because I have to plan my schedule around theirs to get them to and from school because their Daddy has gone back to work. It’s hard…it’s very hard. I was getting depressed a couple days ago because I’m like, I have to quite school again; I have to put my life on hold because I have no one to watch them while I leave them for a couple of minutes

until the bus comes. I was getting depressed, like I'm a failure and I can never finish anything I start. I felt like my husband was going to call me a failure but, I 've come along way and I keep telling myself that it will get better and that I am gonna find more resources and I registered for my classes and I'm just turning it over to God. Socially, I think the boy's behaviors get worse during the summer…well, I do not really know if it's the heat but summer and winder are my worst times. I think in the winter, because the sun doesn't come out much and it's cold, but summer, I guess because the routine changes where they were used to getting up and going to school but during the summer, things change. I tried to get them into a summer camp, but with their behavior, they would not take them so they got kicked out. The routine changed, I think, has a lot to do with their behavior. (JB, age 43, married, has two boys, ages 4 and 10, both of whom have autism.)

Personally, I do not think it has affected me. I've always been a very blunt person and I do not care what people think if he has a melt-down in public. I've always kept him in public and we have learned together. If it's too bright in a restaurant, I tell him to look down; if it's too loud, we leave and go back later when it is less crowded. I've never treated him like he has autism. If you meet him, you would never know. I treat him like I would treat anyone else. Physically, everything is normal for me. I do not know anything different because he is my only child. I let him have his melt downs and then I talk to him. I tell him if has a problem, to grab whoever is around until he calms down. Psychologically, it has affected me.

> Socially, it hasn’t affected me because everywhere I go, my son goes with me. I do not date and will not until he’s older. I do not want different men coming in and out of his life. (CG, age 37, divorced, son, age 10)

Although all participants clearly discussed both the positive and negatives of raising a child with autism, the preceding responses were the most extreme on the negative and positive end.

Essence Statement

The *essence*, or the common theme, found in this study is that raising a child with autism is stressful and takes a lot of patience given its unique symptoms, whether one falls on the mild or severe end of the spectrum. The commonalities from participant interviews yielded personal experiences, beliefs, and the needs of the participants. The essence statement was developed to reflect what it is like to raise a child with autism, especially with a limited income. Because of this study, the essence statement that described the phenomenon of raising a child with autism is:

Raising a child with special needs can be stressful to parents but given the unique characteristics of autism, raising a child with autism can be even more stressful as parents struggle to understand their child’s needs. When the child is non-verbal, it can exacerbate the parent-child relationship as the parent struggles to communicate with the child. Parents of children with autism who have access to resources such as speech and occupational therapy, can learn ways to communicate with their child but when finances are a factor and families cannot afford these services, not only does it impact the child in terms of learning to express him or herself, but it can also present even more challenges for the parents who struggle to understand their child and thus fulfill the child’s needs. Due to the behavioral demands associated with autism, as well as the communication and social deficits that accompany the disorder, many children are content in being alone but this can also cause parents to feel isolated as they often feel the need to stay at home rather than going out into a public or social setting with their child. Regardless of a parent’s income, when resources are available to help children with autism improve their communication and social deficits, or to provide techniques to help them cope with any repetitive or stereotypical behaviors, this may also reduce parental stress and may lead to improvements in the child’s behavior and in the parent-child relationship altogether.

Evidence of Trustworthiness

Credibility

This study utilized social media, as well as fliers placed in strategic locations throughout a local college to solicit participants. Those who were interested, notified me via a special e-mail that was set up just for this study and in response, consent forms and a demographic sheet were sent for signature. Participants printed, signed and returned consent form and demographic sheet via scanning and e-mailing back to me within a two-week period. Once the participant was deemed eligible to participate in the study based on the criteria for the study, I contacted participants via text or telephone to schedule a time for the actual interview. Participants were given the option of meeting in person or conducting the interview over the phone. I met individually with three participants in a private room at a local college library and telephoned the remaining participants. All interviews were digitally recorded to ensure transcription accuracy once the interviews had been completed. Follow-up questions were used for those participants whose responses required additional clarity unless a participant seemed particularly distressed due to the sensitivity of the research topic.

Transferability

Kafle (2011) stated the importance of transferability, or the ability to show that findings are applicable in other contexts and Creswell (2007) defined transferability as the potential for the reader to apply data from a study to other studies and situations. Creswell (2007) believed that the use of thick description could be provided by detailed descriptions of the participant experiences. Transferability in this study was used to relay the thick description of participant experiences to the reader. Participants were both single and married women of various ages who all had at least one child with autism, although one mother had two children with autism. Thirteen participants were included in the study: six of whom were not employed outside the home and seven who were employed outside the home. Of these seven, two worked part-time, one because of the "his autism is so severe" and three of whom have both a full and a part-time job. Two participants reported an annual household income of $10,000 or Below; four reported incomes of $10,001-$20,000; three reported incomes of $20,001-$30,000; three reported incomes of $30,001-$40,000, and only one participant reported an income of $40,001-$50,000. Ten families included at least two adults living in the home; five families had two children living in the home, seven families had one child living in the home and one family had three children living in the home. Results from this study could apply to other low-income families who have children with autism in similar situations.

Dependability

Dependability in research is defined as an ability to duplicate the research study and get comparable results (see Creswell, 2007). For duplication of a study to occur, the original author must have provided extensive detail in the design, implementation, details for the data collection process, and the effectiveness of the processes used (Houghton et al., 2012). Each step in this study has been thoroughly documented including the data collection and effectiveness of the methodology. The possibility exists however that the same significant variation in responses may or may not occur in a duplicated study due to the individual's financial situation as well as the severity of autism that their child experiences. For this study, I established the inclusion criteria that resulted in a broad range for annual income under $50,000. Low income requirements were based on family size compared to reported family income. The dependability of this study was also accomplished by having participants who were well acquainted with the research topic and who had an established amount of time to reflect on the interview questions and provide the appropriate responses.

Confirmability

As mentioned in Chapter 3, the steps I took to establish confirmability included having another researcher review my findings. Simple data charts were used to record responses from each individual participant for each individual research question from which themes were manually identified in the responses provided.

Findings

This section describes the essence, themes, and subthemes that emerged from the analysis of the experiences of parents who have children with autism. This study consisted of four main research questions and twelve interview questions which allowed the parents to provide a through description of their daily lived experiences. The first research question focused on the daily experiences of low-income parents raising children with autism. Six interview questions were used so participants could share their personal perspectives as they provided a general description of the child and the child's uniqueness, their daily experiences of raising a child with autism, the quality of their pregnancy and the birth process, including any complications if applicable, when they first noticed a problem and their experiences throughout the diagnostic process, the relationship between their current household income and the effect it has had on their ability to raise their CWA, including any resources their child has received in the past or is currently receiving, and also provided them with the opportunity to share their strengths and weaknesses as parents of CWA and share information they want others to know that might not have been specifically asked during the interview

Essence of the Parents' Experiences

The essence of raising a child with autism was described with the words "stressful", "overwhelming," and "emotional." Participants were able to describe their children in a positive manner such as (e.g., "a loving, sweet, sensitive child," "the sense he has is just ridiculous compared to other kids his age," "very playful and he likes kids," "very smart and highly, I mean highly intelligent," "amazing. He is very smart in math.").

Themes related to challenges that were shared included parental stress, some of which was attributed to inadequate incomes and the inability to provide necessary resources for their children, difficulty understanding their child's needs due to communication deficits, social isolation and separation from extended family members, unsupportive community responses to autism, and differences in parenting techniques and understanding of autism by spouses which had a negative impact on the marital relationship.

All participants described the positives and negatives of raising a CWA and a common theme that continued to surface from all participants it is “stressful” and “challenging” and requires “a lot of patience”, is a very “emotional” experience, especially as “behaviors get worse” and as the child gets older and lacks appropriate social skills to form close friendships with other children. Six participants had cesarean births; two reported the use of the vacuum during birth, two had a natural delivery, one with no pain medication or drugs of any kind, and three did not specify their birthing methods. Eight participants reported some complications during pregnancy such as “being sick every day”, two reported “high blood pressures”; one of whom also reported that her pre-pregnancy high blood pressure and diabetes worsened during pregnancy and that she had already had several prior miscarriages, which made her pregnancy very high-risk; one because she broke up with her boyfriend during pregnancy and was going to be a single mom, and another because of financial and family issues during pregnancy. Three reported no complications during pregnancy and only two participants reported no complications during the labor and birthing process, but included long labors; the longest lasting four to five days. One participant was a week beyond her due date; one child had acid reflux, another one had gastroesophageal reflux disease (GERDS); two were born breech and the worst one was born at 23 weeks of gestation with a 50/50 chance of survival, weighing one pound, three ounces and was eleven inches long and was thus labeled as a medically fragile child.

> Both of my pregnancies were premature and both boys were born at 36 weeks. My pregnancy was high-risk. I was seen out of the hospital from 3 months to 36 weeks of pregnancy with both of them. I had high blood pressure and diabetes; I had it before but it got worse during pregnancy. It was very stressful for me because I had had several miscarriages before that. I was in and out of the hospital every month or every other month with each pregnancy to keep from losing the babies. I did have birthing complications due to my high blood pressure. I had two C-sections and I was not able to have a normal delivery. Both babies came home when I came home. (JB, age 43, married, has two boys, ages 4 and 10, both of whom have autism)

> My pregnancy was pretty good for the first five months but during a trip to Florida for a family reunion on Labor Day, I started hurting and hurt the whole time I was down there and it got worse and I started spotting so I went to the doctor. He checked me and told me my cervix was weak and gave me some medicine. Two weeks later, I ended up in the hospital, dilated 1 cm with a bulging bag of water. The plan was to keep me in the hospital for at least another month because I was 23 weeks at the time, but two days later, I was in severe pain so they gave me medicine and told me I should stop hurting, but when they checked

> me 10 minutes later, they found that my mucus plug had passed and I was 5 cm so they had to make a decision if they were going to let me have him or try to hold off. Doctors came in and told me the worst-case scenarios…he has a 50/50 chance of survival and if he does survive, he will be severely retarded, he will have brain bleeds and may not be able to see, walk, or talk. I had a C-section later that afternoon and when the doctor pulled him out, he was breech. You know the saying about breech babies and how they will have learning disabilities and other stuff but he came out crying and the doctor said he was the first preemie he had seen who came into the world crying. He only weighed 1 pound, three ounces and was 11 inches long. (CW, age 35, divorced, son, age 10)

These responses are consistent with previous research that acknowledges the difficulty parents of children with autism face as symptoms surface during pregnancy and continue through the first two years as they begin to recognize developmental milestone delays in their children and attempt to seek a diagnosis (Committee on Children with Disabilities (CCD, 2001). Further complicating parental attempts to care for the child with autism, is the addition of a secondary diagnosis, such as epilepsy or intellectual impairment (Frombonne, 2003) which often requires more effort from the parent and thus elevates their overall stress levels (Sivberg, 2002). As indicated above, some of these parents' experienced complications during their pregnancies, as well as in the birthing process, which was just the beginning for the challenges to come. Having a child with autism can impede a parent's ability to work outside the home, as well as to provide the resources to the degree the parent feels will be most conducive to the child's overall development. Children of parents with low income are more prone to premature births and chronic health conditions (Committee on Children with Disabilities, 2010).

Participants indicated that they first became aware that something was wrong with their child between the ages of nine months to six years old as indicated below:

> At first, it seemed like everything was going fine. They give you a sheet that shows you what your child should be doing by the months …. I noticed what he was supposed to be doing but he was not doing any of these things … I noticed around nine or 10 months old that he was regressing. He would eat in his high chair but then he didn't want to eat his food anymore. He started to look at us in the eyes but then he stopped; the emotional connection was gone but no one ever noticed. I went to his pediatrician and told him something was going on because he's not doing any of the things he is supposed to be doing. It took almost a year to get a diagnosis of autism. He was also diagnosed with an extreme language and communication delay and an extreme motor skill delay at the time. (AC, age 32, married, son, age 4)

The next participant noticed differences in her older child after her younger child started kindergarten when she began comparing the two and what the younger one was doing. For example, she noticed the youngest child did not know how to write in pre-K, but when the older child was in pre-K, he could write his first and last name. Although the older child was a good reader, even though his writing skills were always an issue, much to his mother's surprise, he was not held back in kindergarten.

> I noticed differences in kindergarten …. but I never really pushed the issue because he's my child and I'm gonna love him no matter what, but I noticed that he did need one on one time. We went to the Renaissance Center in Albany but they only did a 15-minute test. I didn't approve of the tests they used but they wouldn't redo it. His pediatrician was very good with trying to help me find different things and his teachers were very good with giving me things to help him with at home. His teachers just said ADD and focusing issues. Even the pediatrician was in denial of autism because he was on top of things as far as his talking and walking and he was at his age level except for the visual motor skill problem. In February 2016, the occupational therapist tested him and that is where we found out that he had dysgraphia and visual motor skills problems so then we took him off his medication because we knew those were throwing off his ADD and ADHD symptoms, but we didn't even know if we were really medicating for the right things. … there is something that is throwing off the dysgraphia and visual motor skills; he would not have just dysgraphia and visual motor, so the doctor told me to call Journey's in Albany; they do all kind of testing there, ... The school went through all of his paperwork … but there were two tests … that the school would need to do to see if he would meet the criteria to get into special ed. I was supposed to find out last week but the school psychologist was out. They sent home a sensory processing paper and another autism form which I was a little aggravated about because he was just diagnosed five months ago off medication;

> the whole purpose for any testing was off medication so we can get a true measure. (AD, age 34, married, son, age 5)

Participants described their daily experiences of raising a child with autism. The participant below not only has a child who has been diagnosed with autism but during the diagnostic process, her husband was also diagnosed with Asperger's Syndrome. She describes her daily experiences as follows:

> That's a long story… It is hard…it is very hard. My part-time job is that I am a family support partner for families who have children with mental disorders and I have my own autism support group for parents of kids with autism online. I live this life and I know how hard it is how hard it is to cook dinner for you and your husband, but you know your child isn't going to eat any of it, but you know you will have to make something else because the child is a good eat, but the child has to eat and it's not one of those he will eat when he is hungry; it's one of those he will eat when he finds something that he can be. When there's a meltdown or he's upset it's heartbreaking because he cannot tell you what he needs so you can fix it; you just have to wait until it gets better. His improvements over the years have made it better but it's still hard. He is a very loving child but he doesn't like to show affection because it is very uncomfortable for him and my husband is the same way because they both at the same kind of common denominator so it is very lonely it's very lonely. My son sometimes makes eye contact it is really hard for him because he will get to a point and then he will look away and then start talking about something completely different so you will not want to talk to him

> anymore because he's just so uncomfortable it just bothers him to that point. (JD, age, 34, married, son, age 5)

Another participant described her experiences as sometimes being sad to watch, especially when he is left out because he cannot play with his same aged peers because he is so slow in figuring out what they are doing. This participant described her son as:

> He is only capable of playing "next to" others and not "with them" because he has processing disorders anyway and when you have a social communicative disorder, by the time he figures out what the other child is doing, that child is done and has moved on to something else. Then there's the scripting… e doesn't always understand… like he will be sitting in the grocery store and yells, "Help! Help!"…he doesn't understand that people will think something is really wrong. He goes into one of his scripts in his mind where someone yelled help, so he is imitating it, but he is very empathetic and he truly wants everybody to… he reads emotions and feelings but because he's almost always overloaded on sensitivity to where I cannot cry because I am not allowed because it will upset him. If I am having a disagreement with someone or if I get angry and start to cry or get too loud, he gets upset on my behalf. (AP, age 30, Never Married, son, age 4.)

Another participant described her daily experiences as follows:

> I know all kids have challenges; some days have really bad days all day to me: some days we have really good days. She is very meticulous about some things to me: she likes her routine; she has two have a routine. So, when we do things off her routine, she gets really upset. That's really how it is she likes her routine. We

> have a routine and I try to stick to it much and I can. (BW, age 26, Never Married, daughter, age 5.)

Another participant described her child as having a difficult time leaving the house, especially in the mornings for school because he does not want to leave so he tries to waste time.

> It is very stressful because he does not understand feelings; he cannot tell a joke from the truth so you have to be very serious with him. Everything has to be on a routine; if you do not show up and 5 o'clock to get him, he panics. He likes structure and routine and if he does not have it, we will have issues!... he will have a meltdown! We cannot go anywhere because getting him to leave the house is like pulling teeth. In school, he had to repeat the third grade because he was behind in math; everything else was. He gets numbers mixed up in his head. This year, so far, everything is going fine at school and it's much better now than it was in the previous years. In the mornings, we have a difficult time getting out of the house because he gets sidetracked very easily; it's like he forgets what he needs he's got to have this or he's got to have that, or what you have he is just he doesn't want to leave the house. (MF, age 34, Married, son, age 8.)

When asked to describe the relationship between their current household income and their ability to raise their child with autism, all except three respondents indicated that income was not a problem when it came to providing for their child. These three respondents either lived with their who helped him financially or they have their own personal private insurance that help cover some of the expenses involved with caring for a child with special needs.

> It’s real hard…. they get disability, SSI, and the amount they get each month….by the time, I have to buy food out of their income, and the medicines they are on makes them eat, so that little bit of income goes to buy groceries and then they gain weight so I constantly have to buy new clothes… and they love electronics…. So, I have to buy things to keep them occupied… To keep them from just sitting there being bored because you know… When I take them out, they act out and I just cannot… I probably shouldn’t say should not say this as a parent but I be embarrassed because people judge me as a parent, so I keep them in the house and if we do go out, we have to rush out and rush back in before they start Actonel and the extra money that I did have when I was working, I do not have it anymore… It all goes on bills and on them so they so I do not have the money to do like recreation stuff or other stuff. My kids have a new psychiatrist who is very patient and spend a lot of time with us. He talks to us to see what is really going on. They have in-home counseling about three times per week or whatever I need them and they tried to help me. When the kids have an outburst, I can call this emergency number and someone will meet me at the hospital so that’s a good thing. The counseling is for all three of us because I have a mental diagnosis of bipolar so it’s like a family counseling cousin didn’t have this before and now I can tell them how really feel. It’s good when you can vent to someone who understand you and can help you instead of telling them your problems and

> then feeling worse after telling them your problems because they do not understand. If money were no option I would add more counseling for the parents even though the kids need counseling, parents need more education and counseling because they are embarrassed to say, “I need help.” (JB, age 43, Married, has two boys, ages 4 and 10, both of whom have autism.)

If money were no option, some of the additional services participants would like to increase or obtain for their children and their families include specialized daycares, more speech and, if needed, more occupational and physical therapy, music and art therapy, more resources in the schools, equine therapy and more counseling for parents. One participant recommended increased funds for athletic programs and electronic toys, while another participant recommended the legalization of cannabis oil “just to try to see if it helped anything.”

> With the income thing…it is kind of a big problem... It’s very stressful on my marriage; it’s very stressful on a lot of things...it’s very stressful on me. … I have real bad anxiety now, … my financial problems come into effect. We only have one vehicle due to financial problems. Our rent gets 6 to 8 months behind and we end up owing lots and lots of money because we cannot pay our rent on time, so … knowing that you are just getting more and more behind in rent is just not a good thing. (AC, age 32, Married, son, age 4.)

> It’s a struggle because he’s still in diapers… we have to get the sleeping underwear so it’s a little more expensive. We probably spend about $80 a week in diapers because he is getting older and the older he gets, the more expensive it

gets…we cannot get him potty trained...he will do it every once in a while; we've tried… The food that he eats… He will go through a lover bread in a day so that's not expensive, but if you are having to buy it every day just for him, all of that adds up…that boy can eat some food! He's five and 67 pounds; his older sister weighs 59 pounds... The ABA therapy isn't covered under insurance and it's a hundred dollars an hour and they want to come multiple times to do it but we cannot because we do not have a hundred dollars an hour… That's an extreme amount of money … it will be awesome for him … I'm trying to figure out exactly what they will be doing so I can do it, but I cannot figure it out. He gets speech therapy at school and I think he gets OT but from what I've read, he cannot get ABA therapy in school because it's kinda of aggressive. They do use pictures at school… He listens to his teachers and therapists a lot better than he does to me. (JD, age 34, Married, son, age 5.)

Trying to pay for his medications and everything is hard. I'm in the process of trying to find a second job. His medications can range each month from $100 to $120, depending on what he needs and what he is out of in terms of his prescriptions. (MF, age 34, Married, son, age 8.)

It's very hard… I try to have a job where I can have some flexibility… I get paid more than minimum wage so I do not feel I cheat myself out of what I can do… I just know that because I am her caregiver, I do a lot of things that are very unrealistic. (BW, age 26, Never Married, daughter, age 5.)

DePape and Lindsay (2015) pointed that, parents of children with autism often experience increased financial risks compared to parents of typically developing children because they often have to pay for services out of pocket or may have to travel or move to areas with specialized treatment providers.

Participants were asked to identify any strengths they feel they have developed as parents of children with autism and indicated unanimously that patience is a must. Other strengths mentioned included becoming a kinder, more empathic person towards others who have special needs, flexibility in learning new coping strategies to decrease their own frustration levels, becoming more personally resourceful in terms of increasing their knowledge of autism, becoming a better listener, becoming more loving, and learning how to become a better advocate at school, in the community, and even in their own families to educate others about the needs of their child and the unique symptoms of autism. Some weaknesses that were identified included increased or the development of parental anxiety, short-tempers, not just with their children, but more so with members from the community who lack an understanding of autistic symptoms and the special needs of a child who may be exhibiting behaviors the person may not understand and think are simply the result of poor behaviors or poor parenting skills. Another weakness was being overly sensitive when others criticized the child, or when the child was compared to same aged typically developing peers, being more emotional and crying more easily, sometimes due to not being able to communicate effectively with the child to determine the child’s needs, or just out of sheer frustration in not being able to do more to help the child progress. The one element that most parents agreed they could use more of was sleep as many fail to get adequate sleep on a consistent basis because they worry about their child getting up in the night and perhaps leaving the house or because they child experiences sleep problems as well and the parent has to monitor the child closely to ensure his or her safety.

The second research question asked participants what effects the child with autism's communication deficits had on parental stress, if any, and which of the three hallmark characteristics of autism: social or communication deficits, or repetitive behaviors was the most challenging and why and how these three symptoms have changed over the years, if at all. Sixty-nine percent of participants indicated that communication deficits were the most challenging symptom of autism. Twenty-three percent indicated that social deficits, specifically behavior, was the most challenging symptom.

JB reported that her 10-year-old son does well on medication but every summer, about two weeks before school starts, he gets to a point where he has to go to River Edge Crisis Center. She stated that she had just had an episode with him where his behavior got outrageous and he attacked his maternal grandmother and that he and his brother "are always fighting."

> My 10-year-old choked my mother; he got on top of her and started choking her. I was in the hospital and he just started slinging her furniture and he…. like he just went out of it…they were fussing over the broom. It was the first time that he attacked my mom, but this wasn't the first time that he attacked an adult. He attacked me when I was six months pregnant and they put him in the

> crisis center and last year, he attacked me again and he had to go back to the crisis center. He was treated for aggressive behavior and depression. He was being bullied and I didn’t know it and he was just taking it out on me. He has communication issues… He doesn’t know how to express himself so he acts out in the form of that. He can talk about certain things… he knows how to express himself about certain things and when he doesn’t, he acts out… his behavior changed and he was being aggressive… that’s when I found out that he was being bullied on the school bus. My four-year-old has social behavior all the time. He and his brother can be sitting there watching TV and my 4-year-old will slap his older brother and start scratching him; he scratches and bites him and he just fights all the time… just starts hitting him… his social behavior is bad all the time; at church, at school, no matter where he’s at… he is very aggressive. My four-year-old stutters… now he’s the one who really cannot verbalize what he’s trying to say…he gets frustrated when you do not really understand him and that’s his way of trying to communicate by acting out. (JB, age 43, Married, has two boys, ages 4 and 10, both of whom have autism.)

Although all three symptoms are challenging to AC’s son, she identified communication deficits as the most challenging because her son is non-verbal and he cannot verbalize his needs to her. Because he is nonverbal, he cannot express how he feels or what he wants, so he takes her by the hand or arm to get what he wants. Socially, AC stated that it is hard because nobody takes the time to get to know her son because he cannot talk. As a result, her son does not socialize with others. His repetitive behaviors included in the session with straight lines and Lyman toys up in a row. AC reported that she has been working a lot with her son's communication and social abilities and feels that he is doing a tad bit better with some of his social and communication skills. For example, he notices people more now than he used to. "He didn't use to respond but now he will look at people and he will recognize them and he will try to say things." AC reported changes to be very small over the years.

> There is always gonna be regression. I feel like anytime he starts doing well, and he starts catching on, there's a mental block on all of them; it's just like it cuts off and then we are right back to stage I all over and then we have to redo it. It has taken me a year to teach him the things that I have taught him through repetition; it's taken a long time.

AD identified communication deficits to be most challenging because "you have to constantly repeat yourself to him." AD's son is easily distracted so she has to make sure that he is paying attention and not focus in on anything electronic so she can get through to him. She has to make him look her in the eye which is a challenge but, she reported that if he wants to talk to you, he will come up to you and look you in the eye and tell you what he wants to tell you that when she wants him to do something like clean his room, he will not answer her but he will not remember anything she told him five minutes later. Socially, AD's son sticks to himself. He has one or two friends, but otherwise he's typically alone. He doesn't like crowds and he does not go out of his way to make new friends. AD reap reported very little change in symptoms throughout the years and attributes that to possibly just now working with him and changing things to know how to keep him from having a meltdown.

> You have to repeat yourself a million times before he gets the point that he's got to go… Every morning, it's repeating myself about what clothes he needs to put on because something else is on his mind and he has a one-track mind. He very easily gets off track. (AD, age 34, Married, son, age 9.)

JD also identified communication deficits as the most challenging because her son cannot talk and cannot tell her if he is sick or not feeling well. She described an incident where she could tell he didn't feel good for several days but she couldn't figure out what was wrong with him. When she took him to the doctor, she was told that he had a cavity in his mouth. Because he grinds his teeth when he's angry, he had grounded his teeth down to the nerve and she didn't know that was why he was screaming in pain. The two that gotten infected and abscessed. Because she did not know, when she found out, she cried.

> There's no way…. It's just pitiful that he couldn't tell me, "hey, I've got this abscess in my tooth and it's hurting me" so to me, that's just the worst part of all of it…is him not being able to communicate with us.

When JD's son wants something, he takes her by the hand or gets a cup if he wants a drink. Socially, he has shown improvement.

> He used to not play with anyone… he did not look at us or do anything… when he was first diagnosed, we were told not to let him get comfortable…. We were told to get in his space, be friends with him, let him know that you are there. So

> now, he plays with kids. … I think when people who have been with us and have been through everything, he is starting to play with them and interact with them. He plays with others sometimes at school … He likes one little girl at school and plays with her and there's another little girl who is only two but, I think, intellectually, they are on the same level... She tells him what to do and he will listen to her in a heartbeat…. It's just adorable and she doesn't know any difference because it's always been that way and it doesn't faze her one bit if he takes off all his clothes…she's like "W," put your clothes back on! and they just go on playing… he repeats himself and annoys others and when he is happy, he's got this weird way that he does his hands …. He just twirls it around when he's really happy, he will take his hand and stick it between his legs and he'll start laughing and it's just adorable. He has made some improvements over the years…he is finally able to form words a little bit better and…says I want a drink and he'll walk over and get it or give his cup…if he wants tater tots, he will go to the freezer and get them, or go to the fridge…Socially, we couldn't go anywhere for a year or two because … he couldn't take the stimulation, but this year, we are planning on going to Thanksgiving … Last year, we had his first birthday party and we only invited two people … we haven't been able to do that so yes, I see major progress over the years, it's just a slow process but I feel like he is finally trying to break away from whatever is in his mind that has held him back for so long. (JD, age 34, Married, son, age 5.)

When it comes to communication deficits and the struggles that parents have experienced, participants responded as follows:

> It hurts me to tell my kid, “I love you and I care about you” but him not to be able to say that back ... I’ve experienced a lot of problems and it breaks my heart not to hear my child tell me, “I love you too, mom!” It’s hard for me to think that my child loves me because it’s like he is so secluded and to himself and he’s not able to express that to me and it’s really hard. (AC, age 32, Married, son, age 4.)
>
> One time, he stuck his hand in an ant bed and I didn’t realize what was going on until he had a gazillion ant bites… he was screaming and I noticed that he had all the ant bites and I thought if he’d been able to speak, he would have yelled and I could have gotten there sooner. It’s just stuff like that that makes it… It’s just horrible to let things happen like this. (JD, age 34, Married, son, age 5.)
>
> Speech therapy was helpful because they have these jaw exercises that helped him to work the muscles. He was nonverbal … the first time that my baby articulated a full sentence, he said, “I do not want you to go back to work.” When I asked why, he told me that my ex-husband “beat me while you was at work.” I became upset because neither one of them had told me about this. This was their stepdad but he is no longer in the picture. (CW, age 35, Married, son, age 10.)
>
> You do not always know what she wants but that has gotten better. I can tell when she is hungry or sick. The only thing she doesn’t tell me is when she has to go potty… potty training has been a challenge for me… we are like half way potty

> trained. They are working with her at school and at daycare so that helps. (BW, age 26, Never Married, daughter, age 5.)

The last research question asked parents to describe their relationships with family members and their social experiences outside the home. They were asked to describe the impact that ASD has had on them personally, physically, psychologically, and socially and then to describe how ASD has impacted their social and professional experiences outside the home, including with external family members and friends.

Personally, JB reported that she became depressed because it "delayed her career" since she had to stop working. She is currently enrolled in school but due to the boy's aggressive behaviors and her high blood pressure and diabetes problems, she has struggled academically, as well as physically and feels like she ever gets to finish what she starts because her family needs her attention. Physically and psychologically, she has been hospitalized three times in the past for depression, including suicidal ideation. She described being overwhelmed and feeling like whoever can handle her children could have them because she simply did not know what to do to help. Currently, she describes her life as stressful and believes that after the incident with her mother, is he has become even more stressful because she will have to quit school again and put her life on hold because she has no one to watch her children until she gets home from school. She believes her depression, from feeling like a failure and never finish in anything she starts. She also feels like her husband sees hers as a failure, even though she keeps telling herself that life will get better as she finds more resources and completes her education. She admits that her marriage has suffered as a result of her family's situation. She feels socially isolated, other than the one or two friends she has from school, both of whom also have children with autism.

AC believes that she has personally become a better person and a better parent. She describes herself as more patient, empathetic and understanding toward others and she believes that parenting a child with autism has built her character because her experiences with autism have prepared her with skills to handle more than what a parent of a typically developing child would endure based on the unique and challenging symptoms of autism. Physically, she describes herself as tired and worn out because parenting a child with autism is a lot of work, especially when your child is active like hers.

> At times, it’s frustrating because there are limited things that he enjoys doing, so if he wants to go outside, I have to literally go out and stay with him. Right now, it’s summer time so it’s like 90 or hundred degrees. He’s in and out all day and I have to sit outside with him … I cannot get my school work done; I cannot do my homework … When he is running around the yard, I have to watch him all the time because he doesn’t understand the danger aspects. If he goes out into the road or if he gets into my neighbor’s electric fence, he doesn’t understand that he is gonna get hurt, so you really have to watch him a lot more than you would a child his age; a normal child. Psychologically, it is mentally draining. When I go to bed at night, I am just so mentally exhausted. …It’s just really difficult and stressful to deal with it. Socially, I tend to talk to people a lot more than I used

> too… I do not have any help from any other outside sources… it's stressful on me because every day, is the same thing. (AC, age 32, Married, age 4.)

AD described the impact of autism on her as a parent as being "rough" and attributes this to "not being able to do more to help" her son sooner. Although she denied any psychological changes, she blamed herself for "not noticing the symptoms of autism earlier" and instead, just thinking that her son was "uninterested or lazy" in learning skills such as "tying his shoes are riding a bicycle". She also expressed guilt regarding the frustration she feels been having to repeat herself "a million times" to communicate effectively with her son. She does not feel that any physical changes have occurred. Socially, she has a friend who has a son diagnosed a couple years ago with similar symptoms as her own son, so the two have partnered to bring more awareness of autism to their local school system. (AD, age 34, Married, son, age 9.)

Personally, JD experiences some guilt as she realizes that focusing on her son and unique needs have caused her to neglect her daughter more due to time constraints. Physically, JD describes herself as "physically drained," "mentally exhausted," and feeling "tired all the time." Psychologically, "having to change your five-year-old's diaper, it gets to you… I'd do it for the rest of his life if I needed to, but it does take a toll on you." Socially, she believes she has a good support system with her friends and family. She stated that if people do not understand, then she doesn't consider them friends. She does not think that she has been affected socially by raising a child with autism but she does believe that she has become more socially active in the community in terms of raising awareness of autism and advocating for the resources that her son needs in the school system.

Personally, MD only trusts family members with her child. She admitted that she "does not get much sleep" and states that although she is not selfish, "sometimes you just want to get out." She stated that she loves her son, but sometimes she just "needs a day." Psychologically, she believes that her son is "less stressful than her other children." She pointed out that her friends often tell her they would rather keep her son than her daughter because her son is "quiet and can entertain himself." Physically, she has experienced blood pressure problems and stated that "when you are living with the stress of trying to potty train, it can sometimes be a bit much; but, it gets better." Socially, MD stated that she "has not been out in a while." (MD, age 30, Never Married, son, age 5.)

CG does not feel that raising a child with autism has influenced her personally. She stated that she "has always been a very blunt person and doesn't care what other people think." In spite of "meltdowns in public," CG stated that she has "always kept him in public" and that they "have learned together how to prevent them." If they are in a restaurant and the light is too bright, she tells her son to look down; if it is too loud, they leave and return later when it is less crowded. CG has never treated her son like he has autism and does not believe that anyone would even know unless they already knew. She treats her son as she would anyone else. Physically, she reported everything to be normal. She also pointed out that she doesn't "know anything different because he is my only child." She lets him have his meltdowns and then she sits down to talk to him and tells him that if he is a problem, "to grab whoever is around" until he calms down. She does not feel that she has been affected psychologically or socially in any way and stated that her son “goes everywhere” she goes. But she’s they that she does not date and will not until her son is older because she does not want different men coming in and out of his life.

Personally, MF stated that she is always at home and doesn’t go anywhere because she wants to be with her son. She stated that she does not want to be anywhere other than where her son is now. Physically, she admits that she is drained and that she cannot really do very much because she’s just exhausted from trying to make sure that her son has everything we supposed to have, or that he is getting to the doctors to get his medicine, or going to therapy, or to school. Psychologically, “it is very stressful” because she’s the one who typically takes him “to and from appointments and makes sure that his routine is in place.” If anything needs to be added to his routine, she has to add very carefully. She experiences anxiety and depression of her own at times as “parenting a child with autism can be very stressful.” Socially, she stated she is always with her son and husband and that they “do not go out very much” because the son doesn’t want to go. She also does not like to be around people “who are unfamiliar with autism symptoms, because they do not understand.” When they do go out, she makes sure that it is somewhere where her son can have earplugs if it is going to be noisy to avoid sensory overload for him. He does have tantrums and public meltdowns and she “constantly gets responses from others” but “with autism, you cannot confine the child.” They had a Camaro but traded it in for a four door because her son “felt too confined sitting in the backseat and had claustrophobia.”

CH provided a very concise description of the effects of autism on herself and simply stated that personally, she feels like she has “failed her son at times.” Physically, she had gained and lost weight. Psychologically, she admitted that she has “been in the psychiatric ward twice and in rehab twice for substance abuse.” She stated that she is now better and is actually happy. “When I say all this stuff, I am describing myself prior to me getting out of my own funk because of this.” Socially, she believes she isolates herself. (CH, age 28, Married, son, age 5.)

Personally, BJ feels her anxiety “has gotten worse since her child was born,” especially since her husband was diagnosed with Asperger’s about the same time that her son was diagnosed with autism. She stated that her husband took her son’s diagnosis “a lot harder” than she did because he felt like it was his fault since “all the studies show that it is genetic” and “he thought that since he was the one on the spectrum, that he is the reason” their son is on the spectrum, although she tells him “it just happened.” BJ believes that “God only gives you so much” and that “God gave me my son because somebody else would not be able to handle him.” Physically, she does believe it wears on her energy levels and stated that she gets sick “more than anyone else in the house” but points out that she’s not only raising her child with autism, but she also works two jobs to help pay for everything and it has “taken a toll on her personal life” as many of her friends have “backed off” once they realized she has a child with special needs. Psychologically, it has taken a toll on her mentally. She also recognized that she “sleeps less” because her son has night terrors and sleep walks, which makes her paranoid so she does not sleep well. They have installed alarms on the doors “just in case he tries to go out at night" while there all sleep so she will hear him. "He has wondered off in the night before and going over to the neighbor's house that they brought him back." Socially, because some of her friends have backed away, she created a Facebook social group for parents of children with autism. She works with her best friend of 16 years at a local grocery store in the pharmacy department and her friend is very good about noticing when BJ is really stressed and wall take her out to dinner or for drinks "to have some adult talk time so she can regain her sanity." BJ sees her best friend as her "biggest support," in addition to her mother and sisters. When her son was diagnosed, her husband's family did not respond well. BJ described them as "extremely religious" so to her in-law's, her son's diagnosis was her and her husband's punishment for having done something wrong; therefore, the in-laws felt BJ and her husband had to suffer for it. When BJ's husband was diagnosed, his family did not acknowledge it and swept it under the rug, even though they told BJ about her husband's behaviors when he was a child that match so closely with their son's behaviors. The in-laws do not spend as much time with their son as they do with their other grandkids. BJ only has one child and is not planning on having more because she "had such a difficult pregnancy" and because she and her husband "do not feel it would be fair to the second child" since so much of their attention is given to their son. (BJ, age 32, Married, age 7.)

Personally, AP believes that most of the time, she's fine but admitted that when others "make comments or compare" her son to typically developing children and point out that her son "is slower," it hurts her feelings. Physically, she described herself as having "mom body." She works a full-time job and then comes home to take care of her son and admitted that “it is stressful” so “it is good to have the family support” that she has. When her son was 13 months old, she divorced her husband and because he lives in Seattle, he only gets to see his dad about twice a year, although they call each other a couple times a week. Psychologically, she does not believe raising a child with autism has changed her. Socially, AP enjoys doing things together with her son on weekends, such as overnight trips out of town or going to the movies. (AP, age 30, Divorced, son, age 4.)

Personally, BS sees her son and his autism as “a gift because it has changed my perception of the world; it has changed how I deal with other people” in terms of being judgmental. She also feels that her experiences with her son has increased her patience and improved her ability to provide better care for the patients whom she serves when she is working as a nurse. Due to her son’s behaviors, she is currently working part-time but because of her patience, when a patient enters the ICU department, she is often assigned to work with those who are “coming off a drug overdose” because her supervisors believe that she “understands better how to communicate and talk to people like this” based on her personal experiences with her son. Physically, BS believes raising her child with autism has affected her a lot. She does not get a lot of sleep “except on weekends when her son is really tired and sleeps 12 to 14 hours a day on Saturday” and then she will try to sleep in a little. Her son typically likes to stay up late at night “because he just cannot go to sleep” and as a single parent, she cannot “go to bed and leave him up.” Psychologically, she described her experiences as “very stressful” because she “cannot exercise” the way she would like to, which is her stress relief. She believes her experiences have strengthened her spiritual growth, has made her more nurturing, and has made her stronger overall. A few months ago, BS's mother, whom her son was very close to, passed away and, as a result, BS's son became "aggressive and violent." During this time, BS's daughter was pregnant and decided to stay away from her mother and younger brother "to protect her unborn child, just in case he had a meltdown" while they were visiting. As a result, BS nor her son could interact with her daughter and new grandchild as frequently as they would have liked. Socially, BS stated that she does not date and that she does not go out to dinner very often. When she and her son to go to dinner, "it takes a lot of getting ready" as she has to encourage her son to remember what he can do while they are in the restaurant are in public places. If the restaurant is too crowded, they will leave to avoid sensory overload and will go back another time when the restaurant is less crowded. (BS, age 50, Divorced, son, age 10.)

CW does not think that raising a child with autism has affected her and instead believes that it has made her "grow as a woman." She also feels that she is "better able to critically evaluate" her child and others and to reach out to the mothers of other children with special needs to help them since she knows what they're going through. Physically, CW admitted that "in the beginning, it was draining and frustrating" because she did not feel like she had anyone to help her or anyone who was in her corner who understood. As a result, she felt drained because she tried to get her son to be as sociable as possible with the regular kids his age so he would not be picked on by others or looked down on by the other kids. Over the years, he has made a little progress in this area. Psychologically, CW admits that she was depressed and that "it messed with me." She is currently taking antidepressants from time to time. She believes that once she came to grips with her son's diagnosis that her depression dissipated. Socially, CW admitted that she has no social life. She described herself as "a mom who doesn't go anywhere." She has family support from her mother who watches her children from time to time, but CW is also the primary caregiver for her grandmother and her children so she has to be cautious in picking and choosing her battles. To maintain her social life, once a month she has a dinner party and invites friends over for the evening.

BW stated that she personally has never been judgmental but raising the child with autism has made her "more judgmental about everything and everybody" and has made her "more sympathetic" and "more empathetic and understanding because some people will never understand." She has developed "a lot of respect for people like teachers and people who deal with kids every day," as well as respect for life itself because she wants to have a good quality of life. Physically, BW believes that "finances are the main issue" for her at this time. When her daughter was born, she reported that she was "not financially stable at the time" but was working and trying to build herself up. Shortly afterwards, she began school and has paid off her school debt and bought herself a car and is trying to move. She admitted that she has "to do things in baby steps" because she "cannot do it all, even though she has to do it all." "It's physically exhausting to manage everything" and although some of this is attributed to the autism, she believes the majority of her stress is contributed to the finances. The most challenging or stressful part about autism is "not knowing how to handle the problems." Because of this, BW has begun to do her own research in an attempt to educate yourself more about autism and its symptoms, including reading books on the subject and talking to teachers, her therapist, and people who take care of her daughter mentally, so when they are at home, BW can try to follow what is being done at school, such as developing and sticking to a daily schedule or routine. Psychologically, it’s a challenge because BW does not feel she has support from others. She has support from her school and her daughter’s daycare, but she doesn’t have support from her family and she feels like nobody understands. Although she lives with her mother and brother, they do not support her in the way she thinks they should. Her boyfriend helps her out when he’s not working, but “he works a lot too” so she doesn’t get a break and is with her daughter most of the time. Socially, a lot of her friends live in a different town, and due to finances, BW does not to get to visit them very often. BW does have a few friends in her new town, whom she thinks understands, because when she cannot go out with them, “they seem to be satisfied in just talking on the phone or texting.” When her boyfriend is not working, she and her child will spend time with him going places and doing things, such as going to the mall or going to get something to eat. BW admitted that she is the type of person who can deal with people and is okay, but if she doesn’t talk to people or is not around people then she’s okay too. (BW, age 26, Never Married, daughter, age 5.)

Research indicated that parents and relatives of children with autism often experience higher levels of major depressive disorders and social phobias, including grandparents, aunts, and uncles, based on family history (Piven and Palmer, 1999). Responses above concur with Pivot and Palmer’s conclusion that parents of children with autism often experience higher rates of psychiatric disorders such as depression, anxiety, and social issues, although Pivot and Palmer pointed out that the stress of having a child with autism alone does not explain the high rates for major depression. Results from this study also revealed that some parents may also be more prone to higher blood pressure levels, possibly due to the higher levels of stress they experience in their daily lives.

Discrepant Case Analysis

Discrepant case analysis involves elaborating, modifying, or refining a theory to modify an emerging theory verses refuting it (Houghton et al. 2012). Overall, there were no discrepant cases in this study; however, there were a few discrepant areas as previously mentioned where applicable.

Summary

The purpose of this study was to examine the lived experiences of low-income raising children with autism. Using the hermeneutic phenomenological methodology, appropriate steps were taken through phenomenological reduction to acquire and interpret participant data provided through face-to-face and telephone interviews (Creswell, 2013). The four research questions that were foundational to this study provided the detail needed to allow for a rich description of what it means to raise a child with autism when income is low and the ability to obtain resources is limited. The textural and structural description comprised from participant data were themed to address the inquire posed in each research question. The subsequent themes provided the basis for the true essence statement to emerge. The essence statement therefore, reflects the summation of what it is like for low-income parents to raise children with autism.

Chapter 5 will present the interpretation of the study findings as well as the limitations, recommendations, and social change implications.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of the present study was to explore the lived experiences of low-income parents of children with autism to determine how autism has affected their daily lives, as well as their marital and family relationships. I used hermeneutic phenomenology to give voice to participants who provided rich descriptions of their daily experiences as they lived them. This study constituted an extension of the literature on autism and parental experiences in the state of Georgia and revealed the impact that autism has had on parents and families in general.

The research questions (RQs) developed for this qualitative study were as follows: (RQ1) How do low-income parents describe their daily lived experiences of raising a child with autism? (RQ2) What effects does the CWA's communication deficit have on parental stress, if any? (RQ3) How do parents describe their relationships with family members and their social experiences outside the home? (RQ4) How do parents indicate their child's autism has impacted their marital relationship and family? The participants were determined to be low income based on family size and the current annual household income according to the United Stated Poverty Guidelines (Healthcare Facility Regulation, HFR, 2015) and the Federal TRIO Programs, Current-Year Low-Income Levels United States Department of Education, OPE (HFS, 2017).

Social Media and Participant Requirement

Participants were recruited from two local college campuses after attempts to recruit in local physician offices and an autism center at a local hospital did not yield any participants. Fliers were placed around the campus, and an e-mail was sent to all faculty so they could share the flier with their students. I met face to face with only three participants who qualified for the study. The remaining 10 participants were recruited after I shared my flier on Facebook and my friends shared with their friends. These participants responded to my study by contacting the e-mail address I created specifically for this study. All participants were e-mailed a consent form, as well as an individual flier for the study. Once the consent form was returned, I corresponded with each participant via telephone to schedule an interview. All participants were given the option of meeting in person or participating via telephone. Ten participated via telephone. All interviews were recorded using a digital recorder, which I used to transcribe each interview using Microsoft Word.

A limitation of recruiting via social media is that I may have missed eligible individuals who may have limited access to or may be unfamiliar with communicating online. Additionally, potential participants with limited online skills may not be knowledgeable in creating online profiles, and may be hesitant to interact with others even in specific groups where there is a common interest. Recruitment of these individuals would require other methods.

In the current study, I collected data from low-income parents raising children with autism through face-to-face or telephone interviews. The failure to recruit more participants in the local area was partially due to the inability to post fliers in local physician offices or schools where parents of children with autism might be found. Future research that includes more culturally diverse low-income parents raising more than one child with autism from across the United States would provide more insights regarding their lived experiences and may add to the current available research. Additionally, a comparison of parents with and without insurance or public funding, regardless of household income, could expand the understanding of the connection between income and parents' ability to acquire quality resources to help their children.

Only one of the participants in the study actively participates in a support group for parents of children with autism although there are many local and Facebook groups available. All except four of the participants stated that their children are with them most of the time. Most of the participants in the study turned to friends and family members for support. One participant viewed her son's autism in a much more positive light than the other participants and stated that "most people cannot even tell." Family and friends were described by participants as having a limited understanding of their life with autism, and most participants described feelings of frustration about perceived judgmental attitudes of those outside of their home. All 13 participants described a life with limited or nonexistent social relationships with anyone outside their family or work for those who were employed.

Interpretation of Findings

I examined the results using the biopsychological theoretical model and the family systems theory as participants shared the impact of autism on themselves and their families. Participants expressed the biopsychosocial effects of autism including physical (elevated blood pressure and diabetes) and psychological effects (elevated levels of anxiety and depression) of stress exacerbated by autism and its symptoms, including decreased marital satisfaction. Because the family works as a system with one person being dependent on the other, when one person does not function as well as the others, it affects the entire family (Cridland et al., 2014; Cridland et al., 2015; Goepfert et al., 2015; Neely-Barnes & Dia, 2008). DePape and Lindsay (2014) found that parenting a child with autism has a profound impact on family life, including roles and responsibilities that parents assume, especially when the child has abnormal communication, repetitive and restrictive interests, and impaired social functioning. Woodgate, Ateah, and Secco (2008) found that many parents of children with autism described their lives as “living in the world of our own” (p. 1078), but parents who felt this way tended to isolate themselves purposefully to avoid awkward social encounters with those outside the autism community.

The unique focus of the current study was the effect of low income on family functioning in families who have children with autism. Although all 13 participants described the positives about their children in addition to the negatives associated with autism, one parent reported very limited negatives regarding the impact of autism on her family. Overall, participants expressed four significant themes: higher levels of stress and depression, decreased social interaction, less personal and professional satisfaction, and lower levels of marital satisfaction. Only three of the 13 participants denied that income was a factor in their ability to raise their child with autism, and 77% reported difficulties in acquiring resources such as speech and occupational therapy outside of the school system, even though they believed their child would do better with additional services. Only one participant identified behavior as the most challenging symptom because her child who was 10 years old had already been hospitalized three times in a psychiatric facility for his severely aggressive behavior toward himself and others. The remaining 93% of participants attributed their elevated stress and lack of patience to communication deficits, particularly those who had nonverbal children, although a lack of social skills development was a close second for those who had older children.

Sixty-two percent of participants in the study admitted that raising a child with autism has had a negative impact on their marital relationship. Several participants attributed this to their increased stress levels or to their overall physical well-being pointing out that after the children are in bed and household chores are done, they are often too tired to spend quality time with their spouses. Several participants reported that they carve out time to have date nights or date lunches with their spouses to maintain intimacy in their relationships. Three participants denied any negative impacts of raising a child with autism on their marital relationship, and two reported that she and her husband work well together and recognize when the other needs a break. Sixty-two percent of participants admitted that having a child with autism has led to a lack of quality relationships with family and friends as many do not understand the symptoms of autism and that every child is different, so to avoid negative comments the preference is to self-isolate by remaining in the comfort of their homes.

Schieve et al. (2007) pointed out that although there is no proven cure for autism, treatment goals typically focus on increasing a person's overall quality of life by promoting the development of social, adaptive, behavioral, and academic skills as well as decreasing maladaptive and repetitive behaviors. Woodgate et al. (2008) stated that evidence has indicated that treatment should begin before the age of 5 and should include intensive behavioral training involving an applied behavioral analysis (ABA) therapist or a similar behavioral training approach to establish and reinforce desirable behaviors and to decrease undesirable behaviors. Hastings and Brown (2002) reported that many parents of children with autism struggle with their child’s negative behaviors resulting from their autistic symptoms. Ingersoll (2010) found that communication problems presented the most challenges for parents raising children with autism.

Regardless of which symptom parents found the most challenging, most researchers agreed that raising a child with a disability or special needs is stressful for the parents or caregivers. Ingersoll and Hambrick (2011) found that the more severe the symptoms of autism, the more prone parents were to experience higher levels of stress and depression. Hartley et al. (2012) found that stress and depression can negatively impact marital satisfaction in couples. Hall et al. (2012) concurred regarding the effects of stress and depression on parents raising children with autism, but also pointed out that parents who experience higher levels of stress can be resilient, especially when both partners in a two-parent relationship support each other.

General Discussion

In the current study, none of the 13 participants admitted to not knowing much about autism prior to having a child with autism, and all indicated that they learned about autism from their doctors and from working with their children. One parent had two children with autism and appeared to be the most distressed of all participants, particularly given the severity of her oldest child who has been hospitalized on three separate occasions due to his aggressive behavior toward his mother and his grandmother. There were 14 children included in the study, with ages that ranged from 4 to 10; 56% were age 4 to 6 while 29.21% were age 7 to 10. Sixty-nine percent of participants were age 30 to 39, 15% were 29 or younger, and 15% were 40 to 52. Only one 4-year-old child had not yet received services, although his mother reported that he needs speech therapy. The remaining 92% were currently receiving or had received speech and occupational therapy, and only one had received physical therapy. One child had received music and art therapy although the parent reported she does not have the money to continue those services. Two parents reported that equine therapy had been recommended to them by therapists or physicians but is not covered by Medicaid, insurance, or other financial providers, so none of the children are currently participating in equine therapy. Other therapies that were recommended included specialized day care, counseling for the family, education for parents on autism, ABA therapy, social skills and behavioral therapies, cannabis treatment, music and art therapy, summer camps, and more resources in the school system.

Only three participants identified the behavioral characteristic that accompanies their child’s diagnosis of autism as being the most challenging of the three characteristic symptoms. The remaining participants agreed that communication deficits, particularly when a child is non-verbal, is the most challenging because they do not always understand when the child is in pain or what the child wants which, they believe leads to a melt-down. One parent pointed out a huge distinction between a “tantrum,” identified as a misbehavior that a child engages in when he or she does not get their way and a melt-down which she described as the result when a child with autism has no way of clearly expressing their frustration as they attempt to express their needs, including pain, or wants to their parents.

All participants in this study reported annual incomes of less than $42,000 and 77% indicated that income is a factor in their ability to raise their child with autism because it adds to their overall stress level for the same reasons as any other parent, but also because it limits the frequency and types of resources that can provide for their children to ensure a better quality of life overall. Sixty-two percent of participants reported that their child's autistic symptoms have had a negative impact on their social relationships outside of the home, as well as their marital relationships; the 23% who are currently divorced, although none blamed their divorces on autism per se, reported that autism was a factor. For example, all three indicated that differences in parenting styles, as well as their husband's denial of the autistic diagnosis for their child, differed significantly and was a significant factor involved in their decision to divorce.

Limitations of the Study

A limitation for the current study was that participants were all mothers. Results may differ if fathers had participated or if only fathers were interviewed as their perceptions may differ from the mothers who participated in this study, particularly those who assume primary responsibility for the CWA's overall and daily well-being the majority of the time.

Telephone interviews. as opposed to face-to-face interviews had several disadvantages as I was unable to observe body language or facial expressions during the interviews and had to rely solely on tone of voice and inflections to determine emotional distress with various questions discussed. Because telephone interviews were conducted at convenient times for the participant, some had to stop to address the needs of their child during our conversation which extended the time needed to complete the interview.

Another limitation of this study was the potential for participants to have diverse opinions and perceptions due in part to a broad range of participant ages, educational levels, and the child's age. Obviously, those with younger children have not had as much experience in dealing with autism as those who have older children. Parents with older children may have had exposure to more resources, including parental education on autism, than parents of younger children and thus may have learned what and what does not work well for their children through trial and error or application of parenting techniques that may have been shared by others.

Future research is needed to examine how parents of younger children who are newly diagnosed with autism cope daily as they struggle to find appropriate resources for their children.

Recommendations

Given the stressors associated with the specific symptoms of autism, more emphasis could be made by professionals to educate parents and to provide professional services to include individual and family therapy to address any mental concerns that may develop during, as well as after, a diagnosis of autism has been received. In addition, a list of available services and resources, including referrals to local and online support groups for parents of children with autism could be provided to parents to help decrease their stress and frustration levels as they learn about autism and its effect on their individual child and explore the most conducive resources for their child. Future research could address the differences in parental psychological and physical well-being when resources, including income, is adequate or plentiful.

Several participants indicated that having a child with autism has impaired their ability to work or to work as frequently as they did before the child was born because of a lack of specialized daycare due to the symptoms of autism. Future research is needed to determine how specialized daycares could benefit society as parents of children with autism may be able to return to the workforce as full-time employees. In addition, future research could assess the benefits of respite care for all parents of children with autism, even those who chose not to work outside the home.

The present study found that low-income parents of children with autism are interested in additional resources to improve the quality of life for their children outside of the school system but are limited to the amount and types of services they can provide due to inadequate incomes. Future research assessing the benefits of music, art, or equine therapy is needed to provide additional resources for children with autism to future educate on non-academic levels, provided these services are available to all children at an affordable cost.

Implications for Social Change

Numerous opportunities exist to make positive social change for low-income parents of children with autism. The findings from the current study can positively contribute to the existing body of literature used to understand the psychological impact of autism on parents who are committed to raise their child to the best of their ability.

Parents need access to resources, regardless of their income, to provide the best quality of life for their children and to enrich the everyday lives of families who have children with autism.

One aspect of the current study found that participants perceived the presence of social stigma from family, friends, and society in general. In considering this, continued public education within the community is vital to educate the general population about autism in general but more specifically about the varying symptoms of autism and how they can affect each child differently and alert them to the unique struggles that parents of children with autism face in their daily lived experiences of raising their children to decrease the social stigma that occurs from a lack of understanding and knowledge of autism and the impact on the family as a whole.

Additionally, to further the understand the impact that raising a child with autism has on parents and individuals, as well as the marital relationship, further qualitative research is warranted on a much larger scale to explore the psychological well-being of couples raising children with autism who have limited, or non-existent social contacts, as well as parents who are forced to forego their professional goals to care for their child with autism. The feedback generated from caregivers of children with autism could contribute a subjective analysis of the perceived benefits and concerns in alleviating social isolation and obstacles that prevent professional success for parents in this population. The success of this research could lead to the development of training programs for extended family members who may be able to assist parents of children with autism in caring for their children, whether for respite care or to supplement with after school care for the child as the parent focuses on their own professional or educational development. In addition, the development of safe daycares that specialize in caring for children with autism would be a bonus that could improve the parent's ability to increase their family's annual incomes and to enjoy a better quality of life from a mental and physical perspective overall.

Given the unique symptoms of autism and the impact that raising a child with autism has on society, including the nuclear family, opportunities exist for mental health professionals to work in partnership with other professionals, as well as with parents, as a team to develop programs that can address both the needs of parents and children with autism, particularly for low-income parents. Although many parents may be initially unfamiliar with autism, parents know their children and families better than others and may be instrumental in the development of the most conducive programs to improve overall family functioning and satisfaction which could lead to significant social change as low-income parents of children with autism may develop improved self-esteems, higher levels of confidence in knowing that they have contributed in a positive manner, regardless of their income levels, and that their voices have been heard. This may also encourage more social interaction which would decrease their feelings of social isolation and may, in turn, eliminate or decrease levels of depression as they are taught to participate and to advocate more for themselves and their child's needs.

Conclusion

The aim of this study was to gain a better understanding of the lived experiences of low-income parents raising children with autism. Although the study was available to both fathers and mothers of children with autism, only mothers participated by sharing the impact of autism on themselves, as well as their families. Findings in this study share both similarities to and differences from previous research conducted in the area.

The social stigma referred to by some participants regarding extended family members or those in the public were consistent with the Canadian research study conducted by Hoogsteen and Woodgate (2013) attributed the behavioral problems associated with autism as that of “bad parenting” and the fact that autism is not a very well understood phenomenon by the public.

Participant responses were consistent with current research in that most agree that in addition to typical stresses that most parents experience daily, such as juggling work, household chores, childcare, and finances, PCWA have additional stressors that can have a negative impact on their marital relationship, if not handled appropriately (Benson & Dewey, 2008) thus making the family systems theory much more applicable for assessing individual roles within the family, as well as individual behaviors and feelings surrounding the CWA (Cridland et al., 2015).

Also, consistent with current research was the social isolation felt by many participants in this study as they explained that family members outside the home, as well as friends, frequently fail to understand or accept the symptoms of autism and how they affect their child, thus leaving them feeling alone and are not sure who or where to turn for assistance (Lord & McGee, 2001).

Participants also concurred with present research findings that because of the specific and unique demands of caring for a CWA, some parents have been forced to choose between continued employment or quitting their job to stay at home to care for the CWA, thus reducing their family's annual income and increasing tension between the couple (Benson & Dewey, 2008). Schieve et al. (2007) reported that parental aggravation was directly associated with poverty, single-parenthood, and lower parental education. One difference in this study is that 69% of participants had at least one semester of college or more and the remaining 30% all had a GED or high school education.

Participant responses were consistent with current research and indicated that stress plays a vital role in one's overall mental and physical well-being, including high blood pressure, diabetes, depression, and anxiety, all of which can increase conflict with their spouse (Montes & Halterman, 2007; Mungo et al., 2007). Two participants revealed that they had been suicidal in the past. One reported that she has been hospitalized on three separate occasions for depression and feelings of suicide because she "feels like a failure as a mother." Another reported that she turned to food, drugs and alcohol to self-medicate for depression. As a result, this participant has been hospitalized twice for psychiatric care and has participated in a rehab program twice as well. This participant described feeling like she "failed him at times" referring to her CWA. She also described an overall deterioration of health and stated that her "teeth went bad" which led to her "socially isolating" herself.

Unlike other studies, this study specifically assessed the lived experiences of lower income PCWA and the impact on the parent's ability to provide essential services, treatments, and other resources necessary to provide their child with a better overall quality of life, in addition to the role that autism played on the parent as an individual, family and on the marital relationship. All participants indicated that they actively advocate for their children, particularly with their local school systems to acquire the services they feel their child needs, although these services are mostly limited to speech and occupational therapy. Because 67% of participants believed communication deficits to be the most challenging of the three symptoms surrounding autism, many parents indicated that they have unsuccessfully advocated for extended amounts of time for speech therapy. Although none of the 13 parents indicated they would like more speech therapy for their children, only three parents have opted to privately provide additional speech therapy to their children outside of the school system as their income allows.

As a CWA ages, parents place more emphasis on the need for social skills training. Only one participant revealed that their son is currently playing baseball to enhance his social skills. This participant indicated that she has had to inform and remind coaches that her son does not like to be touched so he cannot "pat him on the back like the other children." One other child is actively involved in church-related activities although his mother reported that "because he has been there for a while, the other children and the teachers know him and have learned how to interact with him" which keeps negative behaviors to a minimum.

Social change and financial opportunities exist for mental health providers and other professionals in terms of developing treatment programs that will allow participation for all children and parents, including those from families with low-income, to include additional speech and occupational therapy, social skills and behavioral training, ABA therapy, specialized daycare programs, counseling for families to include education on autism and coping techniques for parents, more resources in schools, summer camps, music, art, and equine therapy, and one participant even recommended the inclusion of cannabis oil to see if would have any type of impact on the symptoms associated with autism. Companies who can work with these professionals to implement the programs in an online format may be able to reach more families of children with autism and thus make a significant difference in the lives of children with autism, as well as their family members who might not otherwise be privy to these resources due to income restrictions.

References

Adolphs, R., Tranel, D., & Damasio, A. R (1998). The human amygdala in social judgment. *Nature, 393*, 470-474. doi:10.1038/30982

American Academy of Pediatrics. (2010). *Ages and stages.* Retrieved from http://www.healthychildren.org/english/ages-stages/Pages/default.aspx

American Academy of Pediatrics, Committee on Children with Disabilities. (2001). The pediatrician's role in the diagnosis and management of autism spectrum disorder in children. *Pediatrics*, *107*, e85. doi:10.1542/peds.107.5.e85

American Psychiatric Association. (1968). *Diagnostic and statistical manual of mental disorders* (2nd ed.). Washington, DC: Author.

American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed. Rev.). Washington, DC: Author.

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

Anderson, C. (2010). Relieving parental stress and depression: How helping parents help children. Retrieved from http://www.iancommunity.org/cs/articles/parental_depression

Antshel, K. M., & Joseph, G. R. (2006). Maternal stress in nonverbal learning disorder: A comparison with reading disorder. *Journal of Learning Disabilities, 39,* 194-205. doi:10.1177/00222194060390030101

Autism Society. (2013). *Approaches to improve communication.* Retrieved from https://www.cdc.gov/ncbddd/autism/treatment.html

Autism Treatment Acceleration Act, 42 U.S.C. 280, 284, 12101, 12182 (2009). Retrieved from http://www.gpo.gov/fdsys/pkg/BILLS-111s819is/pdf/BILLS-111s819is.pdf

Baird, G., Cass, H., & Slonims, V. (2003). Diagnosis of autism. *British Medical Journal, 327,* 488-493. doi:10.1136/bmj.327.7413.488

Baker, J (2007). *Marriage and divorce in America: Fact sheet.* Retrieved from http://www.relationshipsforlife.ca/pdf/marriage_divorce_in_america-FS.pdf

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. M., Konstantareas, M. 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. doi:10.1007/BF01486971

Benjak, T., Mavrinac, G., & Simetin, I. (2009). Comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia. *Croatian Medical Journal, 50,* 403-409. doi:10.3325/cmj.2009.50.403

Benson, B., & Dewey, D. (2008). Parental stress and needs in families of children with autism spectrum disorder. *International Journal of Disability, Community & Rehabilitation, 7*(1), para. 4. Retrieved from http://www.ijdcr.ca/VOL07_01_CAN/articles/benson.shtml

Billups, F. D. (2012). Qualitative data analysis: An overview for beginning qualitative researchers [PowerPoint slides]. Retrieved from http://scholarsarchive.jwu.edu/research_methodology/4/

Blue Cross Blue Shield Insurance Company of North Carolina. (2009). Corporate medical policy: Rehabilitee therapies. Retrieved from http://www.bcbsnc.com/assets/services/public/pdfs/medicalpolicy/rehabilitative_therapies.pdf

Bolman, W. M (2006). *The autistic family life cycle: Family stress and divorce.* Paper presented at the Autism Society of America's 37th National Conference on Autism Spectrum Disorders, Providence, RI. Retrieved from http://asa.confex.com/asa/2006/techprogram/S1940.HTM

Borrell-Carrio, F., Suchman, A. L., & Epstein, R. M. (2004). The biopsychosocial model 25 years later: Principles, practice, and scientific inquiry. *Annals of Family Medicine, 2,* 576-582. doi:10.1370/afm.245

Boyd, B. A., Woodard, C. R., & Bodfish, J. W. (2011). Modified exposure and response prevention to treat the repetitive behaviors of a child with autism: A case report. *Case Reports in Psychiatry, 2011,* 1-5. doi:10.1155/2011/241095

Brobst, J. B., Clopton, J. R., & Hendrick, S. S (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24,* 38–49. doi:10.1177/1088357608323699

Browndyke, J. N. (2002). *Autistic behavior: Etiology and evaluation.* Retrieved from http://www.neuropsychologycentral.com/interface/content/resources/page_material/resources_general_materials_pages/resources_document_pages/autistic_behavior_etiology_and_evaluation.pdf

Cappe, E., Wolff, M., Bobet, R., & Adrien, J. L (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. Quality of Life Research, 2011 Oct;20(8):1279-94. doi: 10.1007/s11136-011-9861-3

Cashin, A. J (2003). A hermeneutic phenomenological study of the lived experience of parenting a child with autism. Retrieved from http://hdl.handle.net/10453/20054

Centers for Disease Control and Prevention (2004). *Prevalence of the autism spectrum disorders (ASDs) in multiple areas of the United States, 2000 and 2002.* Retrieved from http://www.cdc.gov/ncbddd/autism/documents/AutismCommunityReport.pdf

Centers for Disease Control and Prevention (2007). *Autism information center: Screening and diagnosis.* Retrieved from http://www.cdc.gov/ncbdd/AUTISM/screening.htm

Centers for Disease Control and Prevention (2009). *Prevalence of the autism spectrum disorders (ASDs) in multiple areas of the United States,* 2006. MMRW Surveillance Summaries, December 18, 2009, 58(SS10); 1-20. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

Centers for Disease Control and Prevention (2012). *Press Release: CDC estimates 1 in 88 children in the United States has been identified with having an autism spectrum disorder.* Retrieved from https://www.cdc.gov/media/releases/2012/p0329_autism_disorder.html

Centers for Disease Control and Prevention (2013). *Developmental disorders: Specific conditions.* Retrieved from http://www.cdc.gov/ncbddd/developmentaldisabilities/specificconditions.html

Centers for Disease Control and Prevention (2015). *Autism spectrum disorders: Data & statistics.* Retrieved from http://www.cdc.gov/ncbddd/autism/data.html

Chew, K. (2007). Divorce a "common side effect" of autism? Retreived on November 20, 2008 from http://www.blisstree.com/autismvox/divorce-a-common-side-effect-of-autism/

Committee on Children with Disabilities (CCD; 2001). The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics, 107,* 1221–1226. doi:10.1542/peds.107.5.1221

Courchesne, C. M., Davis, H.R., Ziccardi, R., Carper, R. A., Tigue, Z.D., Chisum, H. J., Moses, P., Pierce, K., Lord, C., Lincoln, A. J., Pizzo, S., Schreibman, L., Haas, R. H., Alshoonoff, N.A., and Courchesne, R. Y (2001). Unusual brain growth patterns in early life in patients with autistic disorder. *Neurology,* 57(2), 245-354. doi: 10.1212/WNL.57.2.245

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five traditions (2nd Ed).* Thousand Oaks, CA: Sage.

Creswell, J.W. (2013). *Qualitative inquiry and research design: Choosing among five approaches (3rd ed.).* Thousand Oaks, CA: Sage.

Cridland, E. K., Jones, S. C., Magee, C. A., and Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. Autism: The International Journal of Research and Practice, 18(3), 213-222.

Cridland, E. K., Jones, S. C., Stoyles, G., Caputi, A. P., & Magee, C. A (2015). Families living with autism spectrum disorder: Roles and responsibilities of adolescent sisters. *Hammill Institute on Disabilities: Focus on autisms and Other Developmental Disabilities,* 2-12. Doi: 10.1177/1088357615583466

Dahlgren, S. O. & Sandberg, A. D. (2008). Referential communication in children with autism spectrum disorder. *Autism, 12,* 335-348. doi: 10/1177/1362361308091648

Daire, A., Munyon, M., Carlson, R., Kimemia, M., and Mitcham, M (2011). Examining distress of parents of children with and without special needs. *Journal of Mental Health Counseling, 33(2)*, 177-188. ISSN: 01931830

Daniels, J., Forssen, U., Hultman, C., Cnattingisu, S., Savitz, D., Feytchting, M., & Sparen, P (2008). Parental psychiatric disorders associated with autism spectrum disorders in the offspring. *Pediatrics, 121,* 1357–1362. doi:10.1542/peds.2007 -2296

Davis, N. O., & Carter, A. S (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38,* 1278–1291. doi:10.1007/s10803 -007-0512-z

DePape, A-M. & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research, 5(4)*, 569-583. doi:10.1177/1049732314552455

Dowling, A. S. (2005). Images in psychiatry. *American Journal of Psychiatry, 162(*11), 2039 – 2039. Retrieved from https://doi.org/10.1176/appi.ajp.162.11.2039

Duba, J. D., Hughey, A. W., Lara, T., & Burke, M. G (2012). Areas of marital dissatisfaction among long-term couples. *Adultspan Journal, 11,* 39–54. doi:10 .1002/j.2161-0029.2012.00004.x

Dumont-Mathieu, T., & Fein, D (2005). Screening for autism in young children: The Modified Checklist for Autism in Toddlers (M-CHAT) and other measures. *Mental Retardation and Developmental Disabilities Research Reviews, 11,* 253–262. doi:10.1002/mrdd.20072

Dunn, L. M., & Dunn, D. M (1981). *Peabody Picture Vocabulary Test-Revised (PPVT-R).* San Antonio, TX: Pearson Education.

Dunn, M. E., Burbine, T., Bowers, C. A., Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, (1)*: 39-52. PMID: 11300666

Eddy, L. L., & Walker, A. J (1999). The impact of children with chronic health problems on marriage. *Journal of Family Nursing, 5,* 10–32. doi:10.1177 /10748407990000102

Edwards, S., Letts, C., & Sinka, I (2011). *New Reynell Developmental Language Scales (NDLS).* Camberwell, Australia: ACER Press.

Ellis, C. R., Schones, C. J., & Roberts, H. J (2012). *Childhood habit behaviors and stereotypic movement disorder.* Retrieved from http://emedicine.medscape.com/article/914071-overview#a0101

Engel, G. L. (1980). The clinical application of the biopsychosocial model. *American Journal of Psychiatry, 137,* 535–544.

Englander, M. (2012). The Interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology*, 43, 13–35. doi: 10.1163/156916212X632943

Erikson, E. H (1950). *Childhood and society.* New York, NY: W. W. Norton.

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbot, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism, 13(4): 375–387. doi: 10.1177/1362361309105658

Falk, N. H., Norris, K., & Quinn, M. G (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *Journal of Autism Developmental Disorders*, 44(12), 3185-3203. doi: 10.1007/s10803-014-2189-4

Federal Poverty Guidelines (FPG). (2017). Federal Poverty Guidelines annual income levels are published in the Federal Register of January 31, 2017, Volume 82, Number 19, on pages 8831-8832.

Food and Nutrition Service (FNS). (2017). Child nutrition programs: Income eligibility guidelines. Retrieved from https://www.federalregister.gov/documents/2017/04/10/2017-07043/child-nutrition-programs-income-eligibility-guidelines

Freedman, B. H., Kalb, L. G., Zablotsky, B., & Stuart, E. A (2012). Relationships among parents of children with autism spectrum disorders: A population-based study. *Journal of Autism Developmental Disorders,* 42*,* 539–548. doi:10.1007/s10803 -011-1269-y

Frombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: an update. *Journal of Autism Developmental Disorders, 33(4)*:365-82. PMID: 12959416

Georgians for a Healthy Future. (2016). PeachCare Income Guidelines for Parents. Retrieved from http://healthyfuturega.org/wp-content/uploads/2015/12/Income-Tables-2015.pdf

Gerrard (2006). *Models of autism*. October 26, 2006. Retrieved from www.scm.keele.ac.uk/research/knowledge_modelling/km/.../autism.pdf

Goepfert, E., Mulé, C., von Hahn, E., Visco, Z., & Siegel, M (2015). Family System Interventions for Families of Children with Autism Spectrum Disorder. *Child and adolescent psychiatric clinics of North America*, *24*(3), 571-583.

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

Georgia Department of Community Health (GDCH, 2017). United States Federal Poverty Level Guidelines (FPG). *Healthcare Regulations Division, Office of Health Planning.* Retrieved from https://dch.georgia.gov/sites/dch.georgia.gov/files/2017_Federal_Poverty_Guidelines.pdf

Gottman, J. M (1997). *What predicts divorce? The relationship between marital processes and marital outcomes*. Hillsdale, NJ: Lawrence Erlbaum.

Grandin, T. (1984). My experiences as an autistic child and review of selected literature. *Journal of Orthomolecular Psychiatry, 13*(3), 144–174. Retrieved from http:// www.orthomolecular.org/library/jom/1984/pdf/1984-v13n03-p144.pdf

Grinker, R. R (2007). *Unstrange minds: Remapping the world of autism*. Cambridge, MA: Basic Books.

Grosso, K. (2011). Do couples divorce because of autism? *Psychology Today,* (March 3, 2011). Retrieved from https://www.psychologytoday.com/blog/autism-in-real-life/201103/do-couples-divorce-because-autism

Hall, H. R., Neely-Barnes, S. L., Graff, J. C., Krcek, T. E., Roberts, R. J., & Hankins, J. S (2012). Parental Stress in Families of Children with a Genetic Disorder/Disability and the Resiliency Model of Family Stress, Adjustment, and Adaptation. Issues in Comprehensive Pediatric Nursing, 35(1), 24-44. doi:10.3109/01460862.2012.646479

Harrington, J. W., Rosen, L., Garnecho, A., & Patrick, P. A (2006). Parental perceptions and use of complementary and alternative medicine practices for children with autistic spectrum disorders in private practice. *Journal of Developmental and Behavioral Pediatrics, 27,* S156–S161. doi:10.1097/00004703-200604002-00014

Harris Interactive. (2008). Living with autism study. *Easter Seals Disability Services*. p. 23. Retrieved from http://www.easterseals.com/site/DocServer/Study_FINAL_Harris_12.4.08.pdf?docID=83143

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

Hastings, R., & Brown, T (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation, 107,* 222–232. doi:10.1352/0895-8017(2002)107%3C0222:BPOCWA%3E2.0.CO;2

Healthcare Facility Regulation Division/Office of Health Planning, Georgia Department of Community Health. (2015). Federal Register/Vol. 80, No. 14/Thursday, January 22, 2015/Notices. Retrieved from http://dch.georgia.gov/sites/dch.georgia.gov/files/related_files/document/2015_Federal_Poverty_Guidelines.pdf

Hermansen, M. S. and Miller, P. J (2008). The lived experience of mothers of ADHD children undergoing chiropractic care: A qualitative study *Clinical Chiropractic*, 11(4), 182-192.

Hoogsteen, L. and Woodgate, R. L (2013). Embracing autism in Canadian rural communities. The Australian Journal of Rural Health, 21(3), 178-182. doi: 10.1111/ajr.12030

Houghton, C., Dympna, C., Shaw, D., and Murphy, K. (2012). Rigor in qualitative case-study research. *Nurse Researcher, 20(4)*, 12-17. Retrieved from http://dx.doi.org/10.7748/nr2013.03.20.4.12e326

Ingersoll, B. (2010). The differential effect of three naturalistic language interventions on language use in children with autism. *Journal of Positive Behavior Interventions, 13(2)*, 109-118. doi:10.1177/1098300710384507

Ingersoll, B. & Hambrick, D. Z (2011). The relationship between the broader phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5(2011)*, 337-344.

Interactive Autism Network (2008). IAN research findings: Special diets. *IAN Research Reports: Kennedy Krieger Institute, November 11, 2008.* Retrieved from http://www.iancommunity.org/cs/ian_treatment_reports/special_diets

Jennings, S (2005). Autism in children and parents: Unique considerations for family court professionals. *Family Court Review, 43,* 582–595. doi:10.1111/j.1744-1617.2005.00057.x

Kafle, N. P (2011). Hermeneutic phenomenological research method simplified. *Bodhi: An Interdisciplinary Journal,* 181-200. ISSN: 2091-0479

Kanner, L (1943). Autistic disturbance of affective contact. *Nervous Child, 2,* 217–250. Retrieved from http://www.aspires-relationships.com/articles_autistic_disturbances_of_affective_contact.htm

Karande, S. (2006). Autism: A review for family physicians. *Indian Journal of Medical Sciences, 2006 May, 60(5),* 205-215. Accession #: 21031476

Kennedy Krieger Institute (2010, May 19). 80 percent autism-divorce rate debunked in first-of-its kind scientific study. *ScienceDaily*. Retrieved from http://www.sciencedaily.com/releases/2010/05/100519143403.htm

Kim, Y. (2015). The pilot study in qualitative inquiry: Identifying issues and learning lessons for culturally competent research. *Qualitative Social Work, 10(2),* 190-2016. doi: 10.1177/1473325010362001

Lakhan, S. E. (2006). The biopsychosocial model of illness. *Connextions Module, m13589*. Retrieved from http://www.medschool.lsuhsc.edu/medical_education/undergraduate/spm/SPM_100/documents/BiopsychosocialModel.pdf

Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., & Prosser, L. A. (2014). Economic burden of childhood autism spectrum disorders, *Pediatrics, 133*(3), e520-e529. doi: 10.1542/peds.2013-0763

Lessenberry, B. M., & Rehfeldt, R. A (2004). Evaluating stress levels of parents of children with disabilities. *Exceptional Children, 70,* 231–240.

Liu, J. (2004). Childhood externalizing behavior: Theory and implications. *Journal of Child and Adolescent Psychiatry Nursing, 17*, 93–103. doi:10.1111/j.1744-6171 .2004.tb00003.x

Lord, C., & McGee, J. P (2001). *Educating children with autism*. Washington, DC: National Academy Press.

Lord, C., Risi, S. Lambrecht, L. Cook Jr., E. H., Leventhal, B. L., DiLavore, P. C., Pickles, A. and Rutter, M. (2000). The Autism Diagnostic Observation Schedule—Generic: A Standard Measure of Social and Communication Deficits Associated with the Spectrum of Autism. *Journal of Autism Developmental Disorders, 30:* 205. doi:10.1023/A:1005592401947

Montes, G. & Halterman, J. S (2007). Psychological functioning and coping among mothers of children with autism: a population-based study. *Pediatrics, 119-5*, e1040-e1046. doi:10.1542/peds.2006-2819

Moore, K. A., & Vandivere, S (2000). *Stressful family lives: Child and parent well-being.* Retrieved from http://www.urban.org/UploadedPDF/anf_b17.pdf

Mori, K., Ujiie, T., Smith, A., & Howlin, P (2009). Parental stress associated with caring for children with Asperger's syndrome or autism. *Pediatrics International, 51,* 364–370. doi:10.1111/j.1442-200X.2008.02728.x

Mount, N., & Dillon, G (2014). Parents' experiences of living with an adolescent diagnosed with an autism spectrum disorder. *Educational & Child Psychology*, 31(4), 72-81.

Moustakas, C. (1994). *Phenemonological research methods*. Thousand Oaks, CA: Sage.

Mullen, E. M (1995). *Mullen scales of early learning.* San Antonio, TX: Pearson Education.

Mulligan A, Anney R.J., O'Regan M, Chen W, Butler L, Fitzgerald M, Buitelaar J, Steinhausen H.C., Rothenberger A, Minderaa R, et al. (2009). Autism symptoms in Attention-Deficit/Hyperactivity Disorder: A Familial trait which Correlates with Conduct, Oppositional Defiant, Language and Motor Disorders. *Journal of Autism and Developmental Disorders,* 39(2), 197-209. doi: 10.1007/s10803-008-0621-3.

Mungo, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes, 27*, 5–22.

National Center for Health Statistics (2009). Births, marriages, divorces, and deaths: Provisional data for 2008. *National Vital Statistics Reports, 57*(19), 1–6. Retrieved from http://www.cdc.gov/nchs/data/nvsr/nvsr58/nvsr58_25.htm

National Institute of Mental Health (2011). A parent's guide to autism spectrum disorder. *National Institute of Mental Health, NIH Publication No. 11-5511.* Retrieved from http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/index.shtml#pub9

National Institute on Deafness and Other Communication Disorders (NIDCD; 2009). *Autism and communication* (NIH Pub. No. 09-4315). Retrieved from http://www.nidcd.nih.gov/health/voice/pages/autism.aspx

Neely-Barnes, S. L., & Dia, D. A (2008). Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early and Intensive Behavior Intervention*, v. 8(3), 93-107. ISSN:1554-4893

Olney, M. F (2000). Working with autism and other social communication disorders. *Journal of Rehabilitation, 66*(4), 51–65.

Parker, J., Mandleco, B., Roper, S., Freeborn, D., & Dyches, T (2011). Religiosity, spirituality, and marital relationships of parents raising a typically developing child or a child with a disability. *Journal of Family Nursing, 17,* 82–104. doi:10 .1177/1074840710394856

Parish, S. L., Thomas, K. C., Williams, C. S. & Crossman, M. K. (2015). Autism and families' financial burden: The Association with Health Insurance Coverage. *American Journal on Intellectual and Developmental Disabilities:* March 2015, 120(2), 166-175. i: http://dx.doi.org/10.1352/1944-7558-120.2.166

Pfeiffer, S., Norton, J., Nelson, L., & Shott, S (2005). Efficacy of vitamin B6 and magnesium in the treatment of autism: A methodology review and summary of outcomes. *Journal of Autism and Developmental Disorders, 25,* 481–493. doi:10.1007/BF02178295

Pisula, E (2007). A comparative study of stress profiles in mothers of children with Autism and those of children with Down's Syndrome, *Journal of Applied Research in Intellectual Disabilities, 20*, 274-278. doi:10.1111/j.1468-3148.2006.00342.x

Pisula, E. & Kassakowska, Z (2010). Sense of coherence of coping with stress among mothers and fathers of children with autism. *Journal of Autism & Developmental Disorders*, *40*(12), 1485-1494.

Piven, J. & Palmer, P. (1999). Psychiatric disorder and the broad autism phenotype: Evidence from a family study of multiple-incidence autism families. *American Journal of Psychiatry, 156(4),* 557-563.

Rao, P. A. & Beidel, D. C (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification, 33(4),* 437-451. Doi: 10.1177/0145445509336427

Rhoades, R. A., Scarpa, A., & Salley, B (2007). The importance of physician knowledge of autism spectrum disorder: results of a parent survey. *BMC Pediatrics*, v. 7(37), doi:10.1186./1471-2431-7-37

Rodgers, S. J (2009). What are infant siblings teaching us about autism in infancy? *Autism Research, 2(3)*, 125-137. doi: 10.1002/aur.81

Rodier, P. M., Ingram, J. L., Tisdale, B., Nelson, S., & Romano, J (1996). Embryological origin for autism: Developmental anomalies of the cranial nerve motor nuclei. *The Journal of Comparative Neurology, 370,* 247–261. doi:10.1002/(SICI)1096-9861 (19960624)370:2%3C247::AID-CNE8%3E3.0.CO;2-2

Roid, G. H., & Miller, L. J (1997). *Leiter International Performance Scale (LIPS).* Torrance, CA: Western Psychological Services.

Rutter, M., Le Couteur, A., & Lord, C (1994). Autism diagnostic interview-revised. Torrance, CA: Western Psychological Services.

Ryan, G. W., & H. R. Bernard. 2000. Data management and analysis methods. In Handbook of qualitative research, 2d ed., edited by N. Denzin and Y. Lincoln, 769–802. Thousand Oaks, CA: Sage.

Satcher (1999, C. 2, p. 72). US Department of Health and Human Services; US Department of Education; US Department of Justice. *Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda*. Washington (DC): US Department of Health and Human Services; 2000. Conference Proceedings. Available from: http://www.ncbi.nlm.nih.gov/books/NBK44232/

Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics,* 119*,* S114–S121. doi:10.1542/peds2006-2089Q

Schlosser, R. W., & Wendt, O (2008). Effects of augmentative and alternative communication intervention on speech production in children with autism: A systematic review. *American Journal of Speech and Language Pathology, 17,* 212–230. doi:10.1044/1058-0360(2008/021)

Schopler, E., Van Bourgondien, M. E., Wellman, G. J., & Love, S. R (2010). *Childhood Autism Rating Scale* (CARS2, 2nd ed.). Upper Saddle River, NJ: Pearson Education.

Shah, K. (2001). What do medical students know about autism. *Autism, 5(2),*127–133. PMID: 11706861 [PubMed].

Siegel, B. (2003). Helping children with autism learn: Treatment approaches for parents and professionals. Oxford university press.

Siklos, S., & Kerns, K (2005). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28,* 9–22. doi:10.1016/j.ridd.2005.09.003

Simon, M. K., & Goes, J (n.d.). *What is Phenomenological Research?* Retrieved from http://dissertationrecipes.com/wp-content/uploads/2011/04/PhenomenologicalResearch.pdf

Singer, G. H., Ethridge, B. L., & Aldana, S. I (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 357–369. doi:10.1002 /mrdd.20175

Sivberg, B. (2002). Coping strategies and parental attitudes, a comparison of parents with children with autistic spectrum disorders and parents with non-autistic children. International Journal of Circumpolar Health, 61(sup2), 36-50.

Smith, A. L., Romski, M., Sevick, R. A., Adamson, L. B., Bakeman, R (2011). Parent stress and its relation to parent perception of communication following parent-coached language intervention. *Journal of Early Intervention, 33(2),* 135-150. doi:10.1177/1053815111405526

Sobsey, D (2004). Marital stability and marital satisfaction in families of children with disabilities: Chicken or egg? *Developmental Disabilities Bulletin, 32(1),* 62-83.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A (2005). *Vineland Adaptive Behavior Scale* (VABS-II, 2nd ed.). San Antonio, TX: Pearson Education.

Sponheim, E (1996). Changing criteria of autistic disorders: A comparison of the ICD-10 research criteria and DSM-IV with DSM-III-R, CARS, and ABC. *Journal of Autism and Developmental Disorders, 26,* 513–525. doi:10.1007/BF02172273

Tassé, M. J., Aman, M. G., Hammer, D., & Rojahn, J (1996). The Nisonger Child Behavior Rating Form: Age and gender effects and norms. *Research in Developmental Disabilities, 17,* 59–75. doi:10.1016/0891-4222(95)00037-2

Tehee, E., Honan, R., & Hevey, D (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities, 22,* 34–42. doi:10.1111/j.1468-3148.2008.00437.x

Thorndike, R. L., Hagen, E. P., & Sattler, J. M (1986). *The Stanford-Binet Intelligence Scale, fourth edition: Guide for administering and scoring.* Chicago, IL: Riverside.

Tidmarsh, L., & Volkmar, F. R (2003). Diagnosis and epidemiology of autism spectrum disorders. *Canadian Journal of Psychiatry, 48,* 517–525.

Tsai, L (2003). *Pervasive developmental disorders*. Washington, DC: National Dissemination Center for Children with Disabilities.

U.S. Department of Agriculture, Food & Nutrition Services. (2017). Child nutrition programs: Income eligibility guidelines, July 1, 2017 – June 3, 018). Retrieved from https://www.gpo.gov/fdsys/pkg/FR-2017-04-10/pdf/2017-07043.pdf

U.S. Department of Education. (2017). Federal Trio Programs: Current year low income levels. Retrieved from https://www2.ed.gov/about/offices/list/ope/trio/incomelevels.html

U.S. Department of Health and Human Services. (2017). Federal Trio Programs: Current-year low-income levels. Retrieved from https://www2.ed.gov/about/offices/list/ope/trio/incomelevels.html

Waltz. M (2002). *Autistic spectrum disorders: Understanding the diagnosis & getting help* (3rd ed.). Sebastopol, CA: O'Reilly & Associates.

Wang, L. W., Trancredi, D. J., & Thomas, D. W (2011). The Prevalence of Gastrointestinal Problems in Children across the United States with Autism Spectrum Disorders from Families with Multiple Affected Members *Journal of Developmental & Behavioral Pediatrics*, *32*(6), 351-360. doi: 10.1097/DBP.0b0013e31821bd06

Wechsler, D (1989). *Manual for the Wechsler preschool and primary scale of intelligence* (rev.). San Antonio, TX: The Psychological Corporation.

Wechsler, D (1991). *Manual for the Wechsler intelligence scale for children* (3rd ed.). San Antonio, TX: The Psychological Corporation.

Weiss, J. A., & Lunsky, Y (2011). The Brief Family Distress Scale: A measure of crisis in caregivers of individuals with autism spectrum disorders. *Journal of Children and Family Studies,* 20*,* 521–528. doi:10.1007/s10826-010-9419-y

Whiteley, P., Rodgers, J., Savery, D., & Shattock, P (1999). A gluten-free diet as an intervention for autism and associated spectrum disorders: Preliminary findings. *Autism, 3,* 45–65. doi:10.1177/1362361399003001005

Wing, L (1981). Asperger's syndrome: A clinical account. *Psychological Medicine, 11,* 115–129. doi:10.1017/S0033291700053332

Wing, L. & Potter, D (2002). The epidemiology of autism spectrum disorders: Is the prevalence rising? *Mental Retardation Developmental Disabilities Research Reviews,* 8(3), 151-161. doi: 10.1002/mrdd.10029

Wise, T. N (2001). George Engel: A tribute and a farewell. *Psychosomatics, 42,* 93. doi: 10.1176/appi.psy.42.2.93

Woodgate, R. L., 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), pp. 1075-1083. doi:10.1177/1049732308320112

World Health Organization (1992). *ICD-10 classification of mental and behavioral disorders: Clinical descriptions and diagnostic guidelines*. Geneva, Switzerland: Author.

Wymbs, B. T., Pelham, W. E., Jr., Molina, B. S., Gnagy, E. M., Wilson, T. K., & Greenhouse, J. B (2008). Rate and predictors of divorce among parents of youths with ADHD. *Journal of Consulting Clinical Psychology, 76,* 735–44. doi:10.1037 /a0012719

Appendix A: Interview Questions

Research Questions	Interview Questions
1. How do low income parents describe their daily lived experiences of raising a child with autism?	1. Tell me about your child. a. Describe the quality of your pregnancy? b. Describe your experiences of the birthing process?...Were there any complications? 2. When did you first become aware that something may be wrong in terms of your child's development? Whom did you first ask for help? How long did it take your child to receive a diagnosis of autism? 3. Describe your daily experiences of raising a child with autism. 4. Describe the relationship between your current annual household income and your ability to raise your CWA.
2. What effects does the CWA's communication deficit have on parental stress, if any?	4. Autism affects everyone differently. The three primary characteristics of autism are communication and social deficits and repetitive behaviors. Tell me specifically how these three symptoms have affected your child. a. Which ones have been the most challenging and why? b. Describe the changes in these symptoms over the years, if any. 10. Describe your child's communication abilities and any struggles that you experience as a result.
3. How do parents describe their relationships with family members and their social experiences outside the home?	5. Describe the impact of ASD had on you as a parent? a. personally b. physically c. psychologically d. socially 11. Describe how ASD has impacted your social and professional experiences outside

	the home, including with extended family members and friends.
4. How do parents indicate their child's autism has impacted their marital relationship and family?	6. Describe any resources your child is currently receiving and the impact this has on you both. a. If money were no option, what resources would you add and why? 7. Describe the impact that raising a CWA has had on your marital relationship. a. When you are feeling overwhelmed, what coping techniques do you use? b. When your spouse is feeling overwhelmed, what coping techniques does he/she use? 8. Describe your families level of functioning when your CWA is away (e.g., in respite care, at school, with extended family members, etc.) 12. Describe any strengths you feel you have developed as a PCWA?.... weaknesses?

Appendix B: Demographic Survey

1. How many children do you have?
a. How many children do you have you have been diagnosed with Autism Spectrum Disorder? ________

b. List the specific diagnosis: ___________________________________

c. At what age was the child with autism (CWA) diagnosed? _____

d. CWA's current age? _____

e. Current ages of your other children? __________________________

2. Total number of people currently living in your home? ______________

a. Number of adults: _________

b. Number of children: _______

3. What is your relationship to the CWA? (Circle one)

Biological Mother Biological Father Not Related

4. Indicate your current annual household income. (Check one)

a. ☐ $10,000 or Below

b. ☐ $10,001 - $20,000

c. ☐ $20,001 - $30,000

d. ☐ $30,001 - $40,000

e. ☐ $40,001 - $50,000

f. ☐ $50,001 - $60,000

g. ☐ $60,001 or Above

5. a. What was your age when your CWA was born? _____ Current age? ___
b. What was your spouse's age when your CWA was born? ____ Current age? _____

6. Indicate grade or number of years of school both you and your spouse *completed*.

You	Spouse
High School	
College	
Graduate School	

7. Are you employed outside of the home? Yes or No
    a. If yes, how many hours per week do you work outside the home? ___
    b. If yes, who takes care of your CWA while you work?

8. Does your spouse work outside the home? Yes or No
    a. If yes, how many hours per week does he/she work outside the home?

9. Please check to indicate ethnicity:

You	Spouse	CWA
Caucasian ☐	Caucasian ☐	Caucasian ☐
African-American ☐	African-American ☐	African-American ☐
Hispanic or Latino ☐	Hispanic or Latino ☐	Hispanic or Latino ☐
Asian/Pacific Islander ☐	Asian/Pacific Islander ☐	Asian/Pacific Islander ☐
Native American ☐	Native American ☐	Native American ☐
Other (please list) ☐	Other (please list) ☐	Other (please list) ☐

Appendix C: United States Federal Poverty Level

U.S. FEDERAL POVERTY GUIDELINES USED TO DETERMINE FINANCIAL ELIGIBILITY FOR CERTAIN FEDERAL PROGRAMS

There are two slightly different versions of the federal poverty measure: poverty thresholds and poverty guidelines.

The **poverty thresholds** are the original version of the federal poverty measure. They are updated each year by the **Census Bureau**. The thresholds are used mainly for **statistical** purposes — for instance, preparing estimates of the number of Americans in poverty each year. (In other words, all official poverty population figures are calculated using the poverty thresholds, not the guidelines.) Poverty thresholds since 1973 (and for selected earlier years) and weighted average poverty thresholds since 1959 are available on the Census Bureau's Web site. For an example of how the Census Bureau applies the thresholds to a family's income to determine its poverty status, see "How the Census Bureau Measures Poverty" on the Census Bureau's web site.

The **poverty guidelines** are the other version of the federal poverty measure. They are issued each year in the Federal Register by the **Department of Health and Human Services** (HHS). The guidelines are a simplification of the poverty thresholds for use for **administrative** purposes — for instance, determining financial eligibility for certain federal programs.

The poverty guidelines are sometimes loosely referred to as the "federal poverty level" (FPL), but that phrase is ambiguous and should be avoided, especially in situations (e.g., legislative or administrative) where precision is important.

Key differences between poverty thresholds and poverty guidelines are outlined in a table under Frequently Asked Questions (FAQs). See also the discussion of this topic on the Institute for Research on Poverty's web site.

The January 2017 poverty guidelines are calculated by taking the 2015 Census Bureau's poverty thresholds and adjusting them for price changes between 2015 and 2016 using the Consumer Price Index (CPI-U). The poverty thresholds used by the Census Bureau for statistical purposes are complex and are not composed of standardized increments between family sizes. Since many program officials prefer to use guidelines with uniform increments across family sizes, the poverty guidelines include rounding and standardizing adjustments in the formula.

HHS POVERTY GUIDELINES FOR 2017

The 2017 poverty guidelines are in effect as of January 26, 2017.

See also the Federal Register notice of the 2017 poverty guidelines, published January 31, 2017

2017 POVERTY GUIDELINES FOR THE 48 CONTIGUOUS STATES AND THE DISTRICT OF COLUMBIA

Persons in family/household	Poverty guideline
For families/households with more than 8 persons, add $4,180 for each additional person.	
1	$12,060
2	$16,240
3	$20,420
4	$24,600
5	$28,780
6	$32,960
7	$37,140
8	$41,320

2017 POVERTY GUIDELINES FOR ALASKA

Persons in family/household	Poverty guideline
For families/households with more than 8 persons, add $5,230 for each additional person.	
1	$15,060
2	$20,290
3	$25,520
4	$30,750
5	$35,980

2017 POVERTY GUIDELINES FOR ALASKA	
Persons in family/household	**Poverty guideline**
6	$41,210
7	$46,440
8	$51,670

2017 POVERTY GUIDELINES FOR HAWAII	
Persons in family/household	**Poverty guideline**
For families/households with more than 8 persons, add $4,810 for each additional person.	
1	$13,860
2	$18,670
3	$23,480
4	$28,290
5	$33,100
6	$37,910
7	$42,720
8	$47,530

The separate poverty guidelines for Alaska and Hawaii reflect Office of Economic Opportunity administrative practice beginning in the 1966-1970 period. Note that the poverty thresholds — the original version of the poverty measure — have never had separate figures for Alaska and Hawaii. The poverty guidelines are not defined for Puerto Rico, the U.S. Virgin Islands, American Samoa, Guam, the Republic of the Marshall Islands, the Federated States of Micronesia, the Commonwealth of the Northern Mariana Islands, and Palau. In cases in which a Federal program using the poverty guidelines serves any of those jurisdictions, the Federal office which administers the program is responsible for deciding whether to use the contiguous-states-and-D.C. guidelines for those jurisdictions or to follow some other procedure.

The poverty guidelines apply to both aged and non-aged units. The guidelines have never had an aged/non-aged distinction; only the Census Bureau (statistical) poverty thresholds have separate figures for aged and non-aged one-person and two-person units.

Programs using the guidelines (or percentage multiples of the guidelines — for instance, 125 percent or 185 percent of the guidelines) in determining eligibility include Head Start, the Supplemental Nutition Assistance Program (SNAP), the National School Lunch Program, the Low-Income Home Energy Assistance Program, and the Children's Health Insurance Program. Note that in general, cash public assistance programs (Temporary Assistance for Needy Families and Supplemental Security Income) do NOT use the poverty guidelines in determining eligibility. The Earned Income Tax Credit program also does NOT use the poverty guidelines to determine eligibility. For a more detailed list of programs that do and don't use the guidelines, see the Frequently Asked Questions (FAQs).

The poverty guidelines (unlike the poverty thresholds) are designated by the year in which they are issued. For instance, the guidelines issued in January 2016 are designated the 2016 poverty guidelines. However, the 2016 HHS poverty guidelines only reflect price changes through calendar year 2015; accordingly, they are approximately equal to the Census Bureau poverty thresholds for calendar year 2015. (The 2015 thresholds are expected to be issued in final form in September 2016; a preliminary version of the 2015 thresholds is now available from the Census Bureau.)

The poverty guidelines may be formally referenced as "the poverty guidelines updated periodically in the Federal Register by the U.S. Department of Health and Human Services under the authority of 42 U.S.C. 9902(2)."

https://aspe.hhs.gov/poverty-guidelines

United States Department of Agriculture, Food & Nutrition Services: Child nutrition programs: Income eligibility guidelines, July 1, 2017 – June 3, 2018.

INCOME ELIGIBILITY GUIDELINES

Effective from July 1, 2017 to June 30, 2018

HOUSEHOLD SIZE	FEDERAL POVERTY GUIDELINES	REDUCED PRICE MEALS - 185 %					FREE MEALS - 130 %				
	ANNUAL	ANNUAL	MONTHLY	TWICE PER MONTH	EVERY TWO WEEKS	WEEKLY	ANNUAL	MONTHLY	TWICE PER MONTH	EVERY TWO WEEKS	WEEKLY
48 CONTIGUOUS STATES, DISTRICT OF COLUMBIA, GUAM, AND TERRITORIES											
1	12,060	22,311	1,860	930	859	430	15,678	1,307	654	603	302
2	16,240	30,044	2,504	1,252	1,156	578	21,112	1,760	880	812	406
3	20,420	37,777	3,149	1,575	1,453	727	26,546	2,213	1,107	1,021	511
4	24,600	45,510	3,793	1,897	1,751	876	31,980	2,665	1,333	1,230	615
5	28,780	53,243	4,437	2,219	2,048	1,024	37,414	3,118	1,559	1,439	720
6	32,960	60,976	5,082	2,541	2,346	1,173	42,848	3,571	1,786	1,648	824
7	37,140	68,709	5,726	2,863	2,643	1,322	48,282	4,024	2,012	1,857	929
8	41,320	76,442	6,371	3,186	2,941	1,471	53,716	4,477	2,239	2,066	1,033
For each add'l family member, add	4,180	7,733	645	323	298	149	5,434	453	227	209	105
ALASKA											
1	15,060	27,861	2,322	1,161	1,072	536	19,578	1,632	816	753	377
2	20,290	37,537	3,129	1,565	1,444	722	26,377	2,199	1,100	1,015	508
3	25,520	47,212	3,935	1,968	1,816	908	33,176	2,765	1,383	1,276	638
4	30,750	56,888	4,741	2,371	2,188	1,094	39,975	3,332	1,666	1,538	769
5	35,980	66,563	5,547	2,774	2,561	1,281	46,774	3,898	1,949	1,799	900
6	41,210	76,239	6,354	3,177	2,933	1,467	53,573	4,465	2,233	2,061	1,031
7	46,440	85,914	7,160	3,580	3,305	1,653	60,372	5,031	2,516	2,322	1,161
8	51,670	95,590	7,966	3,983	3,677	1,839	67,171	5,598	2,799	2,584	1,292
For each add'l family member, add	5,230	9,676	807	404	373	187	6,799	567	284	262	131
HAWAII											
1	13,860	25,641	2,137	1,069	987	494	18,018	1,502	751	693	347
2	18,670	34,540	2,879	1,440	1,329	665	24,271	2,023	1,012	934	467
3	23,480	43,438	3,620	1,810	1,671	836	30,524	2,544	1,272	1,174	587
4	28,290	52,337	4,362	2,181	2,013	1,007	36,777	3,065	1,533	1,415	708
5	33,100	61,235	5,103	2,552	2,356	1,178	43,030	3,586	1,793	1,655	828
6	37,910	70,134	5,845	2,923	2,698	1,349	49,283	4,107	2,054	1,896	948
7	42,720	79,032	6,586	3,293	3,040	1,520	55,536	4,628	2,314	2,136	1,068
8	47,530	87,931	7,328	3,664	3,382	1,691	61,789	5,150	2,575	2,377	1,189
For each add'l family member, add	4,810	8,899	742	371	343	172	6,253	522	261	241	121

Federal TRIO Programs Current-Year Low-Income Levels

(Effective **January 31, 2017** until further notice)

Size of Family Unit	**48 Contiguous States, D.C., and Outlying Jurisdictions**	**Alaska**	**Hawaii**
1	$18,090	$22,590	$20,790
2	$24,360	$30,435	$28,005
3	$30,630	$38,280	$35,220
4	$36,900	$46,125	$42,435
5	$43,170	$53,970	$49,650
6	$49,440	$61,815	$56,865
7	$55,710	$69,660	$64,080
8	$61,980	$77,505	$71,295

For family units with more than eight members, add the following amount for each additional family member: $6,270 for the 48 contiguous states, the District of Columbia, and outlying jurisdictions; $7,845 for Alaska; and $7,215 for Hawaii.

The term “low-income individual” means an individual whose family’s taxable income for the preceding year did not exceed 150 percent of the poverty level amount.

The figures shown under family income represent amounts equal to 150 percent of the family income levels established by the Census Bureau for determining poverty status. The poverty guidelines were published by the U.S. Department of Health and Human Services in the Federal Register on January 31, 2017.

INCOME TABLES

Income Guidelines for
Parents, Caregivers and Kids

INCOME LIMITS FOR MEDICAID AND PEACHCARE FOR KIDS, 2016

How big is your family?	How old is your child?			
	Medicaid			PeachCare for Kids
	CHILD AGE **0 TO 1** 210% FPL	CHILD AGE **1 TO 5** 154% FPL	CHILD AGE **6 TO 19** 138% FPL	CHILD AGE **0 TO 19** 252% FPL
1 person	$2,080 monthly income limit $24,960 annual income limit	$1,526 monthly income limit $18,312 annual income limit	$1,367 monthly income limit $16,404 annual income limit	$2,496 monthly income limit $29,952 annual income limit
2 people	$2,804 monthly income limit $33,648 annual income limit	$2,057 monthly income limit $24,684 annual income limit	$1,843 monthly income limit $22,116 annual income limit	$3,365 monthly income limit $40,380 annual income limit
3 people	$3,528 monthly income limit $42,336 annual income limit	$2,588 monthly income limit $31,056 annual income limit	$2,319 monthly income limit $27,828 annual income limit	$4,234 monthly income limit $50,808 annual income limit
4 people	$4,254 monthly income limit $51,048 annual income limit	$3,120 monthly income limit $37,440 annual income limit	$2,796 monthly income limit $33,552 annual income limit	$5,104 monthly income limit $61,248 annual income limit
5 people	$4,978 monthly income limit $59,736 annual income limit	$3,651 monthly income limit $43,812 annual income limit	$3,272 monthly income limit $39,264 annual income limit	$5,973 monthly income limit $71,676 annual income limit
+ more EACH ADDITIONAL FAMILY MEMBER	$730 monthly income limit $8,760 annual income limit	$536 monthly income limit $6,432 annual income limit	$480 monthly income limit $5,760 annual income limit	$876 monthly income limit $10,512 annual income limit
How to apply	Visit **compass.ga.gov**. If you need help with your application, there are community partners who can help you for free. Visit **compass.ga.gov** or call **1-877-423-4746** for a list of partners in your area.			Call 877-GA-PEACH (877-427-3224) or go online to **www.peachcare.org**.

** All ranges are based on 2016 FPL guidelines.*

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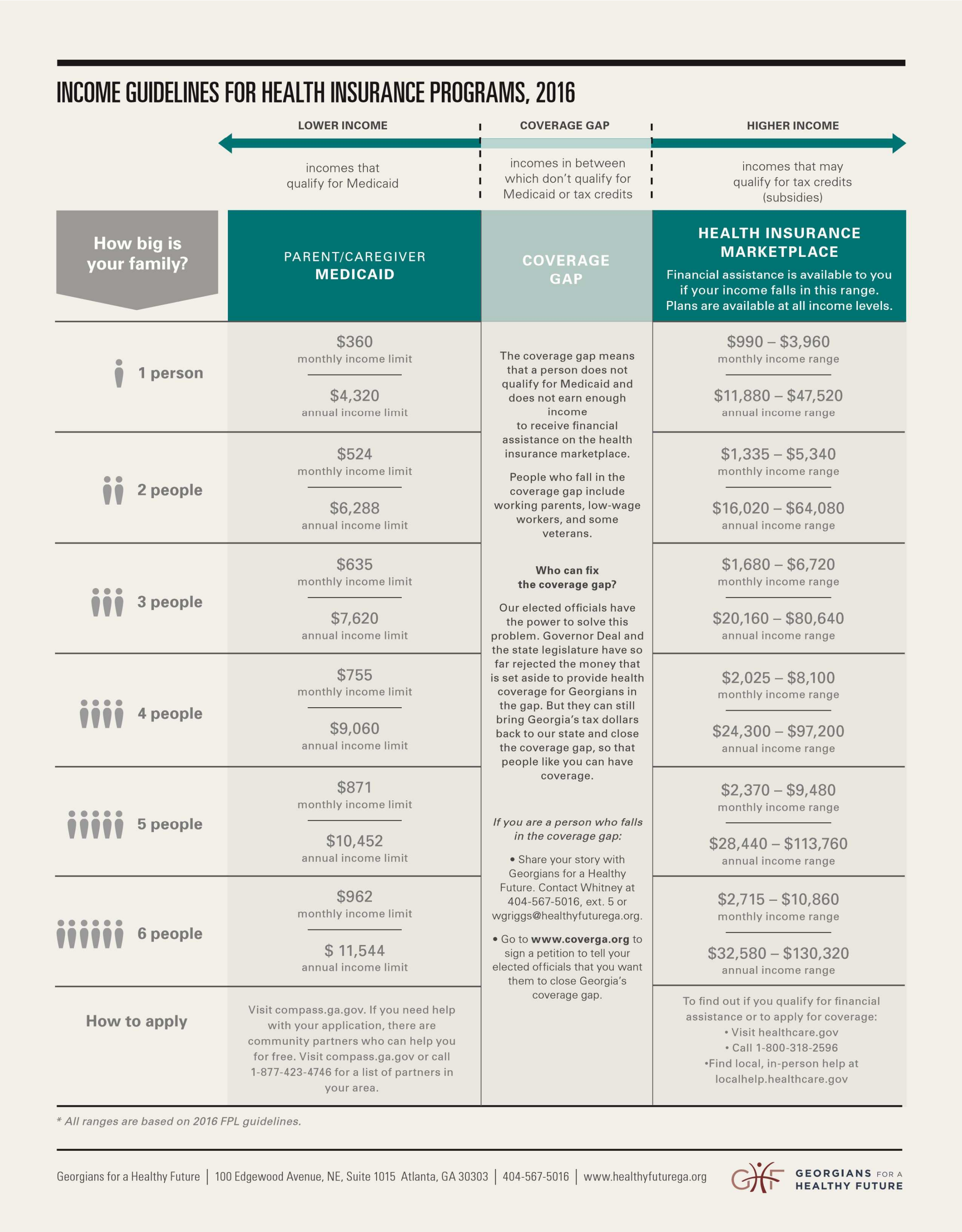
GEORGIANS FOR A HEALTHY FUTURE



INCOME GUIDELINES FOR HEALTH INSURANCE PROGRAMS, 2016

LOWER INCOME	COVERAGE GAP	HIGHER INCOME
incomes that qualify for Medicaid	incomes in between which don't qualify for Medicaid or tax credits	incomes that may qualify for tax credits (subsidies)

How big is your family?	PARENT/CAREGIVER **MEDICAID**	COVERAGE GAP	HEALTH INSURANCE MARKETPLACE Financial assistance is available to you if your income falls in this range. Plans are available at all income levels.
1 person	$360 monthly income limit $4,320 annual income limit	The coverage gap means that a person does not qualify for Medicaid and does not earn enough income to receive financial assistance on the health insurance marketplace. People who fall in the coverage gap include working parents, low-wage workers, and some veterans. **Who can fix the coverage gap?** Our elected officials have the power to solve this problem. Governor Deal and the state legislature have so far rejected the money that is set aside to provide health coverage for Georgians in the gap. But they can still bring Georgia's tax dollars back to our state and close the coverage gap, so that people like you can have coverage. *If you are a person who falls in the coverage gap:* • Share your story with Georgians for a Healthy Future. Contact Whitney at 404-567-5016, ext. 5 or wgriggs@healthyfuturega.org. • Go to **www.coverga.org** to sign a petition to tell your elected officials that you want them to close Georgia's coverage gap.	$990 – $3,960 monthly income range $11,880 – $47,520 annual income range
2 people	$524 monthly income limit $6,288 annual income limit		$1,335 – $5,340 monthly income range $16,020 – $64,080 annual income range
3 people	$635 monthly income limit $7,620 annual income limit		$1,680 – $6,720 monthly income range $20,160 – $80,640 annual income range
4 people	$755 monthly income limit $9,060 annual income limit		$2,025 – $8,100 monthly income range $24,300 – $97,200 annual income range
5 people	$871 monthly income limit $10,452 annual income limit		$2,370 – $9,480 monthly income range $28,440 – $113,760 annual income range
6 people	$962 monthly income limit $ 11,544 annual income limit		$2,715 – $10,860 monthly income range $32,580 – $130,320 annual income range
How to apply	Visit compass.ga.gov. If you need help with your application, there are community partners who can help you for free. Visit compass.ga.gov or call 1-877-423-4746 for a list of partners in your area.		To find out if you qualify for financial assistance or to apply for coverage: • Visit healthcare.gov • Call 1-800-318-2596 •Find local, in-person help at localhelp.healthcare.gov

** All ranges are based on 2016 FPL guidelines.*

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Georgians for a Healthy Future. (2016). PeachCare Income Guidelines for Parents. Retrieved from http://healthyfuturega.org/wp-content/uploads/2015/12/Income-Tables-2015.pdf

Appendix D: Study Recruitment Letter and Flyer

Dear

My name is Renee Sullivan and I am a student in the Ph.D. Clinical Psychology program at Walden University. I am completing my dissertation. My study involves parents of children with autism and I am in need of participants. I would be very grateful if you could share the enclosed flyer with your patients who have children with autism. I am particularly interested in low-income parents of children with autism who have lived with the child for at least a year post-diagnosis.

The study information is listed on the flyer, along with my contact information. Participants will complete a brief demographic survey to ensure eligibility for the study. I will then conduct a personal interview via telephone that will last approximately one hour and will consist of 12 major study questions. If you have any questions, please do not hesitate to contact me at (478) 718-1306. Thank you in advance for your help.

Sincerely,

Renee L. Sullivan, M.A., CCLC
Walden University Student

WANTED: PARENTS OF CHILDREN WITH AUTISM

Has your child been diagnosed with autism for more than a year? If so, you are invited to participate in a study on autism and parental stress. You will first be asked to complete a brief survey to determine if you meet study requirements.

If you are chosen to participate, you will be given a consent form to make sure you understand what to expect as a participant in the study. You will then participate in a telephone interview in which you will be asked 12 questions about your experiences of raising a child with autism. The interview will last approximately one hour. In the case that additional information or clarification is needed, research may follow-up telephone call may be necessary.

Your participation and all information shared will be confidential and you will not be identified in any way. Please email or call me and I will send you a link to complete the brief survey, or I will complete it with you over the telephone.

Please contact me today so we can get started and thank you for participating in this study.

Renee L. Sullivan, M.A., CCLC
Walden University Student
PhD Clinical Psychology Program
(478) 718-1306
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Appendix E: Patient Debriefing

Thank you for participating in my study. I feel that it is important to talk to parents about their experiences raising children with autism to gain a better understanding and to inform professionals and the general public of your daily lived experiences and needs to improve the quality of life for you and your family, particularly the child with autism. The aims of this study were to gather information about your experiences of raising a child with autism and the impact it has had on your family. I hope that this information will help suggest ways that readers can develop more empathy and understanding for yours and your family's experiences. The information you have given me will be held confidential. This means that I will not disclose what you have told me, all information will be treated as from the total group of parents. If you think of any questions you would like to ask me, please do not hesitate to contact me.