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Caregivers' Challenges in Accessing Services for Children with Autism

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Abstract

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Abstract

The perspective of the caregiver is vital to understanding the experiences of raising a child with autism, including the challenges faced in accessing services. The purpose of this qualitative, transcendental phenomenological study was to examine the lived experiences of primary caregivers raising a school-age child with autism and to bring about an understanding of the challenges faced in accessing services. Resiliency theory provided the conceptual framework for the study. Semistructured, in-depth interviews were conducted with 11 participants raising a child with autism in the Washington, DC metropolitan area. Data were analyzed using Moustakas's descriptive approach. Results yielded 5 themes: overall experience, challenges, relationships, access to services, and stressors. Findings revealed effective ways to support caregivers through programs and services and highlighted the importance of supportive relationships and family connections. Implications for social change include opening conversations regarding the unique perspectives and needs of primary caregivers of children with autism, supporting awareness of the stressors associated in daily caregiving, and engaging in broader discussions regarding the importance of establishing supportive relationships among physicians, mental health providers, specialists, social workers and care managers in order to support the advocacy efforts of caregivers.

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Dedication

I would like to dedicate my dissertation to my mother, the late Missionary Emma Elizabeth Spencer Payne, my daughter Elizabeth Ann Payne, and my grandson Sayj Cairo Spencer Edwards. My mother passed away during Christmas of 1991. Mama, you were a catalyst for change and my living example of what it meant to be an advocate and committed to making a difference in the lives of others. I hold dear to me your favorite scripture from Luke 12:48 “For unto whomsoever much is given, of him shall be much required: and to whom men have committed much, of him they will ask the more.” Elizabeth, thank you for pushing me beyond my comfort zone. Sayj, it was just enough to know you are Nana’s Poodah. You all have been my motivation.

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Chapter 1: Introduction to the Study

Autism is a lifelong diagnosis. Xu, Strathern, and Liu (2018) and the Centers for Disease Control and Prevention (CDC, 2018) reported that 1 in 59 children in the United States was identified as having a diagnosis of autism. Autism is the fastest growing developmental disability and the most common of the pervasive developmental disorders (Autism Society, 2011). The disorder is often characterized by a delay in the child's development in the areas of social interaction, language, and behavior (Autism Society, 2011). Children with autism experience difficulties in initiating conversations in social settings, building relationships, and maintaining them. Sometimes a limited capacity to understand and predict the behavior of others while socially interacting may exist. Also, these children may not share the same interests in activities as their counterparts who do not have a diagnosis of autism, and their actions and interests are often repetitive (American Academy of Pediatrics, 2013).

According to Smith et al. (2010), raising a child with autism can be a stressful experience. The caregiver's perspective may provide specific components that convey how the experience of raising a child with autism may be different than their counterparts raising a child without a diagnosis of autism (Smith et al., 2010). There are challenging elements of the caregiving experience that may shed light on the support caregivers need in accessing services (Woodgate, Ateah, & Secco, 2008). The aim of the present study was to describe what was involved in managing the needs of a child with autism. Challenges included, but were not limited to, learning about autism, partnering with providers, and the lack of service providers who had experience in working with children with autism.

Background

Although autism can vary in severity and level of functioning across ethnic and socioeconomic groups, autism is characterized by deficits in communication, developmental delays, impairment in social interaction, and repetitive patterns of behavior (National Institutes of Health [NIH], 2014). A gap in the current literature exists on the challenges facing caregivers of school-age children with autism between the ages of 5 and 8 years. Early identification of an autism diagnosis, documentation of the age of onset, the child's level of functioning, practitioners'/service providers' skill in treating and providing services to children with autism, resources, and community support are integral factors in facilitating a caregiver's ability to address challenges faced in raising a child with autism (Brown, Ouelette-Kuntz, Hunter, Kelley, & Cobigo, 2011. Services and resources should be child specific, age appropriate, based on level of functioning, and timely (Brown et al., 2011).

The CDC (as cited in Baio, 2014) conducted a study in which a baseline age of 8 was established as the prevalence point of autism. The data used for this study, provided by the Autism and Developmental Disability Monitoring Network (ADDM), suggested increases in the prevalence of autism in children 8 years of age among sites participating in the study. However, the sites did not represent a national sample as ADDM estimated the age of the prevalence of autism by monitoring caregivers with children 8 years of age who resided within ADDM's 14 sites in the United States (Baio, 2014). It is important to know the unmet needs of children diagnosed with autism from the perspective of the primary caregiver (Brown et al., 2011). This will aid in allocating the resources needed when challenges caregivers face are addressed to meet the specified need (Brown et al., 2011). Common themes related to unmet needs include, but are not limited to, more information needed about the diagnosis, services, and resources available; opportunities for social inclusion to occur; managing the difficult behaviors that often accompany the diagnosis, and the need for services to be provided on an ongoing basis versus only when the child is in crisis (Brown et al., 2011).

Angell and Solomon (2014) added to the discussion on autism information on the family and provider relationship and the parallel between the relationships established and health care outcomes. Not only has attention been drawn to the importance of provider/family relationships, but attention has also been drawn to the impact of the child's behavior on the primary caregiver and the family (Huang et al., 2014). Activities had to change or were restricted altogether in accommodating the needs of the child with autism (Huang et al., 2014).

Primary caregivers sometimes face challenges in navigating the health care system when accessing services and care for the child with autism. Strunk, Pickler, McCain, Ameringer, and Myers (2014) determined that services could be inadequate, the providers possessed limited knowledge on how to work with and treat children with autism, parent knowledge was limited, and the voices of the primary caregiver was not heard in most instances. Nolan, Orlando, and Liptak (2007) argued that communication between parents, service providers, and the school system can be improved when parents are included in the decision-making process for their child. Advocacy may be needed to ensure the services needed for a child with autism to function within the school setting are provided. The needs determined by recommendations from evaluations and providers should be addressed within the individualized education plan (IEP) when appropriate (Nolan et al., 2007).

Advocacy for unmet needs can be addressed through a case manager or care manager providing care coordination services. As a specific component of family-centered care (FCC), provision of care coordination services can improve health outcomes for children with special needs and their families when needed (Kuo, Bird, & Tillford, 2011). The current study was needed to gain insight into the lived experiences of caregivers raising children ages 5-8 with autism and the challenges they face in accessing services. Also, a better understanding was needed to develop supportive programs and services that mitigate the challenges.

Problem Statement

To meet the service needs of children with autism, the daily challenges faced in accessing needed services must be known and understood. Although the research on the challenges caregivers of children with autism face in accessing services illuminated important findings, I did not any studies that addressed primary caregivers of school-age children ages 5-8. Further research was warranted to address the documented problem of challenges caregivers of child with autism face in accessing services (Strunk et al., 2014). The number of children being diagnosed with autism was increasing at alarming rates (Chiri & Warfield, 2012). However, Xu et al. (2018) and the CDC (2018) reported that 1 in 59 children in the United States were identified as having a diagnosis of autism. This represented a decrease from 1 in 68 (CDC, 2014). With limited and sometimes no support, caregivers are left to understand the diagnosis on their own (Strunk et al., 2014).

The gap in literature suggested that further study was needed to explore these challenges from the perspective of the primary caregivers of school-age children with autism between the ages of 5 and 8. Although some studies addressed the topic of access to and timeliness of services (Autism Speaks, 2016; U.S. Department of Health and Human Services, 2016), there was limited literature available on the challenges faced by primary caregivers raising children ages 5-8 with a diagnosis of autism. Chiri and Warfield (2012) determined that families of children with autism were more inclined to encounter challenges in preventive care, mental health services, therapy, specialty care, and providers who possess the skills to address the child’s needs. Options relating to care and services often do not include consideration of the child’s specific needs (Cotugno, 2009; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007).

The quality of life of children with autism can be impacted by social exclusion and cognitive limitations. Some children with autism throw tantrums, wander away from their caregivers, become physically aggressive, or are unable to read social cues (Huang et al., 2014). Other children may lack the ability to communicate their needs or wants effectively or perform daily activities like bathing, dressing, and toileting (Huang et al., 2014). A diminished capacity may exist in areas of self-perception, self-direction, and/or the ability to problem solve. This can result in children with autism being victimized (Huang et al., 2014). According to Huang et al. (2014), children with autism may be seen as different in comparison to their counterparts with a disability due to autistic behaviors. In some instances, raising a child with autism has impacted family functioning in a negative way as families may experience frustration (Hoefman et al., 2014). Frustration sometimes occurs due to lack of knowledge about the diagnosis and an understanding of appropriate treatment interventions along with quality of life being affected (Hoefman et al., 2014). Frustration may lead to caregivers and families experiencing stress (Huang et al., 2014) and social restrictions (Hoefman et al., 2014). In some cases, families may adapt, develop resilience, and become tighter.

Purpose of the Study

The purpose of this qualitative, phenomenological study was to gain an understanding of the lived experiences of primary caregivers raising a child with autism. Caregivers' lived experiences were explored to understanding the challenges faced in accessing services.

Research Questions

A qualitative, transcendental phenomenological approach was identified as the best research design to answer the following research questions:

1. What are the lived experiences of primary caregivers raising a child with autism?
2. What challenges, if any, have primary caregivers faced in accessing services?

Conceptual Framework

Resiliency theory provided the framework for examining the lived experience of raising a child with autism and the challenges faced in accessing services. Resiliency theory, as a strengths-based approach (Zimmerman, 2013), served as a conceptual framework to understand the challenges faced by primary caregivers. Resilience is developed by using the strengths of the family to function despite the challenges faced (Zimmerman, 2013). Resilience is seen in an individual's ability to experience positive outcomes despite barriers, challenges, and stressors (Rutter, 2013). Rutter (2013) defined *resilience* as an "interactive phenomenon" (p. 474) in which their counterparts, those without a diagnosis of autism,did not experience positive outcomes to the same degree. The challenges caregivers face in accessing services may vary based on their interpretation of their life experiences in raising a child with autism. However, the outcomes experienced (positive or negative) may impact whether the process of resilience occurs. Family relationships are important in promoting resilience (Rutter, 2013).

Rutter (2013) challenged any ideas that propose resilience as a treatment modality or prevention measure. Rutter noted that the factors that contribute to a family's ability to bounce back despite adversity should be confirmed. Rutter also noted that the impact of risk factors and protective factors on the resilience process may vary. Garmezy (1993) concluded that vulnerability and resilience are twin constructs. Werner (2005) drew attention to how caregivers are able to bounce back. The child with autism is able to experience some positive outcomes in the face of adversity and barriers that contribute to challenges in accessing care and needed services (Werner, 2005).

Nature of the Study

The nature of this study was a qualitative, transcendental phenomenological approach. The phenomenological approach was used to gain a better understanding of and to highlight the lived experiences of primary caregivers raising school-age children with autism and the challenges they faced in accessing services. This study examined the overall experience and included descriptions of the similarities as well as the differences based on the caregiver's perspective.

Definitions

Applied behavior analysis: Principles combined with techniques that are applied to bring about meaningful and positive change in behaviors of children with autism (Autism Speaks, 2015). The focus is on replication of desired behaviors and interactions that are transferrable to home, community, and school.

Autism: A developmental disorder identifiable by impairments in social interaction and awareness, verbal and nonverbal communication, and imaginative play usually with an onset by age 3 (NIH, 2014). For the purpose of this study, autism and autism spectrum disorder were used interchangeably.

Care coordination: An established partnership between a client and service professional resulting in information exchange, a shared knowledge of available resources and how to access those resources, and integrated care to promote appropriate delivery of services (McDonald, Sundaram, Bravata, Lewis, Lin, et al., 2007).

Family-centered services: A service delivery strategy girded by family systems theory, family-centered services is the delivery of services to children and their families that promotes positive outcomes (Dempsey & Keen, 2008).

Primary caregiver: Anyone responsible for the overall care and well-being of a child with autism. This may include, but is not limited to, biological parents, adoptive parents, individuals, heterosexual and same-sex couples, guardians, or custodians.

Resilience: The ability to experience positive outcomes despite the barriers and challenges faced (Zimmerman, 2013).

Resiliency: The process of experiencing positive outcomes and returning to a stable state before the crisis occurred (Rutter, 2013; Zimmerman, 2013).

S*chool-age children*: Children between the ages of 5 and 8.

Assumptions

Assumptions are based on the type of research design chosen. A qualitative, phenomenological research study was conducted to collect data on the challenges faced by primary caregivers in raising a school-age child with autism. The intent was not to explain the phenomenon but to bring about an understanding of the experience from the perspective of the primary caregivers. I assumed primary caregivers would honestly share their lived experiences. Also, I assumed the phenomenon of raising a child with autism was similar even though the settings differed among primary caregivers. Next, I assumed that risk factors and positive outcomes must be present to conclude that participants experienced the resilience process. Finally, I assumed that primary caregivers, practitioners, and service providers wanted to establish collaborative working relationships on behalf of the child with autism.

Scope and Delimitations

The work of Moustakas (1994) guided this qualitative research design, and the strategy of inquiry was transcendental phenomenology. The lived experience of primary caregivers was explored through the use of semistructured interviews. Primary caregivers were selected as participants because they are responsible for the care and well-being of the child with autism. Open-ended questions were asked of primary caregivers of school-age children with autism between the ages of 5 and 8 because limited research existed on this population of children.

It was not the intent of the study to address the lived experiences of primary caregivers raising a child with autism between the ages of 5 and 8 over the child's life span. The study focused on school-age children because this is the age when the child begins to access services like early intervention and applied behavior analysis. Also, the child is entering the school setting and the primary caregivers may experience more lived experiences in working with the educational system in meeting the child's academic and behavioral needs. Additionally, the study was limited to participants from the Washington, DC metropolitan area.

Limitations

A limitation of this study was that only primary caregivers raising a child with autism who reside in the Washington, DC metropolitan area were participants. The findings of the study are not generalizable to all caregivers of children with autism because of the small sample size.

Significance

To effect social change relating to the challenges faced by primary caregivers, there must be an in-depth understanding of the factors that negatively influence caregivers’ ability to be their child’s best advocate. The results of this study may prompt changes to current programs and how services are delivered. Results may also influence how caregivers are educated about their child’s diagnosis of autism and are empowered to care for their child in the context of their diagnosis (Tsai, Tsai, & Lotus, 2008). Limited research had been conducted on this subject from the primary caregiver’s perspective. The study filled a gap in understanding the process of accessing services, the caregivers’ experience in using services, the range of sources of care, and decision-making regarding the treatment methods.

Implications for Social Change

Primary caregivers raising a child with autism experience challenges that impact overall family functioning, sibling relationships, parental expectations, health, and marriages. This study addressed the gap in research relating to the primary caregiver’s experiences in raising a child with autism and the challenges faced in accessing services. Findings provided a better understanding of not only the experience of raising a child with autism, but also the best way to support the caregivers through programs, services, and resources.

Findings may also be used to promote supportive relationships among physicians, mental health providers, specialists, social workers, and care managers. It was important to encourage collaborative working relationships among primary caregivers, practitioners, and service providers to improve health care outcomes (Knapp, Madden, & Marcu, 2010). Established, supportive, and collaborative working relationships are the pillar of FCC (Knapp et al., 2010).

Coordinating care for a child with autism may include services to the caregivers in hopes of alleviating some of the stressors brought on by raising a child with autism. There is no cure for autism, and raising a child with autism is a lifelong journey. Coordination of services should address not only the needs of the child, but also the primary caregiver who is to support the child. Some caregivers raising children with autism experience high levels of stress; however, others reported the joy experienced in raising a child with autism. According to Toomey, Chien, Elliott, Ratner, and Schuster (2013), the quality of care for a child increases with care coordination of services. Primary caregivers need support to become their child’s best advocate.

Finally, the research findings may enhance the understanding of the role primary caregivers play and may shed light on areas where support can be provided and funding allocated to improve the child’s and caregivers’ quality of life. Understanding the factors that contribute to the development and delivery of health care services could facilitate a primary caregiver’s access to information regarding the diagnosis, resources, and services. The perspective of the primary caregiver sheds light on how they can best be supported.

Summary

Studies addressed access to and timeliness of services from the caregiver's perspective regarding the health care needs of adolescents and adults with autism. However, there was a gap in literature, from the primary caregiver's perspective, on the challenges faced in raising school-age children between the ages of 5 and 8 who have a diagnosis of autism. No studies addressed this population. The purpose of this qualitative, transcendental phenomenological study was to explore the lived experiences of primary caregivers to better understand the challenges faced by primary caregivers in raising children ages 5-8 with autism. Primary caregivers were selected because they are responsible for the child's overall care. Semistructured interviews were used to gather data based on open-ended questions. A supportive and trusting environment was established that allowed the primary caregivers to share their experiences. Previous studies on autism and topics related to autism like care coordination services and unmet needs of children with autism are reviewed in Chapter 2.

Chapter 2: Literature Review

This chapter provides an extensive review of literature on the prevalence of autism, problems accessing care, family and practitioner relationships, parent experiences, care coordination, family-centered care, parental perceptions and expectations, and unmet needs. Also, the chapter presents information on the study's conceptual framework based on the resiliency theory. Previous research on autism includes, but is not limited to, the prevalence of autism, autism spectrum disorder, Asperger's syndrome, pervasive developmental disorder, causes, treatment, classroom inclusion, applied behavior analysis, early diagnosis, early intervention services, and statistics. The purpose of this qualitative, transcendental phenomenological study was to gain a better understanding of the caregiver's lived experiences. Additionally, I sought to explore the challenges primary caregivers face in accessing and using services.

Strunk et al. (2014) noted there were no studies that addressed parents' experience in raising a child with autism as it relates to managing the child's health care needs. A lack of research on parents' experience pertaining to the challenges faced by primary caregivers raising a child with autism and in accessing services exists. There was no research on the target group: primary caregivers of children with autism between the ages of 5 and 8. The difference in this study is was how *primary caregiver* may be defined. The primary caregiver may not be the biological parent. The primary caregiver may be a sibling, grandparent, heterosexual couple, same-sex couple, single parent, adoptive parent, or foster parent. Some studies focused on the biological parent raising adolescents with autism (Hoefman et al., 2014; Strunk et al., 2014).

Literature Search Strategy

Information was collected from peer-reviewed sources, published dissertations, online services, and books. Databases searched included Academic Search Complete, ERIC, Expanded Academic ASAP, ProQuest, SAGE, Education Research Complete, PubMed, MedLine, SocIndex with Full Text, PsycArticles, PsycInfo, and CINAHL. Key words, singular and grouped, included *autism*, *autism spectrum disorder*, *pervasive developmental disorder*, *challenges*, *lived experiences*, *qualitative study*, *caregiver*, *primary caregiver*, *family-centered services*, *care coordination*, *accessing care*, *accessing services*, *school-aged children ages 5-8*, *caregiver well-being*, *coping*, *developmental disability*, *social support*, *provider relationships*, *parental well-being*, *resiliency theory*, *barriers*, *stress*, *family functioning*, *daily experiences*, *child*, *children*, *family relationships*, and *parental expectations*. Additional key words, singular and grouped, included parental stress, *family functioning*, *daily experiences*, caregiver provider relationships, mothers, fathers, health care, Michael Rutter, Norman Garmezy, families, Emmy Werner, *provider-family partnership*, family systems, Reuben Hills, family stress theory, strengths perspective, case management, collaboration, care management, physician-patient relationships, *unmet needs*, child and family outcomes, parental perceptions and expectations, and *family relationships*.

Prevalence of Autism

Although autism can vary in severity and level of functioning across ethnic and socioeconomic groups, it is characterized by impairments in communication, developmental delays, impairment in social interaction, and repetitive patterns of behavior (NIH, 2014). One in 59 children is affected by autism (CDC, 2018). It is the most prevalent developmental disorder in the United States with a ratio of 4:1 males to females (Southwest Autism Research and Resource Center, 2015).

The Autism and Developmental Disability Monitoring Network (ADDM) monitors the prevalence of autism among children ages 8 years over 11 sites across the United States. One in 42 boys and 1 in 189 girls were identified as having autism (Baio, 2014). Children identified with autism and IQ scores in the range of intellectual disabilities included non-Hispanic black children at a rate of 48% (Baio, 2014). The focus of the study was to illuminate the need for a standard way to document the level of functioning, symptoms, early identification, and receipt of community support. One in 68 children age 8 was identified as having a diagnosis of autism (Baio, 2014, p. 6). Findings could not be generalized as the 11 sites chosen for monitoring were not representative of the United States (Baio, 2014).

Today, many children with autism are presented with the opportunity to experience social inclusion and inclusion in sports. For example, in Washington, DC Health Services for Children with Special Needs (HSCSN), an organization funded by Medicaid to provide comprehensive care coordination to children with special needs ages 0-26, has developed a youth athletic program (HSCSN, 2015). This program includes basketball, T-ball, cheerleading, flag football, and soccer. Skills required to play each sport have been modified to accommodate the child’s disability needs. Additionally, Girl Scouts and a Young Adult Support Group were established to promote social inclusion and support friendships and skills required to maintain them (HSCSN, 2015). Although there has been an increase in the number of children diagnosed with autism, awareness and understanding of autism have been heightened through the efforts of organizations like Autism Speaks (Quirantes, 2009). Also, Broder-Fingert, Ferrone, Glauque, and Connors (2014) acknowledged children with autism have high rates of medical service utilization.

Problems Accessing Care

Chiri and Warfield (2012) determined that families of children with autism were more inclined to encounter disparities in unmet needs and providers who do not possess the skills to address the child's needs. Chiri and Warfield used the 2005-2006 National Survey of CSHCN to conduct a comparison between children with autism and children with other emotional, behavioral, and developmental health care problems. Four core health services and access problems emerged: receiving routine preventive care, specialty care, therapy services, and mental health services (Chiri & Warfield, 2012). The CDC (2014) reported that more children than ever before are being classified as having autism. Chiri and Warfield shared the following findings:

1. Children with autism more likely than the children with other special health care needs to have unmet needs and will experience access problems.
2. Unmet service needs varied by service type.
3. Specific access problems varied by service type.
4. The more severe the disability, the presence of possessing an unmet need is greater.

The purpose of the study conducted by Vohra, Madhavan, Sambamoorthi, and St. Peter (2014) was to highlight information on how parents perceive accessing services for children with autism between the ages of 3 and 17. A comparison was made between the perception of parents with children with autism and their counterparts with other varying disabilities (Vohra et al., 2014). Similarly, as with families who participated in the Chiri and Warfield (2012) study, parents experienced problems with accessing services and the quality care (Vohra et al., 2014). Also, the impact of the family on the process was noted as an outcome (Vohra et al., 2014). Vohra et al. proposed that parents with children who had a diagnosis of autism face more difficulty as it relates to all three outcomes.

The one size fits all approach does not bring about provision of access to the appropriate level of care and access to autism-related services for children with autism. Thomas, Ellis, McLaurin, Daniels, and Morrissey (2007) contributed to the discussion on the access to care. They acknowledged access to care was often limited depending upon race, ethnicity and level of education of the parents (Thomas et al., 2007). Through information sharing with the caregiver expected to provide support to the child with autism and ensure they attend appointments and receive services, multiple options can be provided taking into account the child’s individual specific needs (Thomas et al.,, 2007) and the parent’s right to be part of the decision-making process on choosing the treatment recommendations employed. It was determined the earlier a child can be diagnosed and access services, the better the health care outcomes (Thomas et al., 2007). Also, it was noted minority’s race and ethnicity often contributed to delays in diagnosis. Thomas et al. (2007) reported several studies have been conducted confirming the difficulties families face in accessing care for a child with autism and limited studies conducted on the characteristics contributing to the use of services .

The authors used the Anderson and Andy Model of Access to Health Care as their framework to identify families (Thomas et al., 2007). The findings revealed differences in patterns of utilization of services depending on the type of service and the major treatment approached chosen by families. Insurance coverage, whether Medicaid or private insurance, contributed to access and use of services for children between the ages of 5-8 (Thomas et al., , 2007). However, if a parent or family had no insurance, they gained access to a Case Manager or developmental pediatrician who could help them access outpatient services and specialty care (Thomas et al., 2007). The odds of using services were higher when parents and families stress levels were higher. Mistrust of the system, stigmas associated with the diagnosis and discrimination contributed to low service use (Thomas et al., 2007).

Family and Practitioner Relationships

Angell and Solomon (2014) provided information on the relationship between families and practitioners across diverse settings. An ethnographic method of inquiry was used to gather data through a review of the health records of children with autism. The study revealed how relationships between families and practitioners are established. Factors contributing to disparities that are associated with having a diagnosis of autism and access to services were identified (Angell & Solomon, 2014).

Family and provider relationships, being considered as the cornerstone of FCC, contributes further to the discussion regarding provider and parent relationships and the correlation between the relationship established and health care outcomes for children with special health care needs (CSHCN) as emphasized by Knapp, Madden, and Marcu (2010). The authors demonstrated a parent's perception of the relationship is affected by the time spent building a collaborative relationship. This resulted in less use of the emergency room and more use of outpatient services and preventive care, and partnering in the decision-making (Knapp, Madden, & Marcu, 2010). Overall, health care outcomes improved, the child and the family were given access to community-based services, and information sharing resulted in a usual and consistent source of care for the CSHCN (Knapp, Madden, & Marcu, 2010).

In order to gain a better understanding of the big picture regarding provider-family or provider-parent relationships, research regarding the partnering professional's attitude toward collaborating with parents should be considered. Bezdek, Summers, and Turnbull (2010) demonstrated through their study on professional's attitudes on partnering with families of CSHCN, the provider perspective on partnering and the effects on health care outcomes. They believed that partnerships are "mutually supportive interactions between families and providers; collaborations based on trust" (p. 357). Limited research has been conducted on the professional's perspective of partnerships. The findings revealed professionals agreed, based on their experiences in working with families, a positive working relationship with families is needed (Bezdek, Summers, & Turnbull, 2010). Also, they expressed sometimes the "level of involvement of families was not consistent and often nonexistent" (p. 359). Additionally, the professionals believed the partnership improved communications between the provider and the family

(Bezdek, Summers, & Turnbull, 2010). Although some of the professionals may have verbalized using the FCC approach, their actions projected otherwise.

A study conducted by Broder-Fingert, Ferrone, Glauque, and Connors (2014) examined physician's competency to care for children with autism. The study included resident's self-perception of their competence, knowledge and comfort in treating and caring for patients with autism. It was determined additional training is needed to improve communication of care plans to the child and the family, and to increase the number of referrals for resources that would support further assessment of the child's needs and the family supporting them (Broder-Fingert, et al., , 2014). Many of the residents had only cared for a child with autism within the hospital setting. Thus, there comfort level was low. However, as their competence in understanding the diagnosis, assessing the needs of the child, and in communicating care plans increased, so did the comfort level in treating and caring for children with autism (Broder-Fingert, et al., 2014). More training was needed on how to care for children with autism in clinical settings.

According to the Broader-Fingert et al (2014), this is the first study on pediatric residents and the study revealed the resident's education and schooling did not adequately prepare them. As the prevalence of autism increased, lack of comfort in plan of care and resources should be of concern. Also, it was determined there were increased rates of co-morbidities that led to higher rates of utilization of medical services (Broder-Fingert, et al., p. 1391). However, this resulted in patients being confronted by physicians who felt incompetent to discuss with them their plan of care (p. 1392). The authors and the residents agreed more education was needed in order to better understand the child’s diagnosis in order to effectively communicate their plan of care that supported follow through on treatment recommendations.

Parent Experience

The experiences of parents who managed the care of their children alone was captured in a study conducted by Strunk, Pickler, McCain, Ameringer and Myers (2014). Parents raising children with autism faced challenges in navigating the health care system, educating themselves about the diagnosis, obtaining social support, and there was a lack of knowledge regarding medications that could be prescribed (Strunk, et al., 2014). Four themes emerged—inadequacy of health care services provided to include the service provider’s knowledge of working and treating children with autism (parents felt they were doing the educating versus the other way around); no advocacy for their child’s health care needs and the parent’s voice was not being heard (limited time spent in getting to know the child in order to address their individual specific needs); parental knowledge was limited on potential comorbidities needing to be managed and the time needed to do so along with the child’s inability to assess what was safe and the uncontrolled emotional outbursts; and parents found themselves searching for the answers they needed and suggesting to providers what treatment interventions should be employed (Strunk, et al., 2014). More importantly, there was no collaboration across disciplines, in a coordinated way, to link children and their families to needed resources (Strunk, et al., 2014).

Ninety-six parents were asked to journal on their daily experiences on raising adolescents and adults with autism. In turn, their experiences were compared to the daily experiences of mothers with adolescents and adults without disabilities (Smith et al., 2010). Mothers caring for an adolescent or adult with autism found they spent more time on caring the person with autism than spent on family fun activities. Daily experiences relating to parental well-being centered on concepts like supportive services, FCC, and care coordination (Smith et al., 2010). Stressful events were more common among mothers of individuals with autism. According to the authors, raising a child with autism is a profoundly stressful experience. They noted a greater negative impact and poorer well-being in comparison to parents of children with other developmental disorders (Smith et al., 2010).

Similarly, to the beliefs of Strunk et al (2014), the researchers noted the daily accounts of the caregiver's lived experiences contributed to their individual experiences being unique despite some similarities (Smith et al., 2010). They used the diary as part of their research design. Although interviews were conducted telephonically every evening for a period of eight days, the diaries contained journal entries of cumulative experiences regarding stress, the parent's feelings and thoughts, stress and subjective well-being (Smith et al., 2010). Additionally, behavior of one individual in the family system was linked to the experiences of other family members—use of time, multiple stressors experienced daily, daily fatigue, lower positive effects and higher levels of negative experiences, ability to work, and less time for the parent's own personal care (Smith et al., 2010). Although the findings are not generalizable, knowledge and insight was provided in areas where support was needed. Additionally, why children with autism are such a vulnerable population is highlighted (Smith et al., 2010).

Care Coordination

Toomey, Chien, Elliott, Ratner, and Schuster (2013) explored the effects of care coordination as an unmet need. Also, disparities in unmet needs were noted. The authors found the quality of care for the child with autism increased with care coordination of services; but, could not say with certainty if the increase in quality of care would abate the disparities (Toomey, et al., 2013). Furthermore, the authors mentioned it was imperative to know if parents requested care coordination (Toomey, et al., 2013). However, many parents were unaware of resources and services, like care coordination, that would benefit their child (Toomey, et al., 2013).

Although Toomey et al. (2013). Chien, Elliott, Ratner, and Schuster (2013) could not say with certainty what caused the increase in quality of care for CSHCN, Nolan, Orlando and Liptak (2007) proposed care coordination of health care services improves the health and well-being of CSHCN. The findings revealed that a majority of the children with autism and their families, who were provided with care coordination as a family-centered intervention, were able to access specialty care as recommended and needed. However, adversity was experienced in securing durable medical equipment (DME) (Nolan, Orlando, & Liptak, 2007). Also, the lack of communication between schools and medical professionals was conveyed as being poor. In these instances, someone who provided care coordination to a CSHCN and their family served as a gatekeeper to ensure the needs of the child and family was communicated.

In order for the needs to be addressed by the school system and to be included in the child's individualized education plan (IEP), the parent could sign a release of information giving permission to the care coordinator to provide the clinical documentation needed to secure services while attending school (Nolan, Orlando, & Liptak, 2007). This allowed the care coordinator to be in compliance with HIPAA. Also, the authors reported provider's rarely included the parent or family in the decision-making process regarding treatment interventions (Nolan, Orlando, & Liptak, 2007). It was noted that better communication between providers and families facilitated easier access to services. This supported the concept of established provider-parent or provider-family relationships illuminated in studies conducted by Angell and Soloman (2014), Bezdek, Summers, and Turnbull (2010), and Knapp, Madden and Marcu (2010).

Challenges encountered in accessing care often resulted in the parent or family experiencing additional stress. However, as Nolan, Orlando and Liptak (2007) suggested, care coordination was family-centered and could be used to meet the child's individual specific needs. FCC provided through care coordination can be used to even decrease instances where the child may have an unmet need. The focus of care coordination, as a component of FCC, was to ensure the child and family receives optimal benefits provided through support and monitoring of needs and services (Nolan, Orlando, & Liptak, 2007).

Family-Centered Care

Kuo, Bird, and Tillford (2011) demonstrated within their secondary study there was a correlation between FCC and health care outcomes for children with special needs. The authors conducted an analysis of a survey conducted by the 2005-2006 National

Survey of Children with Special Health Care Needs (CSHCN). The impact of FCC on health care outcomes was determined by family responses relating to the provider's ability to address family concerns. In comparison to their healthy counterparts, CSHCN experienced negative outcomes when care was not family-centered (Kuo, Bird, & Tillford, 2011). Families experienced delayed health care for the CSHCN, unmet needs, less time devoted to care, and used the emergency room more than preventive care services or specialty care. (Kuo, Bird, & Tillford, 2011). When FCC was provided, health and family outcomes were positive. There was improved health status, stability of health care needs and time invested in developing partnerships based on trust. Another result reported by families was better access to care. Often, families raising a CSHCN faced difficulty in maneuvering services and being an integral part of the decision-making process. FCC promoted providing knowledge to the family regarding the diagnosis, how to better manage the child's care, encouraged utilization of health care services to include outpatient services and decreased anxiety brought on by lack of information relating to diagnosis and treatment and the lack of trusting relationships between the provider and the family (Kuo, Bird & Tillford, 2011).

When it comes to the topic of FCC or help-giving practices, Kuo, Bird and Tillford (2011) and Dempsey and Keen (2008) agreed there was a link between FCC and health care outcomes for children with a disability and their families. Dempsey and Keen (2008) emphasized the manner in which services, resources, and care was provided to children with disabilities could potentially have positive or negative effects on the child and the family. The authors applied Family Systems Theory, as the model of service delivery, and reinforced the needs of the child and family must be considered. Parents should have control over the choice of services and interventions recommended, treatment goals should be agreed upon, and a provider-family partnership (PFP) must be established. Building the capacity of the parents to support their child, affects the child as well as the family's overall quality of life (Dempsey & Keen, 2008).

Parental Perception and Experiences

The relationship between the functioning of a child with autism and the unmet needs of the parent was explored by Brown et al (2011). A cross-sectional study was conducted using 97 families of school-aged children ages 5-8 with autism. It was determined that child who were classified as high functioning experienced less unmet needs. However, children with a moderate level of functioning experienced more unmet needs (Brown et al., 2011). The more severe the child's disability, the greater the impact on the family. This resulted in more unmet needs. Parents served dual roles—advocate and service coordinator (Brown et al., 2011). Parents lacked information on the diagnosis, treatment interventions, received no care coordination or FCC. They experienced trouble navigating the system. Brown et al (2011) believed the perspective of the individual seeking help should be an established part of the framework in order to understand the parent's perception and experiences of the impact of the child's diagnosis and unmet needs on the family. Also, it was illuminated how families cope with disabilities in diverse ways (as cited in McConachie, 1994; Stein & Reissman, 1980).

Hamdani et al. (2014) suggested caregivers can network within the family to provide interventions, share tasks, and support to the child with intellectual disabilities in order to improve outcomes. The caregiver's perspective was explored. It was determined there was a gap between the needs of the caregiver and the services available to meet the need (Hamdani et al., 2014). Hamdani et al. (2014) suggested following this social model in reducing the stigma associated with raising a child with an intellectual disability and development disorders and the treatment gap for underserved populations. A lack of trained service providers presented was a barrier to accessing needed care globally as well. In Pakistan, community health workers were overburdened. Parents reported high stress levels and negative impacts on family finances. Globally, less funding is allocated to addressing the barriers to meeting the needs; thus, resulting in misdiagnosis and mismanagement of their treatment needs (Hamdani et al., 2014). The authors believed in the importance of looking at the big picture through the eyes of the caregivers. Networking within the family and providing training to family members to provide the nonclinical support needed, bridged the gap in receiving needed services. Not only was the stigma associated with raising a child with a disability minimized, the reasons for inclusion in education and integrating the child into society was highlighted (Hamdani et al., 2014).

The importance of giving a voice to parents and allowing them to express the challenges they faced was also explored by Resch et al. (2010). The authors explored the source of challenges faced by parents of children with disabilities. As noted by Hamdani et al. (2014), the authors of the study agreed parents faced financial barriers and this was voiced by parents (Resch et al., 2010). The themes emerging from the study as barriers for the parents included, but was not limited to, access to information and services, school and community inclusion, and family support. All of these affected parental well-being. Resch et al. (2010) acknowledged the services, support and resources should address the individual specific needs of the caregiver and be made available within the community (p. 139). Primary caregivers of children with disabilities had the most influence when it came to the child’s overall health and well-being (Resch et al., 2010). The well-being of the caregiver and the family affected challenges faced in meeting the child’s needs. Although similarities existed in the experiences of a caregiver raising children with disabilities and the caregiver raising a child without disabilities, the differences in the experience placed the caregiver raising a child with disabilities at greater risk of psychological distress (Resch et al., 2010).

Ascertaining the caregiver is the one constant in the child’s life, the authors believed the caregiver was the most knowledgeable of the specific health care needs of the child (Resch et al., 2010). Delivery of services must be family-centered. A collaborative approach could be designed that addressed the truths of the daily lived experiences of caregivers raising a child with a disability (Resch et al., 2010, p. 140).

Unmet Needs

According to a study conducted by Brown, Ouellette-Kuntz, Hunter, Kelley, and Cobigo (2012), parental perception helped to illuminate the areas where support was strong and services were accessible. However, it will also shed light on needs that continued to be unmet. Not only are the needs of the child with autism identified, the unmet needs of the families providing support to the child with autism are highlighted as well (Brown, et al., 2012). The authors added to the discussion on unmet needs by focusing on the commonalities of the unmet needs of families. Also, attention was given to some of the differences. Although primary caregivers perceived themselves as the initial case manager of the child with autism, there was a need for more information on the diagnosis, age-appropriate interventions, and availability of services. Care coordination services were specifically identified as an unmet need.

Eighty-nine percent of the caregivers believed constantly repeating their story on experiences in raising a child with autism and challenges faced is cumbersome. In analyzing the 2005-2006 US National Survey of CSHCN, the authors determined service providers failed to adequately communicate information to parents of school-aged children between the ages of 3-9 regarding medications, family support, and family functioning (Brown, et al., 2012). Another service identified as an unmet need was respite and an adequate number of respite providers. The authors found there was limited research conducted on school aged children between the ages of 3-9 and believe that the number of similarities would be different if more attention was given to the individual specific needs of the child with autism. They agreed this could potentially bridge the gap in research and heighten awareness regarding the specific needs of this age group (Brown, et al., 2012). When it comes to the topic of continuity of care, the authors agreed there was a need for special programs, services and providers with the skill set to meet the services of children with autism ongoing versus only addressing the crisis (Brown, et al., 2012). One implication noticed was the re-occurrence of the identification of unmet needs and the impact of this on the consistency of provision of services (Brown, et al., 2012).

Resilience Theory

Resilience was seen in an individual’s ability to experience positive outcomes despite the barriers, challenges and stressors they faced (Rutter, 2013). Rutter (2013) defined resilience as an “interactive phenomenon (p. 474) where the counterparts of those who fared well did not experience positive outcomes to the same degree. The author acknowledged Werner and Smith (1982) as leaders in the study and research on the importance of resilience; illuminating the role social support played in the process of resilience. Rutter (2013) acknowledged it was not known beforehand those who would experience resilience. Thus, he reminded us of the need for assessments to be completed in order to know the risk factors as well as the protective influences as determined from the Kauai Longitudinal study conducted by Dr. Emmy Werner (Rutter, 2013). Additionally, “the factors within the environment that mediate risks must be known” (Rutter, 2013, p. 476). Furthermore, Rutter (2013) asserts one cannot “assume all risks and protective factors have similar effects in all situations in all people” (p. 476).

The importance of family relationships in promoting resilience is emphasized by Rutter (2013). The author challenges any ideas that propose resilience as a treatment modality or prevention measure (Rutter, 2013). He confirmed determining the factors that must be present in order to facilitate an individual or a family’s ability to bounce back despite adversity is a priority (Rutter, 2013). Adams (1986) wrote a paper on Reuben Hill and the State of Family Sociology. The author acknowledged and agreed with Hill on the concept that one can adapt to adversity with the appropriate resources in place. Also, Adams (1986) shared Hills belief that the goal should be overcoming the barriers by problem solving. However, Adams (1986) alluded to the difference between coping and problem solving as endorsed by Hill— "one can cope without ever solving the problem" (p. 347). If the problem was seen through the eyes of the family, one would comprehend the ability of the family to problem solve in order to remediate the crisis (Adams, 1986).

While Rutter (2013) understood the impact of risk factors and protective factors on the resilience process may vary, Garmezy (1993) added an interesting twist. He concluded vulnerability and resilience were indeed twin constructs. Vulnerability was the presence of single or multiple risk factors while resilience was the product of adaptability accompanied by the presence of protective factors that promoted outcomes that showed flexibility despite the risk factors that existed (Garmezy, 1993).

Patterson and Garwick (1994) added to the discussion of resilience the impact stressful life events had on family functioning. The authors emphasized the importance of the meaning the family gives to the stressful life event as this could lead to changes in how the family system is viewed (Patterson & Garwick, 1994). In exploring various studies on resilience, it was determined families may change in response to the crisis or stressful event. As it relates to the proposed study on the challenges caregivers and families may face in raising a child with autism in accessing services and care, much was learned from Reuben Hills work on family stress theory (FST). Patterson and Garwick (1994) pointed out the relationships between the levels of meaning within FST.

According to Masten, Best, and Garmezy (1990), the existence of positive relationships helped to facilitate a family's ability to adapt to situations and life events when they were presented with challenges. In turn, these relationships promoted better outcomes and the sustained competence of the child under stress. Similarly, Suzuki, Kobayashi, Moriyama, Kaga, and Inagaki (2013) believed in a parent’s ability to adjust to the challenges they faced in raising a child with developmental disabilities. They introduced this as a concept called parenting resilience (Suzuki, Kobayashi, Moriyama, Kaga, & Inagaki, 2013).

The authors define resilience as “the process of positive adaptation to the difficulties of rearing children with developmental disorders and consists of internal (efficacy, coping skills) and external factors (social support)” (Suzuki, et al., 2013, p. 104). Another essential point emerging from their research was the premise that two elements must be in place in order for the process of resilience to occur— “exposure to adversity and the achievement of positive adaptation” (p. 105). For parents of children with a developmental disability, like autism, caring for the child could be seen as unfortunate (Suzuki, et al., 2013). Furthermore, they concluded when positive adaptation had occurred, it was after an intervention like parent training had been applied (Suzuki, et al., 2013). Additionally, other factors contributing to resilience were identified and included, but was not limited to, family, community and social support, resources for parents, and obtaining information about the diagnosis (Suzuki, et al., 2013).

Based on the findings from a Kauai Longitudinal Study, Werner (2005) determined one third of the high risk children participating in her study displayed resilience and developed into “competent, caring and confident” (p. 12) despite their developmental history. The factors influencing resilience were a strong bond established with an individual who was not the primary caregiver and community support (Werner, 2005). Werner (2005) added to the literature on autism in that attention was drawn on how caregivers were able to bounce back. Additionally, the child with autism was able to experience some positive outcomes in the face of adversity and barriers that contributed to challenges in accessing care and needed services (Werner, 2005). The Kauai study was the only study that followed participants from birth to adulthood (up to age 40) (Werner, 2005). The author monitored the participant's development as it related to developmental life stages over time that were critical to "developing trust, autonomy, industry, identity, intimacy and generativity (Werner, 2005) (as cited in Werner & Smith, 1982; 1992; 2001). Furthermore, Werner (2005) was able to note a clear distinction between the at-risk children who developed problems coping during their childhood from those who defied against the odds and experienced positive outcomes based on three factors: protective factors within the child as an individual, protective factors in the family, and protective factors in the community (p. 13).

When considering risk, resilience and recovery, Werner (2012) was adamant in her belief that a person should not be characterized as resilient and that resilience was a process. She further explains that in the face of hardship, people are able to adapt (Werner, 2012). Also, adversity would lead to positive outcomes from which one would be strengthened (Werner, 2012). Additionally, Werner (2012) emphasized the outcomes were dependent upon the existence of quality, supportive relationships and the difference in the outcomes may be due to the individual's response to adversity despite their vulnerability.

Bekhet, Johnson, and Zauszniewski (2012a) acknowledged caregivers within the family of children with autism played a vital role in managing aspects of the child’s care despite the challenges they faced. Based on the findings, the authors were able to report positive benefits relating to the experience of raising a child with autism as they went through the process of resilience; one benefit being an enhanced sense of meaning in life (Bekhet, Johnson, & Zauszniewski, 2012a). The study enhanced the current literature on resiliency and drew from the research of Werner (1995) and her belief that resilience is balancing risk and the protective factors in the face of adversity. In turn, resilience helped caregivers to manage the day-to-day challenges of caring for a child with autism and contributed to the child and the family’s ability to thrive (Bekhet, Johnson, & Zauszniewski, 2012a, p. 338). The authors agreed with Werner (1995) that the protective factors reduced the effects of risk factors my minimizing negative outcomes (Bekhet, et al., 2012a). The caregivers were more resourceful and asked for help from others when needed. Based on empirical evidence, Bekhe et al (2012a) concluded resourcefulness promoted independent, healthy, and productive lifestyles (as cited in Rosenbau, 1990) as caregivers were better equipped in addressing the challenges.

An extensive review of literature was conducted on resilience in family mental health of persons with autism. Bekhet, Johnson, and Zauszniewski (2012b) found evidence of indicators of resilience, risk factors, protective factors, and outcomes of resilience (p. 650). Based on the review, the authors proposed it’s a benefit to families raising a child with autism and to the children as well, to “enhance resilience” in order to “better manage the adversity associated with caring for a child with autism” (p. 650). The indicators of resilience the parents possessed that was discovered in literature included, but was not limited to, “optimism, positive family functioning, self-efficacy, acceptance, sense of coherence, and enrichment” (p. 652). Optimism regarding the child’s quality of life increased as there were fewer negative experiences relating to stress (Bekhet, Johnson, & Zauszniewski, 2012). Acceptance of the diagnosis helped the family members to embrace their thoughts, feelings and emotions (p. 652). A sense of coherence contributed to the development of positive coping strategies like seeking help or social support (p. 653). Bekhet, Johnson, and Zauszniewski (2012) pointed out optimism contributed to effective coping in mothers of children aged 6-11.

Kapp and Brown (2011) contributed to the research on resilience in families adapting to autism. A study was conducted in Africa focusing on a family’s capacity to adapt to living with a child with autism. The authors were able to expand upon the literature relating to autism and family resilience. They were able to determine, the factors contributing to a biological mother’s ability to bounce back despite the challenges and difficulties faced that sometimes accompany a diagnosis of autism. Werner (1995) and Kapp and Brown (2011) agreed social supports helped to promote resilience in families. Kapp and Brown (2011) concluded “the relationships between spouses, family time, togetherness and routines” (p. 460) were equally as important in promoting resilience. The authors took into consideration, as other researchers of resilience, the effect a diagnosis of autism would have on every area of family functioning (Kapp & Brown, 2011). Families were expected to support the child and manage their behavior and care regardless of their own vulnerability to factors lending the family to be susceptible to stress (Kapp & Brown, 2011). Hence, the authors recognized copings skills as a resource of resilience for families. One family shared “everyone in this lifetime has challenges, but we just differ in degrees and reactions to those” (Kapp & Brown, 2011, p. 461) challenges.

Greeff and Nolting (2013) added to the discussion of parental stress experienced by families raising a child with disabilities in comparison to their counterparts raising children with no disability. The authors believed parents made an attempt to acclimate to thoughts of the quality of life their child may have (Greeff & Nolting, 2013). A study was conducted in South Africa and it was discovered despite the diagnosis of an intellectual or developmental disability, some families exhibited resilience and were able to adjust and flourish (Greef & Nolting, 2013). As Kapp and Brown (2011) and Werner (1995) discovered, Greef and Nolting (2013) agreed resources available to families that promoted resilience was limited; even in South Africa. Thus, they wanted to establish the factors that promoted family resilience. Hence, these factors could potentially be used to advance current support programs and interventions or establishing new ones to assist families in adapting to the diagnosis and challenges they may face (Greeff & Nolting, 2013).

The researchers acknowledged support and resources were not only needed for the child, but for the family as well (Greef & Nolting, 2013). Additionally, it was determined as the child matures, families experience more stress relating to balancing their time and commitments (Greef & Nolting, 2013). The authors proposed research should be conducted evaluating the perceptions and experiences of family members that compared their resilience before and after diagnosis of the child’s disability (Greef & Nolting, 2013).

Peer and Hillman (2014) shared similar beliefs as Greef and Nolting (2013) that parents caring for a child with disabilities experienced more occurrences of stress than parents caring for a child with no disability. Despite the stress experienced, multiple studies have been conducted noting parental resilience to include, but was not limited to, studies by Bekhet, Johnson, and Zausniewski (2012a), Werner (2012), and Kapp and Brown (2011). Where Werner (2012) differs in her belief was that resilience is a process that parents and families go through in an effort to adapt to the diagnosis and face the challenges in raising a child with developmental disability. Also, she discovered individual responses contributed to the outcomes.

The authors emphasized the importance of identifying the factors that promote resilience as this could influence the services the family could access or receive (Peer & Hillman, 2014). Overall, when it comes to the topic of stress and resilience of parents of children with intellectual and developmental disabilities, Peer and Hillman (2014) concurred there was a correlation between the factors contributing to resilience and the parent’s ability to adjust. This adds further to the discussion and Peer and Hillman (2014) believed this premise must be understood in order to affect change in the functioning level of families and their ability to cope with the diagnosis and all that comes with it.

Summary

This review of literature takes into consideration subtopics relating to autism, but was not exhaustive. However, the review does help to provide an understanding of the effects raising a child with autism may have on parental or family functioning, the factors that promote resiliency and a parent (s) or a family's ability to adapt after a child has been diagnosed with autism. Studies on the following subtopics were reviewed: the prevalence of autism, challenges faced in accessing care, the importance of the family and practitioner relationship in addressing the challenges, the parent experience in managing the health care needs of the child, the effects of care coordination as an unmet need as well as care coordination as a supportive resource to caregivers and families, the influence of FCC on health care outcomes for children with special needs and their families, the relationship between the child's functioning and the unmet needs of the caregiver, the influence of resiliency as a process, and the factors that promoted resiliency.

According to Strunk et al (2014), the study they conducted was the first to address the parent's perspective on their lived experiences in managing the health care needs of adolescents with autism. Based on the review, no studies were found that addressed the parent's perspective on the challenges faced in raising a school-aged child with autism between the ages of 5-8 and in accessing services and care. Thus, the qualitative, phenomenological study addressed the gap in literature while at the same time added to the current literature as it relates to caregiver's raising school-aged children with autism.

Chapter 3: Research Method

The challenges faced by caregivers caring for adolescents and adults with autism have been addressed in research. However, there needs to be an understanding, from the primary caregiver's perspective, of the challenges faced in raising a child with autism. The purpose of this study was to gain an understanding of the challenges faced from the primary caregiver's perspective about the diverse, lived and often common experiences of primary caregivers raising a child with autism. I sought to explore the challenges in accessing care and using services.

Interviews were conducted to gain the primary caregiver's perspective on lived and often common experiences in raising a child with autism. This included caregivers' perspectives on accessing care and using services. The qualitative research design chosen was the phenomenological, transcendental approach. Resiliency theory undergirded the qualitative, phenomenological study of the lived experiences of raising a child with autism. Also, resiliency theory served as the conceptual framework on how to best support primary caregivers (see Zimmerman, 2013). The role of the researcher was defined to address researcher bias and how it was managed, and plans to address ethical issues as they arose.

Primary caregivers composed the participant sample. In Chapter 3, I describe the sampling strategy, number of participants, participants recruitment strategy, data collection instrument, data collection strategy, and how content validity was established. I also describe the types of data collected and software used to assist in analyzing the data, including coding procedures and how discrepancies were addressed. The strategies used to ensure credibility (internal validity), transferability (external validity), dependability, and confirmability are explained. I also describe the treatment of participants to ensure they were not at risk of harm. Other ethical concerns included approval to gain access to study participants through the IRB application, recruitment process, informed consent, data collection, participants choosing not to remain involved in the research to the end, and confidentiality of data.

Research Design and Rationale

The research questions guided the study and supported the conceptual framework based on resiliency theory as proposed by Garmezy (1993), Rutter (2013), Werner (2005), and Zimmerman (2013). The study was guided by the following transcendental, phenomenological research questions:

1. What is the lived experience of primary caregivers raising a child with autism?
2. What challenges have primary caregivers faced in accessing and using services?

The phenomenon explored was the lived experiences of primary caregivers concerning the challenges they faced in raising children with autism and their experiences in accessing and using services. When inquiring about a phenomenon focusing on the participant's perspective, I employed a qualitative research design. Primary caregivers were able to expound upon their experiences and provide an understanding of those experiences.

Research Tradition

Maxwell (2013) defined qualitative research as an interactive approach, and Rutter (2013) defined resilience as an interactive phenomenon. Resiliency theory was the conceptual framework applied to the current study. I was the key instrument, and the research process was flexible and evolved over time. Additionally, my background was taken into account as a possible influence on data collection and analysis.

Transcendental phenomenology was the appropriate qualitative approach to gain an understanding of the challenges primary caregivers faced in raising a child with autism and in accessing services. Challenges arose in introducing my personal understanding of the experience and in identifying primary caregivers who had experienced challenges in raising a child with autism. The phenomenological approach illuminated the diverse, lived experiences from the primary caregiver's perspective. This was accomplished through use of textual descriptions (what did the primary caregiver experience) and structural descriptions (context in which the phenomenon of raising a child with autism was experienced) (see Moercer-Urdahl & Creswell, 2004; Moustakas, 1994).

Rationale for the Methodology

A qualitative approach with a transcendental phenomenological design was selected over a quantitative or mixed-methods approach and the other qualitative designs (narrative, grounded theory, case study, and ethnography) (see Creswell, 2013). Loh (2013) noted that narrative inquiry was a form of qualitative research that addressed an individual's life through the collection and telling of stories. Grounded theory would not have been the appropriate research design because theory was not being developed in the current study (see Brinchman & Sollie, 2014). A case study approach entails a study of one or more cases to develop in-depth, thick descriptions (Tager-Flusberg & Kasari, 2013). However, this would not have allowed me to explore the lived experiences of primary caregivers and the challenges they faced in raising a child with autism. Lastly, an ethnographic design would have not have been the best approach to use because it would have required interviews and observations to describe and interpret the culture of a group (see Badone, Nicholas, Roberts, & Klen, 2016). The rationale for choosing a qualitative approach with a transcendental, phenomenological design over the other choices was the attention given to the primary caregivers' testament of the lived experience from their perspective.

The use of open-ended questions while conducting in-depth interviews allowed me to probe the responses given by the participant. This allowed me to gather thick, rich data. The purpose of the study was to obtain the essence of the lived experience through use of the interview as a means of collecting data on the primary caregiver's perspective. This approach facilitated an understanding of caregivers' individual experiences in raising a child with autism and the challenges they faced. A qualitative, phenomenological design was appropriate to provide a better understanding of the primary caregiver's experience in raising a child with autism and in accessing care and using services.

Role of the Researcher

I served as the instrument in collecting data. Also, I was responsible for the research design. Participant selection and the recruitment of participants were also my responsibility. Data collection included nonverbal communication observed by me during the interview. However, clarity was obtained from participants as to the meaning of the nonverbal cues. I developed the interview protocol and provided participants with an understanding of the purpose of the study, their rights, informed consent, incentives, and explanations of each phase of the study.

Analysis of the data and reporting of the findings was provided by the researcher. It was essential for me, as the researcher, to share my background and experiences relating to the topic of study. Any questions asked by participants was recorded as data as well as the researcher's responses to those questions. The researcher was responsible for ensuring confidentiality of records and data as well as the identity of the participants and their responses. Also, confidentiality was explained to participants to include any limitations of confidentiality that may exist. I was diligent in being aware of potential biases and a way to address those biases. As the the researcher, I was responsible for developing a plan to address other ethical concerns as they arose.

Methodology

The research design chosen influenced how the participants were selected. The plans for the study included the logic as to how the sample is identified and selected, the type of data collection instrument used, the source for the data collection instrument, and the data collection procedures. This included where the data was collected, who would collect the data, how data was recorded, how often the interviews occurred and the length of time it would take to conduct the interviews, contingency plan in the event participants left the study before it was completed, how participants would exit the study and procedures for follow up as needed.

Participant Selection Logic

The population studied was primary caregivers raising children with autism. Participants included primary caregivers of children who had autism between the ages of 5-8, residing in the larger Washington, DC, metropolitan area. The plan was to recruit at least 12 participants through criterion sampling (Creswell, 2013; Mason, 2010; Strunk, Pickler, McCain, Ameringer, & Myers, 2014), as this sampling strategy would result in the selection of participants who had actually experienced raising school-aged children with autism ages 5-8 and was sufficient to capturing the essence of that experience. Although there was support for using 12 participants for this type of study, I was prepared to return to recruitment to ensure my data analysis reflected saturation of the data (Mason, 2010). The data analysis reflected a saturation of the data with the 11 participants recruited.

Flexibility was allowed in case the sampling strategy changed. Although there were concerns regarding researcher bias influencing the participants selected, this issue was addressed based on the fact clear criteria for selection had been identified. Additionally, criterion sampling helped to establish the worthiness of the phenomenon being studied (Strunk, et al., 2014).

Instrumentation

In depth interviews were conducted with primary caregivers raising children with autism between the ages of 5 – 8. The interviews lasted up to one hour and 15 minutes as it allowed time to probe deeper in an effort to obtain information rich responses. I functioned in the role as the instrument as the interviews were conducted and questions were asked by me. An interview protocol (see Appendix A) consisted of open-ended questions and follow-up questions were asked for clarification. This allowed primary caregivers to fully share their experiences from their perspective. According to Rubin and Rubin (2005), the main interview questions were introduced first to ensure the problem being researched was exhaustive. Next, follow-up questions were asked to obtain specifics regarding comments made by the participants and ideas shared helped to bring about a better understanding of the lived experiences (Rubin & Rubin, 2005). When appropriate, probing questions were asked to gather in-depth and information rich data whichprovided clarity regarding responses. However, they were "limited in number and unobtrusive…" (p. 139). Rubin and Rubin (2005) even suggested participants would be asked probing questions that provided sequential descriptions. Two examples of these type of questions were "What happened next"? or "Can you give me an example of that"? (p. 137). The interviews were audio recorded. Also, nonverbal data was collected as well and documented on each participant's interview protocol.

The interview protocol served as a procedural guide and provided consistent information to be addressed with each participant (Jacob & Furgeson, 2012). Planned language included introductions, instructions, and explanations about the interview process as well as the study.

Procedures for Recruitment, Participation, and Data Collection

Primary caregivers raising a child with autism between the ages of 5-8 were selected through criterion sampling. Participants were responsible for the overall management and care of the child's day-to-day needs. This ensured the heart of the lived experience was captured. Participants were recruited from the larger Washington, D.C. metropolitan area. Participants were recruited through service providers, schools with autism classrooms, and community organizations within the Washington, D.C. metropolitan area. The same criteria for selection was exercised at all sites.

Once approval had been given by the Institutional Review Board (IRB) to begin the study, flyers (approved by IRB), were provided to professional contacts at multiple sites for distribution to their clientele. The flyer included my name and contact information as the researcher. Also, it included information on why the study was being conducted, a section on eligibility criteria to participate, benefit of participation, what participants were asked to do, and a stamped date of the IRB's approval. The researcher determined if potential participants met the criterion when calls were received expressing their interest in participating in the study.

Once the participants had been selected and agreed to participate in the study, informed consent was obtained from each participant. Structured, in-depth interviews were conducted to obtain the participant's lived experiences in raising a child with autism. Interviews were audio recorded to ensure accuracy. An interview protocol (see Appendix A) consisting of open-ended questions was used. This included, but was not limited to, their perspective, nonverbal communication, and additional questions asked to obtain clarity and in-depth information. The audiotaped interviews took approximately one hour and 15 minutes. The interviews were conducted at locations selected by the participants, ensuring an environment in which the participants felt comfortable in sharing their honest perspective on the lived experiences in raising a child with autism. Promoting honest sharing of their feelings and experiences yielded data that was reflective of the experience and not based on what the participants thought I would like to hear.

Data Analysis Plan

What the primary caregiver experienced and how they experienced it (essence of the experience) was analyzed and descriptive in nature. Researcher identity had the potential to influence the interpretation of data. Throughout the research process, my views or biases regarding the challenges primary caregivers face in raising a child with autism and in accessing services and care was documented. Also, my personal and work experiences in working with children with autism and their primary caregivers was documented as well. It is important for me, as the researcher, to achieve epoche in order for my full attention to be given to the experiences shared by the caregivers while suspending my own judgments and views (Moustakas, 1994).

As the researcher, I must be able to understand the information-rich data collected while conducting interviews for this qualitative, transcendental phenomenological study. This promoted researcher awareness and this information was disclosed to the participants. Moustakas (1994) phenomenological approach to analyzing this data was descriptive in nature. Therefore, once the interviews had been completed, each interview protocol was transcribed into the participant’s exact words. Next, the primary caregiver’s experiences were clustered into the themes that emerged. The themes and textural descriptions were synthesized into a description of the experience (Moustakas, 1994). Notations in the margins of the interview protocol included any additional data gathered while conducting the interviews like nonverbal communication. Additional questions asked of the participants, in order to probe further to obtain clarity and in-depth information, was documented as well.

Descriptive coding was one strategy that was employed to describe what is in the data based on passages of text (Taylor & Gibbs, 2010). NVivo, a computer software program, was not used to store, organize, manage and analyze the qualitative data collected (QSR International, 2014). Also, NVivo was not used to run multiple query searches and analyses of the data. Using NVivo would have allowed more time for me to analyze and interpret the data, “identify themes and come to worthwhile conclusions” (QSR International, 2014). A running list of codes and categories was not developed or used. Additionally, NVivo was not used to display codes, categories, and analyses graphically.

Issues of Trustworthiness

Research based on clearly defined principles showed rigor and promoted trustworthiness of the findings and why the proposed topic was worth being studied. The research was guided by principles that addressed belief in the findings (credibility), how applicable the findings were in other environments or settings (transferability), consistency of findings and the capacity for the findings to be repeated (dependability), and whether the findings were shaped by the participant’s responses or researcher bias which included personal and professional interests (confirmability) (Lincoln & Guba, 1985).

Credibility

As the researcher and instrument, I was an integral part of the process as I was collecting, analyzing, interpreting the data and conveying the findings. According to Creswell (2013), Mason (2010), and Strunk et al (2014), five to 25 participants was sufficient as more participants would not lead to more new information. The sample of 12 participants, collected through criterion sampling, was expected to be sufficient to ascertain data on what the primary caregivers experienced and how they experienced (Mason, 2010). Mason (2010) believed a small sample size in qualitative research was sufficient as emerging themes began to repeat and no new perspective was introduced. Although there was support for using 12 participants for this type of study, I was prepared to return to recruitment to ensure my data analysis reflected saturation of the data (Mason, 2010). However, saturation of the data was achieved with the 11 primary caregivers who met the criteria to participate in the study. Four techniques were employed in an effort to achieve credibility of findings: member checking, using a peer reviewer, audit trail and triangulation. A summary of the data collected was shared with participants and feedback obtained as to whether the researcher accurately captured their experiences. Also, a peer reviewer examined the transcripts and conclusions drawn. This added to the credibility of the findings.

The trustworthiness of findings in qualitative, transcendental phenomenology research, as it related to credibility, took into consideration the influence of the researcher on the research process and the findings (Morse, 2015; Whitehead, 2004). Thick, rich descriptions were obtained from the researcher's perspective and the participant's words while answering the questions of what and how relating to the phenomenon being studied (Whitehead, 2004). This helped to show the rigor of the research and authenticity of the findings (Whitehead, 2004). Strategies used to collect data included, but were not limited to, observation, reflective exercises, repeating the semi-structured interviews, and obtaining thick, rich descriptions. Authenticity of the findings was promoted through member checking, triangulation, and clarifying the researcher's bias (Ajjawi & Higgs, 2007; Whitehead, 2004).

Transferability

The applicability of the study to other settings or environments (transferability) was ascertained through use of thick descriptions. Probing questions were asked of participants as needed in an effort to obtain clarity regarding responses given and to probe deeper to gain thick, information-rich descriptions of the lived experiences. At times, the exact words of the participants were shared as life was brought to the experience. Use of different sites serving the same population added to the transferability of the findings.

Dependability

Establishing the findings as consistent across times and being able to be repeated conveyed the conclusions drawn were dependable. The entire research process was documented as it evolved over time. This included the research activities, any influences on data collection, the emerging themes, and data analysis. The written research process was specific and clearly demonstrated. Acknowledging the similarities as well as the differences among the participant's lived experiences in raising a child with autism supported the findings as being consistent.

Confirmability

When a reader of the study was able to confirm the findings, confirmability was achieved (Morrow, 2005). Also, an audit trail of the research activities included information about the researcher, the context in which the research was conducted, trust and rapport established between the researcher and participants, and the research process was documented (Guba & Lincoln, 1982; Lincoln & Guba, 1985). This attested to the integrity of the research as well as the findings. I became aware of any personal and professional biases relating to my own lived experiences in raising and working with a child with autism so this would not influence the responses of the participants. In order to show researcher reflexivity, a balance wascreated between my interpretation of the responses given by participants and the responses that were shared. In conveying the findings, strategic use of some participant's exact words showing the essence of their lived experiences was shared in order to confirm the findings.

Ethical Procedures

Ethical issues can arise at any time and was anticipated when conducting research. As the researcher, I was prepared with a plan as to how they would be addressed. Gaining approval from the IRB of the recruitment materials, process, and permission to conduct the study was vital to moving forward with the research.

The following precautions were put into place to address potential ethical issues that arose:

1. Secured a signed inform consent form from each participant.
2. Informed participants of their rights relating to participation in the study and their right to withdraw from the study at any time .
3. Informed participants the interviews would be audiotaped.
4. Confidentiality of the identity of the participants was ensured by assigning each participant a pseudo name to be noted on all documentation.
5. All audio tapes, forms, completed interview protocols/responses were kept in a locked file cabinet.
6. Electronic files were protected by an encryption password known only by the researcher.
7. Thoughts and ideas about the topic of study were documented as data in order to ensure researcher was aware of potential influences that would affect data collection and interpretation of data.

Summary

The research questions guiding the qualitative, transcendental phenomenological study were:

1. What is the lived experience of primary caregivers raising a child with autism?

2. What challenges have primary caregivers faced in accessing and using services?

When IRB approval had been obtained, 11 participants were recruited through criterion sampling from the larger, Washington, D.C. metropolitan area. In-depth interviews were conducted in locations selected by the participants based on options provided. Through open-ended questions and probing follow up questions, the participants' experiences were recorded. Also, each interview was audio-recorded to ensure accuracy. NVivo was not used to store, organize, manage, and analyze the data. Also, it was not used to graphically display the analyses.

Issues of trustworthiness were addressed by allowing the participants to review transcripts of their individual interviews to ensure their respective experiences was captured accurately. A peer reviewer was enlisted to review not only the transcripts of the interviews, but any conclusions drawn. Carefully and clearly documenting each step of the research process included similarities and differences that promoted consistency of the findings. Findings were confirmed by using participants' exact words in an effort to convey their lived experiences. Obtaining informed consent, conveying to participants their rights as it relates to the study and that the interview would be audiotaped, and ensuring confidentiality of their responses and identity, was the plan to address ethical issues as they arose. Confidentiality was maintained by using pseudo names, placing hard copy files and audio tapes in a locked cabinet, and encrypting electronic files.

Chapter 4: Results

This chapter includes a review of the purpose of the study and the research questions. I also describe the data collection process, number of participants, and any variations in data collection from the plan presented in Chapter 3. Additionally, I provide data analysis outcomes and evidence of trustworthiness.

The purpose of this transcendental, qualitative phenomenological study was to gain an understanding of the challenges faced, from the primary caregiver's perspective, about the diverse, lived, and common experiences of primary caregivers raising a child with autism. I explored the challenges in accessing care and using services. The study was guided by the following research questions: What are the lived experiences of primary caregivers raising a child with autism? What challenges, if any, have primary caregivers faced in accessing services? Question 1 served as the broader question guiding the study, and Question 2 was a secondary question addressing the specific challenges primary caregivers faced.

Demographics

This study consisted of 11 participants who served as primary caregivers of school-age children ages 5-8. Participants consented to be a part of this study and to share their perspective regarding the essence of their experience. The primary caregiver was responsible for the overall care and well-being of a child with autism. Within my study, this included biological parents, adoptive parents, individuals, heterosexual couples, and guardians. All participants resided in the greater Washington, D.C. metropolitan area, which comprises D.C. and the states of Maryland and Virginia. The school-age children raised by these caregivers were males and females. There were two primary caregivers who added a unique perspective relating to the lived experience of raising twins with autism and the challenges they faced. One was a primary caregiver of fraternal twin boys, and the other was the primary caregiver of identical twin boys with autism. The first was never married, and the other was twice divorced and was a single mother.

Table 1 displays the demographic characteristics of the research participants. The demographic information included specific relationship to the child, age of the child, grade in school, gender of the child, and the city, county, and state in which they reside.

Table 1

Participant Demographics

Participant	Relationship	Age of child	Grade in school	Gender of child	City, state
P1	Biol. mother	8	3rd	Male	Capital Heights, MD
P2	Biol. mother	7	2nd	Male	Prince William, VA
P3	Biol. mother	5	K	Female	SE, DC
P4	Biol. mother	5	K	Female	Upper Marlboro, MD
P5	Biol. mother	6	1st	Male	Laurel, MD
P6	Adop. mother	7		Male	SE, DC
P7*	Biol. mother	5	K	Male	Columbia, MD
P8**	Biol. mother	8	3rd	Male	District Heights, MD
	Biol. mother	8	3rd	Male	District Heights, MD
P9	Biol. mother	5	K	Male	NE, DC
P10	Biol. mother	5	K	Male	Columbia, MD
P11	Biol. mother	5	Pre-K	Male	SE, DC

Note. *Fraternal twins in the same household (separate interviews). **Identical twins in the same household (one interview).

Participant 7 was interviewed once as the identical twins were on the same end of the autism spectrum, had the same level of functioning, and were diagnosed with the same comorbidities. Separate interviews were conducted for the fraternal twins due to the differences in the caregiver’s experience based on the boys being on different ends of the autism spectrum. A total of 11 participants agreed to be interviewed.

Data Collection

Data for this study were collected from 11 primary caregivers of school-age children with autism. Flyers (see Appendix C) were distributed to professional contacts within the greater Washington, D.C. metropolitan area. Flyers were placed where resources were made available to clients/consumers in these organizations. Initially, there was difficulty in recruiting participants from distribution of flyers alone. However, my professional contacts began a word-of-mouth campaign that resulted in gaining the remaining number of participants needed. In responding to both recruitment strategies, participants called and expressed an interest in participating in the study. Based on criterion sampling, participants who had experience raising a school-age child with autism ages 5-8 were selected.

Interviews were conducted with all participants on an individual, face-to-face basis. The locations of the interviews were mutually agreed upon places to provide a setting that would support open dialogue and sharing of lived experiences. In-depth interviews were conducted that lasted between 45 minutes and 75 minutes. An interview protocol (see Appendix A) that consisted of open-ended questions was used. Follow-up questions were asked, as needed, to provide clarity and to ensure accuracy of responses; probing questions were asked to obtain information-rich responses. Some examples of follow-up questions were the following:

1. Have you ever experienced a day when you did not have a snack for him and if so, what was that like?
2. Does he have an IEP at school and if so, what services are included on his IEP?
3. What happens when a change is made to her schedule?
4. What type of resources and support do you need?
5. Please share the signs you recognized that he had a diagnosis of autism.

This allowed the primary caregivers an opportunity to share their experiences from their perspective. Nonverbal communications were documented in the border area of the interview protocol for each participant.

Before an interview was conducted, I established rapport with the participant. After the purpose of the study was explained and signed consent was obtained, a recorder was used to record each interview to ensure quality of sound and to minimize background noise and feedback that could impede transcription. Also, batteries were placed in the recorder and the power cord was plugged in as well to ensure continuation of recording. An external, plug-in microphone was used versus the microphone within the recorder. I transcribed each recorded interview, and the data collected were reviewed only by me.

As the researcher, I had sole access to interview protocols, transcribed data, audio recordings, initial participant list with the participant’s name and assigned pseudonym, the recorder, signed informed consent forms, flash drive, laptop, thematic analysis notes, and any other information related to the study. When not in use, all of these items were kept in a locked file cabinet. Additionally, all data were backed up on the hard drive of the laptop, which was password protected. No information was shared with participants via e-mail. Furthermore, the laptop required an encryption password before I could log into the system to access programs and files. Transcript review was conducted by mailing participants their respective interview transcript. A self-addressed stamped envelope was provided to return the interview transcript with corrections, or participants were given the option to call me with any corrections that would result in a more accurate reflection of their perspective. No calls or interview transcripts were received with correction requests.

Data Analysis

Moustakas' (1994) phenomenological approach to analyzing data was employed and descriptive in nature. Therefore, once the interviews were completed, each interview protocol was transcribed into the participants exact words. Although primary caregivers can live as well as share the experiences of raising a child with autism and the challenges they faced, their account of the experience based on their perspective was different. Next, the primary caregiver's experiences were clustered into the themes that emerged. The themes and rich, textural descriptions were synthesized into a description of the essence of the experience (Moustakas, 1994). A connection was made between the emerging themes and the following research questions:

1. What are the lived experiences of primary caregivers raising a child with autism?
2. What challenges, if any, have primary caregivers faced in accessing services?

Subthemes were identified as well (see Table 2).

Table 2

Themes and Subthemes

Themes	Subthemes
Overall experience	Lack of information
Challenges	Change in routine/transition
	Lack of support
	Limited providers
	Individual-based services
Relationships	Family
	Service providers
	School staff
Access to services	Finances
	Insurance coverage
Stressors	Behavior
	Wait list
	Acceptance of the diagnosis
	Unmet needs
	Lack of family resources
	Emotions

Theme 1: Overall Experience

There were similarities as well as differences in their experiences in being the primary caregiver of a child ages 5-8 with autism. For example, one caregiver viewed raising a child with autism as an adventure. She shared:

> There are highs, you know, when they accomplish things. Also, there are lows when you get overwhelmed. I would definitely describe it as an adventure because it can be very unpredictable. Some days everything goes as planned and other days just not so much.

Another caregiver noted:

> It is extremely hard. It's a lot of challenges and unknowns. It's a lot of figuring out how to do this and to do that. It is completely different than raising a child that

> does not have autism. It is much harder. I'm talking totally different as far as hygiene, speech, potty training; everything from A to Z.

This caregiver was raising fraternal twin boys who are on different ends of the autism spectrum. The youngest twin is high functioning, verbal, and in mainstream classes to be pulled out only to receive services as identified on his IEP (individualized education plan). The older twin is full time special education and nonverbal. One caregiver enjoyed being a caregiver as her son was "very high functioning and his autism was almost undetectable. He is more so on the spectrum because of the social aspect."

Other participants reported not understanding what their child was going through or knowing enough about the diagnosis itself. Also, this caregiver was the only one to share her son was not being assigned to a specific grade as he attends a school where every student is in special education, receives special education services, and students are listed by age. One of the only two caregivers who was married expressed the following:

> I never thought about what it is like to be a caregiver of a child with autism. I guess sometimes it is surprising in regards to the fact that every day he does something that surprises me and that makes me happy. One day when I came home, he had the mail. He informed me I had mail. As he gets older and starts to become more of his own, he is more confident in himself and he has a better understanding of things. Sometimes we even have normal everyday conversation. He told me I had a coupon to Toys R Us because he wanted to go there (smile and laughter). There are days where it is difficult because his speech is still growing

> and sometimes we have to ask him 2 or 3 times to repeat himself which makes him very frustrated.

A caregiver, who is a single mother, distinguished between a good day and a bad day by reflecting on her experience:

> You learn a lot about your child. There are good days. Then of course, there are bad days too. You learn their strengths, their weaknesses, things they go through in school, and at home. Being a caregiver of a child with autism has built in me patience I never knew I had and I became an active listener. I had to in trying to understand what he was trying to say in relaying messages to me. But, that is part of the process of being a parent. A good day could be him coming from school and he shares he learned something new from a classmate or teacher. A bad day could be him not wanting to participate in gym because he feels like he is going to be judged if he does not dribble the ball right or if he cannot catch the ball.

The overall experience was challenging for one caregiver as the word "challenging" was the first word that came to mind. She expressed the following:

> It shows you what you are made of and what you are not. Honestly. It shows you your level of patience. It has shown me the things I thought I was strong in like time management and areas where I need to improve as a parent. More importantly, I learned quickly it is not all about me.

A single mother who works in the health care field and is a mother of two, one child with autism and one teenage child without autism, recalled raising her son with autism as a learning experience. "It is something you kind of figure out as you go. There is no set rule book for how each kid is going to act. The resources available may not specifically apply to your child. It's really a lot of learning as you go."

The other caregiver of identical twins, who are nonverbal, expounded how surprised she was at the communication resources available that would allow her to understand her boys. When asked what type of communication resource, she replied:

> A communication picture board. This changed things drastically for me and my boys. Early on I questioned myself as to what I did wrong to cause this. I felt broken. There were so many unknowns. I later learned it had nothing to do with me. One thing was for sure, I quickly realized it was their world and I was privileged to live in it.

Overall, each caregiver expressed the highs and lows of being a caregiver of a child with autism ages 5-8. They shared the experience of getting to know their child while at the same time getting to know themselves all over again.

One caregiver shared "there are a lot of unknowns about the diagnosis." "Initially, I had to figure some things out on my own" stated another caregiver. Four caregivers shared they felt shame because they did not know how to help their child nor did they understand what their child was going through. Ten out of the eleven caregivers expressed concerns regarding the lack of information provided at the time their child was diagnosed. They wondered what caused autism. "Would my child ever experience normalcy? Would he ever be self-sufficient? Would she ever be able to go to prom, secure a job, or even be able to get married one day? How is autism treated? What about his education?" These were all questions that, in some way, concerns of ten out of eleven of the participants. Since information was not provided at the onset, one caregiver decided to search the internet. She noted “I went on the internet to teach myself about my child’s diagnosis. I did not know where to begin. Can I say information overload.”

Theme 2: Challenges

Challenges emerged throughout the interviews with participants. All 11 participants shared challenges were faced whenever there was a change in the child’s routine despite age. From not giving the child a piggy-back ride to his classroom, as usual, because the caregiver hurt her back the day before to not having a snack ready for him when he is picked up from school, would result in the child having a tantrum or experiencing frustration. Structure, explaining changes beforehand, and sticking to a schedule was important to all of the caregivers in minimizing the challenges faced in raising a child with autism.

A single mother of a 5 year-old with autism shared:

> He does not do well with change. So, he might throw a tantrum. If he does not throw a tantrum, he becomes very resistant. So, you kind of got to coach him. Also, when we were approved for ABA services, there was a wait list. I realize once the ABA services are in place, things will be calmer, the behaviors will be addressed, and he will begin to learn social skills in order to better communicate with his peers and others.

An adoptive mother of one child with autism and three others without a diagnosis shared:

> There is a limited number of providers who are knowledgeable on how to treat children with autism for basic services from dental care to behavioral services. When you find a provider, there is normally a wait list. In the meantime, my child gets 1 hour of speech per week, 30 minutes of occupational therapy, and 1 hour of physical therapy in the school setting. However, he needs much more. My other children, at first, were afraid of him because of the noises he made. They asked, why does he scream like that? Finding fun activities that all of the kids could do together was difficult because of his sensory needs relating to light and sound.

A married mother of two, one being an 8 year-old with autism was not sure what was going on at times. When he was younger, the caregiver noted:

> It was frustrating. If his routine was broken, he would get ornery and upset. As he got older he learned how to work the changes to his favor. For example, he would ask, can I get five more minutes of TV time mom? Or, can I get five more minutes of YOU TUBE? It was important to keep him on track as it not only affected him, but my younger daughter as well.

Most of the caregivers shared that their child was diagnosed with autism around the age of 2. One shared her child was diagnosed at age 3. There was a lack of resources for the family expected to care for the child with autism, a lack of support from family and within the community to assist with care, and the services provided in some of the schools were general and not specific to meet the individual child’s needs. Often, these challenges were hard to overcome. A young caregiver expressed concerns regarding her daughter backing away from interacting with her peers. She said:

> I worry about her future and what will it be like. I question whether she will ever be able to live on her own, go to college, get a job, get married, and even have a family. I want her to experience normal things in life. The unknown, for her, scares me. I can help support her financially, emotionally, and educationally; but, I wonder if that's enough.

Even where there are two parents in the household, things can still be difficult and challenges are faced. A married mother of two, one child with autism, expressed concern regarding her husband's initial denial of the diagnosis. She shared:

> I knew something was wrong. He was once talking and now he does not say Ma Ma or Da Da. He was not responding to his name. It was difficult to potty train him and he is still not potty trained. My husband informed me he would grow out of it. It became even more challenging to do family trips as I am not sure if he can handle flying because of the noise and his ears would pop. Amusement parks are out. When I go to the grocery store, and if there are no available carts or the lines are long, I have to leave and try another day. My son gets agitated when standing in lines for long periods of time. If he gets in the bed late, it throws the schedule off as there is a domino effect. Time is lost in other areas and he usually goes to school the next day sleepy. However, I do report it to the staff when I drop him off at school so that they are aware.

Another participant reported difficulty in meeting the conditions of the IEP. The IEP noted for both of her twin boys that someone had to walk them across the street and wait for the bus to arrive. When they returned home, she had to go to the bus stop and walk them back across the street. There was no door-to-door service. She expressed the following:

> It was challenging. I could not take them to daycare. No daycares existed that could meet their needs. Aides would quit on me and tell me they could not handle it anymore. I was here alone as all of my family lived in New York. When someone would agree to watch them, they wanted to charge me $100 per hour to watch them. I could not afford that. The bigger challenge became trying to hold on to my house and pay for services for the boys for which they were already wait listed or I could not afford. I went from being married with twin boys with autism to being divorced by the time by boys were 18 months old. Their father left. He could not handle it. To this day, he is not involved in their life. I gave up my home and we now live in a 2-bedroom apartment. I had to change my work shift that I had been on for years to accommodate meeting the conditions of the IEP. On a good note, my mother and other family members started coming down from time to time and spent as much time as needed to help me. This has made a tremendous difference.

Many of the caregivers shared challenges they faced. Some were similar and many were different. One thing they all shared in common was the need to overcome the challenges they were experiencing in an effort to ensure the best outcomes for their child. They recognized they were the best advocate their child would have. Denying the diagnosis was not going to make it go away, overcoming the challenges and putting the right services in place would allow their children to experience some normalcy like their counterparts being raised who do not have a diagnosis of autism.

Subtheme: Change in Routine

All eleven caregivers noted, after diagnosis, there were changes in the routine. The child with autism needed more assistance depending upon whether they were low or high functioning. Also, dinner and meeting the needs of other family members in the home was adjusted to ensure the child with autism had an establsihed routine. They quickly learned how important consistency was and to minimize changes in the child's routine whenever possible. One caregiver shared:

> I learned my son's level of patience. We normally would go to Olive Garden to eat out. Once we arrived to the restaurant, we noticed there was a long line. After 45 minutes had gone by and we were still waiting to be seated, he became agitated and restless. Then came the loud noises. Therefore, we made a family decision to go somewhere else, pick up something through the drive through, and go home and eat.

All caregivers admitted that the routine provided structure. Structure and an established routine minimized the outbursts, loud noises, tanturms, and aggressive behaviors. Wake up time, bath time, breakfast time, options provided at breakfast, time to go out the door for school, homework time, family time, dinner time, bath time, and bed time needed to be precise. When changes did occur, down to the type of snack provided in the afternoon, it helped to explain the change and why.

Subtheme: Lack of Support

For half of the caregivers, friends and family members lack of knowledge and understanding of the diagnosis caused them to conclude the children were just "being bad." They did not understand the behaviors exhibited at church or during social and family events. This often resulted in unwillingness to baby sit the child with autism. In the beginning, there were times when they rarely experienced couple time or me time. However, when the caregivers became versed about the diagnosis, treatment, and behaviors associated with the diagnosis, they were able to educate their families.

One of the single caregivers, lived away from her family. There was no family support. For two caregivers, there was a lack of support in the home from their spouses. One caregiver had a spouse that was not on board in the beginning as he was in denial regarding their son being diagnosed with autism. The other caregiver shared her husband gave up on her twin boys and their marriage. She said, "I became a single mother of twin boys with autism. I did not know what the future held for us. What I did know was God had not forgotten me or my family. Family members came from New York, to include my parents, to help out". Four of the other caregivers wondered if other parents of children with autism shared similar experiences and where did they go for support. They were astonished after being introduced to supportive networks like Autism Speaks, Easter Seals, and Autism Society of America. A caregiver shared "we love to go to the gala every year as a family. Our supportive network and our family, has grown."

Subtheme: Limited Providers/Individual-Based Services

Seven out of eleven of the caregivers expressed concerns regarding a lack of providers with the skillset to treat school-aged children with autism. From their perspective, the best doctors who specialized in autism were located in the Baltimore, MD area. “They are the because they make us an integral part of the team and the decision without thought.” Transportation to see these proivders was a barrier along with the length of time it took to secure an appointment. The few doctors that specialized in autism in Washington, DC and in neighboring counties in Virginia had long wait list for appointments as well. Four caregivers were satisfied with the primary care physician rending services to their child. Other needed providers in short supply, as expressed by all of the caregivers, were speech therapy, physical therapy, occupational therapy, and ABA (Applied Behavioral Analysis). The providers were even more limited within the school setting. Additionally, all of the caregivers stated in their own way “I do not want my child to receive cookie-cutter services. I want my child to receive individualized specific services as identified on their IEP (individualized education plan) and as recommended by their doctor. Keep in mind every child is not on the same end of the autism spectrum.”

Theme 3: Relationships

Less time being spent together doing family activities outside the home, less couple time, less me time, and establishing relationships with their children service providers and school staff were competing forces that must be managed in their child’s best interest. The caregiver of the fraternal twin boys shared:

> Both of my twin boys are very healthy medically. However, one has severe behavioral problems. When I went back to nursing school, I thought I could practice some of the techniques I learned. Unfortunately, I could not. After he had his tonsils removed, he developed white coat syndrome. Therefore, I communicated with his doctors the need for them to take off their white lab coats. Allowing them to listen to his breathing with the stethoscope was a stretch. Knowing my son had autism, the doctors had no problem complying. His doctors are excellent and we have a great working relationship. The nursing aides that now come to the home are a big help. Can you imagine doing everything for two children who need help with all of their ADLs and then turning around and doing the same for yourself? I would be totally exhausted. For years, I was, until the boys were approved for personal care assistance hours. It’s not all I need, but it is better than doing it all alone.

The caregiver who works in the health care field shared her son receives no services on an outpatient basis. She noted:

> A Montessori school would be better for him than a regular public school. However, there are no Montessori schools in DC that are equipped to give him the individualized attention he needs. At his current school, he is in an autism classroom. However, the children are on different ends of the spectrum. So, the teachers are not necessarily able to spend the one-on-one time to give him what he needs. My child is very smart and achieved some milestones ahead of time. He has been reading since he was three years old. So, I do what I can at home. It

> helps that I have an excellent relationship with the service providers. If I have any concerns, they address them and I feel comfortable bringing those concerns to them.

Working with the school staff and service providers has been a great partnership per one caregiver with the exception of the dental provider. The provider had no quiet room without a lot of pictures on the wall that limited distractions her son would face when attending his dental appointment. Also, the treatment area was one big open area. After changing dentist, it is a much smoother process as they have a quiet room where her son would allow the dentist to provide him services. She reported:

> The exchange of information is good. Communication is key. Goals set for him to achieve at school by the end of the year, he achieved in a month. For example, there was a goal for him to follow 2-step directions consistently. Within a couple of months, he had achieved that goal and the next goal was set to follow 3-step instructions. They communicated with me when things were working and when things were not working. We worked together to be consistent in holding him accountable for things as far as expectations. Even with the providers, it was not a situation where I had one expectation and they had another. We were on the same page. Thus, when he started school, I already had his IEP. I had activities in place in the home. Therefore, I was able to share what we were doing at home. This made it much easier to be consistent as he learned the same things done at school were being done at home. Before I would pick him up, if he had a bad day, I had been notified. Staff would text me and they had an application call DOJO where I

> could go and read how his day was progressing and to obtain updates. If he had a rough morning at home, I would write a note in his homework folder to let them know. We worked together. My husband and I would love to plan a trip out of the country. However, there is no family member who is willing to be responsible for him. God forbid if we were to pass away, who would care for him as he needs to be cared for? More work needs to be done on family relationships and more work needs to be done to prepare someone to care him in our absence.

Not all caregivers shared the same experiences relating to relationships between them and their families, school staff, and service providers. Either the providers answered their questions or they were not as forthcoming as the caregivers desired them to be. Others were not satisfied with the answer given at times by school staff and service providers. One thing all of the caregivers shared in common was their willingness to keep asking questions and research on their own, until their concerns were addressed.

Subtheme: Family

When seven of the caregivers expressed how important it was to have family as a part of their supportive network, it spoke volumes. The consensus was “it is important to have people familiar with my child’s diagnosis, behaviors, and needs. My family knows how to calm him when he is upset.” One caregiver said “the best way to move on is to embrace the fact it is their world and we are privileged to live in it and learn from them. Often, they see things differently in a unique kind of way. My family learned this and did embrace it.” Additionally, three caregivers noted “when I needed to yell, scream, cry, or complain, my family was there. I got to release it versus holding it in. Can you imagine what that felt like? To be honest about how I was feeling?" Lastly, for every participant, with the exception of one, family supported them in taking care of themselves. Per the caregivers, "family became a central source of strength for me." The other caregiver illuminated the service providers and school staff as her source of strength."

Subtheme: Service Providers

All of the caregivers agreed it was important to have a solid relationship with the service providers. "The education about the diagnosis, effective treatment interventions, and suggestions regarding other provider options relating to specialized services is carried out by the service providers" noted one caregiver. Other caregivers said "it helps to give me a piece of mind. I can ask all the questions I need to without feeling inadequate and my questions are answered. They care about me and my child." A single mother who was having a difficult time with getting the school to provide her son with services to meet his specific needs, was able to discuss her concerns with the primary care physician (PCP). She said "raising a child with autism is not easy. I was able to talk to his PCP. In speaking with her, I learned she was familiar with my struggle up close and personal. She too was raising a child with autism and faced similar challenges as I did. She lived it every day."

Subtheme: School Staff

Many of the caregivers viewed the relationship with the school staff as a "partnership. Most of the services my child needed and received were at school. Either the insurance did not cover it or there was a wait list for outpatient services. Instead of delaying access to services, the school worked with her." One of the caregivers expressed joy in the teachers “use of technology and online educational tools to prove me with periodic updates and to alert me on what kind of day he had.” Two caregivers specifically shared “in order for my daughter to experience positive outcomes at school, I must be active in the development in her IEP and an integral part of creating a positive learning atmostphere along with school staff. “My son loves to go to school.” He gets up before I do. One day, he said Mommy, you are going to make me miss by bus. He knew his schedule and the time his bus would arrive. The behaviors I was seeing, I do not see as much anymore.” Two caregivers who were able to secure ABA services for their son and daughter, respectively noted “the school allowed my child’s ABA provider to come to the school periodically to provide services in the school setting.”

Theme 4: Access to Services

Even for children without a diagnosis of autism, accessing needed services and care can be inhibited due to lack of financial resources or proper insurance coverage. Out of all the participants, five had an issue in this area as it related to insurance coverage. They were on different ends of the continuum with their responses. For two caregivers, it was not that they did not have insurance, it was that it appeared to them most of the services that were available and that their child was in need of, they were over income to receive. One caregiver shared:

> A lot of the services are for people with Medicaid. As far as in DC, they have a lot of programs for persons who are low income. Private insurance may cover some of the services. However, the number of providers in network are not readily available and there is a wait list. There are so many more resources for people that

> are low income and they really do not consider people who have private insurance. Some will only take Medicaid.

Another caregiver had more than one insurance. However, she still could not access all of the services her son needed. She reported the following:

> Financially it has been draining. So, my husband works for a private company and you know at one point the benefits were great. But with changing health needs and a diagnosis of autism, the evaluations were not even covered. We ended up with astronomical health care bills. Now, the legislature has passed some laws and regulations. However, it is still difficult navigating through the insurance process and knowing what to ask. Even when we thought things were covered, they were not. He has yet to be seen by a psychologist or psychiatrist outside of the school system. For the past 1 ½ years, I have been making payments on previous medical bills and I did not want to accumulate more. I have done the research to switch our insurances. However, I must wait until the new enrollment period. My husband's insurance was before mines. He did not drop us; thus, we thought we had two insurances and that his would be secondary to mine. However, that is not how the insurance companies work. Because my husband's birthdate is before mine (by the month) and he is a parent also, his insurance would not be the primary for me; but, would be the primary insurance for the children. You see, my husband's insurance was a PPO and mine was an HMO. For it to be covered, we have to wait.

Other caregivers expressed more information is needed and should be provided by insurances to provide clarification regarding what the insurance cover when there is more than one insurance and which insurance would be primary and secondary in the situation described. Also, more programs need to be in place, along with a larger provider network, that take private pay as well as Medicaid or a managed care insurance.

Subtheme: Finances

Three parents paid out of pocket for services until there insurance could be secured through their child becoming eligible for SSI (Social Security Income). Two other caregivers shared they exhausted their savings and withdrew funds from their 401 (k). The single mother raising twin boys on different ends of the autism spectrum shared "I down graded our living quarters from a house to a 2 bedroom apartment. I had to change my shift at work and people tried to take advantage of my situation as I could not keep a personal care assistant. Some proposed pay of $100 an hour for their services." Limited sessions being provided under the insurance plan became not only a problem with the insurance, but a financial problem as well.

Subtheme: Insurance Coverage

The main issue the other caregivers had, relating to insurance, was the lack of coverage for recommended services. Per the two caregivers affected by the lack of coverage provided by insurance plans, "autism services can be costly, but worth every penny. Limited sessions are provided and once those have been exhausted, we were left to pay out of pocket." Securing grants or other alternative funding sources was an idea employed to cover serveices the insurance would not cover while defraying cost of evaluations and therapy sessions.

Despite those caregivers who paid for services privately, those who had insurance, or those who were eligible for Medicaid, they often had to pay out of pocket for specialty activities like social skill building and equipment. All of the caregivers agreed it would be helpful if information was provided to them regarding alternate funding sources.

Theme 5: Stressors

After receiving the diagnosis of autism and along the journey to having their child evaluated, services recommended, and a quest for the child to access services, multiple stressors affected the caregiver and the family’s ability to secure services in a timely manner or the appropriate services. First, they had to get past the acceptance of the diagnosis. The caregiver of the fraternal twins and the caregiver of the identical twins, did not understand or know anything about the diagnosis except for what they were told. Their initial thoughts were relief, but they experienced feelings of being overwhelmed and unsupported. One caregiver stated she “smiled and prayed to God to order her steps, show her the way, and guide her.”

Three caregivers reflected on their thoughts and emotions in detail. The first caregiver shared the following:

> The only thing I was thinking was what did I do wrong. Where did I make a mistake? Like after the diagnosis, I was like that’s what it was. Emotionally, I was

> scared and upset because I had no details or information on it. I did not know if it was a neurological disorder where there was a short life expectancy on it.

Another caregiver said:

> Wow! I was stunned. I am an adult with learning disabilities and now I have a child with a diagnosis. My thought was it would have skipped my child; having a disability that is. But, certain things happen for a reason. I began to not see it in a bad way anymore. I'm like, if I am doing all of these great things despite my disability, I know my son can do and will be great as well.

A third caregiver shared:

> My initial thought was I have no clue what the doctors just told me. I know they called it a disability and it was something affecting the neurological system throughout the body, and it also affected the brain. That's all I heard. All I could comprehend was both of my boys have a disability and it has something to do with their nervous system and it's affecting their brain. My boys were diagnosed with autism one week apart.

Four caregivers shared they were placed on wait list due to no available appointments with service providers whose panel was closed to new patients. All 11 participants eventually accepted the diagnosis. Six of the caregivers felt when the diagnosis was given, there should have been a packet provided with resources in it regarding services for the family, organizations and groups that provided support and community services for the child diagnosed with autism, information about autism, next steps, a list of advocates that can assist with securing the appropriate school placement and services on the child’s IEP, and programs that offered a care coordinator to assist with identifying providers and scheduling of appointments. The caregivers wanted options. All of the caregivers expressed difficulty at times in getting someone to care for their child so they could get some me time and a much needed break due to the child’s behavior. One caregiver said, “my child’s behavior and temper tantrums were so extreme. No one was trying to understand. In all honesty, I do not think they wanted to be bothered.”

Finally, analysis of the themes emerging from the information shared by the caregivers resulted in a comprehensive list of unmet needs as follows: physical therapy, ABA services, in home therapy, behavior modification, home care services, psychological evaluations, occupational therapy, speech therapy, and the same services in the school setting due to staff vacancies that have yet to be filled.

Subtheme: Behavior

The caregiver raising twin boys who were both nonverbal, expressed dismay and being emotionally exhausted. She shared “both of my boys are nonverbal. Initially, I found it very difficult to communicate with them and I am sure they found it difficult to communicate their needs to me. The aggressive behaviors and tantrums that would last up to 30 minutes at a time emotionally overwhelmed me.” Six other caregivers who also experienced problems with their child’s behaviors said “I was stressed out and needed to be taught how to cope with these behaviors. I’m sure my child was stressed out as well trying to communicate their needs, wants, and hurts to me. In some instances, I felt powerless, yet hopeful; guarded, but open.”

Subtheme: Wait List/Unmet Needs

Seven out of eleven of the caregivers, wait list delayed access to services/interventions that are critical in the early stages. This resulted in their child having unmet needs. Also, five of the children waited up to two years for services. The services the children were wait listed for included autism evaluation, neurological evaluation, psychological evaluation, physical therapy, speech therapy, behavior modification, occupational therapy, personal care assistance hours, and ABA (Applied Bheavioral Analysis) services.

Caregivers shared they were told “evaluations help to confirm the diagnosis of autism as there are other diagnoses that share similar behaviors, deficiencies, and symptoms. The evaluations also help the specialist to determine what specific services would bring about the best results.” After the diagnosis had been confirmed, three of the caregivers noted the family would benefit from personal care assistance hours as the aides assist the caregiver who is overwhelmed while at the same provide the child with needed care and assistance as well. The caregiver of twin boys on different ends of the autism spectrum shared it was difficult to maintain an aide due to the extreme behaviors and needs.

One caregiver shared her son’s speech delay could have been a result of developmental delay. Another caregiver explained “the lack of social interaction skills could have been the result of disorders that can come in clusters like ADHD and autism. My daughter’s secondary diagnosis is ADHD.” All of the caregivers stated they were informed by the child’s pediatrician that it is “critical to have a professional working with their child that can distinguish between something as simple as to why their child exhibits poor eye contact."

Subtheme: Acceptance of the Diagnosis

Four of the caregivers admitted "it is hard to accept something you know absolutely nothing about and easier to do so; but, I did." For one married couple, the caregiver (mother) did not become concerned until his speech continued to be delayed. Family members told her "he is just progressing slower than other children his age", and my husband was in denial altogether. However, now, he is our son's biggest supporter. Mine too." The other caregiver, that was married, explained the difference in raising children in the home who have a diagnosis of autism and those that do not. "My husband never accepted the diagnosis and left our family and marriage because of it." This presented the caregiver with multiple challenges. However, she came to this conclusion: "living with autism is not a choice, but accepting autism is. I have accepted it."

Subtheme: Lack of Family Resources

The caregivers made it clear, before they could ask for help, they had to better understand "what autism is, behaviors, associated with the diagnosis, and in what way could others support their family in caring for their child." Many of the caregivers expressed some family member's had apprehensions about baby sitting or covering in the caregiver's absence; however, they had no problem in running errands or helping out financially. One of the caregivers had to change her shift at work. Another needed someone to put her boys on the bus in the morning and be there to receive them in the afternoon. Once she communicated what support was needed, support from family was readily available.

Three of the caregivers shared “I needed me time. I am always with my daughter.” With children in the home without a diagnosis of autism, help was needed in the form of watching the child with autism so the caregiver could attend events for the other child in the home at school, in the community, or quality time with the caregiver. All of the caregivers admitted having to grapple with understanding how to provide their child with emotional and social support in order to help family and community support to understand how to do so.

Subtheme: Emotions

Primary caregivers, of children with autism, may share some commonalities as well as differences regarding the emotions they may feel at any given time when raising a child or children with autism. During an interview, the youngest caregiver said “is there a right or wrong way to feel?” Three caregivers shared the first emotion they felt was anger. Another expressed feeling guilty as she believed there was something she did during the pregnancy or after that resulted in her child having autism. Two other caregivers were frustrated because they expected family to understand versus being judgemental and concluding their child was just bad. Three caregivers experienced anxiety about their child’s future.

All of the caregivers noted they experienced being stressed out, sad, depressed, angry, confused, joyful, experienced good days, bad days, relief, worry, and happiness. They admitted although the the emotions experienced would go away, they could resurface at any given time. Thus, "it was important for them to learn how to care for themselves and to feel no guilt in doing so. It helped them to have someone to talk to in order to process their feelings. Also, asking for help and taking a break was okay and instrumental in them being at their best to care for their child."

Evidence of Trustworthiness

All of the participants of school-age children, between the ages of 5 – 8, were primary caregivers of children with autism. Interviews were conducted, using open-ended questions, with 11 participants. Also, the interviews were audio-taped and transcribed by me. Member checking was used to ensure accuracy of the information captured during the interview. Participants were mailed a copy of their respective transcript with instructions to review for accuracy and to make any needed corrections on the transcript. Also, a self-addressed stamped envelope was provided for participants to mail back corrected transcripts to ensure accurate responses were captured. No corrected transcripts were received after a 2 ½ week wait period.

An audit trail was kept of all of the steps taken in the qualitative, phenomenological research study from beginning to end. This included, but was not limited to, research design, data collection, and managing, analyzing, and reporting the data. Also, triangulation of the data was used to gain a comprehensive understanding of the common, as well as the diverse, lived experiences from the primary caregiver's perspective. This process helped to achieve credibility of the findings. Additionally, sharing the thick, rich descriptions of the participant's exact words showed the rigor of the research and authenticity of the findings (Whitehead, 2004).

Probing questions were asked, when needed, to obtain clarity regarding responses given, when answers were vague, and resulted in obtaining more in-depth information. Examples of probing questions asked are as follows:

- You said that sometimes there are good days and sometimes there are bad days. Do you mind sharing examples of a what a good day and a bad day looks like?
- In managing his health care needs, did you have someone to assist you? If so, who assisted you and what did they do?
- Can you think of a service that you thought your child would have benefitted from, but at the time they were not offering it or the insurance did not cover it? Please provide details.
- What scares you and why?
- So, has the family gotten closer? Explain.

Sharing the exact words of the participants also brought life to the heart of the experience. Additionally, the use of different sites, serving the same population, added to the transferability of findings.

The entire research process was clearly documented over time as it evolved. For example, there were broader themes and subthemes that emerged as reflected in the data analysis. Specificity of the research process needed to be known as well as the similarities and differences of the lived experience captured as it established the findings as consistent over time. Also, it showed the findings were able to be repeated and resulted in the conclusions drawn as being dependable.

Confirmability of the findings was achieved through employing the following strategies: documenting all research activities, establishing a rapport with the participants and building trust, and sharing some information about myself as the researcher and my own lived experiences. Also, sharing the participant's perspective of the essence of the experience, using their own words, confirmed the findings.

Summary

This chapter provided the results of the data collected during semi-structured interviews conducted with 11 primary caregivers of school-aged children with autism that participated in the study. All of the participants were from the greater Washington, DC metropolitan area. The following themes and subthemes emerged:

1. Overall experience
    - Lack of information
2. Challenges
    - Change in routine/Transition
    - Lack of Support
    - Limited providers
    - Individual based services
3. Relationships
    - Family
    - Service providers
    - School staff
4. Access to services

- Finances
- Insurance Coverage

5. Stressors
    - Behavior
    - Wait list
    - Acceptance of the diagnosis
    - Unmet needs
    - Lack of family resources
    - Emotions

The participant list detailing demographic and contact information, interview protocols, audio tapes, signed consent forms, flash drives, external hard drives, and the transcripts were locked in a file cabinet when not in use. Also, data and files were housed on two laptops that were password protected. Findings were credible, transferrable, dependable, and confirmable.

The purpose of this study was to gain an understanding of the challenges faced, from the primary caregiver's perspective, about the diverse, lived experiences of primary caregivers raising a child with autism. Also, the study sought to explore the challenges in accessing care and using services. Probing follow up questions help to illuminate the similarities and the differences in the lived experiences.

Chapter 5 will reiterate the purpose of the study and convey the findings. The findings of the study will be compared to findings revealed based on a thorough review of peer-reviewed literature. Additionally, findings of the study will be discussed in the context as to how they relate to resiliency theory as the conceptual framework. The chapter will also include limitations of the study, recommendations regarding further research and actions, and implications for positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to explore the lived experiences of primary caregivers raising a child with autism and the challenges they faced in accessing and using services. Although there were some similarities in their lived experience, each caregiver shared, from their perspective, something unique about their experience as well. I used a transcendental, qualitative phenomenological design to organize and analyze the data. Also, the essence or heart of the phenomenon was obtained (see Moustakas, 1994). A review of literature revealed a gap in research on parents' experience pertaining to the challenges faced by primary caregivers raising a child with autism and in accessing services. There was no existing research on the target group: primary caregivers of children with autism between the ages of 5 and 8. The study addressed the gap in literature while at the same time adding to the current literature. Findings provided a better understanding of the experiences of primary caregivers. Conclusions may impact social change in how current programs are structured, development of new programs, and how services are delivered, including the education of primary caregivers regarding their child's diagnosis.

Through an in-depth analysis of data, five themes and subthemes emerged: (a) overall experience (lack of information); (b) challenges (change in routine, lack of support, limited providers, and individual based services); (c) relationships (family, service providers, and school staff); (d) access to services (finances and insurance coverage); and (e) stressors (behavior, wait list, acceptance of the diagnosis, unmet needs, lack of family resources, and emotions). Findings indicated that all 11 primary caregivers faced challenges in raising their child with autism. Also, caregivers struggled with accessing general services and individual-based, specific services. Two of the primary caregivers were parents of fraternal twin boys with autism. For one, obtaining services through use of private insurance was a battle that resulted in services not being in place. The other primary caregiver had no problems in accessing services as she was approved for fee-for-service Medicaid, which covered all services deemed medically necessary. Six of the primary caregivers reported that it was difficult to plan family trips, family nights out to a restaurant, and Sunday morning at church. One of the caregivers who had difficulty planning family trips was concerned that if something happened to her and her husband on the trip, no one would be willing to take on all that was required to raise their son.

All of the caregivers agreed that applied behavior analysis (ABA) services would be beneficial to their child in building socialization skills, improving interaction with peers, and modifying behavior. However, caregivers shared that there was either a wait list or a limited number of providers who rendered the service. Furthermore, of the four caregivers who were married, one was divorced because the father could not deal with the diagnosis and what it would take to care for their twin boys. Two caregivers shared that raising a child with autism made their relationship with their spouses stronger, and they learned how to play off of their strengths to meet the needs of their child with autism while also meeting the needs of their child who did not have autism. One caregiver acknowledged that she was dealing with the reality of the diagnosis, but her husband was in denial. This placed stress on their marriage. Eventually, through information sharing and research, they both accepted their son’s diagnosis to move forward with providing him an optimal quality of life.

Interpretation of the Findings

Nineteen open-ended questions were used to obtain thick, rich descriptions of the essence of the caregiver’s experience in raising a child with autism. Not only did the answers given to the questions help to inform research, but the caregiver responses also brought about an understanding of those experiences by addressing the transcendental, phenomenological research questions that guided the study:

1. What is the lived experience of primary caregivers raising a child with autism?
2. What challenges have primary caregivers faced in accessing and using services?

In previous literature, the severity and level of functioning due to autism varied. Autism was characterized by impairments in communication, developmental delays, impairment in social interaction, and repetitive patterns of behavior (NIH, 2014). Also, autism awareness and understanding had been illuminated through community efforts of organizations like Autism Speaks (Quirantes, 2009), Autism Society of America, and Easter Seals.

Findings from the current study extended the knowledge in the discipline regarding disparities in unmet needs as expressed by the primary caregivers, and in the less than desirable experiences the caregivers endured when they realized the providers lacked the knowledge and skills to treat their child (see Chiri & Warfield, 2012). Also, the research by Chiri and Warfield (2012) and Vohra et al. (2014) was valuable in confirming the problems the target population encountered in accessing services and the quality of care they received. The cookie cutter approach to providing access to the appropriate level of care and rendering services to school-age children that is child specific does not contribute to identifying key factors to be taken into consideration in the development and delivery of healthcare (Strunk et al., 2014).

Findings from my study were consistent with Strunk et al. (2014). The two similar themes were the overall experience and challenges. One caregiver in the current study shared that there was a lack of information provided on the overall diagnosis. This was why she did not know what to expect from one day to the next. Sometimes the child's speech was difficult to understand, and the next they could have a normal conversation. Another caregiver noted that every day was an adventure with highs and lows. The caregiver raising twin boys on different ends of the autism spectrum realized her sons needed access to services and resources that would meet their individual needs. However, the one service they both needed, ABA, had a long wait list, and there were limited providers. The other caregiver raising twins had no support to provide her with a break, like respite services, and no family member or resource to assist with getting them on and off the bus. For her, everyday living became overwhelming. Each participant shared at least one positive outcome when discussing their overall experience despite the barriers, challenges, and stressors they faced due to their resilience (see Rutter, 2013).

In this study, caregivers recognized the importance of family relationships and the impact on positive outcomes for their children. Parenting resilience facilitated their ability to adjust to the challenges, which was also noted by Suzuki et al. (2013). Other subthemes that surfaced in the current study and the study conducted by Kapp and Brown (2011) were spousal relationships, family time, and routines. School staff helped to establish a regular routine for the child with autism while away from home. The children in the home who did not have a diagnosis of autism supported their sibling, which created a sense of togetherness as expressed by many of the caregivers. Stressors the parents experienced were eased. Although the dynamic had changed after the diagnosis, they became closer than ever with the exception of the caregiver of the fraternal twins. She was divorced from her husband shortly after the twins were diagnosed, and the family adjusted.

Greef and Nolting (2013) compared stress levels of families who had a child with autism versus those that did not. The similar finding revealed in my study was having a child with autism and one without in the same household tested caregivers' resolve and ingenuity in planning activities that met the needs of the entire family. The child with autism gaining access to needed services depended on the type of insurance they had: no wait list and access to services for the children with autism who had Medicaid, and a wait list for those who had private insurance due to a limited number of service providers. Increased rates of utilization of medical services was noted in the study by Broder-Fingert et al. (2014) and was identified by three of the caregivers in my study.

Within this study, all of the caregivers said it was important that the service provider possess the skillset to treat their children and help them to address as well as understand the change in behaviors. Angell and Solomon (2014) provided the premise for understanding those service provider and family relationships. This helped to facilitate the primary caregiver’s acceptance of the diagnosis while at the same process their emotions regarding this major life change and the struggle with how to pay for services. Similar to findings from a Thomas et al. (2007), caregivers in the study expressed a desire for support to address the unmet needs and to access much needed resources and support. Broader-Fingert et al. (2014) espoused the importance of increasing the service provider’s confidence to care for children with autism by enhancing their understanding of the diagnosis which facilitated access to care which would help to meet some of the unmet needs.

Limitations of the Study

Four limitations of this study were identified:

1. Choosing a qualitative research design as the method of inquiry, the findings will not be generalizable beyond the sample participants.
2. Primary caregivers, as defined for the purpose of this study, renders the findings of the study to be limited.
3. Participants may experience problems recalling information accurately; thus, having a direct impact on the “essence” of the experience shared. However, the participants freely shared the effects on them as the primary caregiver and on their families and the challenges they faced.
4. Unconscious biases tend to influence choices one makes. As the researcher, helping to raise my grandson who is a child with autism, set the stage for preconceived notions and my own personal experiences regarding the

> “essence” of the experience. Because I was fully aware of these unconscious biases, I explored each participant’s experience further, through additional questioning, to ensure the data collected was the lived experience of the primary caregivers and not my own. Also, a technique called reframing was employed and allowed the participant, in real time, to know the experience shared has been captured accurately.

Recommendations

Expanding the current research to include the establishment of collaborative partnerships between health care providers, social workers, educators, community service providers, and the primary caregivers, would inform all parties on how to meet the general, as well as, individual specific needs of the child with autism and their primary caregivers. Also, the usefulness of existing resources as well as accessibility to those resources can be explored.

Additionally, further inquiry should be conducted around the 5 themes and the 16 subthemes that emerged. For example, one theme that emerged from the data was the overall experience of the primary caregivers in raising a school-aged child with autism. Within this theme, one major subtheme surfaced—lack of information. When it is suspected a child may have a diagnosis of autism or when a diagnosis of autism is confirmed, a packet of information could be provided to the primary caregiver. Within this study, a gap in the provision of information packets was revealed, as five primary caregivers shared they received no packet at the point of the initial diagnosis. This packet would include, but would not just be limited to, information in laymen terms about the diagnosis, autism fact sheet (one page), next steps, provider information, basic information on treatment interventions, doctors or specialists in the area with the skillset to treat a child with autism, support group information, and other resources. Service providers would benefit from the outcomes of future research that will promote change in how services are delivered to the primary caregivers as well as the child with autism. As a considerable gap in literature exists on primary caregivers of school-aged children with autism, further research could bring about a full understanding of the experience the primary caregivers faced, while at the same show the study can be replicated.

Implications

As noted in Chapter 1 of this manuscript, primary caregivers raising a child with autism experience challenges that impact overall family functioning, sibling relationships, parental expectations, health, and marriages. The implications for social change are many. One challenge revealed is the gap in research relating to the primary caregiver's experiences in raising a child with autism and the challenges faced in accessing services. Findings helped to bring about a better understanding of not only the experience of raising a child with autism, but also the best way to support the caregivers through programs, services and resources. This included, but is not limited to, the provision of specific information regarding the diagnosis, behaviors, expectations, treatment modalities, where to find services providers with the skillset who can provide treatment, support groups, other resources, and the like.

A single mother who worked in the health care field and is a mother of two, one child with autism and one teenage child without autism, recalled raising her son with autism as a learning experience. “It is something you kind of figure out as you go. There is no set rule book for how each kid is going to act. The resources available may not specifically apply to your child. It’s really a lot of learning as you go”. Every caregiver experienced there being a limited number of providers who are knowledgeable on how to treat children with autism for basic services from dental care to behavioral services and the long wait list often encountered when you find a provider before the services can even be accessed or used.

Also, the study made known implications for change in how supportive relationships are to be established between the physicians, mental health providers, specialists, social workers and care managers. Coordinating care for a child with autism should include services that would be provided to the caregivers in hopes of alleviating some of the stressors brought on by raising a child with autism. There is no cure for autism; thus, raising a child with autism is a life long journey. Care coordination of services would meet not only the needs of the child, but the primary caregiver who is to support the child with autism. Some caregivers raising children with autism experience high levels of stress; however, some reported the joy experienced in raising a child with autism. According to Toomey et al. (2013), the quality of care for a child increased with care coordination of services. Primary caregivers need support too in order to become their child’s best advocate. First and foremost, the primary caregiver should be perceived as an integral part he collaborative process in choosing a service provider based on options given and making informed decisions regarding the treatment interventions to be employed. Also, their unique and often common experiences should be valued, based on their perspective, as “the heart” of the experience.

Researcher Reflections

Although I am a grandmother of an adolescent with autism and I have been a helping professional for over 25 years, serving children with autism and their families for 15 of those years, I realized there was so much more I needed to learn. The task that came easy within my study was conducting the interviews. The most difficult tasks was analysis of the data and recruitment of participants. I left each interview asking myself, what would I have done? Why? Quickly, I realized the importance of having a resource list available outlining free and low-cost counseling/mental health services (Appendix B). Analysis of data was difficult as the participants shared a wealth of information, rich stories, and were very forthcoming in sharing their perspective. As IRB approval was given towards the end of the academic school year for schools in the Washington, DC metropolitan area, the recruitment flyer had to be redistributed three times.

Through the process of conducting research, I realized my passion lies in understanding how one’s vulnerabilities can be used to promote resilience. The study participants, through their honesty and willingness to share, experienced resilience and expressed healing through the process. One caregiver noted “no one has ever asked me how I felt about raising a child with autism or how my day went or the challenges I faced.” Then, she began to cry. Per the participants, the additional resources they were able to identify has strengthened their circle of support. Through this experience, each of the participants acknowledged they will no longer worry about or make attempts to live up to someone elses expectations of where their child should be. Also, they shared it is important to celebrate successes the child and the family achieves, together, along the way. I had experienced helping to raise my grandson who has a diagnosis of autism and is on the high functioning end of the spectrum; but, with each interview and perspective shared, similarities were illuminated, and the differences showed how the essence of the experience was uniquely their own. I was engrossed in actively listening to the heart of their experience until I forgot about my own. Quickly, I realized the difference between their experience and my own was I never functioned as the primary caregiver. This allowed me to keep everything in perspective and clearly, I was able to distinguish between their experience and my own; thus, keeping integrity throughout and ensuring their perspective was captured.

Conclusion

My study focused on the lived experiences of primary caregivers, from their perspective, raising school-age children with autism. Some of the findings from my study were similar to data found within studies conducted by Garmezy (1993), Rutter (2013), Werner (2005, 2012), and Zimmerman (2013). The perspective of the primary caregiver sheds light on how they can best be supported. The defining differences between this study and previous studies was how primary caregiver and school-aged was defined.

I needed to be in a different position to affect social change in such a way that the voices of these primary caregivers would be heard. Conducting this research allowed me to grapple with the gap in literature while at the same time heighten the awareness relating to the primary caregiver’s experience, the unmet needs of not only the child with autism, but the primary caregivers and their families as well. Also, behaviors of the child associated with the diagnosis, emotions after learning of the diagnosis, and eventually the acceptance of it, the change in the family dynamic from vacations that would be taken and where, or even if, to the patience needed to deal with the disruption to marriages emerged. For some, a total change in lifestyle was required that included engaging in more activities in the home than outside the home.

The five themes and respective sub-themes that emerged, led to the conclusion that primary caregivers know how they can best be supported in raising a child with autism. Also, sharing the experiences from their perspective, revealed the primary caregivers were proactive when enough information was not provided about the diagnosis, treatment, and resources. However, they were reactive when attempting to access the services for which their children had been recommended and there were not enough providers in their servicing area or the cost of the services were not covered in full or at all by their insurance.

Difficulties were experienced and challenges faced whether it was a two parent household or a single parent household or whether they had private insurance or government issued insurance (Medicaid). All of the primary caregivers were willing to keep asking questions while advocating for their child until their concerns had been adequately addressed. The research conducted by Strunk et al. (2014) supported the outcomes of my study. Also, at the same time, my study enhanced the existing research which was limited relating to primary caregivers raising school-age children with autism. The disparities in unmet needs, as it relates to services, were addressed in existing research (Chiri & Warfield, 2012) and this study as well. The research of Huang et al. (2014) supported findings within this study regarding the affect of behaviors associated with autism, the impact on the child and the family, the stress experienced, and changes in emotions that can be experienced from day-to-day. The purpose of this study was achieved as challenges faced in raising a child with autism and in accessing services was shared from the perspective of the primary caregiver.

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Appendix A: Interview Protocol

Interview Protocol: Understanding the challenges caregivers of children with autism face in accessing services.

Time of Interview:
Date:
Place:
Interviewer: Anita P. Jones
Interviewee:

The purpose of this study is to gain an understanding about the diverse, lived and often common experiences of primary caregivers in raising a child with autism and the challenges they face in accessing services.

Questions:

1. What is it like to be the primary caregiver of a child age 5-8 with autism?
2. Describe a typical day for you.
3. Share how you learned your child had a diagnosis of autism?
4. After receiving a diagnosis of autism, what were your thoughts? How did you feel emotionally?
5. How has your day-to-day life changed since the diagnosis?
6. How have you managed your child’s health care needs?
7. What support do you need as the primary caregiver?
8. What needs does your child have that remain unmet?
9. Describe the relationship between you and the service providers?
10. What challenges have you faced in accessing services?
11. What challenges have you faced in using services?
12. How has raising a child with autism impacted the family?
13. In your opinion, what services, programs and supports have been helpful and why?

14. Is there any additional information you would like to provide that helps to explain your lived experiences in raising a child with autism and the challenges you have faced in accessing services?
15. How old is your child?
16. What grade are they in?
17. Is your child male or female?
18. What city and county do you reside in within the Washington, DC metropolitan area?
19. What is your specific relationship to the child?
20. Thank you for taking the time to participate in this interview. I will be providing you with a transcript of the audio tape and my notes so that you may review them and make any corrections you deem necessary to ensure your words were captured accurately. The information obtained today and used in the study may be published. Your name and any identifying information about you will be kept confidential as pseudonyms will be used and hard copies of any information be kept in a secured place.

Appendix B: Counseling Services

Free and Low Cost Counseling Services

Department of Behavioral Health

DC ACCESS Helpline at 1-888-793-4357 (24 hours/7 days a week)
Same Day Urgent Care
You can walk into a clinic and be seen the same day without an appointment from 8:30 am to 3 pm. Services include assessment, counseling, psychiatric evaluation and medication management. You may be referred to a community provider for ongoing care. If you have questions, please call (202) 442-4202.

- **Emergency Services**
  Residents experiencing a psychiatric or emotional crisis can be treated at the emergency facility located on the grounds of the old DC General Hospitals. Crisis beds are available for up to a 14-day stay as an alternative to psychiatric inpatient hospitalization. In addition, a mobile crisis team of clinicians on will treat individuals who are unable or unwilling to go to the emergency care facility in their homes, in the community or on the street. The mobile crisis service can be reached by calling the Access Helpline at 1-888-793-4357.

Community Based Service Providers

Provider	CEO	Address	Phone / Email	Child / Youth Service Provider?
Anchor Mental Health	Denise Capaci	1001 Lawrence Street, NE Washington, DC 20017	(202) 635-5900 Denise.Capaci@catholiccharitiesdc.org	No
Community Connections, Inc.	Dr. Maxine Harris	801 Pennsylvania Avenue, SE Washington, DC 20003	(202) 546-1512 MHarris@CCDC1.org	Yes
Contemporary Family Services	Dr. John Monroe	1300 Pennsylvania Avenue SE Washington, DC 20020 6323 Georgia Ave., NW	(202) 735-0761 / (202) 525-1527 jmonroejr@me.com	Yes

		Washington, DC 20011		
Family Matters of Greater Washington	Tonya Jackson Smallwood	1509 16th Street, NW Washington, DC 20036	(202) 289-1510 tsmallwood@fcsdc.com	Yes
Family Wellness	Ms. Sharon Cyrus	2526 Pennsylvania Avenue SE Washington, DC 20020	(202) 748-5641 scyrus@theFWC.net	Yes
First Home Care Corporation	Ms. Gina Fusco	1012 14th Street, NW, #1400 Washington, DC 20005	(202) 737-2554 gina.fusco@uhsinc.com	Yes
Hillcrest Children & Family Center	Juanita Price	915 Rhode Island Ave, NW Washington, DC 20009	(202) 232-6100 jprice@hillcrest-dc.org	Yes
Inner City Family Services	James Walker	2307 Martin Luther King Avenue, SE Washington, DC 20020	(202) 525-4855 Skip@innercityfamilyservices.com	Yes
Latin American Youth Center	Carlos Vera	1419 Columbia Road, NW Washington, DC 20009	(202) 319-2225 carlos@layc-dc.org	Yes
Life Enhancement Services	Dr. Chandra Colvin	1818 New York Ave, NE Washington, DC 20002	(202) 269-2401 CColvin@lesdc.org	Yes
Life Stride	Joyce L. Drumming	3005 Bladensburg Road, NE Washington, DC 20018	(202) 635-2320 jdrumming@earthlink.net	Yes
Mary’s Center	Maria Gomez	2333 Ontario Road, NW Washington, DC 20009	(202) 483-8319 mgomez@marysCenter.org	Yes

MBI	Charles Avery	4130 Hunt Place, NE Washington, DC 20019	(202) 388-4300 Cavery@mbis.com	Yes
MD/DC Family Resource	Dr. Beth Crawford	6192 Oxon Hill Road Oxon Hill, MD 20745 903 Brightseat Road Landover, MD 20785	(301) 567-8311 (301) 333-2980 bcrawford@mfrinconline.com	Yes
McClendon Center	Dennis Hobbs	1313 New York Avenue, NW Washington, DC 20005	(202) 737-6191 (202) 745-0073 dhobb@mcclendoncenter.org	No
Mental Health Services Division	Theresa Donaldson-DePass	35 K Street, NE Washington, DC 20002	(202) 442-4876 Theresa.donaldson@dc.gov	Yes
Neighbors Consejo	Glenda Rodriquez	6323 Georgia Avenue, NW Washington, DC 20011	(202) 234-6855 grodriguez@neighborsconsejo.org	No
Psychiatric Center Chartered	Ellire Hall	3001 Bladensburg Road, NE Washington, DC 20018	(202) 635-3577 ehall@psych-center.com	No
Volunteers of America Chesapeake	Russ Snyder	52 Quincy Place, NW Washington, DC 20001	(202) 223-9630 rsynder@voaches.org	No
Washington Hospital Center / Behavioral Health Service	Tamika Sanford	216 Michigan Avenue, NE Washington, DC 20017	(202) 877-6333 Tamika.R.Sanford@Medstar.net	No

Crisis Hotline	Alexandria, VA	(703) 746-3401
Emergency Services	Arlington, VA	(703) 228-5160 must be a resident of Arlington Co
Fairfax County CSB		(703) 573-5679

Prince George’s County	Mental Health Services	(301) 699-2838
	Maryland Family Resources	(301) 333-2980
	Family Crisis Center, Inc.	(301) 779-2100

Appendix C: Recruitment Flyer

Walden University
IRB Approval Number: #05-10-17-0135382

Seeking volunteers to participate in a study

A study is being conducted on *Caregivers' Challenges in Accessing Services for Children With Autism*. The purpose of the study is to gain an understanding about the diverse, lived, and often common experiences of primary caregivers raising a child with autism. The study will seek to explore the challenges primary caregivers face in accessing and using services.

To participate, you must:

- Be the primary caregiver of a child with autism
- Have a child who is between the ages of 5-8
- Live in the Washington, DC Metropolitan area
- Speak English
- Agree to participate in an interview

And, your child cannot be enrolled with the health plan Health Services for Children with Special Needs.

Interested? Please contact Anita Jones.

Privacy: Your participation is completely voluntary. Nothing will happen to any services you receive if you choose not to participate. A portion of the interview will be published, but will not identify you in any way.

An incentive in the amount of a $20 Visa gift card will be given to each participant at the conclusion of the study.