Obtaining a First Diagnosis of Autism Spectrum Disorder: Process and Contributors from a National Study

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This dissertation conducted the first comprehensive study of the process of obtaining an Autism Spectrum Disorder (ASD) diagnosis for parents in the United States. Parents frequently report that the process is challenging, yet the process is understudied, which has provided little in the way of guidance to ease burden on families. In addition to better describing the process, this dissertation sought to investigate three potential contributors to difficulty experienced in the process: patient-provider relationships, racial identification, and family income. A total of 406 parents of children with ASD were recruited from the SPARK research registry and administered a survey gathering information on 1) participant demographics, 2) the ASD diagnostic process, and 3) the quality of patient-provider relationships (i.e. trust and communication). Descriptive statistics were used to provide a detailed description of the process and its various steps. Continuous variables from the DPQ were used to develop a measure of diagnostic difficulty. A series of multiple linear regression models were used to assess the association between patient-provider relationships and difficulty. One-way analysis of covariance (ANCOVA) was used to evaluate whether race and income influenced difficulty. Results revealed invaluable descriptive information that concretized the steps of the ASD diagnostic process in the United States. Additionally, results revealed that poorer patient-provider relationships were associated with greater difficulty experienced obtaining an ASD diagnosis. There was some evidence to suggest that diagnostic difficulty varied by race, but no evidence that difficulty varied by family income. Results provide novel context that better illustrates what the ASD diagnostic process looks like for

families in the United States. The identification of broader trends lays the necessary groundwork for future in-depth study and presents a wealth of opportunities for social workers to ease the burden on parents of children with ASD and their families.

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Dedication

To my grandparents, Marie Quinn, Arthur Quinn, and Louise MacKenzie.

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1.0 Introduction

Caregivers of children and adults with autism spectrum disorder (ASD) experience poor outcomes, such as stress, depression, anxiety, and poor self-efficacy, at a higher rate than both parents of typically developing children (Keenan, Newman, Gray, & Rinehart, 2016; Padden & James, 2017). Distress in this population has been linked to a wide range of challenges related to parenting an individual with ASD, such as management of symptoms and behaviors, financial burden, navigating service systems, social stigma, and lack of social support (Bonis & Sawin, 2016; Chan & Lam, 2017; Falk, Norris, & Quinn, 2014; Jellett, Wood, Giallo, & Seymour, 2015; Tomeny, 2017). One particularly salient challenge for caregivers is obtaining a formal ASD diagnosis for their children. The process can be quite complicated, which leads to unsatisfying experiences and unnecessarily delays in the initiation of treatment (Corcoran, Berry, & Hill, 2015; Crane, Chester, Goddard, Henry, & Hill, 2016). These challenges may be compounded for families with racial minority status and those with lower income. Furthermore, the quality of relationships with early child providers such as pediatricians or primary care providers, who tend to be the first professionals to field developmental concerns, suggest these professionals may be important gatekeepers to the ASD diagnostic process, perhaps with some bearing on the overall difficulty of the process for parents. Social work perspectives are largely underrepresented in ASD scholarship; however, a greater representation of some of social work's core values in the ASD literature has the potential to make meaningful contributions in this area by better understanding and streamlining the ASD diagnostic process in an effort to better meet the needs and improve the outcomes of diverse caregivers of individuals with ASD.

1.1 The Problem of the Diagnostic Process for Caregivers of Individuals with ASD

Caring for an individual with Autism Spectrum Disorder (ASD) can present unique challenges across the lifespan. One challenge commonly cited by caregivers is the process of obtaining a formal ASD diagnosis for their children (Bonis & Sawin, 2016). Caregivers have reported frustrations with lack of ASD expertise among pediatricians, multiple visits with a wide range of professionals, and feeling as if their concerns were invalidated by providers (Crane et al., 2016a; Gordon-Lipkin, Foster, & Peacock, 2016; Katharine Elizabeth Zuckerman, Lindly, & Sinche, 2015). For many families, the diagnostic process can also involve other diagnoses before arriving at a final diagnosis of ASD (Jónsdóttir, Saemundsen, Antonsdóttir, Sigurdardóttir, & Ólason, 2011; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). These characteristics can often lead to greater delays in diagnosis and greater overall dissatisfaction with the process for caregivers (Crane et al., 2016; Goin-Kochel, Mackintosh, & Myers, 2006; Rosenberg, Law, Landa, Law, & Stuart, 2011; Zuckerman et al., 2015). Furthermore, there is evidence to suggest these challenges may be disproportionately experienced by racial minorities and families of lower socioeconomic status (SES) (Altiere & Von Kluge, 2009; Jimenez, Barg, Guevara, Gerdes, & Fiks, 2012; Magaña, Lopez, Aguinaga, & Morton, 2013; Rosenberg et al., 2011; Katharine E. Zuckerman, Sinche, et al., 2014).

Despite the challenging nature of obtaining a diagnosis, to date, few studies have comprehensively examined the diagnostic process in the United States. Two studies from the United Kingdom and one from France have investigated this process in substantial detail with large samples, which provides preliminary insights into what the process might look like for American parents (Chamak, Bonniau, Oudaya & Ehrenberg, 2013; Crane, Chester, Goddard, Henry, & Hill, 2015; Howlin & Moore, 1997). Other studies have investigated the process using small, regionally

restricted samples of American parents, mixed samples of American parents in combination with parents from multiple other countries, or mixed samples of parents with autistic children in combination with parents of children with other disorders, making it difficult to understand the unique experiences of parents of children with ASD in the United States (Goin-Kochel, Mackintosh & Myers, 2006; Oswald, Haworth, Mackenzie et al., 2017; Wong, Yu, Keyes, McGrew, 2017). These studies have also generally gathered less comprehensive information about diagnostic experiences than those studies conducted in the UK and France. Furthermore, there is little understanding of how intersections of racial identity and class may lead to different diagnostic experiences in the US. Thus, there exists a clear need for a large-scale comprehensive study of the ASD diagnostic process in the United States that investigates the influences of race and class on family experiences and difficulty in the process.

In addition, emerging research suggests that pediatricians and primary care providers may be the first professional consulted by parents with developmental concerns (Chamak & Bonniau, 2013; Chamak et al., 2011; Wong et al., 2017), which makes them important gatekeepers to early screening and the initiation of the ASD diagnostic process. However, while one U.S. study of the diagnostic process found qualitative evidence that patient-provider interactions may be a source of strain throughout the diagnostic process (Wong, Yu, Keyes, & McGrew, 2017), no studies have quantitatively examined how the quality of relationships between parents and their children's pediatricians or primary care providers may be related to overall difficulty experienced throughout the ASD diagnostic process.

1.2 Relevance to Social Work

1.2.1 Social Workers as Care Coordinators

Social workers are already major service providers to individuals with ASD and their families (Casey & Elswick, 2011; Hiebert-Murphy, Trute, & Wright, 2011; Morris, Muskat, & Greenblatt, 2018). They work in myriad capacities in community and state agencies, health and other human service systems, educational systems, and various other therapeutic and support systems that serve individuals with ASD and their families. However, social work perspectives remain underrepresented in ASD scholarship (Bishop-Fitzpatrick, Dababnah, Baker-Ericzén, Smith, & Magaña, 2019). Social work training in systems theory paired with the values expressed in the National Association of Social Workers (NASW) Code of Ethics provide a forward orientation to the diverse experiences of people with ASD and their families as they navigate the social environment across the life course, and an understanding of the complexity of their lives. As per the Code of Ethics, social work practice and scholarship is also rooted in a social justice framework and an understanding of racial disparities, well positioning social workers to address the historical marginalization of individuals with disabilities as well as the intersections of race with disability.

1.2.2 Supporting Caregivers

Most extant research on interventions to improve caregiver outcomes investigates micro-level interventions that improve caregiver knowledge or skills of symptom and behavior management to be used in dyadic interactions between caregivers and their child with ASD. These

interventions tend to be justified by the well-established link between child characteristics, such as ASD symptom severity and challenging behavior, and poorer outcomes for caregivers (Beer, Ward, & Moar, 2013; Estes et al., 2009; Falk et al., 2014; Hou, Stewart, Iao, & Wu, 2018; Jellett et al., 2015; MacHado Junior, Celestino, Serra, Caron, & Pondé, 2016). However, improvements in psychological and emotional outcomes for caregivers who participate in such interventions tend to be modest (Ginn, Clionsky, Eyberg, Warner-Metzger, & Abner, 2017; Karst et al., 2015; Lecavalier et al., 2018; Poslawsky et al., 2015; Reitzel et al., 2013; Suzuki et al., 2014). This may be due to the presence of a wider range of influences of poor caregiver outcomes that are not addressed in current interventions and approaches (Bonis, 2016). In other words, the literature demonstrates that caregiver outcomes are not necessarily an absolute function of ASD behavior and symptomatology, which raises concerns that the primary targets of existing efforts to improve caregiver outcomes may be too narrow in scope. More specifically, limiting intervention approaches to caregiver microsystems overlooks the importance of larger systemic factors that influence poor outcomes, including commonly reported negative experiences with the ASD diagnostic process. Best practice in social work often incorporates an ecological systems framework, which emphasizes assessment and intervention at various system levels. Rooted in this ecological systems perspective, social work scholars working with caregivers can make meaningful contributions to the field by better examining the systems of care that parents of individuals with ASD must navigate in order to meet their needs.

Historically, social work has not had a strong voice in ASD scholarship. The ASD literature has largely been dominated by psychological and psychiatric perspectives, rooted in the medical model (Bricout, Porterfield, Tracey, & Howard, 2004; Eyal, 2013). The dominating medical model often prioritizes micro-level, deficit-focused approaches, specifically geared toward treating

individuals with ASD (Bricout et al., 2004). The medical model's focus on pathology and individual symptomatology often ignores the important—and challenging—role of caregivers in the lives of individuals with ASD. Furthermore, emerging empirical work that does include caregivers tends to follow a similar deficit-based, symptom-treating pattern; caregivers are often tasked with learning an abundance of information related to parenting a child with ASD or undergoing training to develop therapeutic techniques to help enhance developmental skills and/or reduce problem behavior in their children. While these approaches may involve the caregiver, they primarily remain centered on supporting individuals with ASD. Social workers' professional strengths in family support, including recognition of the important and challenging role of family members in the lives of individuals with ASD, may help to place greater emphasis on the development of interventions that address the direct support needs of caregivers. There exists a clear opportunity for social workers to establish themselves in the ASD field as strong family advocates and advance the field in a way that provides more comprehensive support for caregivers of individuals with ASD.

1.2.3 Understanding the ASD Diagnostic Process and Identifying Areas for Improvement

Caregivers' experiences of navigating systems of medical and clinical care throughout the ASD diagnostic process are often described as challenging, frustrating, and confusing (Corcoran et al., 2015). Parents are often plagued by long delays between initial concern and ultimate diagnosis, which leads to commensurate delays in beneficial therapy (Zuckerman et al., 2014). Links have been made between the number of providers seen in the process and overall satisfaction (Goin-Kochel, Mackintosh, & Myers, 2006). However, despite clear indications that the process is notably difficult and unnecessarily delayed, studies providing a comprehensive understanding

of the specific steps involved in the process have yet to be conducted in the United States, making it difficult to draw conclusions about what *exactly* makes the diagnostic process so burdensome. Also of note, a wide range of mostly qualitative studies have revealed that parents tend to describe some sort of interpersonal issues with providers throughout the process, including problems with providers invalidating their initial concerns and providing little in the way of support and transparency throughout the diagnostic process and after the diagnosis is made (Crane et al., 2018; Wong et al., 2017). However, despite persistent references to interpersonal issues between parents and providers throughout the process, researchers have yet to quantitatively examine whether patient-provider relationships are related to difficulty with the diagnostic process.

The social work profession places great emphasis on the value of evaluation of programs and practice. Program evaluation is a key determinant in establishing accountability among service providers, fostering trust among clients and consumers, and ensuring program viability (Centers for Disease Control and Prevention, 2011; Vedung, 1997). More importantly, evaluation provides an evidence base that can more precisely guide program improvement (Centers for Disease Control and Prevention, 2011; Vedung, 1997). Thus, social workers are well positioned to better examine the specific elements of the ASD diagnostic process and better understand how experiences vary across families in an effort to streamline the process and potentially alleviate stress and frustration for caregivers.

1.2.4 Understanding Diverse Caregiver Experiences

Social work's commitment to social justice is desperately needed in the field. Current researcher studying caregiver outcomes and interventions are overwhelmingly lacking in diversity, with homogenous samples of predominantly Caucasian, more affluent participants. However,

there is evidence to suggest that caregivers from vulnerable and oppressed groups, such as ethnic and racial minorities and low income caregivers experience disproportionally poorer outcomes than their white, more affluent counterparts (Mandell et al., 2001; Thomas et al., 2007). This raises serious ethical questions about whether researchers truly understand the impact of caring for an individual with ASD on all caregivers across a range of intersectional identities. Furthermore, there is evidence to suggest that racial and ethnic minorities and low-income families may experience disparities in the ASD diagnosis process. For example, age of diagnosis tends to be later for children of color than it is for white children (Altiere & Von Kluge, 2009; Jimenez et al., 2012; Magaña et al., 2013; Rosenberg et al., 2011; Zuckerman et al., 2014). Additionally, prevalence rates of milder forms of ASD are higher in white children suggesting that non-white children with milder ASD may go undiagnosed (Bhasin & Diana, 2007; Kogan et al., 2015; Ratto, Reznick, & Turner-Brown, 2016). Lower SES is typically associated with limited access to quality health care, which can lead to longer delays in diagnosis (Thomas et al., 2012; Zuckerman et al., 2014). Social work's commitment to social justice should extend to empirical research in the ASD field, with social workers striving for equal representation of vulnerable groups in order to elucidate the experiences of all caregivers of individuals with ASD.

1.3 Overview of Study

The purpose of this study was to better understand the characteristics of the ASD diagnostic process across a range of diverse groups on a national scale using an existing registry of parents of children with ASD. The study also conducted preliminary analysis of a new measure of diagnostic difficulty. Additionally, this study assessed the quality of trust and communication in

the patient-physician relationship to explore whether parent-provider relationships with children's early medical providers were associated with difficulty experienced in the ASD diagnostic process.

Utilizing a cross-sectional survey design, 400 parents of individuals with ASD were recruited across the United States. All participants were administered a survey covering: (1) demographic information, (2) detailed characteristics of the diagnostic process as well as overall satisfaction with the process, and (3) perceptions of the quality of communication and degree of trust with the child's pediatrician or primary care provider at the time of the child's diagnosis. Continuous items from the survey were used to initially develop and analyze a measure of diagnostic difficulty.

The findings of this study provide researchers with a more comprehensive understanding of diagnostic experiences for caregivers of individuals with ASD across a range of diverse groups on a national scale. The implications of these findings can be used to improve the diagnostic process and remove barriers to obtaining an ASD diagnosis.

1.3.1 Study Aims

The present study sought to better understand the ASD diagnostic process as well as the potential influence of patient-provider relationships and sociodemographic variables on overall difficulty of the process by investigating the following specific aims:

Aim #1: Describe the process of obtaining a first diagnosis of autism spectrum disorder (ASD) in the United States. This study gathered information about the various steps in the process of obtaining a formal diagnosis of ASD, including details about initial developmental concerns, the diagnostic process, the final diagnosis, and overall satisfaction with the various steps in the process.

Aim #2: Examine the degree to which perceptions of the patient-physician relationship are related to difficulties in obtaining an ASD diagnosis. This study measured caregiver perceptions of quality of communication and trust in their relationship with their child's primary care provider at the time of diagnosis and examined whether more favorable perceptions are linked to fewer barriers in the diagnostic process.

Aim #3: Explore how difficulty throughout the process of obtaining a first diagnosis of ASD varies by race and family income. Sociodemographic data was collected to provide preliminary insight into how characteristics of the process, as well as trust and communication with primary care providers, varied by racial identification and family income.

2.0 Literature Review

2.1 Overview of Autism Spectrum Disorder (ASD)

2.1.1 Prevalence

In 2014, the Center for Disease Control and Prevention (CDC) reported that the prevalence of children diagnosed with ASD in the United States had risen to 1 in 68, an almost 30% increase in just four years (Center for Disease Control and Prevention, 2014). Though only a handful of such large-scale epidemiological studies have been conducted in the United States, most of them indicate a steady increase in prevalence between the mid-1980s and 2012. The most recent CDC national survey estimates that there are anywhere between 500,000 and 1 million children living with ASD in the United States (Center for Disease Control and Prevention, 2014). Rates of ASD in adults are largely unknown, although some studies estimate that 1% of the adult population is affected by the disorder (Buescher, Cidav, Knapp, & Mandell, 2014). While the true prevalence among adults remains unstudied, we can be certain that the current growing population of children with ASD will soon become a sizable population of adults with the lifelong disorder.

According to the CDC's most recent epidemiological study, boys are 4.5 times more likely to receive an ASD diagnosis than girls (Center for Disease Control and Prevention, 2014). These gender ratios are similar across major racial and ethnic groups (Bhasin & Diana, 2007). Results from the CDC study also estimate that 44% of children with ASD present with average or above-average intellectual ability (IQ > 85), 24% present in the borderline range (IQ 71-85), and 32% have an intellectual disability (IQ $\leq$ 70) (Center for Disease Control and Prevention, 2014).

Distribution of intellectual ability is comparable across Black and white children in the United States; however, ASD prevalence estimates for Latino children tend to be lower overall than those for Black or White children (Mandell et al., 2009).

2.1.2 Characteristics of ASD

According to the most recent diagnostic criteria from the fifth edition of the Diagnostic and Statistical Manual (DSM-V), to receive an ASD diagnosis, individuals must have notable social and communication impairments, as well as the presence of restricted and repetitive behaviors (5th ed.; DSM–5; American Psychiatric Association, 2013). Social and communication impairments may include, but are not limited to, difficulties initiating communication or engaging in conversation, difficulties picking up on social cues or making eye contact, absence of interest in peers, and inappropriate facial expressions and nonverbal communication (American Psychiatric Association, 2013). Restricted and repetitive behaviors encompass a wider range of behaviors. Restricted interests may include, but are not limited to, age-appropriate interests (e.g. Disney movies) that are unique in their intensity or inappropriate or unusual interests (e.g. doorbell tones). They can also include hypersensitivity to sensory stimuli, such as temperature, sound, smells, or lights. Repetitive behaviors may include, but are not limited to, repetitive movement, such as flapping or rocking, repetitive use of objects, such as spinning the wheels of a toy car, or repetitive speech, such as echolalia or scripting (Autism Speaks, 2016). Repetitive behaviors may be characterized by an insistence on sameness or extreme rigidity regarding routines. Children with autism may also experience anxiety, mood, or hyperactivity problems, either with comorbid clinical disorders or just additional symptoms (Autism Speaks, 2016).

Individuals with ASD also commonly exhibit challenging behaviors (McTiernan, Leader, Healy, & Mannion, 2011; Oliver, Petty, Ruddick, & Bacarese-Hamilton, 2012; Schroeder et al., 2014). Minshawi et al. (2014) define challenging behaviors as "those behaviors that interfere with an individual's ability to function and often have the potential to cause harm or damage, such as physical aggression, verbal aggression, property destruction, tantrums, and self-injurious behaviors (SIBs)" (p. 125). Aggression and self-injurious behaviors are particularly common challenging behaviors in individuals with autism (Oliver et al., 2012). Prevalence estimates for self-injurious behaviors, which include head banging, hair pulling, self-biting, and self-scratching, are between 30% and 50% in children with autism (Buono, Scannella, & Palmigiano, 2010; Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007; Richards, Oliver, Nelson, & Moss, 2012). Prevalence estimates for aggression are even higher, with studies showing that 30%-68% of children with autism display behaviors such as hitting, kicking, and verbal aggression (Hill et al., 2014; Kanne & Mazurek, 2011; Murphy, Healy, & Leader, 2009).

Individuals with ASD tend to experience greater challenges with adaptive functioning (H. R. Hall & Graff, 2011). Adaptive functioning, also referred to as functional skills, daily living skills, or adaptive skills, refers to an individual's level of independence in everyday activities, such as feeding, dressing, and personal hygiene (Kanne et al., 2011). Individuals with autism frequently experience problems with adaptive skills in daily living, with particularly well documented challenges in sleeping or eating (Bonis & Sawin, 2016). They may also have extreme reactions to sensory input or sensory-seeking behaviors (Bonis & Sawin, 2016). Medical issues such as gastrointestinal problems, seizures, and genetic disorders are also common (Gaspar de Alba & Bodfish, 2011).

Individuals with ASD also experience a wide range of peripheral problems and diagnoses outside of these core diagnostic features. Comorbid diagnoses of Attention Deficit-Hyperactivity Disorder (ADHD), depression, tics and Tourette's Syndrome are also relatively common (Fernell, Eriksson, & Gillberg, 2013). Individuals with ASD also tend to experience substantial anxiety symptoms (Gaspar de Alba & Bodfish, 2011)(Fernell et al., 2013). Cognitive impairment is also common in many individuals with ASD. One review estimated that comorbid rates of intellectual disability can range from 15% to 20% (Fernell et al., 2013). The most recent CDC prevalence study estimates that up to 46.1% of children with ASD also meet criteria for intellectual disability (Center for Disease Control and Prevention, 2014).

Autism is generally considered a lifelong disorder (Lonnie Zwaigenbaum & Penner, 2018). While the exact causes of autism are still poorly understood, researchers have managed to identify a number of genetic and environmental risk factors. Dozens of possible chromosomal regions and genetic mutations have been identified that may be implicated in the development of autism spectrum disorder (Newschaffer, Fallin, & Lee, 2002). There is also significant diagnostic overlap between ASD and several existing genetic disorders such as Prader-Willi, tuberous sclerosis, and Fragile X syndrome, which suggests possible overlap in their genetic etiologies (Newschaffer et al., 2002). Twin studies suggest that autism is a moderately heritable disorder, which creates increased risk for individuals with family members with the disorder (Hallmayer et al., 2011). There is also an overall greater risk for autism in individuals whose parents are older or have a psychiatric disorder (Larsson et al., 2005). Prenatal factors such as exposure to intrauterine infections, and perinatal and neonatal factors, such as fetal distress, birth trauma, and low birth weight, have been associated with greater risk for ASD (Lyall, Schmidt, & Hertz-Picciotto, 2014)

Autistic-like traits have historically been reported in children exposed to severe trauma or social deprivation (Wolff, 2004), which suggests the social environment plays a key role in the development of ASD. Formal studies of risk factors in the social environment are uncommon, yet some risk factors, such as low parent wealth and the absence of early educational enrichment have been linked with higher risk for ASD (Larsson et al., 2005). Research in this area has instead focused on developing interventions that create more enriching, responsive social environments in order to treat the symptoms of ASD. Treatments such as Applied Behavioral Analysis (ABA) and early intervention have demonstrated success in this population, reducing symptoms, teaching adaptive skills, and improving functional outcomes (Matson et al., 2012; Warren et al., 2011). Intervention-based research provides compelling evidence that autism is not a deterministic genetic disorder; rather, the development of the disorder is dependent upon the interaction between genetic predispositions and the social environment.

2.2 Outcomes for Parents and Siblings

Although a direct examination of parent and family outcomes is beyond the scope of the present dissertation, an understanding of such outcomes provides strong rationale for conducting the present study. Families of children with ASD tend to score lower on measures of family adaptability, congruence, and cohesion and parents often report less family satisfaction (Gau et al., 2012; McConnell & Savage, 2015; Xue, Ooh, & Magiati, 2014). Having a sibling with ASD may present unique challenges, especially during childhood. A meta-analytic review of the impact of having a sibling with developmental disabilities showed small but significant negative impacts on siblings, including higher rates of depression and anxiety and worse behavioral adjustment

(Rossiter & Sharpe, 2001). Siblings have also reported increased loneliness as well as frustrations with some of the more severe behavioral problems common in ASD, such as behavioral disturbances or property destruction (Bagenholm & Gillberg, 1991). However, research in this area is notably outdated and mixed. Some research has found no significant differences in self-concept, self-competence, or social competence between siblings of individuals with ASD and siblings of typically developing individuals (Rao & Beidel, 2009; Rodgrigue, Geffken, & Morgan, 1993). One study found that siblings of children with ASD actually had a more positive self-concept that those siblings of non-disabled children (Macks & Reeve (2007). More work is needed to understand the impact of having a sibling with ASD on children, yet recent reports of poorer family functioning among families of children with ASD suggest there are likely adaptive challenges for all members of the family.

The impact of having a child with ASD on parents is more widely studied and parents of individuals with ASD experience a wide range of poor outcomes across many domains. One of the most comprehensively researched outcomes for parents of individuals with ASD is stress. Generally, it has been well established that these parents experience considerably more stress than parents of typically developing individuals (Al-farsi, Al-farsi, Al-Sharbati, & Al- Adawi, 2016; Keenan et al., 2016; Kissel & Nelson, 2014; Padden & James, 2017; Snow & Donnelly, 2016). Greater stress in this population is associated with a wide range of poor outcomes including increased depression and anxiety, poorer quality of life, lower relationship satisfaction, poorer perceptions of family functioning, and less adaptive coping (Cappe, Wolff, Bobet, & Adrien, 2011; Davis III & Kiang, 2018; Hsiao, 2018; Hsiao, Higgins, Pierce, Whitby, & Tandy, 2017; Sim, Cordier, Vaz, & Falkmer, 2016; Wang et al., 2013; Weitlauf, Vehorn, Taylor, & Warren, 2014).

Parents of individuals with ASD also experience poor mental health outcomes. They experience significantly more depression and anxiety than caregivers of typically developing children (Al-farsi et al., 2016; Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaidan, 2013; Cohrs & Leslie, 2017; Gong et al., 2015; Jeans, Santos, Laxman, Mcbride, & Dyer, 2013; Padden & James, 2017; Snow & Donnelly, 2016) and caregivers of individuals with other developmental disabilities (Hou et al., 2018). Prevalence estimates suggest that caregivers of individuals with ASD experience depression and anxiety at substantially higher rates than those reported in the general adult population (Bitsika, Sharpley, & Bell (2013) (Marshall, Kollia, Wagner, & Yablonsky, 2018). Depressive symptoms can predict more overall negative affect, including more frequent feelings of "distress, fear, and upset" (Pruitt, Willis, Timmons, & Ekas, 2016, p. 977). Depression in caregivers can also lead to decreased parental involvement in their child's life, including fewer and more frustrating parent-child interactions and less knowledge about their child's activities (Pruitt et al., 2016; Schiltz et al., 2018)

Caregivers of individuals with ASD are more likely to perceive problems with family functioning than parents of typically developing individuals (Bonis & Sawin, 2016; Pisula & Porębowicz-Dörsmann, 2017). Perceptions of impaired family functioning are often associated with greater depression, greater parenting stress, and poorer quality of life (Ekas et al., 2016; Hsiao et al., 2017; Kim, Ekas, & Hock, 2016; McStay, Trembath, & Dissanayake, 2014; Pisula & Porębowicz-Dörsmann, 2017; Xue et al., 2014).

The wide body of literature on outcomes for parents of individuals with ASD provides clear justification that this is a vulnerable population in need of additional support. As a result, researchers have been tasked with better understanding the mechanisms underlying these poor outcomes so that they may ultimately be improved.

2.3 Common Caregiving Challenges Associated with Poor Outcomes

The current dissertation study focuses on one specific challenge faced by caregivers of individuals with ASD: the ASD diagnostic process. The time leading up to and following diagnosis is often emotionally distressing for parents and there can be significant challenges to obtaining an appropriate and timely diagnosis (Bonis & Sawin, 2016). The process can be plagued by a host of barriers, including long delays, many different appointments, and negative experiences with providers (Daniels & Mandell, 2014; Martinez et al., 2018; Mazurek et al., 2014; Zwaigenbaum & Penner, 2018; Wong, 2017). Parents tend to report feeling invalidated, confused, and overall unsatisfied with the process (Carlsson et al., 2016; Chamak & Bonniau, 2013; Crane et al., 2018; Oswald et al., 2017; Zuckerman, Mattox, Sinche, Blaschke, & Bethell, 2014).

Poor outcomes experienced by caregivers have also been linked to a wider range of challenges related to parenting an individual with ASD. Although beyond the scope of this current study, a brief summary of these other challenges provides greater understanding of the complex caregiving experience for parents. First, managing issues with ASD symptomatology (i.e. deficits in social interaction or communication, repetitive behaviors, and restricted interests) can also present substantial challenges for caregivers and strong links have been found between general measures of ASD symptom severity and caregiver outcomes. For example, symptom severity is associated with greater parenting stress (Davis & Carter, 2008; Falk et al., 2014; Garcia-Lopez, Sarria, & Pozo, 2016; Kissel & Nelson, 2014; Tomeny, 2017; Wang et al., 2013). There is evidence to suggest that more severe symptomatology also puts parents at greater risk for mental health problems, such as depression, anxiety, and general psychological distress (Benson, 2006; Chan & Lam, 2017; Garcia-Lopez et al., 2016; Tomeny, 2017; Wang et al., 2013; Zablotsky, Anderson, & Law, 2013). Greater symptom severity is also associated with poorer family functioning, lower

family wellbeing, and greater negative impacts on spousal relationships (Kissel & Nelson, 2014; Miller, Shen, & Masse, 2016; Zablotsky et al., 2013).

Challenging behaviors are more common in ASD than in other developmental disabilities (Brobst, Clopton, & Hendrick, 2009; Estes et al., 2009) and can present significant challenges for caregivers. In particular, self-injurious behaviors, such as head banging, hair pulling, self-biting, and self-scratching, and aggression, such as hitting and kicking are quite common, affecting 30-68% of children with ASD (Buono et al., 2010; Dominick et al., 2007; Hill et al., 2014; Kanne & Mazurek, 2011; Murphy et al., 2009; Oliver et al., 2012; Richards et al., 2012). Other behaviors, such as property destruction, tantrums, and elopement, are also common (Minshawi et al., 2014). More severe challenging behavior has been linked to greater parental stress (Athari, Ghaedi, & Kosnin, 2013; Beer, Ward, & Moar, 2013; Davis & Carter, 2008; Estes et al., 2009; Hou et al., 2018; Jellett, Wood, Giallo, & Seymour, 2015; Rezendes & Scarpa, 2011; Warfield et al., 2014). Greater challenging behavior is also associated with higher rates of caregiver depression, anxiety, and psychological distress (Beer et al., 2013; Estes et al., 2009; Falk et al., 2014; Hou et al., 2018; Jellett et al., 2015; MacHado Junior et al., 2016). The presence of challenging behaviors is related to lower family functioning, poorer family quality of life, and lower marital relationship satisfaction (Jellett et al., 2015; Kim et al., 2016; Nuske, Hedley, Tseng, Begeer, & Dissanayake, 2018; Sikora et al., 2013; Sim et al., 2016; Warfield et al., 2014; Xue et al., 2014).

Having a child with ASD can also result in significant financial burden, often due to the enormous costs of care and treatment. One study found that the income of families of children with ASD was 21% ($10,416) less than families of children with other reported health limitations and 28% ($17,763) less than families of children with no health limitations (Cidav, Marcus, & Mandell, 2012). Furthermore, caring for an individual with ASD often necessitates more consistent

care that may be difficult to reconcile with inflexible workplace policies. As a result, many parents, primarily mothers, leave the work force entirely to meet necessary caregiving demands (Cidav et al., 2012). When mothers of children with ASD do work, they typically make less money and work fewer hours than mothers of typically developing children (Cidav et al., 2012). Lower income has been identified as a predictor of poor outcomes, such as greater stress (Falk et al., 2014; Hsiao, 2018), greater depression (Athari et al., 2013; Benson, 2016; Gatzoyia et al., 2014), poorer psychological wellbeing (Garcia-Lopez et al., 2016), and lower quality of life (Hsiao, 2018; Vasilopoulou & Nisbet, 2016). Lower family income is also related to more negative affect in marital relationships, which can introduce significant family strain (Hartley, Papp, Blumenstock, Floyd, & Goetz, 2016).

Identifying, accessing, and managing services, as well as coordination with various service providers, is also difficult for caregivers (Gray, 2006; Warfield et al., 2014; Weiss, Tint, Paquette-Smith, & Lunsky, 2015). In one study, caregivers described their service experiences as a "fight" or "battle" (Hare, Pratt, Burton, Bromley, & Emerson, 2004, p. 438). Parents may also have to travel long distances in order to access appropriate services (Sim, Cordier, Vaz, Netto, & Falkmer, 2017). These barriers to appropriate treatment tend to disproportionately affect racial and ethnic minority families, adults with ASD, and those families living in nonmetropolitan or rural areas (Mandell, Listerud, & Levy, 2001; Thomas et al., 2007). Access to treatment is particularly difficult for families with immigrant status who may not speak fluent English and/or are not familiar with service delivery systems (Weiss et al., 2015).

Finally, parents of children with ASD commonly report experiencing public stigma, defined as "the impact of negative attitudes and behaviors from the general public," which is often associated with negative outcomes (Gray, 2002; Williams, Blair-Loy, & Berdahl, 2013). Parents

of individuals with ASD often face stigma in reaction to their child's odd behaviors (Baxter 1989; Birenbaum 1970; Gray 1993; Kinnear, Link, Ballan, & Fischbach, 2016). Parents also report that public stigma often feels personal. Several studies find that parents believe the public attributes their children's unusual behaviors to poor parenting rather than the symptoms of autism (DePape & Lindsay, 2015; Kinnear et al., 2016). Furthermore, caregivers report feeling as if they are "judged more critically" when their children have no obvious physical demarcations of disability (Bonis, 2016, p. 156; Corcoran et al., 2015). It is not surprising that public stigma is a significant positive predictor of depression, anxiety, and caregiving burden in caregivers (Chan & Lam, 2017).

Parents of individuals with ASD clearly experience a wide range of unique challenges across the lifespan and development of their children. It has been well established that parents of individuals with ASD experience poor outcomes, such as stress and depression, at rates higher than many other parents. Researchers have an emergent understanding of the major influences of these poor outcomes and interventions have been developed to directly target some of them. The majority of existing interventions aim to teach parents how to respond to and manage various characteristics of their children with ASD, such as social interaction, communication, or challenging behavior. However, interventions to address other major influences of these poor outcomes, especially for those influences that are related to the navigation of more complex system factors and service delivery, are not well studied. Despite the lack of intervention in these areas, navigating systems and services remains a consistent challenge for parents, especially when seeking a formal ASD diagnosis for their children. Although the ASD diagnostic process can be highly variable and difficult to research, it is important that researchers make efforts to better understand it as a necessary antecedent to improving experiences for the caregivers who are burdened with navigating it.

2.4 The ASD Diagnostic Process

The ASD diagnostic process often requires the successful navigation of multiple clinical care systems and encounters with various different types of providers who employ a wide range of diagnostic approaches. The process is complicated, which creates the potential for high variability across families. Caregivers have broadly described the process as confusing, frustrating, and fraught with delays and obstacles. Yet little empirical attention has been paid to more specifically explicating the mechanisms underlying this challenging process for all caregivers of individuals with ASD across a range of diverse groups, and even less has been done to improve it.

2.4.1 Benefits of a Formal ASD Diagnosis

A review of the diagnostic process is not complete without a discussion of *why* obtaining a diagnosis of ASD may be beneficial for individuals with ASD and their families. There are several potential benefits to having a formal ASD diagnosis. First, research shows that earlier diagnosis may lead to more favorable developmental outcomes for children with ASD (Constantino & Charman, 2016; Elder, Kreider, Brasher, & Ansell, 2017; Vivanti & Dissanayake, 2016). While ASD is generally regarded in the scientific community as a chronic, lifelong condition, there are a small number of young children who meet criteria for a formal ASD diagnosis early on, but no longer meet the criteria later in childhood (Blumberg et al., 2016). Early initiation of intensive therapy is typically the presumed mechanism underlying the relationship between early identification and better developmental outcomes (Elder et al., 2017; Vivanti & Dissanayake, 2016).

A formal diagnosis is often necessary to be referred for formal intervention services, such as behavioral therapy, speech and language services, physical therapy, and occupational therapy. Similarly, insurance companies require a formal diagnosis of ASD in order to pay for such therapies. Parents often report that obtaining a formal diagnosis of ASD for their children is a necessary step in beginning the treatment process (Wong et al., 2017). A formal diagnosis also qualifies individuals and families for discrimination protections under the Americans with Disabilities (ADA) and special education provisions under IDEA (Individuals with Disabilities Education Act) (Americans with Disabilities Act, 1990; Individuals with Disabilities Education Act, 2004).

There are also potential financial benefits for families that are able to obtain a formal ASD diagnosis for their children. In response to the massive financial burden of medical and therapeutic expenses unique to caring for a child with ASD, many states have passed legislation creating special Medicaid waivers and exceptions for children with ASD, authorizing children with formal ASD diagnoses to be eligible for medical assistance under a special disability category, even if their family's income level is greater than the typical cutoff for Medicaid eligibility (Mandell et al., 2014). Furthermore, having a formal diagnosis may open doors for ASD-specific grants and funding through various non-profit organizations (First Hand Foundation, 2019; Autism Care Today, 2019; Danny's Wish, 2018; C.A.R.E. Foundation, 2017).

Finally, obtaining a diagnosis can be empowering and/or relieving to some families, providing parents with explanations and clearer treatment options for behaviors or other developmental concerns that may have been distressing (Brookman-Frazee, Baker-Ericzen, Stadnick, & Taylor, 2012; Carlsson et al., 2016; Brigitte Chamak, Bonniau, Oudaya, & Ehrenberg,

2011). Because it is generally understood that ASD is a neurodevelopmental disorder, obtaining a formal diagnosis can also decrease feelings of parental guilt (Chamak & Bonniau, 2013).

2.4.2 Determining ASD Diagnosis

Determining ASD diagnosis is not an exact science. While major advances in biomedical research have led to important discoveries about the genetic underpinnings of the disorder, the field is still a long way off from a standardized procedure for biologically identifying the presence of ASD (Lonnie Zwaigenbaum & Penner, 2018). Thus, in order to determine a formal ASD diagnosis, researchers and clinicians typically rely on a variety of standardized criteria, assessment and diagnostic tools, observations, and/or caregiver interviews, which perhaps contributes to the wide variability in experiences across families.

2.4.2.1 The Diagnostic and Statistical Manual of Medical Disorders (DSM)

The Diagnostic and Statistical Manual of Mental Disorders (DSM), developed by the American Psychological Association, is a well-respected classification system that provides mental health professionals with standardized diagnostic criteria that aids them in evaluating presenting symptoms and providing mental health diagnoses that are as objective as possible. The DSM is one of the most commonly used reference tools among clinical professionals for the diagnosis of mental health disorders and ASD and it is the dominant mental health classification system used in empirical research (Clark, Cuthbert, Lewis-Fernández, Narrow, & Reed, 2017; Rogers, Goddard, Hill, Henry, & Crane, 2016). It is also one of two mental health classification systems used by insurance companies for billing purposes.

2.4.2.2 The International Classification of Diseases (ICD)

Published by the World Health Organization (WHO), the International Classification of Diseases (ICD) is an internationally recognized diagnostic reference used to classify medical and mental health disorders. It aims to provide a common language with which medical professionals across the globe can diagnose and treat health conditions. While DSM criteria and ICD classifications of mental health conditions have historically diverged, they have been streamlined in recent years in attempts to make them more comparable (Clark et al., 2017). The ICD is also used by insurance companies for billing purposes.

2.4.2.3 "Gold Standard" for ASD Screening and Diagnosis

Researchers and clinical professionals often refer to the "gold standard" of ASD diagnosis as being a lengthy process consisting of a combination of standardized diagnostic assessments, behavioral observations, and family interviews, ideally completed by a multidisciplinary team (Falkmer, Anderson, Falkmer, & Horlin, 2013; Hansen, Blum, Gaham, & Shults, 2016; Randall et al., 2018). However, a "gold standard" diagnostic evaluation first requires proper screening, flagging, and referring.

The American Academy of Pediatrics (AAP) has published formal guidelines for best practice of ASD screening before diagnosis (American Academy of Pediatrics, 2006). The guidelines offer a screening algorithm for pediatricians who visit with parents concerned about their child's development. These guidelines emphasize the importance of systematic surveillance, defined by the AAP as "the ongoing process of identifying children who may be at risk of developmental delays," at all preventative care visits for all children (p. 1195)(Johnson & Myers, 2007). Surveillance visits consist of gathering information about family psychiatric and medical history, as well as discussing current parental concerns regarding the developmental and

behavioral characteristics of the child. Pediatricians may also ask more direct questions about whether children are meeting their developmental milestones or interact with the child directly. The AAP guidelines also recommend systematic developmental screening at 9, 18, and 30- month preventative visits and ASD-specific screening at 18 and 24 months, and at any visit where substantial developmental concerns may arise (American Academy of Pediatrics, 2006). If screening results are positive or concerning, the AAP guidelines recommend providing parents with psychoeducation and immediate referrals for comprehensive ASD evaluations, early intervention services, and an audiologic evaluation. In addition, it is recommended that pediatricians schedule a follow-up visit to check-in regarding the results of the referrals and complete surveillance and screening again, if necessary (American Academy of Pediatrics, 2006).

2.4.2.4 ASD Screening Tools

The use of standardized screening tools during routine pediatric visits is a necessary part of identifying and appropriately diagnosing ASD. Research shows that without the use of standardized assessments, professionals are less likely to flag true ASD cases (Robins, 2008). Families who participate in screening procedures are also less likely to experience substantial diagnostic delays (Martinez et al., 2018).

The Modified Checklist for Autism in Toddlers, Revised with Follow-up (MCHAT-R/F) is the most widely validated ASD-specific screening tool and has the highest sensitivity and specificity for ASD in lower risk samples (Robins et al., 2014; Siu, 2016; Lonnie Zwaigenbaum et al., 2015; Lonnie Zwaigenbaum & Penner, 2018). The MCHAT-R/F is a short parent questionnaire that includes a brief follow-up interview for responses that indicate medium or high ASD risk (Robins et al., 2014). Other well-validated ASD screening tools that are appropriate for pediatric settings are the Ages and Stages Questionnaire-third edition (ASQ-3), the Screening Tool

for Autism in Two-Year-Olds (STAT), the Social Communication Questionnaire (SCQ), and the Communication and Symbolic Behavior Scales (CSBS) (Rutter, Bailey, Lord, & et al., 2003; Squires, Twombly, Bricker, & Potter, 2009; Stone, Coonrod, & Ousley, 2000; Wetherby & Prizant, 2002; Lonnie Zwaigenbaum & Penner, 2018). These instruments have all been recommended by the American Academy of Pediatrics (AAP) and the Centers for Disease Control and Prevention (CDC) for use by pediatricians to assess for developmental problems and ASD risk.

2.4.2.5 ASD Diagnostic Assessments

There are several useful diagnostic assessments available to clinicians that can provide strong evidence for the presence of ASD. It is generally recommended that clinicians complete more than one diagnostic assessment and that such assessments be used as part of a multimodal diagnostic approach (e.g. extensive interviews, family histories, etc.) rather than as standalone indicators of the presence of ASD (Becker, Becker, Langmann, & Poustka, 2018).

The most commonly used standardized diagnostic assessments are the Autism Diagnostic Observation and Schedule (ADOS) and the ADI-R (Autism Diagnostic Interview). Both are standardized clinical assessments that make it possible to reliably determine the presence of ASD in children as young as two years of age (Lord et al., 2012; Lord et al., 1989; Lord, Rutter, & Le Couteur, 1994). The ADOS-2 is a 40-60 minute observational assessment during which various independent and interactive activities assess the core characteristics of autism: language and communication, reciprocal social interaction, and stereotyped behaviors and restricted interests (Lord et al., 2012). The ADI-R is a 90-150 minute semi-structured interview that is completed by a trained administrator and the parent of an individual with possible ASD (Western Psychological Services, 2018a). The interview consists of gathering targeted information regarding developmental history and observed behavior in the individual's daily life (Lord et al., 1994). Both

assessments have elaborate scoring algorithms that calculate standardized scores, which are then compared with predetermined cut-off scores to determine the presence or absence of ASD. One or both of these assessments are typically incorporated into "gold standard" comprehensive ASD evaluation and have excellent sensitivity and specificity for diagnosing ASD (Medda, 2019). When used together, the ADOS and ADI-R have a correct classification rate of .80-.88 (Falkmer et al., 2013).

The Childhood Autism Rating Scale-second edition (CARS-2) is also commonly used in diagnostic evaluations (Schopler, Bourgondien, Wellman, & Love, 2010). The assessment has an interview structure similar to the ADI-R, where clinicians collect information from caregivers about behaviors across a range of functional domains. The assessment is widely validated and has demonstrated diagnostic utility in clinical samples of children with ASD (Chlebowski, Green, Barton, & Fein, 2010).

2.4.3 Challenges in ASD Diagnosis

Although there is a general professional consensus among researchers and clinicians on what constitutes a "gold standard" ASD diagnosis, there are considerable challenges to diagnosing ASD that are important to note. First, ASD is a heterogeneous disorder, with a spectrum of impairment across multiple different domains. Additionally, individuals with ASD commonly experience comorbid medical and developmental diagnoses, such as Fragile X syndrome, ID, epilepsy, or ADHD, which can further complicate ASD diagnosis (Fernell et al., 2013; Johnson & Myers, 2007; Zwaigenbaum & Penner, 2018). While the disorder is presumed to have genetic etiology, those mechanisms are not all well understood, requiring clinical professionals to rely primarily on formal assessments of symptoms across social, communication, behavioral, and

cognitive domains to determine whether an ASD diagnosis is appropriate. However, even with the availability of standardized tools and criteria, the heterogeneity of an ASD diagnosis still creates many opportunities for error, especially when determining the appropriate assessment approach (Rogers et al., 2016; Zwaigenbaum & Penner, 2018). Furthermore, it is not uncommon for screening and diagnostic approaches, including the types of instruments used, to vary substantially across different clinical professions (Taylor et al., 2016).

An additional challenge is the changing diagnostic criteria in the DSM. As previously mentioned, the DSM is a widely used tool for diagnosing ASD; however, since its addition to the DSM-III in 1980, the criteria for ASD have undergone several major revisions, the most recent being with the publication of the DSM-V in 2015. Consistent revisions to diagnostic criteria are not particularly concerning, as ASD is a relatively new disorder: first identified in 1940, but not truly acknowledged in the medical and academic communities as a neurodevelopmental disorder until the 1970s. Because knowledge of the disorder is still growing, it is not surprising that criteria for diagnosis continues to be refined. However, with each new iteration of ASD criteria in the DSM, the boundaries of ASD diagnosis have substantially shifted, broadening or narrowing the pool of individuals who meet criteria. This has introduced significant complexity into our understanding of epidemiology, symptoms, identification, and treatment. Furthermore, medical professionals (compared to other providers involved in the diagnostic process) are often more prone to using ICD criteria (Clark et al., 2017), which is comparable to DSM criteria but not identical, introducing the potential for systematic variations in diagnosis. Major changes to the DSM have also introduced challenges in summarizing knowledge gleaned from empirical research, since inclusion in ASD research often requires a diagnosis confirmed using the most up-to-date DSM criteria. In other words, the applicability of prior research with individuals with

DSM-IV ASD diagnoses to current research of individuals with DSM-V ASD diagnoses has some limitations (Constantino & Charman, 2016; Sandy Magaña & Vanegas, 2017; Lonnie Zwaigenbaum & Penner, 2018). This consistently shifting landscape may also introduce additional challenges—and opportunities for systematic error—among non-specialists who may be fielding parent concerns and/or providing formal diagnoses.

Another challenge to ASD diagnosis is that "gold standard" screening is costly. The only well-validated, AAP- and CDC- recommended screening tool that is free to use is the MCHAT-R/F. Others cost hundreds of dollars and/or require specific training to administer. Furthermore, becoming familiar with these instruments, and actual administration and scoring of them during patient encounters inevitably takes time, which can often be in short supply during routine pediatric visits (Dosreis, Weiner, Johnson, & Newschaffer, 2006; Elder, Brasher, & Alexander, 2016; Zwaigenbaum et al., 2015). The majority of the recommended screening tools take 10-15 minutes to complete and score. However, the STAT can take up to 20 minutes and the CSBS can take anywhere between 50 and 65 minutes to complete. Medical professionals have noted that the work involved in conducting appropriate screening procedures is not necessarily reimbursable, which introduces another barrier to proper assessment (Penner et al., 2017). Thus, successful administration of standardized screening measures may not always be feasible during routine pediatric visits, especially in lower resourced settings. Additionally, the quality of referral systems is highly variable, due to poor availability of formal, "gold standard" diagnostic evaluation services in some regions and/or a lack of well-established referral and follow-up tracking systems in pediatric settings (Elder et al., 2016; Penner, Anagnostou, & Ungar, 2018; Zwaigenbaum et al., 2015). Taken together, these factors introduce the potential for major systematic disparities in the

way children are screened and whether children at risk for ASD are accurately identified in a timely manner and appropriately referred for "gold standard" diagnostic evaluations.

In the event that concern is detected by screening and appropriate referrals are made, formal diagnostic evaluations can also be quite costly. Standardized diagnostic tools are expensive and require extensive training to administer. For example, extensive training is required for official ADOS-2 administration. Examiners must have a qualifying master's degree or a bachelor's degree with additional licensure and/or certification from an agency that requires ADOS training (Western Psychological Services, 2018b). Examiners must also pay over $600 to register for a 2-day training course (Western Psychological Services, 2018b). Finally, it is generally recommended that trained examiners have ongoing monitoring and supervision of test administration in clinical settings for sustained reliability (Becker et al., 2018). Training to administer to the ADI-R is done through a 16-hour DVD training program with accompanying guidebook (Western Psychological Services, 2018a). The full training program is $985 through Western Psychological Services (Western Psychological Services, 2018a). The cost of such diagnostic assessments can create substantial barriers to "gold standard" diagnostic approaches at medical and/or community mental health care centers (Grodberg, Weinger, & Buxbaum, 2012; McEwen et al., 2016). It is possible ASD diagnosis may be left solely to clinical judgment more often than researchers and clinicians might like.

Finally, funding for clinical and diagnostic services are not commensurate with the increasing awareness of ASD. This has led to greater pressure on already strained health and mental health systems to provide for the families seeking ASD diagnosis and support with their children's developmental problems (Crane et al., 2018; Ure, Rose, Bernie, & Williams, 2018). This introduces significant challenges not only to accessing professionals, but also to accessing

those professionals who are truly knowledgeable about ASD diagnosis and/or well equipped to field developmental concerns and make appropriate referrals.

2.4.4 Characteristics of the ASD Diagnostic Process

To date, there have been a handful of studies of the characteristics of the ASD diagnostic process conducted in the United States, Canada, and the United Kingdom (Howlin & Moore, 1997; McMorris, Cox, Hudson, Liu, & Bebko, 2013; Wong et al., 2017). This research provides a preliminary picture of diagnostic experiences for families around the globe. Generally, findings suggest the diagnostic process is complicated and variable across families.

While "best practice" standardized screening and diagnostic assessments allow for accurate identification and stable diagnosis by age 2 (Zwaigenbaum et al., 2015), the average age of ASD diagnosis tends to be between 3 and 5.5 years of age (Daniels & Mandell, 2014; Martinez et al., 2018; Mazurek et al., 2014; Zwaigenbaum & Penner, 2018). Age of diagnosis tends to have strong links to symptom severity, where children with greater impairment are diagnosed earlier than children with more mild impairment (Berg, Acharya, Shiu, & Msall, 2018; Crane, Chester, Goddard, Henry, & Hill, 2016; Daniels & Mandell, 2014; Mazurek et al., 2014; Rosenberg et al., 2011; Wong et al., 2017). This is not surprising, as more severe symptomatology, such as cognitive impairment, repetitive behaviors, stereotypic motor movements, severe social impairments, etc. are likely easier for parents and professionals to recognize and identify as atypical than milder symptomatology. Diagnosis for boys also tends to occur earlier than diagnosis for girls (Rosenberg et al., 2011); however, the mechanisms underlying this phenomenon remain unclear.

Primary caregivers tend to be the first to recognize developmental problems, although occasionally concerns will be raised by a family member, doctor, teacher, or other caregiver

(Brookman-Frazee et al., 2012; Chamak & Bonniau, 2013; Crane et al., 2016; Wong et al., 2017). The most common initial concerns tend to be delays in nonverbal communication, expressive language, or social behavior (e.g. lack of eye contact, not playing with other children), although some parents have noticed restricted interest or rigid routines, behavioral problems, sensory issues, cognitive delays, stereotypical movements, or motor delays (Chamak & Bonniau, 2013; Chamak et al., 2011; Crane et al., 2016; Gaspar de Alba & Bodfish, 2011; Herlihy, Knoch, Vibert, & Fein, 2015; Johnson & Myers, 2007; Maenner et al., 2013; Oswald, Haworth, Mackenzie, & Willis, 2017; Wong et al., 2017). Delays between time of first concern and first visit can be substantial (Crane et al., 2016). Research suggests that parents can usually identify developmental problems by age 2, yet one study found that the average age of first consultation was when the child was 3.9 years old (Crane et al., 2016). This is perhaps due to lack of awareness of ASD among medical professionals or parents' desire to wait and see if late developmental progress is made (Brett, Warnell, Mcconachie, & Parr, 2016).

Only a few recent studies have collected data about the specific professionals to which parents bring their initial developmental concerns. These studies suggest parents may be most likely to share their initial concerns with their child's pediatrician (Chamak & Bonniau, 2013; Chamak et al., 2011; Wong et al., 2017). Other professionals consulted may be general practitioners, psychologists, or psychiatrists (Chamak & Bonniau, 2013; Chamak et al., 2011; Crane et al., 2016; Wong et al., 2017). Some caregivers may bring their initial concerns to other professionals such as neurologists, geneticists, or social workers (Brookman-Frazee et al., 2012; Wong et al., 2017).

There is no professional consensus on the type of professional who should be providing formal ASD diagnoses, so it is perhaps unsurprising that a handful of large-scale studies have

found that ASD diagnoses may be provided by a wide range of professionals and specialists, including psychologists, psychiatrists, or neurologists (Chamak & Bonniau, 2013; Chamak et al., 2011; Crane et al., 2016; Gaspar de Alba & Bodfish, 2011). Some ASD diagnoses come from multidisciplinary teams of various different professionals (Taylor et al., 2016). Some diagnoses may also come from pediatricians (Crane et al., 2016; Gaspar de Alba & Bodfish, 2011; Rogers et al., 2016; Taylor et al., 2016). The wide range of professionals involved in the diagnostic process, particularly the involvement of non-specialists, introduces the potential for variability in ASD diagnosis across professions (Rhoades, Scarpa, & Salley, 2007; Taylor et al., 2017). However, diagnostic capacity across different providers remains poorly studied (Zwaigenbaum & Penner, 2018).

There are often long wait times between initial professional consultation and final ASD diagnosis. Generally, studies have found that parents may wait anywhere from 6 months to more than 4 years before their child receives a formal diagnosis (Crane et al., 2016; Martinez et al., 2018; Rutherford et al., 2018; Wong et al., 2017; Zuckerman et al., 2015). There are many reasons parents may experience long wait times. Medical professionals may initially defer ASD diagnosis, adopting a "wait and see" approach to developmental delays, which prolongs the process (Elder et al., 2016; Oswald et al., 2017). Studies show that parents may visit with multiple different professionals before a formal ASD diagnosis is obtained (Brookman-Frazee et al., 2012; Wong et al., 2017), which may also contribute to longer delays. Wait times for initial appointments can take several months (Rutherford et al., 2018) and wait times for comprehensive ASD evaluations can take even longer, with some parents waiting up to 7 months for an appointment (Elder et al., 2016; Rogers et al., 2016; Taylor et al., 2016; Wong et al., 2017). The availability of these assessment services also varies by region, which can introduce even longer wait times for individuals in more

remote areas (Daniels & Mandell, 2014; Kalkbrenner et al., 2011). Furthermore, appointments may last several hours and/or evaluations may occur across several different appointments (Carlsson et al., 2016; Hansen et al., 2016; Taylor et al., 2016; Wong et al., 2017). Children may also receive other mental health or neurodevelopmental diagnoses before arriving at a final diagnosis of ASD (Brookman-Frazee et al., 2012; B. Chamak & Bonniau, 2013; Brigitte Chamak et al., 2011; Jónsdóttir et al., 2011), which is associated with later age of ASD diagnosis (Mazurek et al., 2014).

2.4.5 Large Scale, Comprehensive Studies of the ASD Diagnostic Process

Only a handful of national and/or comprehensive studies of the ASD diagnostic process from the perspective of caregivers have been conducted. The procedures and findings from these studies are shown in Table 2.1 and summarized below.

2.4.5.1 Howlin & Moore (1997)

Howlin & Moore (1997) reported on the first large-scale descriptive study of the ASD diagnostic process, which was conducted nationally in the UK. A survey was completed by 1,295 caregivers of individuals with ASD which collected information about caregivers' first developmental concerns and the age of these concerns, the age at which caregivers sought professional help and to which professional concerns were first raised, the number of referral visits after the initial consultation and the child's age(s) at referral appointments, the final diagnosis obtained, general satisfaction with the diagnostic process, and help received following diagnosis.

Results indicated that, compared to previous decades, children were being diagnosed with ASD much earlier, but findings also highlighted substantial diagnostic delays (i.e. time between

Table 2.1 National and/or Comprehensive Studies of the Diagnostic Process

Study	Year	Sample Origin	N	Survey Items	Major Findings	Gaps
Howlin & Moore (1997)	1997	UK	1,295	•Area of residence •First dev. concerns •Child age at first concern •Child age when parents sought help •Type of professional(s) sought first •Number of referral visits •Child age at referral visits •Final Dx obtained •Child age at final Dx •Help/support received following Dx •Parental satisfaction with process	•Avg. age of Dx was 6.11 years •Common initial concerns: delays in language and social development •Delays between first visit and final Dx (mean of 3.81 years) •Delays between first concern and first visit (avg. of 6-7 months) •First professional sought was general practitioner or health visitor. •Avg. age of first professional visit was 2.3 years •One-fifth of parents were offered no help post-Dx •Overall parental dissatisfaction with the process •Differences in age of Dx and overall diagnostic delay by region	•Conducted over two decades ago •UK sample; limited generalizability to US families •No information on disparities by demographic
Goin-Kochel, Mackintosh & Myers (2006)	2006	USA, UK, CAN, AUS, NZ	494	•Parent and child demographics •Total number of professionals seen •Final Dx obtained •Child age at final Dx •Professional who made Dx •Parental satisfaction with the process	•Younger avg. age of Dx than in prior decades •Avg. age of Dx was 4.5 years •Total of 4-5 professionals seen throughout the process •Professional who made Dx most often a specialist, psychologist, or psychiatrist •Significant negative relationship between number of professionals seen and parent satisfaction •Age of Dx significantly later for less impaired children •Age of Dx significantly later for children whose parents have lower income/education	•No information on total delay •No information on race •No information on various types of professionals seen •Limited response options for professional who made final Dx •International sample; limited generalizability to US families •Conducted over a decade ago
Chamak, Bonniau, Oudaya & Ehrenberg (2013)	2013	FRA	248	•First dev. concerns •Child age at first concern •Child age when parents sought help •Type of professional(s) seen •All diagnoses received •Child age at final Dx •Parental satisfaction with the process	•Avg. age of Dx was 5 years •Common initial concerns: social, play, and language delays •Avg age when parents sought professional help was 26 months •First professional sought most often a pediatrician or psychiatrist •Provider who made ASD Dx most often child psychiatrist •Delays between first visit and final Dx ranged 0-11 years •63% of parents overall dissatisfied with the process	•Data collected between 2005 and 2006 on parents whose children received Dx as far back as 1965 •French sample; limited generalizability to US families •No information collected regarding the specific steps in the process •No demographic information

Table 2.1 (continued)

Study	Year	Sample Origin	N	Survey Items	Major Findings	Gaps
McMorris, Cox, Hudson, Liu & Bebko (2013)	2013	CAN	166	•Stability of Dx (current diagnosis and prior diagnoses) •Child age at first dev. concern •Age(s) at which children received current and prior diagnoses •Parent satisfaction with current Dx	•Less impaired children more likely to have experienced diagnostic instability •No differences in age of first concern across Dx type; however, longer diagnostic delays identified for less impaired children •86.7% of parents satisfied with the diagnostic process as a whole	•Canadian sample; limited generalizability to US families •Details on many important steps of the diagnostic process are missing •High satisfaction with the process is inconsistent with prior studies •No demographic information
Crane, Chester, Goddard, Henry, & Hill (2015) *Adapted replication of Howlin & Moore (1997)*	2015	UK	1,047	•Parent and child demographics •First dev. concerns •Child age at first dev. concern •Child age, type of professional seen, and visit outcome for first professional visit and up to 3 subsequent referral visits •Help/support received following Dx •Parent satisfaction with process •Stressful nature of the process	•Common initial concerns: delays in social development and behavioral problems •Avg. age when parents first sought professional help was 3.9 years •Avg. age of final Dx was 7.5 years (82% between ages of 3 and 18) •Avg. delay between first visit and final Dx was 3.6 years •Less impaired children experienced longer delays •Professional who made Dx most often pediatrician or psychologist •Overall parental dissatisfaction with the process •Lower satisfaction ratings associated with longer overall diagnostic delay •56% of parents reported the process was "very stressful"	•UK sample; limited generalizability to US families •No option for parents to indicate additional referrals beyond 3 •Avg. time since Dx for the sample was 4.3 years •Little ethnic diversity in the sample and no racial/income analyses
Oswald, Haworth, Mackenzie et al. (2017)	2017	USA	1,420	•Parent and child demographics •First dev. concerns •Professional response to parent dev. concern •Child age at final Dx	•Avg. age of first concern for children with ASD was 28.4 months •Common initial concerns: social and communication impairment, sameness behavior, and unusual motor movement •Avg. age of final ASD Dx was 5.23 years •Parents often told nothing was wrong and/or the children might grow out of it •Black, non-Hispanic parents were more likely than White or Hispanic parents to receive additional dev. testing	•Secondary analysis of an existing data set where participants have ASD, intellectual disability, and/or dev. delay •Limited response options for first dev. concerns and professional responses •Details on important steps of the diagnostic process are missing •Avg. age at the time of survey was greater than 5 years after Dx •Racial/ethnic analyses conducted on entire sample (including those whose children do not have ASD)

Table 2.1 (continued)

Study	Year	Sample Origin	N	Survey Items	Major Findings	Gaps
Wong, Yu, Keyes, McGrew (2017)	2017	USA	78	• Parent and child demographics • First dev. concerns • Child age at first dev. concern • Type of professional(s) sought first • Total number of professionals seen • Child age at final Dx • Positive and negative experiences of the process • How well parents felt validated by professionals	• Common initial concerns: language delay, social, emotional, and behavioral problems • First professional sought was most often child's medical doctor • Parents consulted with an avg. of 3.3 professionals in the process • Most parents consulted with pediatricians and psychologists. • Avg. delay between first concern and final Dx was 28.72 months • Lower symptom severity was a predictor of longer diagnostic delays • Pediatricians were rated as least likely to validate dev. concerns • Qualitative data provides evidence for poor patient-provider interactions	• Mean age of Dx is not reported • No report of overall delay between first professional visit and final Dx • Details on many important steps of the diagnostic process are missing • Little ethnic diversity in the sample (94.9% white); no analysis of experience by race/ethnicity or income • No quantitative support for poor-patient provider relationships • Not a national sample

first visit with a professional and final diagnosis) and an overall dissatisfaction with the diagnostic process reported by caregivers. This was a landmark study of the ASD diagnostic process; however, it has been over two decades since this study was published and our understanding of ASD diagnosis has changed substantially in that time, which necessitates an updated understanding of the process. Furthermore, the study was conducted in the UK, which operates under different systems of health and mental health care that may not generalize to the experiences of American caregivers.

2.4.5.2 Goin-Kochel, Mackintosh & Myers (2006)

Goin-Kochel, Mackintosh & Myers (2006) conducted a web-based, international survey of 494 caregivers from the US, England/Ireland, Canada, and Australia/New Zealand. The survey collected demographic information, the child's age at formal diagnosis, the professional who made the diagnosis and the specific diagnosis made, the total number of professionals seen throughout the process, and overall satisfaction with the process.

Findings from this study substantiated the younger average age of diagnosis and extensive delays noted in Howlin & Moore (1997) and found a significant negative relationship between the number of professionals seen and caregiver satisfaction with the overall diagnostic process. This study also found that age of diagnosis was significantly later for children who were less impaired and children whose parents had lower income and education. However, the study provided a very broad picture of the diagnostic process for parents, with little attention to more nuanced diagnostic experiences. For example, no information was collected about early developmental concerns and the first professional visit, including the specific professional to whom caregivers brought their initial concerns, the age of the child when professional help was sought, or the outcome of the

initial visit. The study collected information regarding the total number of professionals seen throughout the process; however, information on the specific types of professionals seen, visit outcomes and the corresponding ages of children during these visits was not collected. Response options for the diagnosing professional were also notably limited (family physician/PCP, specialist doctor, psychiatrist, psychologist, and other), raising questions about whether the findings reflect the entire spectrum of professionals potentially involved in making ASD diagnoses and responding to developmental concerns. The international nature of the survey introduces limitations to interpretation in the context of the US health system and also impedes the ability for the authors to draw any sociodemographic conclusions about the process related to race and income in the United States.

2.4.5.3 Chamak, Bonniau, Oudaya & Ehrenberg (2013)

Chamak, Bonniau, Oudaya & Ehrenberg (2013) distributed a survey to 248 French parents of individuals with ASD, with in-depth follow up interview completed with 43 parents. Information collected included child's age at first parental concern, the nature of the concern, the child's age when professional help was sought, the first professional consulted, different diagnoses obtained throughout the process, age of formal diagnosis, parents' reactions to the formal diagnosis, and satisfaction with the process. Findings revealed that parents detected concerns early and most frequently brought their concerns to a pediatrician. Long delays were noted between first concern and formal diagnosis. This study also found that parents' concerns were often invalidated at those initial consultations.

The findings of this study corroborate existing evidence that the ASD diagnostic process is unsatisfying and unnecessarily delayed for parents. Findings also substantiated the general trend in earlier diagnosis for younger generations of people with ASD, noted in both Howlin & Moore

(1997) and Goin-Kochel, Mackintosh & Myers (2006). Results also indicated that parents were able to detect concerns quite early, most often before the age of 2, and that such concerns were typically related to delays in social interaction, appropriate play, and communication. Most parents brought their initial concerns to pediatricians, while psychiatrists made most of the final diagnoses. However, there are some limitations of this study to note. First, the authors surveyed parents who sought help from professionals as far back as 1965, which indicates a great need to revisit these questions and update findings. Furthermore, the study was conducted in France, which limits generalizability to American families. Finally, this study collected minimal information about the specific steps of the process beyond the initial visit and the ultimate diagnosis, which makes it difficult to describe the complexity across all steps in the process.

2.4.5.4 McMorris, Cox, Hudson, Liu & Bebko (2013)

McMorris, Cox, Hudson, Liu & Bebko (2013) examined the diagnostic process for parents of children with ASD in Ontario, Canada. A survey was distributed to 166 caregivers, gathering information on the diagnostic stability of ASD, the delay between caregivers' first concern and formal diagnosis, comorbid mental health problems and their relationship to satisfaction with the process. Findings again corroborated long diagnostic delays, with longer delays for children who were less cognitively impaired. More than half of the parents reported their child had first received other ASD-related diagnoses and just under one third of parents reported their child received other non-ASD diagnoses, which resulted in longer overall diagnostic delays for both groups. Contrary to previous findings, parents in this study reported overall satisfaction with the diagnostic process, regardless of delays.

While this is a larger scale study of the ASD diagnostic process, the data collected do not provide a level of specificity about the process comparable to other studies. In particular, there are

no data in regards to the nature of concerns, the different professionals involved in the process, and the frequency and outcomes of different visits. Furthermore, no analyses investigating varying experiences by race or family income were included. Findings indicated high satisfaction across families, which is inconsistent with other studies of the diagnostic process. Moreover, the study was conducted in Canada, under different systems of health and mental health care, which limit the generalizability of findings to families in the US.

2.4.5.5 Crane, Chester, Goddard, Henry, & Hill (2015)

Crane, Chester, Goddard, Henry & Hill (2015) conducted arguably the most comprehensive study of the ASD diagnostic process to date. Crane and colleagues adapted the original survey used in Howlin & Moore (1997) and administered it to 1,047 parents of individuals with ASD in the UK. The survey collected information on first developmental/behavioral concerns and the corresponding age of the child, details about the first consultation, including the age of the child, the professional seen, and visit outcomes, specific information on referral visits, including professionals seen, visit outcomes, and corresponding child ages, the final diagnosis provided, the professional who made the diagnosis, and the child's age at final diagnosis, stress and satisfaction with the process, comorbid diagnosis, and post-diagnostic support.

Findings indicated that parents' first concerns were usually related to social skills or behavioral problems. Average age of initial consultation with a professional was 3.9 years and first professional consulted was most often a general practitioner or health visitor, a type of community public health nurse who visits families in the UK in their homes and provides assessment and support services. Average delay between first professional visit and final ASD diagnosis was 3.5 years. Satisfaction with the process was low overall and lower satisfaction with the process was significantly associated with longer overall diagnostic delays.

The findings of the study are quite comprehensive; however, the study was conducted in the UK in the context of different systems of health and mental health and referral systems, which limits the ability to generalize some of the more nuanced data collected to family experiences in the United States. Furthermore there are no sociodemographic analyses included as part of the study. Because this is the most comprehensive study of the ASD diagnostic process to date, the survey distributed by Crane and colleagues was adapted for use in the present study.

2.4.5.6 Oswald, Haworth, Mackenzie et al. (2017)

Oswald, Haworth, Mackenzie et al. (2017) conducted a secondary analysis of the CDC's Pathways data set, including 1,420 parents of children with ASD and 2,098 parents with children who had a developmental disability (DD), but not ASD. The primary purpose of the study was to compare diagnostic experiences between ASD and non-ASD/DD groups. Survey items analyzed included the number and type of parental first concerns, provider responses to concerns, and the age of the child when a formal diagnosis was made. Findings on the nature of first concerns largely aligned with earlier research, with parents noting concerns related to eye contact, non-verbal communication, and social interaction. Family income, parent education, and race/ethnicity variables were used to examine differences across provider responses in the entire sample. Black, non-Hispanic families were more likely to report that providers conducted developmental tests, whereas Hispanic families were more likely to report that providers told them nothing was wrong. These findings are compelling and provide evidence that there may be disparities in the diagnostic process. However, the sample includes individuals with both ASD and other DD, which limits the ability to draw conclusions about diagnostic disparities in families of children with ASD only. Additionally, they do not provide a comprehensive picture of the diagnostic process for families,

limiting the ability to pinpoint specific areas in the process where greater difficulty and/or disparities may be more likely to occur.

2.4.5.7 Wong, Yu, Keyes, McGrew (2017)

Wong, Yu, Keyes & McGrew (2017) conducted a study investigating pre- and post-diagnostic experiences of parents of individuals with ASD. A total of 78 parents provided quantitative and qualitative information about their experiences with the ASD diagnostic process. Information collected included age at which concerns were first suspected and the nature of the concerns, who detected the concerns, to what professional the initial concerns were raised, the number of professionals seen before a formal ASD diagnosis was made, the age of the child when the diagnosis was made, and the extent to which parents felt validated by the different professionals they saw throughout the process (where 1 = not at all, 2 = somewhat validated, and 3 = validated). Findings further corroborated prior research noting substantial diagnostic delays, specifically in the United States. Results indicated that parents consulted with an average of 3.3 professionals before receiving an ASD diagnosis, with an average overall delay of 2.4 years between first visit and final diagnosis. The study also found that most parents consulted with pediatricians and psychologists, yet pediatricians were also rated as least likely to validate parental concerns.

This is perhaps the most comprehensive study of the diagnostic process to be conducted in the United States to date. However, the study was relatively small and participants were largely recruited from the greater Indianapolis area. Additionally, the data collected were broad, with a level of specificity similar to the survey distributed by Goin-Kochel, Mackintosh, & Myers (2006), leading to a less comprehensive understanding of the different professionals consulted along the way and the corresponding outcomes of each visit. Additionally, similar to the survey distributed by Goin-Kochel and colleagues, there were limited response choices for the first professional

sought (a relative/friend, my child's doctor, specialist [psychologist/psychiatrist], my child's school, or other), which raises further questions about the professionals involved in fielding initial developmental concerns raised by parents in the United States. Finally, the study did not include an examination of differences in experiences by race or class.

2.4.5.8 Gaps in Current Large-Scale and/or Comprehensive Studies

As might be expected, larger-scale studies (i.e. those with national samples and/or large sample sizes) tend to be less comprehensive, studying only select elements of the diagnostic process. The two largest and most comprehensive studies of the ASD diagnostic process were conducted in the UK, with different medical systems of care (Crane, Chester, Goddard, Henry & Hill, 2015; Howlin & Moore, 1997). Neither study examined the impact of race or income on difficulty, largely due to homogenous samples. Furthermore, both studies included participants who had been diagnosed as far back as 1965, which introduces potential issues of recency bias when recalling more specific details about the process. No studies have investigated racial and economic disparities in family experience specifically for families of individual with ASD. This is perhaps explained by the fact that most existing studies are largely descriptive and none have attempted to quantify difficulty in the process in order to examine differences by race and class. Wong, Yu, Keyes & McGrew (2017) found qualitative evidence that patient-provider interactions may be poor throughout this process, but these concepts have not been assessed quantitatively, nor have they been tied to overall diagnostic process difficulty. More work is needed to understand how the complexity of the diagnostic process impacts American families of individuals with ASD, how these diagnostic experiences may vary for racial minorities and lower income families, and how relationships with important gatekeepers (i.e. pediatricians and/or the child's early primary care physician) may impact overall difficulty of the process.

2.4.6 Major Challenges in the ASD Diagnostic Process for Parents

It is perhaps unsurprising that caregivers report experiencing a range of challenges throughout the diagnostic process. One of the most commonly cited challenges is dismissive professionals and/or invalidation of parents' developmental concerns. It has been widely supported that parents are adept at identifying ASD symptoms in their children early on (Brigitte Chamak et al., 2011; Twyman, Maxim, Leet, & Ultmann, 2009). Yet parents often describe feeling as if their expertise as a parent is disregarded when discussing the possibility of developmental problems with clinical professionals (Burkett, Morris, Manning-Courtney, & Shambley-Ebron, 2015; Crane et al., 2018). Furthermore, parents report that professionals often respond to initial concerns with passive responses (e.g. "don't worry about it), deferment (e.g. "it's too early to know), or total invalidation (e.g. "nothing is wrong")(Burkett et al., 2015; Chamak & Bonniau, 2013; Chamak et al., 2011; Crane et al., 2018; Elder et al., 2016; Oswald et al., 2017; Zuckerman et al., 2014; Zuckerman et al., 2015). Some parents have even reported that professionals blamed developmental problems or concerning behaviors on poor parenting (Brookman-Frazee et al., 2012; Chamak & Bonniau, 2013). These types of responses can be distressing for parents, leaving them unsatisfied with the ASD diagnostic process. Furthermore, research shows that more proactive, validating responses to parent concerns are linked to shorter diagnostic delays (Zuckerman et al., 2015), suggesting that early interactions with dismissive and unsupportive professionals may contribute to prolonged formal diagnosis, which in turn delays age of intervention.

The diagnostic process can be overwhelming, with reports from parents that they often feel unsupported by the professionals they encounter (Brookman-Frazee et al., 2012). They cite a lack of support from primary care providers and pediatricians in providing appropriate referrals for

evaluation, creating a need for parents to identify and self-refer to many of the professionals they see throughout the process (Carlsson et al., 2016). Parents have also reported a need for greater clarity and transparency throughout the diagnostic evaluation process (Carlsson et al., 2016; Crane et al., 2018). They describe feeling overwhelmed by new information during diagnostic evaluations and a desire for more time to ask questions during visits with professionals (Carlsson et al., 2016).

Another challenge for parents is a perceived lack of knowledge and skill among various professionals who are involved in the diagnostic process. For example, one study found that parents were immensely frustrated with the lack of knowledge among providers regarding treatment options and medication management for their children with ASD (Brookman-Frazee et al., 2012). Many parents report media sources (books, webpages, etc.) as their primary source of information about ASD, with only a small subset indicating that they obtained useful information from healthcare providers, therapists, and education professionals (Rhoades et al., 2007). Another study found that perceived lack of autism awareness and training among general practitioners, family doctors, and teachers was a significant barrier to parent satisfaction with the diagnostic process (Crane et al., 2018). The sheer number of different professionals involved with the diagnostic process, often those who are not ASD specialists, may have some bearing on parents' confidence in their providers' capacity to adequately respond to developmental concerns.

2.5 Interactions with Providers

In the medical literature, there is an abundance of evidence linking the quality of patient-provider relationships to patient satisfaction with treatment and symptom management (Baker,

O'Connor, Roker, & Krok, 2013; Hart, Kelleher, Drotar, & Scholle, 2007; Moreno et al., 2018; Stockdale et al., 2018). Results from several studies of the diagnostic process also seem to suggest that patient-provider interactions may be important mechanisms underlying whether a caregiver is satisfied or dissatisfied with the ASD diagnostic process overall (Chamak et al., 2011; Crane et al., 2018, 2016; Wong et al., 2017). Medical doctors, particularly pediatricians, are some of the most commonly consulted professionals when parents have concerns about the development of their child (Wong et al., 2017). However, parents' chief complaints with the diagnostic process seem to center on unfavorable interactions with pediatricians. Parents report that pediatricians and general practitioners are among the least likely to validate their developmental concerns (Wong et al., 2017). They also cite minimal support by medical professionals throughout the diagnostic process (e.g. making appropriate referrals, etc.) and express serious concerns about pediatricians' knowledge of ASD (Crane et al., 2018). However, links between the patient-provider relationship and specific elements of the diagnostic process have yet to be studied. Although patient-provider relationships appear to be related to overall satisfaction with the ASD diagnostic process, the question remains whether strong trust and communication with a child's pediatrician, often the first point of contact for developmental concerns, is related to better overall diagnostic outcomes.

There is some evidence in the medical literature to suggest that patient-provider relationship quality is linked to actual medical outcomes beyond patient satisfaction. Communication is one of the most commonly studied elements of the patient-provider relationship and is associated with a wide range of patient outcomes. For example, some studies have found that better quality communication can lead to greater medication adherence, higher self-efficacy in the management of medical conditions, and better health-related quality of life, with lower ratings of physical pain, pain interference, and symptom burden across diverse groups of people

and a wide range of medical conditions (Baker, Connor, & Krok-schoen, 2016; Beach, Keruly, & Moore, 2006; Cinar & Schou, 2014; Li, Matthews, Dossaji, & Fullam, 2017; Mahmoudian, Zamani, Tavakoli, Farajzadegan, & Fathollahi-Dehkordi, 2017; Moreno et al., 2018; Ruben, Meterko, & Bokhour, 2018). Higher quality communication is also associated with greater proactive and preventative health measures among patients (Beach et al., 2006; Moss, Reiter, Rimer, & Brewer, 2016; Peterson et al., 2016). One study found that poor communication was associated with greater difficulty accepting a cancer diagnosis and connecting with an oncologist among adolescents with cancer and their parents (Phillips, Haase, Broome, Carpenter, & Frankel, 2017). Phillips et al., (2017) concluded that efforts made by health care providers to connect with cancer patients earlier in the diagnostic process might lead to more adaptive coping and greater resilience.

Trust is another important element of the patient-provider relationship that may have strong ties to patient outcomes. Greater trust with a health provider has been linked to better health-related quality of life, and lower symptom-related burden (Birkhäuer et al., 2017). Trust in a physician has also been linked to patients' ability to process medical information, with greater trust leading to a higher likelihood of successful information transmission between provider and patient (Ledford et al., 2010). Both trust and communication tend to be highly associated elements of the patient-provider relationship (Baker et al., 2013; Dalton et al., 2014; Phillips et al., 2017), with better trust often facilitating more favorable patient-provider communication (Dalton et al., 2014; Jiang, 2019). This suggests that patients who have greater trust in their providers may also have more favorable experiences when discussing their medical concerns.

Emerging research strongly suggests that the ASD diagnostic process is both complex and highly variable across families. It is also clearly an unsatisfying and challenging process for

parents. While the handful of large-scale studies of the diagnostic process conducted have provided researchers with some important preliminary descriptive information about the process, they provide little that helps guide researchers toward potential targets for intervention, especially in the context of some of parents' major reported concerns throughout the process: interactions with providers. More work is needed to better understand the role of patient-provider relationships, particularly communication and trust, in the ASD diagnostic process and its potential relationship to diagnostic outcomes.

2.6 Disparities in the Diagnostic Process for Marginalized Groups

Families with racial and ethnic minority status as well as families with lower income experience greater barriers to medical care than their white and more affluent counterparts (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003; Gornick et al., 1996; Nelson, 2002). Racial and ethnic minorities and less affluent Americans also tend to have poorer health outcomes overall (Beckie, 2012; Nazroo, 2003). Similar racial/ethnic and class disparities have been found in the ASD diagnostic process.

The vast majority of research on racial and ethnic disparities in the ASD diagnostic process is related to disproportional diagnostic delays. There is an abundance of evidence to suggest that age of diagnosis is significantly later for Black and Latino children than their white counterparts (Altiere & Von Kluge, 2009; Jimenez et al., 2012; Magaña et al., 2013; Rosenberg et al., 2011; Zuckerman et al., 2014). Formal diagnosis also occurs later for children whose parents have immigrant status than for children whose families are native to the U.S. (Kogan et al., 2015). Limited ASD knowledge in the Latino community and English language barriers have been

identified as potential contributors to longer delays for Latino parents (Mandell et al., 2009). There is some evidence to suggest differential diagnostic delays among Black children may be due in part to misdiagnosis. One study found that Black children with ASD were 2.6 times more likely than white children to be misdiagnosed during their first visit with a specialist (Mandell et al., 2007). Black children who eventually received an ASD diagnosis were more likely to be misdiagnosed with Adjustment Disorder or Conduct Disorder, where white children were more likely to be misdiagnosed with ADHD (Mandell et al., 2007).

Disproportionate delays among racial and ethnic minorities may also be due to well documented implicit racial and ethnic bias among American healthcare professionals, which can emerge in patient encounters (Hall et al., 2015). There is evidence to suggest that interactions with medical providers may be more negative for Black and Latino parents compared to white parents. Black and Latino parents of children with ASD more often report feeling as if visits with professionals are overly rushed with providers who do not listen to family needs, do not act on family concerns, and/or are insensitive to family values (Burkett et al., 2015; Magaña, Parish, Rose, Timberlake, & Swaine, 2012). Compared to white parents, Latino parents have reported that they feel less valued as a collaborator when interacting with medical providers regarding developmental concerns (Magaña et al., 2012). Such racial and ethnic breakdowns in patient-provider interactions may contribute to disproportionate diagnostic delays among these groups.

There may also be racial and ethnic bias in screening and diagnosis, which could potentially contribute to diagnostic disparities. Disproportionate barriers to primary care for racial and ethnic minorities presents fewer opportunities for parents to raise concerns in the first place. Additionally, there is some evidence that BIPOC families who do raise developmental concerns may not actually undergo formal screening procedures at all, despite AAP guidelines (Guerrero, Rodriguez, &

Flores, 2011). Additionally, many early screening tools have been validated in small, predominantly Caucasian samples, which may create additional obstacles to an accurate assessment of ASD risk (Zuckerman, Mattox, Sinche, Blaschke, & Bethell, 2014). Additionally, the ADI-R has demonstrated lower validity in communication domains among Latino children with caregivers with Spanish-speaking caregivers (Vanegas, Magaña, Morales, & Mcnamara, 2017).

Income disparities may create substantial barriers to ASD diagnosis. Individuals with lower income may also experience difficulties accessing healthcare and/or establishing a consistent healthcare provider, which can create obstacles to proper screening and identification (Thomas et al., 2012; Zuckerman et al., 2014). Furthermore, as previously mentioned, existing screening tools and "gold standard" diagnostic assessments are quite costly, which introduces barriers to appropriate diagnosis in lower resourced community health care centers (Durkin et al., 2015, 2010).

Overrepresentation of racial and ethnic minorities among low SES Americans can make it difficult to interpret research in disparities. For example, as previously noted, Black and Latino children often experience diagnostic delays that are significantly longer than white children. This delay is often generally attributed to barriers to health care access and consistent medical care for racial and ethnic minorities, which is also strongly tied to SES differences (Zuckerman et al., 2014). Additionally, white children are overrepresented in prevalence estimates of milder ASD diagnoses, suggesting that Black and Latino children who are less affected by ASD are more likely to be overlooked (Bhasin & Diana, 2007; Kogan et al., 2015; Ratto et al., 2016). Again, SES disparities may be implicated in this phenomenon, as differences in SES often manifest in this population as barriers to primary care. Indeed, there is research to suggest that less impaired

children are more likely to be diagnosed when they come from more affluent neighborhoods and have parents with higher education (Bhasin & Diana, 2007; Durkin et al., 2015).

While it appears that lower SES children and those of racial and ethnic minorities experience greater diagnostic delays, the mechanisms underlying these delays are still poorly understood. Access to healthcare appears to be connected to diagnostic delays, yet little is known regarding whether specific disparities exist in, for example, initial parental concerns, the number and type of professionals seen, the outcomes of visits, the professionals who provide diagnosis, and feelings of satisfaction regarding the process. As previously described, the majority of large-scale studies of the diagnostic process are lacking in diversity and/or lack explicit examinations of the differential experiences across diverse groups. However, we know the process is complex, with many opportunities for systematic differences, which suggests there may be disproportionate disparities for families of color and/or those families with lower income. There is a clear need for a more comprehensive understanding of experiences for these families in order to better pinpoint appropriate avenues for intervention.

2.7 Proposed Study

To date, only a handful of comprehensive studies of the characteristics of the ASD diagnostic process have been conducted at a national level, both of which were completed in the UK (Crane et al., 2016; Howlin & Moore, 1997). While they provide a preliminary picture of experiences for families, more work is needed to understand experiences of the diagnostic process in the United States. Very few studies have examined the impact of sociodemographic characteristics on the complex elements of the diagnostic process, predominantly due to the

limitations of heterogeneous samples. Furthermore, despite the important role of pediatricians in the diagnostic process and identified links between patient-provider relationships and health outcomes in the medical literature, no studies have examined the quality of patient-provider relationships in pediatric care as a possible predictor of diagnostic outcomes.

2.8 Aims and Hypotheses

This study aimed to better understand the diagnostic process for parents of individuals with ASD. It also aimed to explore how early relationships with primary care providers may influence diagnostic outcomes. Finally, this study sought to better understand how intersections of racial identity and family income may influence diagnostic experiences. Specifically, this study aimed to:

Aim #1: Describe the process of obtaining a first diagnosis of autism spectrum disorder (ASD) in the United States. This study gathered information about the various steps in the process of obtaining a formal diagnosis of ASD, including details about initial developmental concerns, the diagnostic process, the final diagnosis, and overall satisfaction with the various steps in the process. There was no hypothesis, as this aim was purely descriptive.

Aim #2: Examine the degree to which perceptions of the patient-physician relationship are related to difficulties in obtaining an ASD diagnosis. This study measured caregiver perceptions of quality of communication and trust in their relationship with their child's primary care provider at the time of diagnosis and examined whether more favorable perceptions are linked to fewer barriers in the diagnostic process.

Hypothesis #1: Parents who report lower quality communication and less favorable perceptions of trust with their child's pediatrician and/or primary care provider will experience greater difficulties in obtaining a diagnosis (e.g. longer time to final diagnosis, more professionals seen throughout the process, etc.) than those parents who report higher quality communication and more favorable perceptions of trust.

Aim #3: Explore how the process of obtaining a first diagnosis of ASD varies across race and family income factors. Sociodemographic data was collected to provide insight into how characteristics of the process, as well as trust and communication with primary care providers, varied by racial identification and family income.

3.0 Research Design and Methodology

3.1 Study Design

The study utilized a cross-sectional survey design. Caregivers were asked to retrospectively answer questions about their experiences with the ASD diagnostic process as well as the quality of communication and level of trust with their child's pediatrician at the time of their first developmental concerns.

3.2 Participants

3.2.1 SPARK Registry, Research Match Program, and Sample Design

3.2.1.1 SPARK Registry

SPARK (Simons Powering Autism Research) is a research initiative, fully funded by the Simons Foundation. The primary aim of the SPARK initiative is to recruit individuals with a professional diagnosis of autism and their families to their national registry. Recruitment to the registry is achieved by partnering with medical schools and autism research centers across the United States who are conducting autism research and adding registry participation to existing study protocols. Registry participation is open to all individuals of any age with a professional diagnosis of ASD. Biological family members and one unaffected biological sibling are also invited to participate. Participation in the registry is limited to residents of the United States, those

who can read and understand English, and those who are biologically family members of the individual with ASD. Registration involves providing SPARK with clinical information about the affected individual, basic medical screening, family history, and a battery of instruments that measure development, symptom severity, and repetitive behaviors.

The SPARK research registry is a national, purposive sample of caregivers of individuals with ASD in the United States. There are currently 84,005 children and 15,303 adults with ASD in the registry for a total of 99,308 registrants. Of those, 70% are white, 17% are multi-racial, 6% are African American, 3% are Asian, 1% are Native American/Native Hawaiian, and 3% identify with an Other racial category. In terms of ethnic identity, 19% of registrants identify as Hispanic. A total of 83% of registrants meet or exceed the Social Communication Questionnaire (SCQ) clinical cutoff of 15. Additionally, 88% of registrants score in the low or moderately low adaptive range, as measured by the Vineland Adaptive Behavior Scales (VABS). The children with ASD in the registry are mostly male (78%) with a mean age of 8 years (SD = 4.3). A small percentage (17%) of children in the registry have co-occuring intellectual disability.

3.2.1.2 Research Match Program

An additional arm of the SPARK initiative is the "Research Match" program in which SPARK partners with outside researchers who study individuals with ASD and their families and provides free recruitment within their large participant network in exchange for data sharing agreements that allow SPARK to further build their resource. The Research Match program was used to distribute the study survey.

3.2.1.3 Sample Design

A total of 407 caregivers were recruited from the SPARK (Simons Foundation Powering Autism Research for Knowledge) research registry to participate in this study. SPARK facilitated targeted sampling of BIPOC early in recruitment to increase diverse representation in the sample.

3.2.2 Inclusion/Exclusion

Participants were included if 1) they were biological parents or legal guardians of a child with a formal autism spectrum disorder (ASD) diagnosis, 2) they were the legal parent or guardian for the affected child at the time a formal diagnosis of ASD was made, 3) they were at least 18 years of age, 4) their children had received a formal ASD diagnosis within the past 3 years, and 5) their children were between the ages of 2 and 9 years of age. The minimum age of diagnosis cutoff of 2 years was determined by the age at which ASD can reliability be detected with standardized assessments (Lord et al., 2012; Lord et al., 1989; Lord, Rutter, & Le Couteur, 1994). The maximum age of diagnosis cutoff of 9 years was determined using the same criteria as prior surveillance studies conducted by the CDC (Centers for Disease Control and Prevention). These national surveillance studies have found that the prevalence of ASD diagnosis peaks around 8 years of age in the United States (Christensen, D.L., Baio, J., Braun, K.V.N., et al., 2016); thus it was determined that establishing an age cutoff of 9 years for the present study would maximize the sampling pool.

3.3 Measures

3.3.1 Demographic Information

The online survey collected demographic information about the gender, race, ethnicity, and age of the child with ASD, the primary caregiver (survey respondent), and the primary caregiver's spouse or partner (if applicable). It also collected information about the child's primary language (e.g., English, Spanish) and current diagnosis. Additionally, the survey asked caregivers to indicate their familial relationship to the child, total household income, use of public assistance, marital status, highest level of education, and employment status. This information was also collected for the primary caregiver's spouse or partner, when applicable.

3.3.2 Diagnostic Process Questionnaire (DPQ)

The Diagnostic Process Questionnaire (DPQ) was adapted from Crane, Chester, Goddard, Henry & Hill (2010), who originally adapted their UK survey from that used in Howlin & Moore's (1997) landmark study of the diagnostic process. Because the questions in the surveys were developed in the context of the British health systems, minor adaptations were made to better reflect the American medical and mental health systems and to ask parents whether formal screening procedures were used during visits with medical doctors.

The DPQ is made up of 6 sections that examine different aspects of the diagnostic process. Section 1 covers initial developmental concerns, Section 2 covers the first consultation with a professional, Section 3 gathers information on up to three subsequent referral appointments, Section 4 asks for information on any additional appointments beyond those described in Section

3, Section 5 covers the final diagnosis, and Section 6 gathers information on post-diagnostic support. Table 3.1 provides a list of sections and data that were collected using the DPQ.

In Section 1 of the DPQ, participants were asked about their initial developmental concerns, including the age of the child at which first concerns were detected, the type of concerns, and the individual who first identified the concern. Section 2 included questions about the first professional visit in which these concerns were raised, including the age of the child, the type of professional consulted, the outcome of the appointment, and whether a formal diagnosis was made. Section 3 asked participants questions about up to three subsequent referral visits, including how the participant got the referral, the age of the child at the first referral visit, the type of professional consulted, and the outcome of the referral visit. Section 4 asked participants to indicate whether there were any additional referrals or other professionals seen, beyond the initial visit and 3 subsequent referral appointments, before arriving at a final diagnosis of ASD. Section 5 asked participants questions about their child's formal diagnosis, whether diagnostic tests or assessments were conducted, the title of the professional who ultimately made the diagnosis, and whether there was follow-up and support after the official diagnosis. Information was also gathered about whether the child had ever been diagnosed with other medical or mental health conditions. Participants were also asked to indicate their satisfaction with final diagnostic visit, their satisfaction with the process as a whole, and how stressful they found the overall process. Section 6 asked participants about post-diagnostic support, including questions about the type of support that was offered and their satisfaction with that support. In this section, participants also had the opportunity to provide an open-ended description of anything they believe could be done to improve the diagnostic process.

Table 3.1 List of Data Collected in Each Section of the Diagnostic Process Questionnaire

Section 1: Initial Concern
Number and nature of first concern(s)
Age of first concern(s)
First person to have concern(s)
Gone through ASD diagnostic process previously with another child?
Section 2: First Visit
Age of child at first visit
Type of professional consulted
Outcome of first visit
Screening procedures conducted
Diagnosis made (if applicable)
Professionals to which referred (if applicable)
Domain 3: Referral Appointments
How was referral obtained?
Type of professional consulted
Age at first referral
Outcome of first referral
Diagnosis made (if applicable)
Professionals to which referred (if applicable)
Section 4: Additional Referrals
Number of additional appointments attended (if applicable)
Type of other professionals seen
Section 5: Formal Diagnosis
Age of formal diagnosis
Specific diagnosis made
Type of professional who made diagnosis
Formal diagnostic tests or assessments completed
Receipt of written report
Follow up appointment made
Offer of help/support following diagnosis
Satisfaction with information given at diagnosis
Satisfaction with manner in which diagnosis was given
Overall satisfaction with diagnostic process
Perceptions of how stressful the diagnostic process was
Other formal diagnoses (past or current)
Section 6: Post-Diagnostic Support
Type of help/support provided
Satisfaction with help/support received after diagnosis

3.3.3 Diagnostic Difficulty Index (DDI)

The Diagnostic Difficulty Index (DDI) is a composite index of difficulty with the diagnostic process that was formed using quantitative data gathered from the DPQ. Table 3.3 shows the 13 DDI items operationalized from the DPQ. All items were coded so that higher scores indicated greater difficulty. Items were z-transformed and then subjected to exploratory factor analyses using varimax rotation to identify the dimensionality of the index. The reliability of the resultant factors were then investigated. Cronbach's alpha coefficients were examined for evidence of reliability using guidelines established in Nunnally & Bernstein (1994), where $\alpha \geq 0.80$ is highly reliable, $\alpha \geq 0.70$ is moderately reliable, and $\alpha \geq 0.60$ is sufficiently reliable. All items with item-total correlations $r < .15$ were removed from the index.

Table 3.2 List of Data Collected in Each Section of the Diagnostic Process Questionnaire (DPQ)

Item	Operational Definition
1. Age at formal diagnosis	Answer to the question: *How old was your child when a formal diagnosis was made?*
2. Total duration of diagnostic process	Difference between the age of the child at diagnosis and at first concern
3. Delay between first concern and first visit	Difference between the age of the child at first visit and at first concern
4. Total number of professional visits before diagnosis was made	Answer to the question: *Approximately how many professionals did you see before receiving a formal diagnosis of ASD?*
5. Total number of non-ASD diagnoses received before ASD	Number of other formal diagnoses indicated that child no longer has
6. Total number of times told "no problem"	Frequency of times parents answered, "Told no problem" on questions about visit outcomes.
7. Total number of times parents had to insist on a referral	Frequency of times parents answered, "referred by a professional, but had to insist on the referral"
8. Total number of times parents self-referred	Frequency of times parents answered, "sought an appointment independently, without a referral from a professional"
9. Formal screening procedures completed in initial visit	Based on answers to the question: *After you expressed your concerns to this professional did you complete any additional screening procedures?* Possible family history; short interview; formal questionnaire; brief observation; other screening = 0; No screening procedures; don't remember/don't know = 1
10. Prior experience with the AD diagnostic process	Answer to the question: *Have you gone through the ASD diagnostic process with another child previously (i.e.an older sibling)?* Yes = 0; No = 1
11. Area of residence	Answer to the question: *How would you describe the area in which you lived when you first had developmental concerns?* *Suburban or Urban = 0, Rural = 1*
12. Satisfaction with the ASD diagnostic process overall	Answer to the question: *Overall, how satisfied were you with the diagnostic process as a whole?* 5 = Very dissatisfied; 4 = Dissatisfied; 3 = Neither satisfied nor dissatisfied; 2 = Satisfied; 1 = Very satisfied
13. Stressful nature of the ASD diagnostic process	Answer to the question: *Overall, how stressful did you find the diagnostic process?* 4 = Very stressful; 3 = Stressful; 2 = Not very stressful; 1 = Not at all stressful

Interview Satisfaction Questionnaire (ISQ)

The Interview Satisfaction Questionnaire (ISQ) is a 12-item questionnaire that measures patient perceptions and satisfaction of the quality of patient-physician communication and was used as a measure of the quality of communication between caregivers and their children's pediatrician or primary care provider at the time of their initial developmental concerns. Responses are measured on a five-point Likert scale, where 1 = strongly disagree, 2 = somewhat disagree, 3 = undecided, 4 = somewhat agree, and 5 = strongly agree. Raw scores are calculated by summing responses. The questionnaire measures satisfaction of patient-physician communication in four domains: open-endedness, empathy, confidence in the physician, and general satisfaction. The ISQ has demonstrated high reliability, with Cronbach's alphas ranging from .74 to .93 (Grayson-Sneed et al., 2016). The ISQ has also demonstrated strong concurrent validity with the Communication assessment Tool (CAT), another commonly used patient-ret measure of the quality of physician communication (Grayson-Sneed et al., 2016).

3.3.4 Wake Forest Interpersonal Trust in a Physician Scale (WFITPS)

The Wake Forest Interpersonal Trust in a Physician Scale (WFITPS) is a 10-item scale that provides a unidimensional measure of a patient's trust in their medical provider and was used as a measure of trust between caregivers and their children's pediatrician or primary care

provider at the time of their initial developmental concern. Responses are measured on a five-point Likert scale where 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree. Negatively worded items are reverse coded and total scores are calculated by summing responses. Raw trust scores can be converted into scaled scores by subtracting the bottom of the raw range (10) from the raw score, dividing by the total raw range, then multiplying by 100.

The resulting scaled score reflects an overall proportion of trust in a provider from no trust (0%) to complete trust (100%). The Wake Forest Interpersonal Trust in a Physician Scale has demonstrated high reliability (Cronbach's alpha = 0.93) (Hall et al., 2002). It has also demonstrated good construct validity with the trust scale developed by Kao, Green, Zaslavski, et al. (1998) (Hall et al., 2002).

3.3.5 Independent and Dependent Measures

Table 3.1 provides an overview of the measures used and their relation to study aims. Aim #1 was a descriptive aim, and so there was no independent variable. Descriptive statistics summarized from the Diagnostic Process Questionnaire were the dependent measure for this aim.

The independent variables for Aim #2 were the patient-provider relationship measures: the Interview Satisfaction Questionnaire (ISQ) and the Wake Forest Personal Trust in a Physician Scale (WFPTPS). The ISQ measured quality of communication and the WFPTPS measured the degree of trust between parents and their providers. For both the ISQ and WFPTPS, parents were asked to rate the quality of communication and degree of trust they had with their child's pediatrician or primary care provider at the time of their first developmental concerns. Independent variables for Aim #3 were racial identification and family income as recorded on the demographic form.

The dependent measures for Aims #2 and #3 were the three difficulty factors that resulted from factor analysis of the original set of DDI items.

Table 3.3 Study Aims, Independent and Dependent Variables, and Statistical Analyses

Aim	Independent Variable	Dependent Variable	Analysis
Aim #1: Describe the process of obtaining a first diagnosis of autism spectrum disorder (ASD) in the United States	N/A	Diagnostic Process Questionnaire (DPQ)	Descriptive statistics
Aim #2: Examine the degree to which perceptions of the patient-physician relationship are related to difficulties in obtaining an ASD diagnosis	Interview Satisfaction Questionnaire (ISQ) Wake Forest Interpersonal Trust in a Physician Scale (WFITPS)	Diagnostic Difficulty Factors	Multiple linear regression, controlling for time since diagnosis and symptomatology
Aim #3: Explore how the process of obtaining a first diagnosis of ASD varies by race and income	Demographic Form: Race Income level	Diagnostic Difficulty Factors	ANCOVA, covarying for time since diagnosis and symptomatology

3.4 Study Procedure

Caregivers who met inclusion criteria were recruited for this study. They were recruited from the SPARK research registry. Most screening for the study took place automatically through existing information in the SPARK system. The SPARK team had basic information (e.g. caregiver status, racial identity, family income) about all cohort members and made sure invitation emails were sent only to those who met inclusion criteria for the study. Additionally, this basic sociodemographic information about most existing cohort member allowed for targeted recruitment of minority racial groups and lower income caregivers in order to obtain a diverse sample.

All participants were recruited via an IRB-approved recruitment email, sent to eligible

caregivers by the SPARK team. The email included a link directing parents to the online consent form. After informed consent was provided, parents were linked to the online survey. The survey asked participants to provide demographic information, information on the diagnostic process, and ratings of the quality of patient-provider communication and trust with their child's pediatrician at the time of diagnosis. It was estimated that participation in this study would take 30-45 minutes in a single online session, although parents had the option of stopping and completing the surveys at a later time through the SPARK portal. Upon completion of the study, the SPARK automated incentive system generated a $10 Amazon gift card code. Participants received a separate email thanking them for their participation with the Amazon gift card code included.

A total of 3,525 parents were invited by SPARK to participate in the survey. Of those, 857 parents (24%) indicated interest in the study and only 10 parents (.28%) indicated they were not interested in participating. A total of 816 parents completed study screening and of those, 303 (37%) screened out. Of the 513 parents who screened in, 498 (97%) provided informed consent and 450 (88%) completed the study.

3.5 Data Analysis

The analytic plan outlines the statistical methods that were used to meet the aims described in Chapter 1: (1) describe the process of obtaining a first diagnosis of autism spectrum disorder (ASD) in the United States, (2) examine the degree to which perceptions of the patient-physician relationship are related to barriers to ASD diagnosis, and (3) explore how the process of obtaining a first diagnosis of ASD varies across sociodemographic factors. Detailed descriptions of these

methods, as well as a power analysis, are provided below. All analyses were conducted using R version 3.4.3.

3.5.1 Sample Description

Descriptive statistics were gathered for child age, gender, race, ethnicity, primary language, and diagnosis. Descriptive statistics were gathered on the primary caregiver and the primary caregiver's partner or spouse, if applicable. Data collected included age, gender, race, ethnicity, income, marital status, educational attainment, and current employment status. The only continuous variables were age of the child, primary, and secondary caregiver for which means, standard deviation, and range were reported. For all other demographic variables frequency and percentage were reported.

3.5.2 Preliminary Analyses

Preliminary analyses were conducted to evaluate the internal consistency of the measures, evaluate data for outliers that may influence parametric testing of aims, examine skewness, and implement non-linear transformations if necessary. The internal consistency of the ISQ and WFITPS were evaluated using Cronbach's alpha. Well-established standards were used to evaluate the degree of internal consistency (Nunnally & Bernstein, 1994). Responses on the DPQ, the ISQ, and the WFITPS were evaluated for potential outliers that could influence bivariate correlations and t-tests in Aims #2 and #3 (described below). Potential careless/inattentive responses were identified by examining total survey response time as well as calculating person-total correlations for all quantitative measures. The survey was expected to take 30-45 minutes; thus, participants

who completed the survey in less than 10 minutes were excluded. Additionally, person-total correlations were calculated to examine individual consistency and reliability on quantitative measures (Curran, 2016). Person-total correlations were calculated by computing bivariate correlations between an individual participant's response to a single item and the mean score of that item across the remainder of the sample (Curran, 2016). Curran (2016) suggests all participants with negative person-total correlations be considered careless/inattentive responders. As such, any individual with a negative person-total correlation was dropped from analysis. Surveys that were less than 75% complete were discarded.

In order to reduce the risk of systematic bias from dropping cases with missing values, the expectation maximization (EM) algorithm was used to calculate estimates for missing values based on the parameters of existing observations (Dempster, Laird, & Rubin, 1977). While the EM algorithm is not appropriate for imputing data on categorical experiences reported on the DPQ, it can be used for imputing missing data on the ISQ and WFITPS.

3.5.3 Analyses of Specific Aims and Hypotheses

Aim 1. To describe the process of obtaining a first diagnosis of autism spectrum disorder (ASD) in the United States. Data collected from the Diagnostic Process Questionnaire (DPQ) was used to achieve this aim. Descriptive statistics were used to report response frequencies for all categorical variables and means, standard deviations, and ranges for all continuous variables across the six domains of the DPQ. Furthermore, the DPQ was used to generate the Diagnostic Difficulty Index (DDI). Scores from the DDI were summarized and used to test subsequent aims.

Aim 2. To examine the degree to which perceptions of the patient-physician relationship are related to difficulties in obtaining an ASD diagnosis. Data collected from the

ISQ, WFITPS, and DDI were used to achieve this aim. Multiple linear regression was used to regress difficulty scores on ISQ and WFITPS scores in separate models. Time since diagnosis was added to these models to account for potential recall bias.

Aim 3. To explore how the process of obtaining a first diagnosis of ASD varies across sociodemographic factors. Data collected from the demographic form and the DDI was used to achieve this aim. One-way ANCOVA models were constructed with the primary between-subjects factor being race to explore how difficulty scores vary by racial identification. Multiple regression was used to explore how difficulty scores varied by family income, controlling for symptomatology and time since diagnosis to control for recall bias. A further exploratory analysis of how communication and trust vary across racial groups and family income categories was also conducted.

3.5.4 Power Analysis

Aim #1 is a descriptive aim and did not require a power analysis. However, a sample size of 400 caregivers throughout the United States was expected to be sufficient for describing national patterns in the process of obtaining an ASD diagnosis. Aim #2 involved multiple linear regression, regressing difficulty in the ASD diagnostic process on patient-provider trust and communication, controlling for time since diagnosis. With a sample size of N = 400 participants at 80% power, it was determined that the present study was able to detect a small effect size of $R^2 = .023$. As such, this study was sufficiently powered to test hypotheses surrounding the relationship between patient-physician trust and difficulty in the diagnostic process. To test Aim #3, exploratory ANCOVA was used to examine how difficulty of the diagnostic process varied by racial identification and family income. With a sample size of N = 400 participants at 80% power, the

present analysis was able to detect race differences of d = .35, which is a medium effect. As such, this study was adequately powered to detect whether there were moderate differences in experiences in the diagnostic process by racial identification and income.

4.0 Results

This chapter presents the results of the statistical analyses outlined in Chapter 3. The characteristics of the sample will be reported first, followed by the results of preliminary analyses to evaluate the internal consistency of the measures, check for outliers and normality, evaluate the survey for careless responding, impute missing data, and develop the Diagnostic Difficulty Index (DDI), which is the primary dependent outcome of the study. Finally, this chapter will present the results of the statistical analyses associated with study aims to: 1) describe the process of obtaining a first diagnosis of autism spectrum disorder (ASD) in the United States, 2) examine the degree to which perceptions of the patient-physician relationship are associated with difficulty experienced throughout the process of obtaining an ASD diagnosis, and 3) explore how the process of obtaining a first diagnosis of ASD varies by race and family income.

4.1 Sample Characteristics

Sample characteristics are shown in Tables 4.1 (child characteristics), 4.2 (primary parent/study informant characteristics), and 4.3 (secondary parent characteristics). Children ranged in age from 3.25 to 8.92 years (M = 6.03, SD = 1.40) and were mostly male (N = 328, 80%).

Primary parents, who were also the primary participants of the study, ranged in age from 21.67 to 65.33 years (M = 36.41, SD = 5.87). Most participants were mothers (N = 379, 93%). Just over one third of participants (N = 134, 34%) identified as Hispanic or Latino. Most study informants were white (N = 248, 63%), with 14% of parents identifying as Black, 10% identifying

Table 4.1 Descriptive Statistics for Participants' Children with ASD

	M (*SD*) N (%)
Age	6.03 (1.40)
Gender (Male)	327 (81%)
Ethnicity (Non-Hispanic)	259 (64%)
Race	
White	238 (60%)
Multi	63 (16%)
Black	55 (14%)
Asian	23 (6%)
Other	20 (5%)
American Indian or Alaskan Native	1 (%)
Primary Language (English)	394 (98%)
Primary Diagnosis	
Autism Spectrum Disorder (ASD)	343 (84%)
Autism or Autistic Disorder	46 (11%)
Asperger Syndrome	13 (3%)
PDD-NOS	3 (1%)
Other	1 (%)
Social Communication Questionnaire (SCQ) - Total Score[a]	20.98 (6.53)
Comorbid/Co-occurring Problems	
Communication	267 (66%)
Feeding and eating	178 (44%)
Sleeping	151 (37%)
Motor	66 (16%)
Intellectual Disability	58 (14%)
ADHD	56 (14%)
Learning	48 (12%)
Anxiety	29 (7%)
Neurological	26 (6%)
Elimination	19 (5%)
Disruptive	12 (3%)
Obsessive Compulsive	10 (2%)
Vision	6 (1%)
Depression	6 (1%)
Auditory	3 (1%)
Schizophrenia	1 (%)

[a] *The SCQ (Social Communication Questionnaire) is an ASD screener that measures symptomatology. Scores range from 0-39 for verbal children and 0-33 for nonverbal children, where higher scores indicate more severe ASD symptoms. Clinical cutoffs vary, but general recommendations are that scores greater than 15 typically indicate the presence of ASD.*

Table 4.2 Descriptive Statistics for Study Participants (Primary Parents)

Variable	*M* (*SD*) N (%)
Age	36.41 (5.88)
Relationship to child with ASD	
Mother	378 (93%)
Father	26 (6%)
Grandmother	1 (%)
Gender	
Female	376 (93%)
Male	28 (7%)
Gender variant/Non-conforming	1 (%)
Ethnicity (Not Hispanic/Latino)	265 (66%)
Racial Identification	
White	245 (63%)
Black	54 (14%)
Multi-racial	38 (10%)
Asian	34 (9%)
Other	17 (4%)
American Indian or Alaska Native	1 (%)
Education	
Some high school	9 (2%)
GED diploma	11 (3%)
High school graduate	48 (12%)
Trade or vocational school	22 (5%)
Associate degree	54 (13%)
Completed some college	83 (20%)
Baccalaureate degree	92 (23%)
Graduate professional degree	85 (21%)
Employment	
Full time	176 (43%)
Part time	61 (15%)
Homemaker	134 (33%)
Unemployed, looking for work	18 (4%)
Unemployed, not looking for work	14 (3%)
Disabled	12 (3%)
Retired	4 (1%)
Full time student	10 (2%)
Part time student	9 (2%)
Other	15 (4%)

Table 4.2 (continued)

Income	
Less than $20,000	51 (13%)
$21,000 to $35,000	61 (16%)
$36,000 to $50,000	48 (13%)
$51,000 to $65,000	34 (9%)
$66,000 to $80,000	34 (9%)
$81,000 to $100,000	49 (13%)
$101,000 to $130,000	46 (12%)
$131,000 to $160,000	23 (6%)
Over $160,000	33 (9%)
Income Received from Public Assistance (Yes)	77 (20%)
Marital Status	
Single, never married	47 (12%)
Married	288 (71%)
Divorced, remarried	10 (2%)
Divorced, never remarried	31 (8%)
Separated	14 (3%)
Widowed	1 (%)
Domestic Partnership	10 (2%)
Other	2 (%)

Table 4.3 Descriptive Statistics for Secondary Caregiver and Household

	M (*SD*) Freq (%)
Age	38.40 (7.41)
Gender (Male)	296 (91%)
Ethnicity (Not Hispanic/Latino)	229 (71%)
Racial Identification	
White	238 (76%)
Black	36 (11%)
Asian	23 (7%)
Other	11 (4%)
Multi-racial	4 (1%)
American Indian or Alaskan Native	2 (1%)
Education	
Did not attend high school	2 (1%)
Some high school	15 (5%)
GED diploma	12 (4%)
High school graduate	63 (19%)
Trade or vocational school	22 (7%)
Associate degree	34 (10%)
Completed some college	52 (16%)
Baccalaureate degree	69 (21%)
Graduate professional degree	55 (17%)
Employment	
Full time	263 (81%)
Part time	23 (7%)
Homemaker	24 (7%)
Unemployed, looking for work	10 (3%)
Unemployed, not looking for work	2 (1%)
Disabled	3 (1%)
Retired	6 (2%)
Full time student	8 (2%)
Part time student	1 (%)
Other	2 (1%)
Household Characteristics	
Number of adults living in the household	2.03 (.62)
Number of children living in the household	2.14 (.96)

as multi-racial, and 9% of parents identifying as Asian. In regard to education level, more than half of parents (N = 260, 64%) reported completing at least some college or higher, with 43% having completed a baccalaureate degree or graduate/professional degree. Over half of the parents in the study (N = 239, 59%) were employed at least part-time. A total of 382 (94%) participants reported family income. Of those, income was fairly evenly distributed, with 42% (N = 162) of participants reporting a family income of less than $51,000 per year, 31% (N = 117) reporting an income between $51,000 and $100,000 per year, and 27% (N = 103) reporting an income of $101,000 or more per year. One-fifth of study participants (N = 78, 20%) reported that a proportion of their family income came from public assistance programs. The majority of parents reported having a parenting partner, whether married, divorced and remarried, or in a domestic partnership (N = 310, 76%). Participants reported an average family size of about 4 members, with 2 adults (*M* = 2.03, *SD* = .63) and 2 children (*M* = 2.16, *SD* = .98) per household.

4.1.1 Sample Characteristics Compared to SPARK registry

At the time of recruitment, the SPARK research cohort was comprised of 25,148 families (i.e. individuals with ASD and at least one parent). When recruitment began, 78% (N = 19,661) of the SPARK registry sample identified as white, 5% (N = 1,234) identified as Black, 2% (N = 490) identified as Asian, 1% (N = 152) identified as Native American/Native Hawaiian, and 10% (N = 2,603) identified as multiracial. The proportion of representation from diverse groups was higher for most racial groups in the present sample, with 60% of children identifying as white, 14% Black, 6% Asian, and 16% multi-racial. Representation of American Indian/Alaska native participants was smaller, however, making up <1% of the sample. In terms of ethnicity, 17% (N = 4,192) of

the SPARK registry identified as Hispanic, whereas 36% of the present sample identified as Hispanic/Latino.

The majority of primary caregivers in the SPARK research cohort identify as female and their children with ASD are most often male. The sample for the present study was also comprised of mostly female caregivers and male children. A total of 82% of children in the sample met or exceeded the SCQ clinical cutoff score of 15, compared to 83% in the total registry. Additionally, 14% of children in the sample had co-occurring intellectual disability, compared to 17% in the overall registry.

4.2 Preliminary Analyses

Before analyzing the primary aims of the study, a series of preliminary analyses were conducted to evaluate the internal consistency of continuous measures, check assumptions for parametric testing, and assess the potential impact of careless or inattentive responding. First, Cronbach's alpha was used to calculate the internal consistency of the Interview Satisfaction Questionnaire (ISQ) and Wake Forest Interpersonal Trust in a Physician Scale (WFITPS). Cronbach's alpha was .97 for the ISQ and .95 for the WFITPS, indicating excellent reliability for both patient-provider relationship measures (Nunnally & Bernstein, 1994).

Table 4.4 shows descriptive statistics, skewness, and non-linear transformation information for continuous study variables. Boxplots were used to detect potential outliers that may influence bivariate correlations, regressions, t-tests, and ANCOVAs in Aims #2 and #3. Variables with extreme values were winsorized. Cut points for winsorization were set by subtracting 2*IQR from the first quartile and adding 2*IQR to the third quartile (Dixon & Tukey, 1968). The expectation

Table 4.4 Descriptive Statistics, Skewness, and Transformation of Continuous Study Variables

Variable	$N_{missing}$	N	*M*	*SD*	Min	Max	Skew (pre)	Transform	Skew (post)
Patient-Provider Relationships									
ISQ Total[a]	9	397	49.27	12.86	12	60	-1.23	x^2	-0.83
WFITPS Total[a]	4	402	37.01	10.93	10	50	-0.73		
Continuous DDI Items									
Dx Age (years)	0	406	3.26	1.27	0.83	7.17	1.07	win(2)	0.98
Diagnostic delay (years)	0	406	1.2	1.13	0	7.42	1.75	win(10), log(x)	0.27
Delay seeking help (years)	3	403	0.43	0.78	-1.25	5.25	2.08	win(16)	0.91
Total number of visits	0	406	3.54	2.23	1	12	1.97	win(22), log(x)	-0.13
Satisfaction	2	404	1.04	1.23	0	4	1.02	$x^{1/2}$	0.26
Stress	0	406	1.99	0.94	0	3	-0.65		
Total non-ASD diagnoses	0	406	0.11	0.33	0	2	2.60	binary(x)	
Frequency told no problem	0	406	0.37	0.61	0	3	1.58	binary(x)	
Frequency insisted on referrals[b]	49	357	0.23	0.54	0	3	2.61	binary(x)	
Frequency self-referred[b]	49	357	0.36	0.67	0	3	1.91	binary(x)	

Note. win(n) = winsorization performed on n outliers
[a]Expectation maximization was used to impute missing values on the ISQ and WFITPS
[b]49 participants were systematically missing data on self-referrals and insisting on referrals because they skipped through the survey sections that covered referral visits

maximization algorithm was used to impute values for missing data on the ISQ and WFITPS. An examination of bivariate correlations indicated that the ISQ and WFITPS were highly correlated (r = .85). To address the potential for collinearity of these variables in Aims 2 and 3, the two measures were *z*-transformed and collapsed into a single patient-provider relationship variable.

After evaluating the normality of key study variables, the reliability of the Diagnostic Difficulty Index (DDI) was assessed. All DDI items were z-transformed before undergoing factor and reliability analysis. Item-total statistics for the DDI can be found in Table 4.5. Overall Cronbach's alpha with the full set of items was .55, indicating unsatisfactory reliability (Nunnally & Bernstein, 1994). A total of four items had item-total correlations below .15: total delay between first concern and first visit, number of non-ASD diagnoses received, previous experience with the ASD diagnostic process, and area of residence at the time of first concern. These items were subsequently dropped from the pool. The resulting Cronbach's alpha with the reduced set of items (Table 4.6) was improved to .64, indicating sufficient reliability (Nunnally & Bernstein, 1994). A scree plot was generated (Figure 4.1) to examine the eigenvalues of DDI items and explore potential item groupings. The Scree plot suggested potential 1-, 2-, and 3-factor solutions. We then performed a factor analysis with the remaining 9 items using exploratory factor analysis with varimax rotation (Table 4.7). Results showed that a three-factor solution was the most optimal fit. Two items (total number of visits and formal screening measures completed at first visit) had loadings below .3 and were dropped from the final set. The remaining seven items were grouped into three subgroups: time barriers, institutional barriers, and parent perceptions (Table 4.8). Cronbach's alpha and item-totals were calculated for each factor, which showed acceptable reliability for time barriers, and lower but minimally acceptable reliability for institutional barriers and parent perceptions (Table 4.9). Given the small number of items per factor and that

Cronbach's alpha is a function, in part, of number of items in the scale, we found these levels of reliability sufficient to proceed with subsequent analyses.

Table 4.5 Reliability Analysis with Full Set of Diagnostic Difficulty Index (DDI) Variables

		Item Total	Alpha Without	N
Cronbach's alpha	.55			
Age at diagnosis		.36	.49	406
Total delay between first visit and diagnosis		.38	.49	406
Total delay between first concern and first visit		-.02	.58	403
Total number of visits		.30	.51	406
Total number of non-ASD diagnoses received		.04	.56	406
Total number of times told no problem		.42	.48	406
Total number of times insisted on referral		.24	.52	357
Total number of times self-referred		.21	.53	357
Formal screening procedures completed		.17	.54	406
Previous experience with the diagnostic process		.12	.55	404
Area of residence		-.02	.58	403
Overall satisfaction with the process		.35	.49	404
Stressful nature of the process		.25	.52	406

Table 4.6 Reliability Analysis with Reduced Set of Diagnostic Difficulty Index (DDI) Variables

		Item Total	Alpha Without	N
Cronbach's alpha	.64			
Age at diagnosis		.31	.61	406
Total delay between first visit and diagnosis		.43	.58	406
Total number of visits		.33	.61	406
Total number of times told no problem		.48	.57	406
Total number of times insisted on referral		.27	.62	357
Total number of times self-referred		.21	.64	357
Formal screening procedures completed		.20	.64	406
Overall satisfaction with the process		.37	.60	404
Stressful nature of the process		.28	.62	406

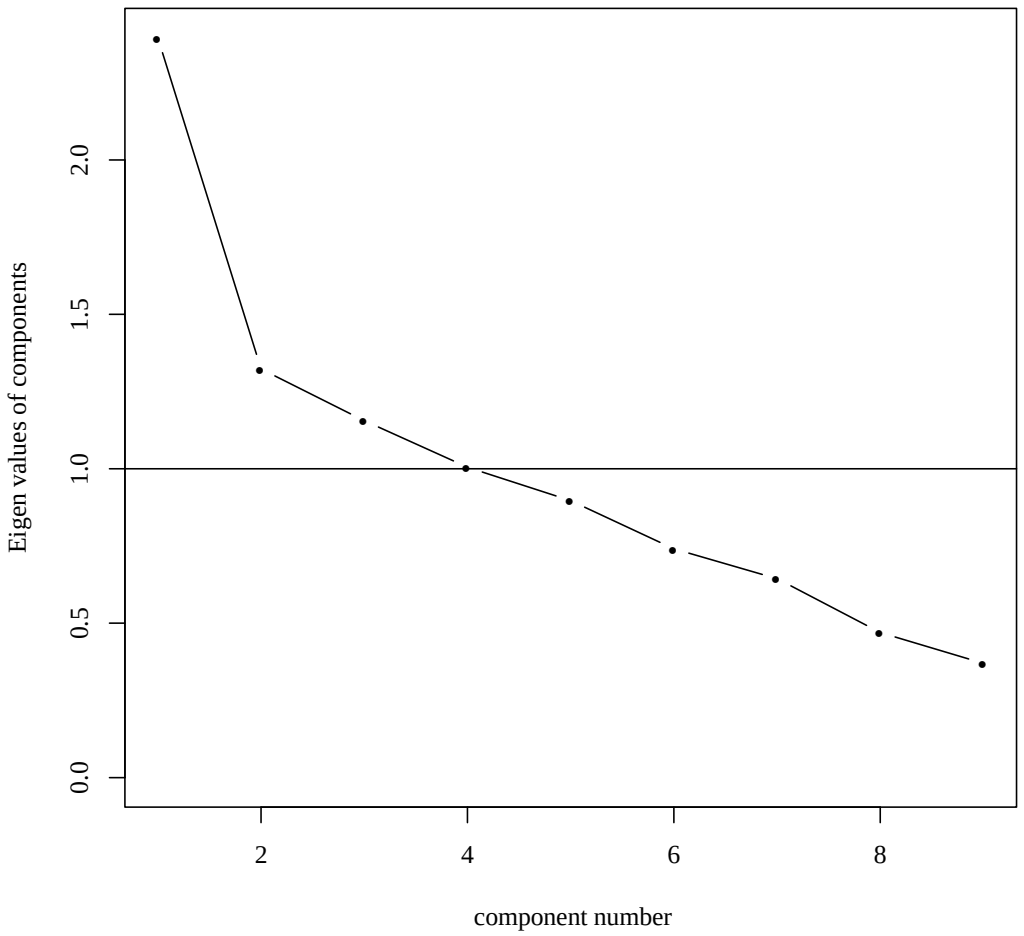

Figure 4.1 Scree Plot Showing Eigenvalues of Diagnostic Difficulty Index (DDI) Items

Table 4.7 Factor Structure of Diagnostic Difficulty Index (DDI)

	1-Factor Solution	2-Factor Solution		3-Factor Solution		
Variable	Factor 1	Factor 1	Factor 2	Factor 1	Factor 2	Factor 3
Child age at formal diagnosis	**.64**	**.59**	.06	**.58**	.05	.06
Delay between first visit and diagnosis	**.80**	**.99**	.13	**.99**	.12	.09
Total number of visits in process	**.40**	.30	.27	.29	.18	.25
Total times told no problem	**.37**	.15	**.78**	.12	**.98**	.11
Total times parents insisted on referrals	.26	.10	**.45**	.10	**.38**	.14
Formal screening completed at first visit	.15	.01	**.36**	.02	**.31**	.07
Total times parents self-referred	.16	.04	.28	.03	.21	.25
Satisfaction with the diagnostic process	**.31**	.17	.29	.14	.11	**.55**
Stressful nature of the process	.19	.06	.26	.03	.09	**.59**

Table 4.8 Final Difficulty Factor Groupings

Time Barriers
1. Child age at diagnosis
2. Total delay between first professional visit and final diagnosis

Institutional Barriers
3. Total times parents were told there was “no problem”
4. Total times parents insisted on referrals
5. Formal screening measures completed at first professional visit

Parent Perceptions
6. Satisfaction with the diagnostic process as a whole
7. Stressful nature of the diagnostic process

Table 4.9 Overall and Item-Total Alphas Within Each Difficulty Factor

Variable	Alpha	Item-Total	N
Time Barriers	.74		
Age at diagnosis		.59	406
Total delay between first visit and final diagnosis		.59	406
Institutional Barriers	.53		
Total number of times told no problem		.48	406
Total number of times insisted on referral		.31	357
Formal screening procedures completed at first visit		.25	406
Parent Perceptions	.50		
Overall satisfaction with the process		.34	404
Stressful nature of the process		.34	406

Next, the survey was analyzed for careless responders by calculating person-total correlations (i.e. individual consistency) for responses on all continuous dependent measures (ISQ, WFITPS, and DDI variables) as well as total survey response time. Person-total correlations were calculated by computing bivariate correlations between individual responses to a single item and the mean score of that item across the remainder of the sample (Curran, 2016). Evaluation of individual consistency revealed there were no study participants with negative person-total correlations, suggesting there were no cases with individual consistency values indicating obvious careless or inattentive responding (Curran, 2016).

Upon examination of survey response times, it became evident that setting the survey response time exclusion threshold to 10 minutes may have been too restrictive. Mean survey response time was 24.38 minutes with a standard deviation of 17.80 minutes. A total of 38 participants completed the survey in less than 10 minutes, 36 of whom had response times within one standard deviation of the mean (i.e. between 6 and 10 minutes), leading to concerns that a significant group of survey respondents with meaningful data may be excluded unnecessarily. As

a result, the exclusion threshold was reduced to one standard deviation below the mean (*SD* = 6.57 minutes, rounded down to 6 minutes) and a sensitivity analysis was conducted to reexamine the main findings of the study with and without the 36 participants with response times between 6 and 10 minutes. The results of this sensitivity analysis can be found in Appendix B. The two participants with response times under 6 minutes were excluded from the analysis, leaving a remaining sample size of N = 406.

4.3 Aim #1: Describe the process of obtaining a first diagnosis of autism spectrum disorder (ASD) in the United States.

Descriptive data gathered from the six sections of the Diagnostic Processed Questionnaire are summarized below.

4.3.1 Early Concerns

Parents provided descriptive information about the number and nature of early developmental concerns and additional contextual information about their child's peer involvement and area of residence at the time of initial concerns. These data are shown Table 4.10. On average, worries began around 1.63 years of age (*SD* = .87). Most developmental concerns were detected by age 5, with 29.03% of parents having concerns within the first year, 76.92% of parents having concerns by age 2, and 99.75% of parents having concerns before their child turned 5. Most parents (N = 296, 73%) reported they were also the individuals who first had developmental concerns. On average, parents reported having about seven different concerns prior

Table 4.10 Early Developmental Concerns Prior to First Professional Visit

Variable	*M* (*SD*) Freq (%)
Child age at first developmental concern (years)	1.63 (.87)
Total number of concerns had by primary caregiver	7.01 (3.64)
Who first had concerns	
I did (study informant)	296 (73%)
Child's doctor	36 (9%)
Partner/secondary caregiver	29 (7%)
Relative	19 (5%)
Child's teacher	11 (3%)
Child's therapist	8 (2%)
Other	4 (1%)
Friend	1 (%)
Involvement in peer activities at time of first concerns	
Daycare	127 (31%)
Preschool	56 (14%)
Clubs or Groups	37 (9%)
Sports	13 (3%)
Kindergarten	9 (2%)
Elementary School	8 (2%)
Area of residence at time of first concerns	
Suburban	217 (54%)
Urban	108 (27%)
Rural	78 (19%)
No prior experience with ASD Dx process	347 (86%)

to their first visit with a professional (*M* = 7.03, *SD* = 3.66). The nature of these concerns is displayed in Figure 4.2. The most common early concern was overwhelmingly a delay in talking (N = 312, 77%), followed by several concerns related to social interaction: lack of eye contact (N = 247, 61%), lack of responsiveness (N = 222, 55%), and not playing with peers (N = 218, 54%). In terms of peer activities and involvement, just under one third of parents (N = 127, 31%) reported that their children were in daycare at the time of first concern and 14% of parents (N = 56) reported that their children were in preschool. Very few parents reported that their children were involved in clubs, groups, or sports at the time of initial concerns. Finally, the vast majority of parents (N =

352, 85%) had no prior experience with the ASD diagnostic process (e.g. having been through the process with another child).

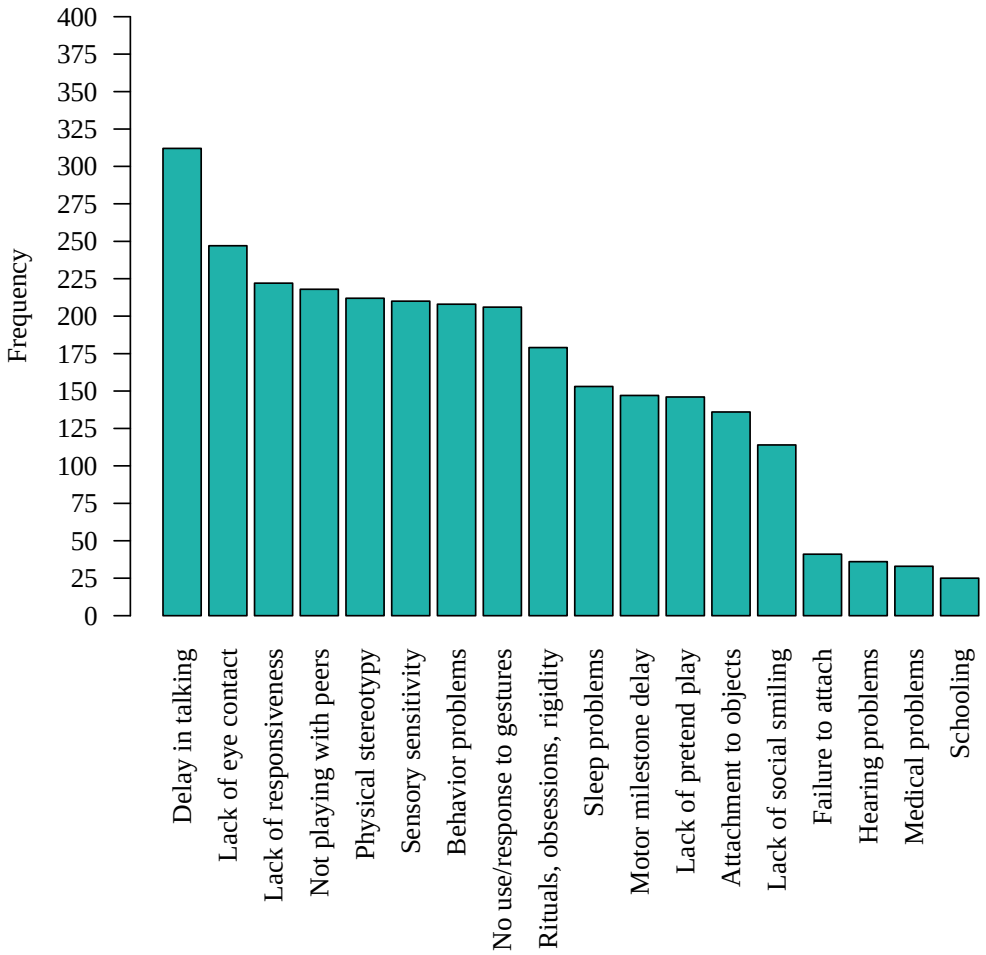

Figure 4.2 Frequency of Early Concerns Reported by Parents (N = 406)

4.3.2 First Professional Visit

Parents were asked to provide information about their first visit with a professional in which their developmental concerns were first raised. Table 4.11 shows descriptive statistics in regards to the first professional visit. Children were about 2 years old (M = 2.06, SD = 1.01) when

Table 4.11 Characteristics of the First Professional Visit

Variable	*M* (*SD*) Freq (%)
Age of child at first professional visit (years)	2.06 (1.01)
Delay between first concern and first visit (months)	5.16 (9.41)
Type of professional seen	
Pediatrician	274 (67%)
General Practitioner (family doctor)	65 (16%)
Other	16 (4%)
Social Worker	13 (3%)
Psychologist	12 (3%)
Neurologist	10 (2%)
Teacher	9 (2%)
Psychiatrist	6 (1%)
Nurse	1 (%)
Formal screening procedures completed during first visit	
Short interview about developmental concerns/behaviors	219 (54%)
Formal questionnaire about developmental concerns/behaviors	195 (48%)
Professional conducted brief observation of child's behaviors	190 (47%)
Professional asked about possible family history of ASD	152 (37%)
No screening procedures were completed	75 (18%)
Outcome of first visit	
Referred to another professional	252 (62%)
Told no problem	113 (28%)
Told to return if problems do not improve	64 (16%)
Diagnosis made	30 (7%)
Other	17 (4%)
Formal ASD diagnosis made at first visit	22 (5%)

parents first raised their developmental concerns with a professional, and the average delay between the first developmental concern and the first professional visit was just over five months. The majority of parents brought their first concerns to a medical doctor, most commonly their child's pediatrician (N = 274, 67%) and less frequently, a general practitioner or family doctor (N = 65, 16%). Even fewer sought help initially from social workers, psychologists, neurologists, teachers, or psychiatrists. During the first visit where developmental concerns were raised, most parents experienced some type of formal screening procedure, with only 18% of parents (N = 75) reporting that no formal screening procedures were completed. In terms of first visit outcomes,

most parents (N = 252, 62%) were referred out to another professional. Over a quarter of parents were told there was "no problem" (N = 113, 28%) and 16% (N = 64) were told to return if their developmental concerns persisted. Only 5% of families (N = 22) received an ASD diagnosis at their first professional visit.

4.3.3 Referral Visits

Parents answered questions about subsequent referral visits, the age of their children at each visit, approximate wait time for appointments, types of professionals seen, and outcomes of each visit. Descriptive statistics related to referral visits can be found in Table 4.12. Most parents (N = 358, 88%) attended at least one referral visit after their first visit with a professional. The average wait time for referral visits was about 5 months (M = 5.02, SD = 3.99) and families attended an average of 3.54 (SD = 2.23) additional appointments before receiving a formal ASD diagnosis. As shown in Figure 4.3, parents reported seeing a wide range of different professionals

Table 4.12 Characteristics of Referral Visits

Variable	*M* (*SD*) Freq (%)
Total number of visits before Dx made	3.54 (2.23)
Referral appointment wait time (months)	5.02 (3.99)
Number of families who received at least one non-ASD Dx before formal ASD Dx	46 (11%)
Number of times a professional said there was no problem in referral visits	
Never	372 (92%)
One time	29 (7%)
Two times	5 (1%)

throughout the diagnostic process. Pediatricians and psychologists were the two most commonly consulted professionals, followed by speech-language pathologists and audiologists. During referral visits, a small proportion of children (N = 46, 16%) received other non-ASD diagnoses. A very small number of parents reported that professionals seen in referral visits told them there was "no problem" (N = 34, 8%).

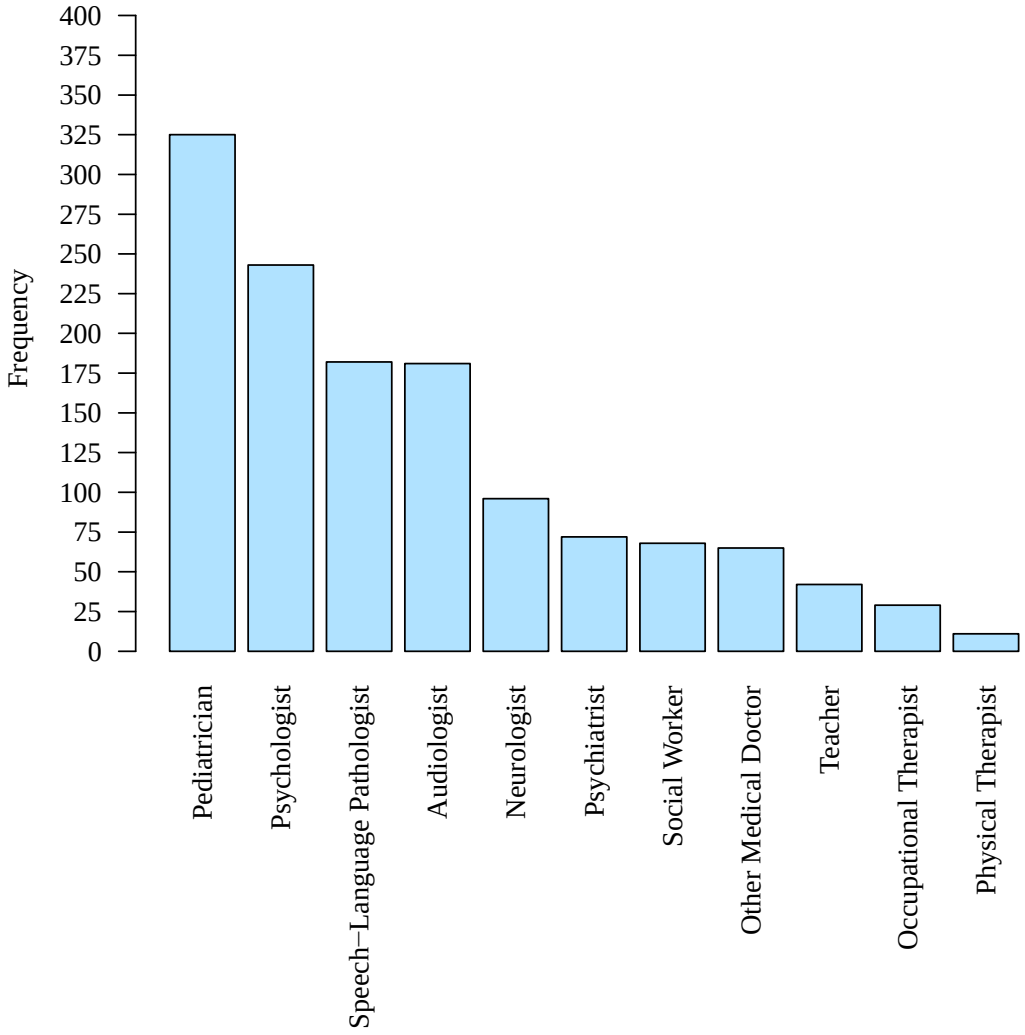

Figure 4.3 Professionals Seen At Least Once in the Diagnostic Process (N = 406)

4.3.4 Formal Diagnosis

Parents were asked to provide information about the visit in which the final ASD diagnosis was made. These data are shown in Table 4.13. Parents reported an extraordinarily wide range of

Table 4.13 Characteristics of the Formal ASD Diagnosis

Variable	*M* (*SD*) Freq (%)
Professional who made diagnosis	
Developmental Psychologist	110 (27%)
Clinical Psychologist	69 (17%)
Neurologist	60 (15%)
Psychiatrist	44 (11%)
Pediatrician	29 (7%)
Developmental Pediatrician	28 (7%)
Unsure/Don't know	25 (6%)
Other	23 (6%)
Educational Psychologist	7 (2%)
Speech Therapist	4 (1%)
Social Worker	3 (1%)
Nurse Practitioner	2 (%)
Audiologist	1 (%)
Diagnostic assessments completed	
Behavioral observations	363 (89%)
In-depth interviews	359 (88%)
Formal behavior/symptom questionnaires	347 (85%)
Family medical history	323 (80%)
ADOS	284 (70%)
None	4 (1%)
Age of diagnosis (years)	3.26 (1.29)
Delay between first visit and final Dx (years)	1.20 (1.13)
Delay between first concern and final Dx (years)	1.63 (1.31)
Number of times families were told there was no problem at any point in the process	
Never	278 (68%)
One time	107 (26%)
Two times	18 (4%)
Three times	3 (1%)

professionals who made the final ASD diagnosis for their children. The most common diagnosing professional was a developmental psychologist (N = 110, 27%), followed by a clinical psychologist (N = 69, 17%), and a neurologist (N = 60, 15%). The majority of diagnostic visits included formal diagnostic assessments, including behavioral observations (N = 363, 89%), in-depth interviews (N = 359, 88%), formal behavior/symptom questionnaires (N = 347, 85%), family medical histories (N = 323, 80%), and the Autism Diagnostic Observation Schedule (ADOS) (N = 284, 70%). A very small number of families (N = 4, 1%) reported that no formal diagnostic assessments were completed as part of the final ASD diagnosis. Average age of diagnosis was 3.26 years (*SD* = 1.29) and the average delay between the first professional visit and final diagnosis was 1.20 years (*SD* = 1.13).

4.3.5 Parent Perceptions of the Diagnostic Process

Parents provided information about post-diagnostic support, satisfaction ratings on several elements of the diagnostic process, and ratings of their relationship with their child's primary care provider at the time of their first developmental concerns. These data can be found in Table 4.14. Following formal ASD diagnosis, less than half of parents reported that they were offered practical help by the diagnosing professional either directly (N = 165, 41%) or indirectly, through referrals (N = 181, 44%). A small proportion of parents (N = 58, 14%) were offered no help at all by the diagnosing professional. Generally, parents were satisfied with the information they received at diagnosis, the professional manner in which the diagnosis was provided, and the help/support provided after the diagnosis was made. Additionally, most parents reported being very satisfied (N = 182, 45%) or somewhat satisfied (N = 116, 29%) with the diagnostic process as a whole.

Table 4.14 Post Diagnostic Support and Parent Perceptions of the Diagnostic Process

	N (%)
Practical help/support offered during or after diagnosis?	
Offered directly	164 (40%)
Signposted toward (referred to)	181 (45%)
No help/support offered	58 (14%)
Satisfaction with information given at diagnosis	
Very satisfied	192 (47%)
Somewhat satisfied	137 (34%)
Neither satisfied nor dissatisfied	42 (10%)
Somewhat dissatisfied	20 (5%)
Very dissatisfied	15 (4%)
Satisfaction with professional manner in which diagnosis was given	
Very satisfied	284 (70%)
Somewhat satisfied	76 (19%)
Neither satisfied nor dissatisfied	21 (5%)
Somewhat dissatisfied	16 (4%)
Very dissatisfied	7 (2%)
Satisfaction with help/support offered after diagnosis	
Very satisfied	165 (41%)
Somewhat satisfied	121 (30%)
Neither satisfied nor dissatisfied	43 (11%)
Somewhat dissatisfied	41 (10%)
Very dissatisfied	36 (9%)
Satisfaction with diagnostic process as a whole	
Very satisfied	182 (45%)
Somewhat satisfied	116 (29%)
Neither satisfied nor dissatisfied	36 (9%)
Somewhat dissatisfied	48 (12%)
Very dissatisfied	22 (5%)
Stressful nature of the diagnostic process	
Not at all stressful	38 (9%)
Not very stressful	67 (17%)
Somewhat stressful	163 (40%)
Very stressful	138 (34%)

However, most parents still found the process to be stressful, with 40% (N = 163) reporting the process was somewhat stressful and 34% (N = 138) reporting the process was very stressful.

Parents also provided ratings on the quality of communication and degree of trust in their child's pediatrician/primary care provider at the time of their first developmental concerns (see Table 4.15). Overall, ratings of the quality of communication with their child's provider were favorable (*M* = 49.30, *SD* = 12.95). Ratings of the degree of trust in their child's provider were less favorable (*M* = 37.01, *SD* = 10.92).

Table 4.15 Descriptive Statistics for Patient-Provider Relationship Measures

Variable	*M* (*SD*)	Range
Interview Satisfaction Questionnaire (ISQ) – Total Score	49.27 (12.86)	12 - 60
Wake Forest Interpersonal Trust in a Physician Scale (WFITPS) – Total Score	37.01 (10.93)	10 - 50

Note. For the ISQ and WFT, higher scores indicate better communication and a higher degree of trust, respectively

Overall, the descriptive findings of Aim 1 suggest that parents continue to identify developmental problems early on in their child's life. They also appear to be more quickly bringing these initial concerns to professionals. Initial concerns are most often discussed with medical doctors first (i.e. pediatricians or general practitioners), who then refer parents to other professionals. Before a formal ASD diagnosis is made, parents attend an average of 3-4 different appointments with a wide range of different professionals, often waiting many months for each appointment. A wide range of different types of professionals are making ASD diagnoses in the United States, but psychologists are the most common diagnosing professional. Parents appear to

be more satisfied with the process than in prior studies, but they continue to report that the process is stressful.

4.4 Aim #2: Examine the degree to which perceptions of the patient-physician relationship are related to difficulties in obtaining an ASD diagnosis

A series of linear regression models were constructed to assess whether there was an association between early patient-provider relationships and difficulty experienced in the ASD diagnostic process. First, bivariate correlations between potential demographic confounders and the three difficulty factors were examined (Table 4.16). Any variable with a significant zero-order correlation with any difficulty factor was entered into the regression models as a potential confounder. Thus, parent age, education, and race were retained. Although child symptom severity did not have a significant bivariate correlation with any of the difficulty factors, symptom severity was also retained due to its theoretical importance and existing evidence that symptom severity is related to various aspects of the ASD diagnostic process that were used to compile the difficulty factors (i.e. age of diagnosis, clinical delay, etc.) (Berg, Acharya, Shiu, & Msall, 2018; Crane, Chester, Goddard, Henry, & Hill, 2016; Daniels & Mandell, 2014; Mazurek et al., 2014; Rosenberg et al., 2011; Wong et al., 2017). Time since diagnosis was also added to each model to control for recency bias.

Results of multiple regression analyses are shown in Table 4.17. Separate models were constructed for each difficulty factor. Each model controlled for time since diagnosis, parent age, education and race, and child symptom severity. A hierarchical approach was taken to analysis, such that confounders were added to the model first, followed by patient-provider relationship to

Table 4.16 Bivariate Correlations Between Demographics and Patient-Provider Relationship and Difficulty Factors

Variable	Time Barriers	Institutional Barriers	Parent Perceptions
Parent Age	.21**	-.00	.04
Parent Gender	-.08	.00	.00
Parent Education	.03	-.04	.11*
Parent Ethnicity	.01	-.04	.07
Parent Race	-.07	-.06	-.10*
SCQ total (symptom severity)	.04	.09+	-.02
Time since diagnosis	-.34**	-.06	-.06
Patient-provider relationship composite	-.14**	-.45**	-.25**

examine the additional variance explained for each domain, after controlling for confounders. Patient-provider relationships had a significant inverse association with difficulty for time barriers (β = -.12, p = .013), institutional barriers (β = -.47, p = .000), and parent perceptions (β = -.24, p = .000), such that better patient-provider relationships were associated with less difficulty experienced by parents in the ASD diagnostic process. The magnitude of this relationship was the strongest for institutional barriers. The additional variance explained by the addition of patient-provider relationships was significant for all three models; however, the R^2 increase was substantial in the institutional barriers model (ΔR^2 = .21, p = .000).

In sum, Aim 2 analyses revealed that the quality of a parent's relationship with their child's pediatrician or primary care provider at the time of their first developmental concern is related to the difficulty they experience in the ASD diagnostic process. Specifically, higher quality relationships are associated with fewer time barriers, fewer institutional barriers, and more favorable parent perceptions and worse relationships are associated with more time barriers, more institutional barriers and less favorable parent perceptions of the process.

Table 4.17 Multiple Linear Regression Analyses Showing Associations Between Patient-Provider Relationships and Difficulty Factors

	Time Barriers B (SE) [β]	Time + Relationship B (SE) [β]	Institutional Barriers B (SE) [β]	Institution + Relationship B (SE) [β]	Parent Perceptions B (SE) [β]	Perceptions + Relationship B (SE) [β]
Time since diagnosis	-.32** (.04) [-.39]	-.32** (.04) [-.39]	-.03 (.04) [-.05]	-.03 (.03) [-.04]	-.03 (.04) [-.03]	-.02 (.04) [-.03]
Parent age	.04** (.01) [.23]	.04** (.01) [.24]	-.00 (.01) [-.01]	.00 (.01) [.03]	-.01 (.01) [-.04]	-.00 (.01) [-.02]
Parent education	-.03 (.03) [-.06]	-.04 (.03) [-.08]	-.00 (.02) [-.01]	-.03 (.02) [-.08]	.08** (.03) [.19]	.07** (.02) [.15]
Parent race - Asian	-.33* (.17) [-.10]	-.31 (.17) [-.09]	-.09 (.15) [-.03]	-.03 (.13) [-.01]	-.40* (.16) [-.14]	-.37* (.16) [-.12]
Parent race - Black	.06 (.13) [.02]	.10 (.13) [.04]	-.17 (.12) [-.08]	-.04 (.10) [-.02]	-.31* (.13) [-.13]	-.24 (.12) [-.10]
Parent race – Multi	-.05 (.15) [-.02]	.00 (.15) [.00]	-.06 (.14) [-.02]	.08 (.12) [.03]	-.12 (.15) [-.05]	-.05 (.15) [-.02]
Parent race - Other	.15 (.21) [.04]	.14 (.21) [.03]	.02 (.19) [.01]	-.01 (.17) [.00]	.22 (.21) [.06]	.20 (.20) [.05]
SCQ total score	.01 (.01) [.07]	.01 (.01) [.06]	.01* (.01) [.12]	.01 (.01) [.07]	-.00 (.01) [-.00]	-.00 (.01) [-.03]
Patient-provider relationship		-.11* (.05) [-.12]		-.36** (.04) [-.47]		-.20** (.04) [-.24]
F-statistic	11.90**	11.43**	1.07	11.80**	2.86**	5.05**
R^2	.22	.23	.02	.24	.06	.12
ΔR^2		.01*		.21**		.05**

*$p < .05$, **$p < .01$

4.5 Aim #3: Explore how the process of obtaining a first diagnosis of ASD varies by race and income.

In order to explore whether difficulty varied by racial identification, one-way analysis of covariance (ANCOVA) was used. Separate models were constructed for each difficulty factor, controlling for time since diagnosis and child symptom severity, with the primary between-subjects factor being parent race. ANCOVA results are shown in Table 4.18. Results revealed there was no main effect of race on difficulty related to time barriers (F = 1.68, p =.154) or institutional barriers (F = .610, p = .656); however, there were differences by race in parent perceptions (F = 2.50, p = .042). Next, a series of post-hoc pairwise comparisons were conducted to explore whether there were any significant mean differences between racial groups across all

Table 4.18 One-way ANCOVA Models Showing the Overall Effect of Race on Time Barriers, Institutional Barriers, and Parent Perceptions

Variable	*df*	*SS*	*F*	η^2	*p*
Time Barriers					
Time since Dx	1	41.95	62.17	.15	.00
SCQ Total	1	1.64	2.43	.01	.12
Parent race	4	4.54	1.68	.02	.15
Institutional Barriers					
Time since Dx	1	.53	.99	.00	.32
SCQ Total	1	2.22	4.13	.01	.04
Parent race	4	1.31	.61	.01	.66
Parent Perceptions					
Time since Dx	1	.97	1.50	.00	.22
SCQ Total	1	.06	.09	.00	.76
Parent race	4	6.48	2.50	.03	.04

difficulty factors. These data can be found in Tables 4.19, 4.20, and 4.21 for time barriers, institutional barriers, and parent perceptions respectively. Results revealed no significant mean differences in difficulty experienced between racial groups for any of the difficulty factors. However, post-hoc analyses were exploratory and likely underpowered due to small sample sizes among some racial groups. Thus, effect sizes were also examined. The two largest effect sizes were observed in comparisons between parents who identified as Asian and those who identified with an Other racial category. Specifically, Asian parents experienced fewer time barriers than parents in the Other racial category (t = 2.11; p = .118; d = .92) and also reported more favorable parent perceptions of the diagnostic process (t = 1.98; p = .160; d = .69).

Table 4.19 Mean Differences in Time Barriers Between Racial Groups

Comparison Group	*M*	*SE*	Reference Group	*M*	*SE*	*t*	*p*	*d*
Asian	-.29	.16	White	.07	.05	-2.17	.12	-.42
Black	.12	.12				.42	.67	.06
Multi-racial	-.04	.14				-.75	.57	-.13
Other	.25	.21				.87	.55	.21
Black	.12	.12	Asian	.29	.16	2.11	.12	.50
Multi-racial	-.04	.14				1.16	.49	.34
Other	.25	.21				2.11	.12	.92
Multi-racial	-.04	.14	Black	.12	.12	-.91	.55	-.18
Other	.25	.21				.54	.65	.14
Other	.25	.21	Multi-racial	-.04	.14	1.19	.49	.36

Note. Pairwise comparisons were corrected using the Benjamini-Hochberg method. Results are z-scored with M = 0, SD = 1.

Table 4.20 Mean Differences in Institutional Barriers Between Racial Groups

Comparison Group	*M*	*SE*	Reference Group	*M*	*SE*	*t*	*p*	*d*
Asian	-.04	.14	White	.06	.05	-.69	.90	-.14
Black	-.11	.11				-1.44	.90	-.23
Multi-racial	.00	.13				-.42	.90	-.08
Other	.07	.18				.07	.94	.02
Black	-.11	.11	Asian	-.04	.14	-.37	.90	-.10
Multi-racial	.00	.13				.24	.90	.07
Other	.07	.18				.51	.90	.17
Multi-racial	.00	.13	Black	-.11	.11	.68	.90	.16
Other	.07	.18				.86	.90	.27
Other	.07	.18	Multi-racial	.00	.13	.32	.90	.10

Note: Pairwise comparisons were corrected using the Benjamini-Hochberg method. One property of this method is that when model comparisons demonstrate little in the way of statistical significance, p-value adjustments are large and often uniform. Results are z-scored with M = 0, SD = 1

Table 4.21 Mean Differences in Parent Perceptions Between Racial Groups

Comparison Group	*M*	*SE*	Reference Group	*M*	*SE*	*t*	*p*	*d*
Asian	-.24	.15	White	.06	.05	-1.85	.16	-.37
Black	-.25	.12				-2.41	.15	-.37
Multi-racial	-.04	.14				-.68	.55	-.13
Other	.26	.20				.96	.43	.25
Black	-.25	.12	Asian	-.24	.15	-.03	.97	-.01
Multi-racial	-.04	.14				.95	.43	.26
Other	.26	.20				1.98	.16	.69
Multi-racial	-.04	.14	Black	-.25	.12	1.14	.43	.24
Other	.26	.20				2.19	.15	.60
Other	.26	.20	Multi-racial	-.04	.14	1.23	.43	.42

Note. Pairwise comparisons were corrected using the Benjamini-Hochberg method. Results are z-scored with M = 0, SD = 1.

To explore whether difficulty varied by income, multiple linear regression models were constructed for each difficulty factor. It was suspected that income alone may not accurately represent the socioeconomic disparity hypothesized to influence diagnostic difficulty without also taking into consideration family size (e.g. considering an annual income of $21,000-$35,000 for a family of 3 as compared to a family of 5). Thus, in addition to income information collected via the DPQ, a separate income variable was generated that weighted income by family size. Comparison of the two income variables revealed no significant differences between the weighted and unweighted models, and so the unweighted variable was used for parsimony in interpretation of findings. Multiple regression analyses assessing associations between income and difficulty, controlling for time since diagnosis and symptom severity, are shown in Table 4.22. Results revealed no significant association between diagnostic difficulty and family income for time barriers (p = .684), institutional barriers (p = .518), or parent perceptions (p = .108).

A further exploratory analysis of whether patient-provider relationships varied by racial group or family income was conducted. First, ANCOVA models were constructed to examine whether racial group influenced patient-provider relationships, controlling for time since diagnosis and child symptom severity. Results revealed a marginal effect of race on patient-provider relations (F = 2.04, p = .089). Pairwise comparisons were conducted to evaluate mean differences in patient-provider relationships between racial groups; however, no significant mean differences were identified (all p > .200). Multiple regression analysis was used to assess whether differences in the patient-provider relationship varied by family income, controlling for time since diagnosis and child symptom severity. Similarly, there were no significant differences in the quality of patient-provider relationships by family income (β = -.04, p = .429).

Table 4.22 Results of Multiple Regression Analyses Showing Associations Between Family Income and Difficulty Factors, Controlling for Time Since Diagnosis and Symptom Severity

	Time Barriers B (SE) [β]	Institutional Barriers B (SE) [β]	Parent Perceptions B (SE) [β]
Time since diagnosis	-.30**	-.04	-.04
	(.04)	(.04)	(.04)
	[-.37]	[-.07]	[-.06]
SCQ total score	.01	.01	.00
	(.01)	(.01)	(.01)
	[.08]	[.10]	[.01]
Family income	.01	-.01	.03
	(.02)	(.02)	(.02)
	[.02]	[-.04]	[.09]
F-statistic	18.78**	1.74	1.31
R^2	.14	.02	.01

*$p < .05$, **$p < .01$

The results of Aim 3 suggest there may be some effect of race on parent perceptions of the diagnostic process, but exploratory pair-wise comparisons were inconclusive. There was no evidence to suggest that race influenced time barriers or institutional barriers. Results also revealed no associations between family income and difficulty for any of the difficulty factors.

5.0 Discussion

5.1 Summary of Findings

The purpose of this study was to describe the broad characteristics of the ASD diagnostic process nationally, assess whether relationships between parents and their children's early medical providers are associated with diagnostic difficulty, and explore whether diagnostic difficulty varies by race and family income. Descriptive findings suggested that parents tend to be the first to have developmental concerns and they develop these concerns early in their child's life. Findings also showed that parents bring these concerns to medical doctors (pediatricians or general practitioners), who typically provide referrals to other types of professionals or sometimes assure parents there is no problem. Parents experience considerable wait times to consult with multiple different professionals across multiple different visits prior to obtaining a formal ASD diagnosis for their children. Additionally, this study found that ASD diagnoses in the United States are made by a wide range of different professionals. Parents generally expressed satisfaction with the diagnostic process, but also reported that the process was stressful.

Results of multiple regression analysis suggested that the quality of the relationship between a parent and their child's pediatrician or primary care provider had some bearing on the difficulty parents experienced in the subsequent ASD diagnostic process. In particular, higher quality relationships with providers were associated with less difficulty experienced across all three difficulty factors: time barriers, institutional barriers, and parent perceptions. The magnitude of this relationship was strongest for institutional barriers.

Surprisingly, there was only some evidence to suggest that diagnostic difficulty varied by race. There was a significant main effect of race on parent perceptions. Yet, pairwise comparisons showed no significant mean differences between racial groups. However, while the overall ANCOVA models were adequately powered to detect moderate effects of race on difficulty, the post-hoc pairwise comparisons were likely underpowered due to small sample sizes in some racial minority groups. There was no evidence to suggest that diagnostic difficulty varied by family income.

In regard to Aim 1, age of diagnosis and the total delay between the first professional visit and the final diagnosis were notably better than in prior studies. Children in the present study were, on average, 3.26 years old when the a formal ASD diagnosis was made, an improvement from prior studies (6.11 years, Howlin & Moore, 1997; 4.5 years, Goin-Kochel, Mackintosh, & Myers, 2006; 5.23 years, Oswald, Haworth, Mackenzie et al., 2017; 4-5 years, Zwaigenbaum & Penner, 2018). In addition, the average delay between the first visit and final diagnosis also continues to shrink with time, with prior studies finding average delays of 4.42 years (Howlin & Moore, 1997), 3.6 years (Crane Chester Goddard, Henry, Hill, 2015), 2.7 years (Zuckerman, Lindly, & Sinche, 2015), and 2.2 years (Zuckerman, Lindly & Chavez, 2017), and the present study identifying an overall delay of 1.2 years.

The age of first concern was consistent with prior work, with most parents developing concerns prior to age 2. The number and nature of early concerns was also consistent with extant literature, with most common concerns being related to delays in communication or social interaction and reciprocity. The present study found that parents expressed having about 7 different types of concerns related to their child's development, similar to findings of Oswald, Haworth, Mackenzie et al. (2017) that parents had an average of 8.2 different developmental concerns. One

notable deviation from prior work is that parents appear to be bringing their developmental concerns to professionals more quickly. Prior studies have found that on average, parents wait 6 months to more than 2 years to raise their developmental concerns for the first time with a professional (Howlin and Moore, 1997; Crane, Chester, Goddard, Henry & Hill, 2015; Zuckerman et al., 2015). However, parents in the present study waited an average of just over 5 months before seeking professional help.

Parents typically did not receive a formal ASD diagnosis during their first professional consultation, which is consistent with prior work (Chamak, Bonniau, Oudaya & Ehrenberg, 2013; Goin-Kochel, Mackintosh, & Myers, 2006). Instead, most parents were referred out; Goin-Kochel and colleagues (2006) found that about half of parents were referred out after their first visit, whereas the present study found that almost two-thirds of parents were given referrals after their first visit. The total number of visits also remains high, with parents attending an average of 3-4 visits prior to receiving the final ASD diagnosis. This visit frequency paired with average appointment wait times of just under 6 months has the potential to contribute substantially to later age of diagnosis.

This study also provided a clearer picture of the professionals parents are consulting throughout the process. Consistent with large scale studies from other countries, this study found that parents most often bring their first developmental concerns to a medical doctor, most often their child's pediatrician, confirming that pediatricians are critical gatekeepers to the process of obtaining an ASD diagnosis, as others have reported (Chamak & Bonniau, 2013; Chamak et al., 2011; Wong et al., 2017). The types of professionals consulted in ensuing referral visits were notably wide-ranging as well, which is consistent with prior work in this area (Chamak & Bonniau, 2013; Chamak et al., 2011; Crane et al., 2016; Gaspar de Alba & Bodfish, 2011). One particularly

novel finding of this study is the sheer number of different professionals who are making ASD diagnoses for children in the United States. No single type of professional accounted for even one third of ASD diagnoses in the sample. Even when combining diagnoses made by clinical psychologists and developmental psychologists into a single "psychologist" category, psychologists only accounted for 44% of total ASD diagnoses made. Furthermore, social workers made up only 1% of the professionals who made formal ASD diagnoses and are likely underutilized in this process.

In regard to Aim 2, higher quality relationships with children's early medical providers were associated with less difficulty experienced by parents in the ASD diagnostic process across all three difficulty factors, thus confirming the hypothesis that parents who report lower quality relationships with their child's provider will experience greater difficulties in obtaining a diagnosis than those parents who report higher quality relationships. This is a novel finding in this particular area (i.e. in the ASD diagnostic process), but is consistent with medical literature suggesting that higher quality relationships (i.e. better trust and communication) with a provider are related to more favorable health outcomes (Baker, Connor, & Krok-schoen, 2016; Beach, Keruly, & Moore, 2006; Cinar & Schou, 2014; Li, Matthews, Dossaji, & Fullam, 2017; Mahmoudian, Zamani, Tavakoli, Farajzadegan, & Fathollahi-Dehkordi, 2017; Moreno et al., 2018; Ruben, Meterko, & Bokhour, 2018; Moss, Reiter, Rimer, & Brewer, 2016; Peterson et al., 2016). The specific mechanisms underlying this association cannot be concluded from the data collected; however, it is clear that parents' early relationships with pediatric and primary care providers serve some important role in the subsequent ASD diagnostic process.

To our surprise, there was no evidence to suggest that diagnostic difficulty varied by family income and only some evidence to suggest that difficulty varied by race. American medical

systems are generally rife with well documented racial bias and health disparities (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003; Gornick et al., 1996; Hall et al., 2015; Nelson, 2002). Prior work on disparities in ASD diagnosis has documented disproportionate barriers for parents who identify as racial and ethnic minorities, have immigrant status, or speak English as a second language, such as longer diagnostic delays, higher frequency of non-ASD diagnoses, or more frequent negative interactions with providers (Altiere & Von Kluge, 2009; Burkett et al., 2015; Jimenez et al., 2012; Kogan et al., 2015; Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Magaña et al., 2013; Mandell et al., 2009; Rosenberg et al., 2011; Zuckerman et al., 2014). Thus, it seemed likely that similar racial inequities and disparities would be reproduced in present study. Similarly, it was also expected that there might be differences in difficulty by family income, due to the well documented challenges faced by lower income families navigating the American health care system as well as prior work identifying ASD diagnostic disparities by income strata (Bhasin & Diana, 2007; Durkin et al., 2015; Thomas et al., 2012; Zuckerman et al., 2014). However, again, these patterns were not overwhelmingly noted. Limitations associated with use of a registry-based sample likely contributed to these differences, and clearly more work is needed, with larger samples of underrepresented minorities, to truly understand the intersections of race and income on the ASD diagnostic process.

5.2 Limitations

There are several limitations of the study to note. First, the survey relied on the self-report and retrospective memory of all participants, which introduces the potential for recall bias. However, most extant studies of the diagnostic process have no restrictions on time since diagnosis

at all, with some participants describing diagnostic experiences for adolescent and adult children who have had their ASD diagnoses for many years. Precautions were taken to limit study eligibility to those who had more recently received their diagnosis in order to minimize recall bias as much as possible. Future work should focus on recruiting families earlier, perhaps while they are still active in the diagnostic process, or recruiting them just after their children receive a formal ASD diagnosis, to further minimize the risk of recall bias.

Additionally, the purposive/availability sampling strategy used to recruit participants limits generalizability of findings. Due to this sampling strategy, the findings of this study essentially describe the SPARK registry, introducing some concerns about whether the registry is representative of other families of individuals with ASD in the United States. SPARK recruits many of its registrants through participation in research studies. It is possible that the families recruited for the present study, that is, families who are actively involved in ASD research, may also be particularly active in their children's medical care, which may have influenced some of the primary variables in this study (e.g. difficulty index items, parental perceptions of the process, etc.). Future work should focus on using probability sampling techniques, and/or recruiting a more community enriched sample in order to understand the different, and potentially more challenging, experiences of families who may be less active in care.

A further limitation of the registry is that it is made up of predominantly families with younger children. Study eligibility was also limited to parents of younger children using established methods in CDC surveillance studies that have cited peak ASD prevalence in the United States at around 8 years of age (Christensen, D.L., Baio, J., Braun, K.V.N., et al., 2016). While these age limitations were necessary to maximize recruitment within the SPARK registry and to minimize recall bias, they also limit generalizability of study findings to the experiences of

families with younger children. It is not uncommon for individuals to receive ASD diagnoses in adolescence or adulthood and it is possible that diagnostic experiences may be different for parents whose children receive formal ASD diagnoses later in life. Future research in this area should specifically elicit the experiences of families of individuals who receive their ASD diagnosis in adolescence or adulthood.

One additional limitation is that the reliability of the Diagnostic Difficulty Index (DDI) did not work as originally planned. Overall reliability estimates with the full set of 13 items were insufficient. While all included items appeared to be theoretically related to diagnostic difficulty, together they did not prove to be a statistically reliable unidimensional measure of difficulty. Reliability estimates were minorly improved after the exclusion of 4 items with low item-total correlations, and exploratory factor analysis provided three adequately reliable dependent measures of difficulty, but again, reliability estimates were not strong overall. Despite these preliminary challenges in developing the DDI, results did suggest that difficulty as a concept may not be unidimensional in this context, which is a meaningful contribution to future inductive theory development. Future research should further draw out the theoretical underpinnings of diagnostic difficulty in order to develop more reliable ways to quantitatively measure it.

Finally, the survey method used introduced limitations to the depth of information that could be collected regarding family experiences, which introduced limitations regarding the types of research questions that could be answered. Most of the findings of this study were descriptive without a lot of explanatory power. However, because the ASD diagnostic process is so understudied in the United States, using a survey method with a brief battery of measures was optimal for maximizing sample size in a relatively short period of time. This method allowed for a preliminary understanding of broader trends and patterns in the ASD diagnostic process, which

lays the necessary groundwork for more in-depth study. There is certainly much more to understand about this process and how it may vary for families. Future work should focus on eliciting richer, more detailed family experiences, as through parent interviews, perhaps with a more comprehensive battery of measures, in an effort to study this process in greater depth.

5.3 Implications for Social Work

5.3.1 Social Work's Role in ASD Science and Practice

Study findings suggested that social workers are minimally involved in the diagnostic process. Despite social workers being major service providers to individuals with ASD and their families, results revealed that only 17% of families saw a social worker at least once throughout the entire process and only 1% of families reported that their diagnosing professional was a social worker. Social workers are also historically underrepresented in ASD scholarship (Bishop-Fitzpatrick, Dababnah, Baker-Ericzén, Smith, & Magaña, 2019; Eyal, 2013). However, their unique training and professional values position them to become leading professionals in diagnostic research and practice for several reasons. First, social workers recognize the importance of supporting individuals with ASD as well as their primary caregivers and family members. Additionally, social workers are driven by person-in-environment perspectives and multi-level approaches, which are immensely beneficial for addressing highly complex social problems. Finally, social work science and practice is rooted in social justice, seeking to understand how systemic bias creates barriers to opportunity for families from marginalized groups. As such, social work leadership in diagnostic research and practice has the potential to make meaningful

contributions to easing family burden, maximizing process efficiency, and identifying and eliminating disparities.

5.3.2 Diagnostic Delays

The descriptive findings of this study suggest that initiation of the process is happening earlier, which may account, at least in part, for the earlier age of diagnosis. However, substantial diagnostic delays remain; families in the present study still waited an average of over one year after raising their concerns before they obtained formal ASD diagnoses for their children. To address lingering delays, the present study suggests several potential avenues for social workers to further examine: long appointment wait times, the degree to which professionals are skilled to respond to parental concerns, and the use of formal screening procedures in pediatric settings.

First, this study identified long wait times for referral appointments (Range: 0-24 months, $M = 5.02$, $SD = 3.99$). Although wait times appear to have improved somewhat from prior studies of this process, parents still waited an average of about 5 months for referral appointments. They also attended an average of 3-4 different appointments before the final ASD diagnosis was made. The combination of long wait times and several different visits has the potential to contribute substantially to delays. Long wait times are often attributed to a shortage in specialists who can provide comprehensive evaluation services for children who are at risk for ASD (Gordon-Lipkin, Foster & Peacock, 2016). This is not for a scarcity of standardized developmental assessments, however; there are several validated, "gold standard" assessments that can reliably detect ASD in children as young as age 2 (i.e. ADOS, ADI-R, etc.) (Lord et al., 2012; Lord et al., 1989; Lord, Rutter, & Le Couteur, 1994). However, these diagnostic assessments are expensive and require highly educated clinicians to undergo extensive training in assessment administration with ongoing

supervision, which potentially restricts availability of these assessments to higher resourced clinical settings. Social workers should advocate for the increased availability of standardized diagnostic assessments across clinical settings, as well as increased funding to appropriately train and supervise test administrators, in order to address the shortage of diagnostic specialists and broaden access to comprehensive evaluations for children at risk for ASD.

Another potential area to explore is the degree to which pediatricians and primary care providers possess the professional skill required to respond to developmental concerns raised by parents. Although professional skill was not directly measured in this study, results did show that 28% (N = 113) of parents were told by a professional that there was "no problem" in their first visit, and in 93% of those cases, parents were consulting with a pediatrician or family doctor. Zuckerman and colleagues (2015) found that more passive pediatric responses, while often well intentioned, may also contribute to unnecessary diagnostic delays. There are many reasons a medical provider may tell a parent there is "no problem" (e.g. age of detection limitations, cautious wait-and-see approaches, poor awareness of ASD and developmental problems etc.), and the specific reasons study participants received such responses are not possible to conclude from this study. Yet regardless of the reasons, reassuring parents that there is no problem when, in fact, there is, suggests medical professionals may not be adequately equipped with the necessary skill to respond to parent concerns. Social workers should work closely with medical doctors to increase awareness of ASD and developmental problems and provide additional support to promote more proactive responses to developmental concerns.

Finally, the American Academy of Pediatrics (AAP) has released guidelines and standards for early developmental screening (American Academy of Pediatrics, 2006), but it is unclear whether guidelines are consistently followed across pediatric clinics. This study collected very

broad information on screening procedures used at the first visit, and it seems that most families underwent at least some further questioning regarding their developmental concerns. However, the specific nature of these screening procedures, and whether or not they adhere to AAP guidelines, cannot be gleaned from this study. The use of formal screening tools has been linked to shorter overall diagnostic delays (Martinez et al., 2018; Zuckerman, Lindly, & Sinche, 2015) and there are several standardized screening tools that are free to use, easy to administer, and quick to score, making them ideal for use in pediatric care settings with substantial time restraints (Robins et al., 2014; Siu, 2016; Lonnie Zwaigenbaum et al., 2015; Lonnie Zwaigenbaum & Penner, 2018). Social workers should further investigate the types of screening procedures used in pediatric care and work to better standardize developmental screening practices and address potential barriers for lower resourced settings in order to reduce diagnostic delays.

This study seems to suggest general improvements have been made in diagnostic efficiency across the last two decades; however, it still raises questions about the lingering delays between the first professional visit and final ASD diagnosis. The findings of the present study point to long appointment wait times, professional skill in fielding developmental concerns, and early screening procedures as potential contributors. A growing body of literature suggests that a larger system overhaul might be most optimal for improving the efficiency of diagnostic systems, and may well address all three issues. Emerging research of "medical home" models, in which developmental and behavioral health professionals with ASD expertise are embedded within primary pediatric care, are promising, showing dramatic reductions in appointment wait times and shorter delays between first visit and final diagnosis (Hine et al., 2018; Hine et al, 2020; Lipkin, Foster, & Peacock, 2016; McNally Keehn et al., 2020). Social workers should further investigate these models and their impacts on diagnostic delays as well as advocate for the implementation of similar

medical home models in primary care settings nationwide in order to better streamline ASD identification and diagnosis.

5.3.3 Professionals Making ASD Diagnoses

This study was one of the first to gather descriptive information about the types of professionals who make ASD diagnoses for children in the United States. Findings revealed a wide range of diagnosing professionals involved in the ASD diagnostic process. This perhaps reflects a growing multidisciplinary presence in the ASD field, a presence which is not only necessary to meet the demands of a complex condition, but also effective for improving the outcomes of individuals with ASD and their families across the lifespan (Strunk, Leisen, & Schubert, 2017). Unfortunately, the findings of the study also confirm that social workers in particular are deeply underutilized as diagnostic professionals. Social workers should invest in efforts that build greater diagnostic capacity across all involved disciplines, perhaps developing educational initiatives to increase professional awareness of ASD guidelines and evidence-based recommendations across all involved disciplines. Social workers may also consider implementing networks that support remote training and supervision of diagnostic assessments. For example, the Global Autism Interactive Network (GAIN) provides trained ADOS test administrators with ongoing supervision remotely via teleconference in an effort to improve test administration proficiency (Weill Cornell Medicine, 2021). Broader implementation of GAIN networks may reduce the need for expert test administrators to be embedded in every diagnostic clinic with newly trained administrators. Social workers may also work to develop similar networks that provide initial test administration training remotely as well. Combined, these efforts may make test administration and ongoing supervision more feasible for lower resourced clinics and/or more rural clinics who may experience financial

barriers to hiring additional clinicians and/or those clinicians who may have difficulty traveling for training and supervision. Finally, with strengths in advocacy, social workers should provide federal, state, and local legislators with evidence-based guidance regarding various policy initiatives that may increase funding for formal diagnostic assessments and administrator training costs, in an effort to further expand diagnostic services for families.

5.3.4 Parent Satisfaction and Stress

The majority of parents in the present study (74%) expressed that they were at least somewhat satisfied with the ASD diagnostic process, which perhaps reflects an encouraging upward trend from prior work in this area. However, 74% of parents maintained that the diagnostic process was at least somewhat stressful. It is difficult to pinpoint the specific mechanisms underlying the stressful nature of this process, primarily due to the novelty of research in this area and the lack of explanatory power in the descriptive findings of this study. Findings provided invaluable preliminary data illustrating broad trends that suggest the diagnostic process is highly complex in the United States, but these data are far from adequate to begin to understand the mechanisms underlying parental stress outcomes.

One way social workers can work toward this understanding is to conduct a formal process evaluation. Process and practice evaluation is a staple of clinical social work, often occurring at a programmatic level (Davis, Dennis & Culberson, 2015; Drisko, 2001; Ventimiglia, Marshke, Carmichael & Lowe, 2000). However, process evaluation can also be quite useful for evaluating complex public health interventions or other complicated processes that transcend ecological levels and involve multiple systems (Steckler & Linnan, 2002). Process evaluations involve in-depth quantitative and qualitative research inquiries that aim to detail the steps of a process, define

success, and then isolate the conditions under which successful outcomes are achieved (Moore et al., 2013, Steckler & Linnan, 2002). Long term investigation of the diagnostic process using in-depth process evaluation methodologies will enable social workers to have a deeper understanding of its specific steps and how its complexities may influence stress and other diagnostic outcomes for parents.

5.3.5 Quantifying Diagnostic Difficulty

Development of the Diagnostic Difficulty Index proved to be a challenge. Reliability estimates for the overall index and item-total correlations were often only just sufficient. In regard to the exploratory factor analysis, the success of the varimax (orthogonal) rotation, rather than oblimin (oblique) rotation, indicated that difficulty factors were formed as a function of their dissimilarity to one another, suggesting that "difficulty" as a construct in the ASD diagnostic process may be comprised of a number of orthogonal indicators rather than an index with multiple correlated dimensions. While the development of a difficulty index was limited in the present study, the process of operationalizing difficulty within the context of obtaining an ASD diagnosis is a worthwhile pursuit for social work methodologists. A more reliable measure of difficulty can open opportunities for social workers to better assess its different predictors within a system and remove barriers to ASD diagnosis. Operationalization of difficulty could also be particularly useful at a community or regional level as a tool for capturing the strengths and weaknesses of diagnostic systems in particular areas. Such an informative tool could highlight specific areas of need where social workers can build on the existing capacity of communities to more efficiently diagnose ASD and support families.

5.3.6 Early Encounters with Child Medical Providers

The findings of this study suggest that relationships between parents and their children's early medical providers serve an important role in the subsequent diagnostic experiences of families. While the exact nature of this role and the mechanisms underlying this association cannot be gleaned from this particular study, it seems plausible that patient-provider relationships could be linked to difficulty in the process due, at least in part, to the likelihood that providers in pediatric and primary care settings will be the first point of contact for parents with developmental concerns (82% of families in the study brought their first developmental concerns to a pediatrician or general practitioner). Potentially salient aspects of those early encounters, such as validation or invalidation of parental concerns, conducting developmental screening procedures, and/or making appropriate referrals, could presumably have some bearing on whether parents leave their first visit on a clear path toward obtaining an ASD diagnosis or not. Plus, the frequency of encounters with medical providers is likely quite high in early childhood; the American Academy of Pediatrics' periodicity schedule recommends a minimum of 10 pediatric well visits in the first 2 years of childhood alone (AAP, 2021). Paired with the sensitive nature of visits in which developmental concerns are raised or discussed, there appear to be ample opportunities for relationships between parents and early medical providers to strengthen or sour. Again, the specific mechanisms underlying the development of these relationships and the ensuing link between relationships and diagnostic difficulty cannot be concluded from this study, but findings broadly suggest that these early interactions, particularly those encounters where developmental concerns are first raised, are an important area of future study.

Social workers should focus on early visits with pediatricians in order to understand how patient-provider relationships are developed and the mechanisms by which relationships are

associated with difficulty experienced in the diagnostic process. Social workers can help medical doctors learn new, more validating ways of interacting with patients that may result in encounters that are more positive overall. Social workers should also specifically investigate early encounters in which developmental concerns are raised, paying close attention to how interpersonal interactions and visit outcomes may shape patient-provider relationships. Finally, social workers should also evaluate the capacity of primary care/pediatric medical settings to adequately support parents after raising developmental concerns. For example, they may advocate to further standardize pediatric screening procedures, by increasing access to and availability of standardized screening instruments in all pediatric settings. They may also work to standardize, streamline, and strengthen pediatric referral systems, to improve diagnostic efficiency and help parents feel more validated and supported by their medical provider after sharing their sensitive concerns.

5.3.7 Race Disparities

As previously mentioned, there was reason to believe that well-documented racial disparities would be reproduced in the ASD diagnostic process, which involves frequent and ongoing interaction with historically racist health care systems. Some evidence for overall differences in difficulty by race emerged for parent perceptions, but there were no significant pairwise differences between racial groups. No overall differences or pairwise differences identified noted for time barriers or institutional barriers. It is possible that racial disparities are present, but were not detected in the present study. Prior work has found significant racial and ethnic differences in some of the items that comprised the time and institutional difficulty factors in the present study (i.e. age of diagnosis, diagnostic delay, screening) (Guerrero, Rodriguez, & Flores, 2011; Mandell et al., 2007; Mandell et al., 2009; Rosenberg et al., 2011; Zuckerman et al.,

2014). However, it is also possible that racial disparities in ASD diagnosis may be shrinking. All of the studies that first identified such gaps were conducted at least 5-10 years ago and the field of ASD diagnosis and treatment is constantly evolving. This study provided evidence that the diagnostic process is more efficient in some areas, with shorter diagnostic delays, earlier age of diagnosis, and earlier initiation of the process by parents. These improvements are perhaps facilitated by growing understanding and awareness of ASD in the United States, as well as major advances in identification, diagnosis, and treatment in the last decade. It is possible that previously identified racial disparities may be shrinking as well, facilitated by the same societal changes and technological advancements in the ASD field.

It is important to note that in general, the ASD literature provides little insight into the experiences of parenting a child with ASD for families from marginalized racial and ethnic groups, despite evidence to suggest that these families experience racism, disproportionate barriers to care, and other forms of systemic bias as they navigate ASD diagnosis, treatment, and care systems (Dababnah et al., 2018; Magaña et al., 2015; Mandell et al., 2007). This makes it difficult to answer questions about the potentially disparate experiences of families from marginalized groups. Increasing representation of diverse families in ASD research is certainly within reach *when intentional efforts are made to do so* (Hilton et al., 2010). Social workers need to commit to investing both the time and resources needed to ensure the inclusion and representation of all racial and ethnic groups in ASD research. Future inquiries should actively seek and center the experiences of marginalized families in ASD diagnosis.

5.4 Conclusions

The ASD diagnostic process is a significant challenge for families of children with ASD. Despite this, it has remained understudied in the United States. Large-scale studies of the process across the globe, as well as smaller studies of different process elements in the United States, have at least helped to construct a piecemeal picture of this experience for families. This study aimed to be one of the first to comprehensively describe the ASD diagnostic process in the United States on a national scale, in addition to evaluate how the role of relationships with early child medical providers, race, and class may relate to overall difficulty experienced by parents.

The study provided a wealth of information describing the process. Parents appear to be doing all that they can, bringing their developmental concerns to professionals quickly and attending many referral visits in pursuit of a formal diagnosis. However, diagnostic delays still remain and the process continues to be stressful. Although the specific reasons for this cannot be concluded from the present study, several potential areas for further study were identified. Associations were found between early patient-provider relationships and difficulty experienced by families, which invites social workers to further investigate the ways in which these relationships are developed and how they may facilitate or obstruct the diagnostic process for families. Finally, uncertainty remains regarding whether there are race or income disparities in the process, which lays the groundwork for social workers to better understand how difficulty may vary across families with different marginalized identities. The findings of this study provide social workers with a more comprehensive understanding of the ASD diagnostic experiences for parents, the implications of which can and should be used to identify the barriers to obtaining a diagnosis and intervene and eliminate them. However, there is much more work to be done.

This study laid a necessary groundwork to better understand the ASD diagnostic process and outlined next steps for researchers. Social workers, in particular, are uniquely positioned to advance work in this area. Core social work values that emphasize supportive work with families, multi-level assessment and intervention, social justice, and advocacy can make meaningful contributions to better understanding the diagnostic process and working to make the process more efficient and less burdensome on families. This study presents a clear opportunity for social workers to lean into their strengths as family advocates and advance scholarship in a way that provides more comprehensive support, and relief, for children with ASD and their families.

Appendix A Sensitivity Analysis

A total of 38 participants in the study had survey response times that fell below the predetermined inclusion threshold of 10 minutes; however, 36 of these participants had reaction times under 10 minutes but greater than 6 minutes, which was within one standard deviation from the mean (M = 24.38, SD = 17.80, Difference = 6.58). The 36 participants with reaction times between 6 and 10 minutes were ultimately retained for main study analyses and a sensitivity analysis was conducted to reexamine main study findings with and without them in order to ensure there were no significant deviations. Appendix B reports on the results of the sensitivity analysis.

Appendix A.1 Aim #1: Describe the process of obtaining a first diagnosis of autism spectrum disorder (ASD) in the United States.

First, two groups were generated: Group 1 included all participants with response times 10 minutes or greater (N = 370) and Group 2 included the 36 participants with response times between 6 and 10 minutes. Next, a series of analyses were conducted to compare Group 1 and Group 2 on child demographics, parent demographics, and all descriptive variables related to Diagnostic Process Questionnaire, including early concerns, first visit and outcomes, referral visits and outcomes, final diagnosis and support received, as well as parent ratings of satisfaction and stress with the process. T-tests were used to compare the two groups on all continuous variables. Fisher's exact test was used for any 2x2 comparisons on binary variables. For categorical variables with two or more levels, chi-squared tests were used.

There were no significant differences between groups on any child demographics. In terms of parent demographics, Group 2 had more male participants as compared to Group 1 (p =.001). Parents in Group 2 reported that their child was older when they first developed concerns (p = .000) and when they attended the first professional visit (p = .001). Additionally, parents in Group 2 reported that they attended fewer visits overall than those in Group 1 (p = .046). In terms of the final diagnosis, Parents in Group 2 were more likely to report that no formal diagnostic assessments were conducted to inform the final diagnosis (p = .041) and reported experiencing significantly shorter delays between their first concern and final diagnosis (p = .046) as well as between the first professional visit and final diagnosis (p =.014). Parents in Group 2 were also more likely to report that the diagnostic process was not at all stressful (p = .031). No differences were observed between groups on any other variable, including on the Interview Satisfaction Questionnaire (ISQ), which measured quality of communication with a provider, and the Wake Forest Interpersonal Trust in a Physician Scale (WFITPS), which measured the degree of trust parents had with their child's provider.

There were some significant differences between groups on some overall infrequent responses. For example, across the entire sample (i.e. across both Group 1 and Group 2), when prompted about the outcome of their first visit, 64 (16%) participants indicated they were told to return if problems didn't improve and 30 (7%) indicated some diagnosis was made. Fisher's tests showed there were significant differences in the likelihood of these responses between groups: parents in Group 2 were more likely to report that they were told to return if problems don't improve (p = .028) and that some diagnosis was made in their first visit (p = .011). Additionally, only 21 participants (5%) across the entire sample received a diagnosis of ASD at their first visit. Yet Group 2 participants were more likely to have indicated they received their ASD diagnosis in

the first visit than Group 1 participants ($p = .006$). These findings are highly tentative and should be interpreted with caution; these responses were likely maximally sensitive to the separation of Group 2 participants because they were already so infrequent across the entire sample.

Appendix A.2 Aim #2: Examine the degree to which perceptions of the patient-physician relationship are related to difficulties in obtaining an ASD diagnosis

Next, a series of analyses were conducted to assess whether the inclusion of Group 2 participants impacted the robustness of associations between patient-provider relationships and difficulty across the three difficulty factors (time barriers, institutional barriers, and parent perceptions). Two multiple linear regression models were constructed for each difficulty factor: one that included all Group 1 and Group 2 participants (i.e. the model used in the main study) and one excluding Group 2 participants. The analyses in the main study found that patient-provider relationships were inversely associated with difficulty across all three difficulty factors. Sensitivity analysis revealed no changes in main effects when Group 2 participants were dropped from the pool; patient-provider relationships remained significantly inversely associated with difficulty for all three factors.

Appendix A.3 Aim #3: Explore how the process of obtaining a first diagnosis of ASD varies by race and income.

Aim 3 analyses of the main study found no effects of racial identification or family income on difficulty. A series of analyses were conducted to examine whether the inclusions of Group 2 participants impacted these non-findings; that is, whether potential significant race or income effects were suppressed by the inclusion of Group 2 participants. One-way analysis of covariance models from Aim 3 were constructed without participants from Group 2. Main effects were consistent with main study findings. There was no significant effect of race on time barriers (F = 1.47, p = .212) or institutional barriers (F = .712, p = .584), but there was a significant effect of race on parental perceptions (F = 3.84, p = .005). Pair-wise comparisons were conducted to explore whether there were significant mean differences in difficulty between racial groups. There was a significant difference between white and Black families on parental perceptions, such that Black parents reported significantly less difficulty (i.e. more favorable perceptions of the process) than white parents (t = -3.25, p = .013). No other effects of race were observed for time barriers or institutional barriers. To assess whether there were any suppressed effects of income on difficulty, separate ANCOVA models were constructed using both weighted and unweighted income variables, excluding Group 2 participants. No differences were observed between use of the weighted or unweighted income variable, and so the unweighted variable was used for greater clarity in interpretation. Results were consistent with main study findings, revealing that there was no main effect of family income on difficulty for time barriers (p = .851), institutional barriers (p = .487), or parent perceptions (p = .252) when Group 2 participants were excluded.

Appendix A.4 Discussion

In regard to Aim 1, patterns in differences between Group 1 and Group 2 appeared to be related to less attentiveness in responding, which might be expected with shorter response times. However, none of the findings prompted concerns for bias as a result of retaining those 36 participants. Furthermore, retaining Group 2 participants also meant that the representation of fathers in the sample was greater. In regards to Aim 2, findings that patient-provider relationships were associated with difficulty were robust whether or not Group 2 participants were included, raising no concerns about including participants with shorter response times. In regards to Aim 3, the main findings of the study did not change. There was an overall effect of race on difficulty, but only for parent perceptions, suggesting that findings are robust to the inclusion of Group 2 participants.

Appendix A.5 Conclusions

The results of sensitivity analyses showed that the characteristics and diagnostic experiences of participants with longer survey response times were not different from those participants with shorter response times in a manner that raised serious concerns for bias. Thus, the advantages of retaining these participants in the sample (e.g. greater representation of men, larger sample sizes for better powered statistical analyses) outweigh the threat of bias.

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