Photocopy and Use Authorization

In presenting this thesis in partial fulfillment of the requirements for an advanced degree at Idaho State University, I agree that the Library shall make it freely available for inspection. I further state that permission for extensive copying of my thesis for scholarly purposes may be granted by the Dean of the Graduate School, Dean of my academic division, or by the University Librarian. It is understood that any copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Signature_____

Date_____

Caregiver Satisfaction with the Autism Diagnostic Process: An Analysis of Perceptions of Wait-Time and Barriers to the Diagnostic Process

by

Diane Keister

A dissertation

submitted in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy in the Department of Psychology

Idaho State University

Fall 2023

To the Graduate Faculty:

The members of the committee appointed to examine the dissertation of DIANE KEISTER find it satisfactory and recommend that it be accepted.

_____
Robert Rieske
Major Advisor, Committee Chair

_____
Velma Payne
Committee Member

_____
Maria Wong
Committee Member

_____
Joshua Swift
Committee Member

_____
Gesine Hearn
Graduate Faculty Representative

April 26, 2021

Robert Rieske
Psychology
MS 8112

RE: Study Number IRB-FY2021-110: Factors affecting caregiver experiences with the autism spectrum disorder diagnostic process

Dear Dr. Rieske:

Thank you for your responses to a previous review of the study listed above. I agree that this study qualifies as exempt from review under the following guideline: Category 2.(i). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording).
The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects.
This letter is your approval, please, keep this document in a safe place.

Notify the HSC of any adverse events. Serious, unexpected adverse events must be reported in writing within 10 business days.

You are granted permission to conduct your study effective immediately. The study is not subject to renewal.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Tom Bailey (208-282-2179; fax 208-282-4723; email: humsubj@isu.edu) if you have any questions or require further information.

Sincerely,

Ralph Baergen, PhD, MPH, CIP
Human Subjects Chair

TABLE OF CONTENTS

List of Figures

List of Tables

Caregiver Satisfaction with the Autism Diagnostic Process: An Analysis of Perceptions of Wait-Time and Barriers to the Diagnostic Process

Dissertation Abstract – Idaho State University (2023)

The diagnostic process for autism can be very dissatisfying for caregivers with many factors that contribute to this. The length of time a caregiver spends waiting for their child to be diagnosed with autism is standardly long, also leading to dissatisfaction with the diagnostic process. Additionally, barriers exist that make it even more difficult to seek out an evaluation, such as living in a rural area with few qualified clinicians and having limited financial means to pursue an evaluation. These barriers can compound the dissatisfaction felt by caregivers about the evaluation process. While these factors have been examined the extant literature on the topic is outdated, from outside of the United States, and does not analyze these factors simultaneously. This study addresses this literature gap by evaluating the relationship between caregiver satisfaction with the autism diagnostic process and the wait time and barriers faced by caregivers in the United States through two hierarchical multiple linear regressions. Findings suggested expected significant relationships between decreased caregiver satisfaction and increased difficulty finding a clinician as well as decreased reasonability of wait time. An interaction between reasonability of wait time and months on a wait list also showed a significant effect with caregiver satisfaction. Unexpectedly, more time since first noticing symptoms of autism was related to increased caregiver satisfaction. Implications, future directions, and limitations were discussed.

Key Words: ASD, autism, assessment, evaluation, satisfaction

Introduction

The process for having a child evaluated for Autism Spectrum Disorder (ASD) can be a long, confusing, and exasperating journey for families to endure. Previous literature has described that there are ongoing issues with the ASD diagnostic process that have occurred for many years. Many factors exist outside of the caregivers' control, both systemic and individualistic, that add to delays in this process and build on the frustration experienced by caregivers. Some of these barriers that delay the process are related to demographic factors experienced by the caregiver, such as living in rural areas, having high levels of financial stressors, and having lower levels of education (Hildago et al., 2015; Mandell & Palmer, 2005; Moh & Magiati, 2012). Some barriers exist due to healthcare providers failing to refer children for a diagnostic evaluation due to stigma surrounding autism or lack of knowledge in early autism symptoms (Bivarchi et al., 2021). Regardless of the etiology of these delays, the slow process has been related to lower levels of caregiver satisfaction with the evaluation (Crane et al., 2016). This diminished satisfaction has a cascading negative effect on caregiver stress and further intervention services that the child with autism could receive (Moh & Magiati, 2012). Through a better understanding of these barriers encountered in the evaluation process, it is hoped that they can be dismantled. Thus, ideally leading to higher levels of caregiver satisfaction, shorter wait times for an evaluation, and fewer barriers to receive these autism diagnostic services.

Autism Diagnostic Criteria

Under the current diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM), approximately 1 in 36 individuals are diagnosed with Autism Spectrum Disorder (Maenner et al., 2023). However, this has not always been the case. The prevalence of

ASD has increased over the years as the diagnostic criteria for ASD has also shifted and developed. While some causes of the increased prevalence are related to the expanded diagnostic criteria, other explanations include more awareness of autism within both the public and qualified professionals, as well as greater research funding for autism (Lord & Bishop, 2010; Rutter, 2005).

Autism was first discussed by Leo Kanner in the 1940's (Kanner, 1943), however the official diagnosis of autism was developed in 1980 in the third edition of the DSM (DSM-III; American Psychiatric Association [APA], 1980). Within this edition's diagnosis of autism, it was characterized by a lack of social responsiveness as well as a disorder of young children (APA, 1980; Rosen et al., 2021). In the revised version of the third edition of the DSM, the DSM-III-R, the diagnosis of autistic disorder was developed to be more flexible and encompassing a broader range of symptoms beyond what was characterized as infantile autism (Rosen et al., 2021). This form of the diagnosis included the three domains of autism that parallel the current diagnostic criteria of autism: impairments in reciprocal social interaction, impairments in communication, and the presence of restricted interests, resistance to change, and repetitive movements (APA, 1987).

While these three domains have remained relatively unchanged from the DSM-III-R to the current edition, DSM-V, the diagnostic criteria are now viewed in a dimensional approach to diagnosing ASD and the first two domains were combined to describe impairments in social communication (Rosen et al., 2021). This allows for the homogeneity of the core symptoms of ASD while allowing for heterogeneity among the amount and quality of the symptoms (Rosen et al., 2021). The DSM-V also classifies autism as a "spectrum," providing levels that categorize the amount of support an individual needs (APA, 2013) as well as including previous diagnoses

that fell into the broader autism phenotype such as Asperger's and Pervasive Developmental Disorder Not Otherwise Specified (Rosen et al., 2021). This "spectrum" classification allows for the inclusion of autistic individuals with a wide variety of cognitive, language, behavioral, and social abilities (National Research Council, 2001). Taken together, the DSM-V diagnosis of ASD includes "persistent deficits in social communication and social interaction across multiple contexts" and the presence of "restricted, repetitive patterns of behavior, interests, or activities" (APA, 2013, p. 50-51). Within the first domain, subdomains of diagnostic criteria include deficits in social-emotional reciprocity, in nonverbal communication, and in maintaining, developing, and understanding relationships (APA, 2013). The second domain includes subdomains of which two must be met: stereotyped or repetitive movements, speech, or object use; insistence on sameness, inflexible routines, or patterns of nonverbal or verbal behavior; restricted interests with abnormal intensity or focus; hyper- or hypo-sensitivity to sensory experiences or unusual sensory interests (APA, 2013). Within these subdomains, illustrative examples of diagnostic symptoms are included, and the onset of these symptoms must be present in the individual's early developmental period (APA, 2013).

In 2022, a revised version of the DSM-V was released, the DSM-V-TR. Within this revision, the criteria for diagnosing autism were slightly amended. The revision now requires "all of the following" subdomain symptoms in the first domain of difficulties with social communication to obtain a diagnosis of ASD (APA, 2022), while in the previous version, the words "all of" were omitted (APA, 2013). This revision suggests that there was ambiguity about the necessity of meeting all the criteria within the first domain of ASD. Due to the recency of this revision, it is unclear how this will affect the diagnostic prevalence of autism as well as the diagnostic process moving forward.

Autism Diagnostic Process

Given the intricacies of an autism diagnosis, the diagnostic process itself often matches this complexity. While there are no predefined criteria or consensus for an assessment process to diagnose ASD, a comprehensive assessment is called for. Additionally, a diagnosis early in a child's development is strived for. When a child is diagnosed early, this allows for early intervention and supportive services which show improved developmental outcomes (Remington et al., 2007). Often, children are diagnosed with autism in early childhood/preschool age, generally around the age of 29 to 48 months old (Hedges et al., 2018; Shaw et al., 2020). However, the American Academy of Pediatrics (AAP) recommend that all children get screened by their pediatrician at 18 and 24 months of age (Hedges et al., 2018; Hyman et al., 2020). There is a free, well-validated screening tool available for children 12 to 30 months old called the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, 2009) that is recommended by the AAP (Hyman et al., 2020). Despite the recommendations of the AAP and the availability of an easily accessible, free screening tool for healthcare providers, the diagnostic process of autism typically begins with a parent or person close to the child (e.g., teacher or other caregivers) noticing developmental or behavioral differences in the child and bring those concerns to a healthcare professional (McCrimmon & Gray, 2021).

First Noticing Autism Symptoms

Due to autism typically first being diagnosed in early childhood, caregivers play a key role in facilitating a diagnosis of autism. Caregivers commonly notice signs of autism before the child is 24 months old (Chawarska et al., 2007). In a qualitative study conducted by Smith-Young and colleagues (2020), they named this stage of the diagnostic process the "Watchful Waiting" period. This phase has two subphases: noticing suspected behaviors and searching for

assessment and diagnosis (Smith-Young et al., 2020). As stated previously, healthcare providers do not typically follow the AAP recommendations of screening all children for autism, citing lack of time and improper training (Bivarchi et al., 2021; Lappé et al., 2018). Additionally, the heterogenous nature of ASD creates difficulty for pediatricians to have a universal method for identifying autism across ages and symptomatology (Lappé et al., 2018). Instead of the pediatrician conducting the recommended precautionary screenings for autism, caregivers are commonly tasked to be the ones to first discuss their concerns about their child's behavior or development with their child's healthcare providers (Crane et al., 2016; McCrimmon & Gray, 2021). This requires the caregivers to both recognize these developmental concerns and feel comfortable with bringing up these concerns with the healthcare provider (Johnson et al., 2020). Common first concerns that caregivers discuss with the child's pediatrician include atypical language development, atypical social development, and general behavioral concerns (Crane et al., 2016; McCrimmon & Gray, 2021). Bringing up these concerns with a healthcare provider can be the start of the autism diagnostic process and seeking out a professional's diagnostic opinion (McCrimmon & Gray, 2021). However, this initial step can also be the start of caregivers' frustration and dissatisfaction with the process. While caregivers often notice these concerns for autism early, there is also commonly a delay in noticing these symptoms and seeking out or receiving a diagnosis. In a study conducted by Zuckerman and colleagues (2015), in a nationally representative sample it was found that children were diagnosed with autism an average of three years after their caregivers first raised concerns with their healthcare providers.

One possible reason for this delay is healthcare providers' reluctance to diagnose a child early or a lack of knowledge on autism. Providers fear misdiagnosing a child and labeling them as autistic so early in their life (Nissenbaum et al., 2002). Healthcare providers may lean towards

the “wait and see” approach to avoid diagnosing a child with autism and to see if they developmentally catch up with their typically developing peers (Bent et al., 2020; Edwards et al., 2021; Smith-Young et al., 2020) despite the well-validated instruments available and the multitude of research that exists recommending against this. Additionally, healthcare professionals may not take the caregivers’ concerns seriously. They can dismiss the concerns of the caregivers or avoid asking autism-related questions entirely (Bivarchi et al., 2021). Previous studies have also found healthcare providers reacting to a caregivers’ concerns for autism in a passive or reassuring way, such as saying the child may “grow out of it” or that nothing is wrong (Oswald et al., 2017; Ryan & Salisbury, 2012; Zuckerman et al., 2015). In a qualitative study conducted by Lappé and colleagues (2018), caregivers reported experiencing frustration with the healthcare providers’ dismissals of their concerns. When healthcare providers make this decision, a delay in diagnosing a child with autism occurs. Furthermore, healthcare providers may lack the knowledge to properly detect concerns for autism or resources to provide for referrals to diagnostic resources (Zuckerman et al., 2015).

Another potential reason for this delay is the stigma surrounding a diagnosis of autism. Caregivers can experience stigmatizing concerns about a diagnosis of autism, leading to delays in seeking out a diagnosis (Bivarchi et al., 2021; Gholipour et al., 2022). They may delay bringing up concerns of autism out of difficulty accepting their child’s differences and their perceptions of the negative implications a diagnosis may have on their child’s future and how they will be accepted by their community (Bivarchi et al., 2021; Farooq & Ahmed, 2020; Gholipour et al., 2022).

Seeking Out a Provider

As diagnosing autism is a complex process, it requires a provider who has a specialty in autism to diagnose it (Johnson, 2007). Typically, if the caregivers' concerns are accepted by their child's healthcare provider, they are referred out to other community providers as their child's general practitioners typically are not knowledgeable in diagnosing autism (Crane et al., 2016; Shah, 2001). Therefore, these general practitioners can serve as gatekeepers in accessing an evaluation for autism (Zuckerman et al., 2015). However, as mentioned previously, healthcare providers do not always provide referrals to support the child's caregivers to pursue an autism evaluation for a variety of reasons. In some situations, the child will be identified by their school district as having developmental concerns and were referred for an evaluation by their school (Locke et al., 2020). In other situations, caregivers seek out an evaluation on their own due to their concerns for their child or due to the concerns of another person close to them (e.g., friend, family member; Locke et al., 2020). Once the child's caregivers understand the need for an autism evaluation, the second subphase of Smith-Young and colleagues' (2020) "Watchful Waiting" phase begins: searching for assessment and diagnosis. Regardless of who they were referred by, caregivers tend to experience dissatisfaction with finding a provider to complete an autism diagnostic evaluation (Bent et al., 2020; Smith-Young et al., 2020). Siklos and Kern (2007) found that caregivers met with an average of 4.5 professionals before receiving an autism diagnosis while Bent and colleagues (2020) found 8 to be the average number of healthcare professionals consulted. Furthermore, the higher amount healthcare professionals consulted were associated with lower caregiver satisfaction with the diagnostic process (Goin-Kochel et al., 2006).

Additionally, while referrals may be provided to the caregiver for an evaluation, the diagnostic process can remain unclear. There is a lack of supports that exist in assisting caregivers to understand and navigate the autism diagnostic process. Bivarchi and colleagues (2021) found in a literature review, that caregivers perceived no clear pathway or informational resources in accessing diagnostic services for autism. Also, several different types of providers are qualified to evaluate for autism, which can further complicate finding a provider to conduct an autism evaluation. Due to the complexities of an autism diagnosis, it is recommended that autism is ideally diagnosed through a multidisciplinary team (Brian et al., 2019; Volkmar et al., 2014). Multidisciplinary teams that assess for autism frequently include psychologists, speech-language pathologists, occupational therapists, and physical therapists (Volkmar et al., 2014). While this is the preferred approach, and associated with higher caregiver satisfaction (McCrimmon & Gray, 2021), this is not always how a child receives a diagnosis of autism. It is recommended that a diagnostic evaluation be performed by a provider who has specialized training in diagnosing autism (Volkmar et al., 2014). Such professionals can include psychologists, pediatricians, neurologists, and speech-language pathologists (Crane et al., 2016). The combination of a variety of possible types of providers to diagnose a child and the lack of proper systemic supports to navigate the autism diagnostic process are contributing factors in the delay of an autism diagnosis and caregiver satisfaction with the process (Bivarchi et al., 2021; Moh & Magiati, 2012).

Making an Appointment

Once a provider has been found to complete the diagnostic evaluation, the next step for caregivers is to obtain an assessment appointment. However, often this step is not that simple and can result in more delays and dissatisfaction from caregivers. It is a standard occurrence for

an immediate appointment to not be available, no matter the type of provider (Ward et al., 2016). Wait times for an assessment appointment can be lengthy (Crane et al., 2016; Oswald et al., 2017; Sansosti et al., 2012). In the United Kingdom, the proposed goal for wait time after a referral is 17 weeks for children to be diagnosed with autism (Le Couteur, 2003). Penner and colleagues (2018) found recommended maximum wait times for various countries to be between 1 and 6 months, however, they noted these guidance documents provided no recommendations for how to achieve these wait times and no evidence for these recommendations. While most studies, especially those conducted in the United States, do not provide average wait times, Sansosti and colleagues (2012) reported the caregivers that participated in their study waited 5 to 7 months with an average of 5.1 months. However, it should be noted this was not a national study and only focused on a small area of Ohio. It was reported by Gordon-Lipkin and colleagues (2016) that wait times were between 6 to 12 months in an underserved area of Tennessee. Ideal wait times for caregivers were found to be around 2 months (Andersson et al., 2014).

There is an association found between longer wait times and greater dissatisfaction with the autism diagnostic process (McCrimmon & Gray, 2021). In a study conducted by Siklos and Kerns (2007), 56 caregivers of children with autism from British Columbia were surveyed about their experiences with the diagnostic process. Among many findings, the authors noted over half of their sample was dissatisfied with the autism diagnostic process as well as many of their sample reporting long wait times (about three years; Siklos & Kerns, 2007). These authors used similar methods as Howlin and Moore (1997) to measure these questions about the autism diagnostic process, only adapted for the Canadian healthcare system. In the United Kingdom, two primary studies exist which examine the associations between caregiver satisfaction and wait

times. Howlin and Moore (1997) surveyed approximately 1300 caregivers of autistic children in the United Kingdom about various factors related to the child's diagnostic process. In this study, the authors identified a relationship between shorter wait times and satisfaction with the diagnostic process (Howlin & Moore, 1997). More recently, Crane and colleagues (2016) sought to update the findings of Howlin and Moore (1997). In their study, the authors surveyed 1047 caregivers of autistic children about their perceptions of the diagnostic process. Similarly, this study identified longer wait times being associated with lower satisfaction with the diagnostic process (Crane et al., 2016).

While the previously mentioned studies examine wait times, as defined by the time since first noticing symptoms and getting a diagnosis, few other studies have examined wait times in relation to time spent on a waiting list specifically. In New Zealand, Eggleston and colleagues (2019) found that among 516 caregivers of children with autism, satisfaction with the diagnostic process was associated with shorter time spent on a wait list. Other studies available on the topic of wait lists are qualitative (e.g., Smith-Young et al., 2020 and Lappé et al., 2018) or use the term wait lists and wait times synonymously while referring to the time since symptoms were first noticed (e.g., McCrimmon & Gray, 2021). However, regardless of the terms or concepts used to identify delays in the process, the research appears to be mostly convergent: longer time waiting is associated with lower caregiver satisfaction with the autism diagnostic process. One study's results did not support this assertion. In a study by Moh and Magiati (2012), 102 caregivers of autistic children in Singapore were surveyed about satisfaction with the diagnostic process. Their findings did not show a significant relationship with the duration of the diagnostic process and caregiver satisfaction. However, several possible explanations exist for this finding such as the caregivers in the sample reporting relatively short wait times (i.e., mean of 12.5 months from

first noticing symptoms to diagnosis) and their sample being comprised of children with higher supportive needs (Moh & Magiati, 2012).

Assessment Appointment

After a caregiver has been able to overcome all the previous steps in seeking out a diagnosis, the assessment appointment arrives. Regardless of the type of provider conducting the assessment, there are recommendations for the types of domains the evaluation should include. According to Brian and colleagues (2019), a diagnostic assessment for autism should include a records review, an interview or interviews with the child's family, and an assessment of core features of autism (i.e., social interaction/communication and patterns of behavior and interest). Additionally, it is recommended that the child's adaptive, academic, cognitive, sensory, motor, behavioral, and emotional functioning be evaluated along with their speech, language, and communication skills and physical health and nutrition (Brian et al., 2019). Within the autism-specific portion of testing, Brian and colleagues (2019) listed some commonly used measures such as the Autism Diagnostic Observation Schedule – 2nd edition (ADOS-2; Lord et al., 2012), Childhood Autism Rating Scale – 2nd edition (CARS-2; Schopler et al., 2010), Autism Diagnostic Interview – Revised (ADI-R; Rutter et al., 2003), and the Social Responsiveness Scale – 2nd edition (SRS-2; Constantino & Gruber, 2012). It is also recommended that the provider or providers consider differential diagnoses and co-occurring conditions when assessing for autism (Brian et al., 2019). These other conditions to be assessed include neurodevelopmental disorders such as attention-deficit/hyperactivity disorder, mental/behavioral disorders such as anxiety disorders and obsessive compulsive disorder, genetic conditions such as Rett syndrome, and medical conditions such as epilepsy (Brian et al., 2019).

While these recommendations exist, whether the providers conducting the assessment utilizes the recommended tools or assesses the recommended domains varies. A study completed by Skellern and colleagues (2005) found that only 19% of providers used standardized autism-specific observational measures such as the ADOS-2 or CARS-2. Furthermore, the types of providers were also related to how the assessment was conducted and what was included within the assessment. For example, psychologists are more likely to complete an assessment of cognitive abilities than psychiatrists and are more likely to gain reports from other informants (e.g., teachers) compared to pediatricians (Ward et al., 2016).

During the assessment appointment, caregivers can be involved to varying degrees. Caregivers who were able to be more involved with the assessment and had higher degrees of collaboration with their child's provider(s) were associated with higher caregiver satisfaction with the autism diagnostic process (Abbott et al., 2013; McCrimmon & Gray, 2021; Moh & Magiati, 2012). Taken together, from the types of assessments done to the amount they are involved in the process, caregivers can have vastly different assessment experiences to achieve the same diagnosis. This can contribute to caregivers being satisfied or not with the autism diagnostic process (Abbott et al., 2013).

Feedback

Following the evaluation of the child for autism, the clinician will provide feedback to the caregivers about the diagnosis of autism. Feedback sessions serve as an interface between the diagnostic evaluation and the period of caregivers understanding the diagnosis and receiving intervention services (Pattison et al., 2021). There are no formally published guidelines that consistently agree with the proper practices for a feedback session (Pattison et al., 2021). In general, feedback sessions should provide the families with accurate information about the

diagnosis in an empathetic manner that allows them to process difficult emotions and provide an optimistic outlook (Perry et al., 2002). Additionally, it is recommended that feedback be provided from a strengths-based approach (Pattison et al., 2021). The feedback session is also a time to discuss post-diagnostic resources and direct the family to supportive services (Makino et al., 2021). The feedback session is also a crucial part of the assessment process that influences caregivers' satisfaction with the diagnostic process. Variables that can influence satisfaction include the manner a clinician provides the diagnosis (Crane et al., 2016), when caregivers were given more time to ask questions and review the report (Abbott et al., 2013), and receiving vague and unclear details about the assessment or diagnosis (Whitaker, 2002). Altogether, this is the final essential component of the autism diagnostic process, and it also can contribute to the satisfaction of the child's caregivers.

The Importance of Caregiver Satisfaction

Little research exists that directly examines caregiver satisfaction with the autism diagnostic process and its impacts on caregivers. Outside of the diagnosis of autism, a positive evaluation experience has been found to be associated with higher levels of acceptance of the diagnostic results, lower levels of parental stress, and being able to implement more effective coping strategies (Leff & Walizer, 1992; Quine & Pahl, 1986; Wooley et al., 1989). However, a positive assessment experience is not the norm for those who receive an autism diagnosis; most caregivers report low satisfaction with the autism diagnostic process (Howlin & Moore, 1997; Mansell & Morris, 2004). This dissatisfaction is concerning as it may lead to increased parental stress, decreased likelihood to follow-through with recommendations, and delays in obtaining treatment services or intervention.

Stress

Caregivers to children with autism have shown higher levels of parenting stress than caregivers of children with other diagnoses (Blacher & McIntyre, 2006). Additionally, higher levels of mood disorders, such as depression and anxiety, as well as a decreased quality of life are observed in caregivers of autistic children (Boyd, 2002; Lee et al., 2009). Higher reports of stress and lower quality of life is attributable to both features that can be related to the child's autism (e.g., differences in socialization and higher externalizing behaviors) as well as interaction caregivers have with professionals (Reed & Osborne, 2012). It is important to note that while these studies focused on caregiver stress of previously diagnosed autistic children, this increased parental stress, decreased quality of life, and poorer mental health are likely to be present before the diagnostic process occurs as the child's autism-related characteristics are present before diagnosis as well as after. Therefore, before beginning the autism diagnostic process, caregivers are likely predisposed to having increased stress and decreased well-being and mental health and more susceptible for dissatisfaction to negatively impact their stress and their and their child's life.

Higher caregiver stress has been associated with lower levels of caregiver satisfaction with the autism diagnostic process (Mansell & Morris, 2004; McCrimmon & Gray, 2021; Moh & Magiati, 2012). Additionally, caregiver dissatisfaction with the autism evaluation process has been linked to higher levels of stress experienced both during and after the evaluation (Jashar et al., 2019). Heightened reported stress levels have been associated with limited caregiver participation in therapy, which can negatively impact a child's potential outcomes (Osborne et al., 2008). Higher levels of caregiver stress have also been linked to more challenging child behavioral problems and greater parenting difficulties (Osborne & Reed, 2010). Additionally,

lower levels of stress at the time of an autism diagnosis have been found to be linked to the caregiver being more accepting of that diagnosis (Da Paz et al., 2018). This acceptance of the autism diagnosis was related to lower levels of caregiver distress and depression (Da Paz et al., 2018). Furthermore, dissatisfaction was found to be more closely related to stress that was secondary to the evaluation process rather than pre-existing stress (Jashar et al., 2019). Not only are reported levels of stress heightened when caregivers are dissatisfied with the autism diagnostic process, but they also report additional feelings of burden placed on families (Howlin & Moore, 1997; White et al., 2009).

Recommendation follow-through and delays in intervention

There are many potential factors that influence the likelihood of caregivers following the recommendations provided during the diagnostic evaluation for autism. Some of these include time, finances, and the ability to access the recommended services (Jashar et al., 2019). Eggleston and colleagues (2019) found that caregivers who were more satisfied with the autism diagnostic process were also more likely to be satisfied with the post-diagnostic intervention services they received. Additionally, delays in seeking a diagnosis have been found to lead to lower levels of caregiver satisfaction (Howlin & Moore, 1997) and has been associated with delays in implementing support and intervention strategies (Moh & Magiati, 2012; Webb et al., 2014). There have also been associations found between lower parental involvement and therapeutic self-efficacy when parents were more dissatisfied or had higher levels of stress (Hastings & Symes, 2002; Konstantareas & Homatidis, 1989). The combination of these factors creates a higher likelihood for intervention services to be delayed or of a lower quality (Reed & Osborne, 2012). When delays in accessing intervention services are present, the potential impact and outcomes the children have tend to be lower. Koegel and colleagues (2014) affirm that an

abundance of previous research suggests that the earlier intervention occurs in the child's development, the better the outcomes that child achieves.

To summarize, caregivers being satisfied with the diagnostic process has the potential to influence how quickly a child receives services, being more accepting of the diagnosis, and having lower levels of stress. Therefore, caregivers being more satisfied with the diagnostic process has the potential to lead to more positive results and long-term outcomes for the children who receive the autism diagnosis.

Sociodemographic Barriers to the Diagnostic Process

Socioeconomic status

Socioeconomic status (SES) includes demographic variables such as household income and levels of education (Durkin et al., 2010). While autism is found among all levels of socioeconomic status (Hodges et al., 2020), those from a higher SES are diagnosed with autism more frequently likely due to disparate access to healthcare services (Durkin et al., 2010). Barriers for caregivers of a lower SES related to their child being diagnosed with autism include the cost of getting those services and having to travel to receive those services as well as a lower awareness of autism symptoms and access to developmental services (Fountain et al., 2011; Thomas et al., 2012). Caregivers with higher educational qualifications and more economic resources tend to be more knowledgeable about autism, therefore, are more likely to bring up concerns of autism, and have more access to the means to undergo the diagnostic process for autism (Hildago et al., 2015; Moh & Magiati, 2012). However, it should be noted that while those with lower education and lower financial resources were related to a later diagnosis, they have not been associated with longer wait times to receive the diagnosis (Moh & Magiati, 2012).

When observing correlates with caregiver satisfaction and a school diagnosis of autism, Hildago and colleagues (2015) determined that caregivers of a lower SES, particularly of lower income and lower levels of education, tended to have lower levels of satisfaction with the diagnostic process. Particularly, they identified that families at or below the poverty line noted a barrier of little to no services available for families in their financial situation for an autism diagnosis that were feasible with their financial constraints (Hildago et al., 2015). Similarly, Goin-Kochel and colleagues (2006) found that those with a higher income and level of education were more satisfied with the autism diagnostic process when they surveyed a sample of 494 caregivers of autistic children within the United States, Canada, the United Kingdom, New Zealand, and Australia. In a qualitative study by Lappé and colleagues (2018), the caregivers described more satisfaction when they experienced a shorter wait time. However, these shorter wait times were typically only possible when they would pay out of pocket for services, which is not an affordable option for many families.

Race/ethnicity

Communities of color have described particular difficulty with receiving an autism diagnosis. Studies suggest lower levels of identification of autism within racial and ethnic minorities (Mandell et al., 2009). However, it should be noted that once adjusted for income levels, autism was found at a similar prevalence rate across race and ethnicity (Durkin et al., 2010; Thomas et al., 2012). Previous literature has documented healthcare professionals dismissing the concerns about autism of caregivers of color (Burkett et al., 2015). Additionally, higher levels of stigma surrounding autism has been found within communities of color (Burkett et al., 2015; Zuckerman et al., 2014). Outside of correlations between being a racial/ethnic minority and SES, little research exists surrounding caregivers of color's satisfaction and the

autism diagnostic process. Additionally, studies of caregiver satisfaction with the autism diagnostic process have an underrepresentation of racial and ethnic minorities within their samples. Despite this, there remains clear differences in the experiences that communities of color have with the diagnosis and treatment of autism and many cultural factors that exists which add to this difference (e.g., Burkett et al., 2015).

Rurality

It has been well documented that those living in rural areas report difficulties with receiving services for the identification and treatment for children (e.g., Centers for Disease Control and Prevention, 2011; Cohen & Hesselbart, 1993; Gona et al., 2016; Green et al., 2013; Slade, 2003). However, despite these difficulties, there is no significant discrepancy found between the prevalence rates of autism within rural and urban locations for population-based studies (Antezana et al., 2017). However, there is a disparate rate of children diagnosed with autism between rural and urban settings both in the United States (Williams et al., 2006) and internationally (Vassos et al., 2016; Wan et al., 2013) when a non-population-based study is conducted. This suggests that those who live in rural areas may endure many challenges to have their children diagnosed with autism. In fact, delays and difficulties with an autism diagnosis occur at a higher reported rate in rural settings than urban settings (Antezana et al., 2017; Centers for Disease Control and Prevention, 2011).

One of these difficulties experienced includes physically limited access to resources (Antezana et al., 2017). Rural areas have healthcare shortages that force those living in these communities to travel far distances, sometimes outside of the state, to receive adequate services (Singh et al., 2019). Often, due to the lack of services available in rural settings, schools become the service providers for these families (Antezana et al., 2017). However, a greater lack of

awareness of autism exists in rural areas from both caregivers as well as health providers and school officials (Antezana et al., 2017). This, therefore, adds to the difficulty and delay in diagnosing autism.

When considering the availability of healthcare providers, it was found by Mandell and Palmer (2005) that in areas in which there was a shortage of healthcare providers (like rural areas), there was a decrease in the number of children who received an autism diagnosis. Urban areas are more likely to have an increased density of resources available for autism compared to rural areas (Antezana et al., 2017). In addition to the previously listed barriers, caregivers are reportedly less likely to seek out supports in rural areas due to cultural differences that include high levels of independence, self-sufficiency, and self-reliance (Strasser, 2003). This can lead to apprehension of healthcare professionals and avoidance of assessing for autism (Antezana et al., 2017).

Rurality has been previously explored as a factor related to caregiver satisfaction of the receipt of autism treatment services (e.g., Mello et al., 2016; Murphy & Ruble, 2012; Rivard et al., 2015). This research has shown that when they were able to access services, caregivers were mostly satisfied with the treatment services they were able to receive. However, parents were less satisfied with the difficulty of finding services, the length of time to travel to receive services, and would question the validity of the services overall compared to urban populations. While this information is available for autism treatment services, no research has directly analyzed caregiver satisfaction with the autism diagnostic process and the barrier of living in a rural area.

Current Study

Considering the lack of current studies evaluating caregivers' satisfaction with the autism diagnostic process, especially within the United States, the current study was aimed at addressing this gap within the existing literature. Additionally, while barriers to the assessment process and caregiver satisfaction have been evaluated, these factors are not typically examined simultaneously or in direct relation to the diagnostic evaluation process for autism. Therefore, this study aimed to include an examination of potential barriers to the autism diagnostic process in relation to caregiver satisfaction. Furthermore, length of wait for an evaluation has been inconsistently evaluated, thus, this study evaluated both length of wait since first noticing autism symptoms and length of time spent on a wait list to observe any difference in the influence these variables may have. Overall, this study aimed to update the existing literature as well as to examine the relationship between caregiver satisfaction, barriers to the evaluation process, and wait times for receiving an evaluation within the same model. Additionally, the study intended to examine how interactions between certain predictor variables related to caregiver satisfaction. Particularly, how caregivers' perception of the reasonability of the wait time interacted with barriers to the evaluation process that have been previously identified within the literature.

Methods

Participants

The current study used an archival data set that was collected through Qualtrics, an online survey system, by the ISU CARES Lab as a part of a larger study focusing on the autism assessment and feedback experiences of caregivers. Participants were recruited online through social media (i.e., Facebook and Instagram), paid advertisements on Facebook, and sharing the study with four colleagues who focus on neurodevelopmental disabilities in university programs

and centers located within the United States who then further distributed the survey. Inclusion criteria comprised of participants being 18 years old or older, a caregiver of at least one child who was diagnosed with autism, a resident of the United States, a previous participant in their child's diagnostic process, proficient in English, and having internet access. Participants whose child was 18 years or older when they were diagnosed were excluded. Data was collected from April to June of 2021.

When considering an appropriate sample size for this proposed study, a study conducted by Crane and colleagues (2016) was utilized to determine the appropriate parameters. The authors of this study investigated the relationship between parental satisfaction with the autism diagnostic process in the United Kingdom and various factors, such as the amount of time taken to get a diagnosis, with 1,047 parents. This study found an overall large effect ($R^2 = 0.49$). Given these findings, a power analysis for a multiple regression with 18 predictors (10 tested predictors [$\alpha = 0.05$, power = 0.80]) was conducted using the G*power statistical software (Faul et al., 2007). This power analysis indicated that approximately 119 participants would be needed to obtain a moderate effect size $f^2 = 0.15$ and 58 participants would be needed to obtain a large effect size $f^2 = 0.35$. Therefore, it was estimated that a sample size of at least 150 participants be used from the archival database to account for potential missing data. The current database contains responses from approximately 370 participants. Upon completion of cleaning the data (i.e., deleting duplicate/counterfeit responses, and incorrect responses to attention checks), the sample size was 345 participants.

Participants in the current sample were from 45 states within the United States (all states except Minnesota, Mississippi, North Dakota, South Dakota, and Wyoming). Based upon the United States census region delineations, see Table 1 for an overview of the regions participants

lived at the time of the evaluation. Following cleaning of the data, descriptive demographic information are provided within the results section.

Table 1

Participants' Regions of the United States

Region	n	Percentage
Northeast	53	15.45%
Midwest	92	26.82%
South	121	35.28%
West	68	19.83%

Materials

As no known, available, and validated measures exist for assessing these factors, researchers created an online survey to collect this information as well as other information about the autism assessment process (see Appendix 1). As the data that was collected was a part of a larger research questionnaire, additional questions were asked of the research participants that were not directly related to this research study. The questions created for the survey regarding the autism assessment process were inspired by the researchers' clinical experiences with this process and existing research on the topic.

Overall, the survey consisted of three sections: demographic information of the child and caregiver, the assessment process, and the feedback process. Within the first section on demographic information, caregivers completed questions regarding their and their child's gender, race/ethnicity, age at the time of evaluation, as well as the caregiver's family income, level of financial stress, size of household, level of education, and zip code when they received the autism evaluation. In the second section, caregivers were asked to answer questions about their experiences prior to the evaluation and during the evaluation. Within the pre-evaluation

section, caregivers were asked about when they first noticed autism symptoms, what those symptoms were, if and what type of regression in skills they noticed with their child, who referred their child for an evaluation, the level of difficulty of finding a clinician to complete the evaluation, time spent waiting after first contacting the clinician for an evaluation, and if this was a reasonable wait. In the section regarding their experience during the evaluation, caregivers were asked about the cost and who covered the cost of the evaluation, if the evaluation was completed in their preferred language, if they had to travel to receive the evaluation and how long that travel took, what was done within the evaluation, who completed the evaluation, the caregiver's level of involvement in the process, and how long it took to complete. Additionally, there were questions about caregiver's comfort, distress, and satisfaction overall with the testing process. In the final section, information was collected about the caregiver's experience during the feedback session (e.g., who attended it, who completed it, provider characteristics, and the caregiver's reactions to the autism diagnosis) and following the feedback session (e.g., their perceptions of their child and responses of others to the diagnosis).

Procedure

The online survey was made available to participants through an advertised, shared, or posted web link. Those who elected to participate in the study were first provided with information on the purpose of the study as well as the criteria necessary to participate in it. Following the participants providing their informed consent, they proceeded to complete the Qualtrics survey online. In the event that the caregiver had multiple children with autism, the caregivers were asked to complete the survey about their first experience getting an autism assessment. This was decided upon to attempt to ensure caregivers' level of familiarity with the process be somewhat similar, regardless of the number of times they went through the diagnostic

process. Four attention checks were placed throughout the survey to verify participant's attentiveness to the questions being asked. These attention checks asked participants to select a specific response (e.g., "Please select number 2"). Participants who failed any attention checks were excluded from the survey. Upon completion of this survey, participants were asked to complete a separate survey containing further questions to be entered into a raffle for compensation. Participants had the opportunity to win a $50 Amazon gift card at a ratio of 1:25. This separate survey was created in order to guarantee the contact information they provided would not be linked to their responses on the research survey.

Hypotheses and Analyses

Hypotheses

The study contains six hypotheses, which examined the factors of wait time and barriers that relate to caregiver satisfaction with the autism diagnostic process (see Table 2).

Table 2

List of Hypotheses

Length of Wait	
Hypothesis 1	Longer times since first noticing symptoms will be associated with lower satisfaction
Hypothesis 2	Longer times spent on a waitlist will be associated with lower satisfaction
Hypothesis 3	Those who indicated the wait time being less reasonable will be associated with lower satisfaction
Barriers	
Hypothesis 4	Higher levels of reported financial stress will be associated with lower satisfaction
Hypothesis 5	Lower levels of reported education will be associated with lower satisfaction
Hypothesis 6	Longer time spent traveling to receive the evaluation will be associated with lower satisfaction

Table 2 (continued)

Hypothesis 7	Higher difficulty finding a clinician will be associated with lower satisfaction
Hypothesis 8	More rural reported locations will be associated with lower caregiver satisfaction
Interactions	
Hypothesis 9	The interaction of a less reasonable wait and more time spent on the waitlist will be associated with lower satisfaction
Hypothesis 10	The interaction of a less reasonable wait and a higher total barrier score will be associated with lower satisfaction

The outcome variable for Hypotheses 1-10 is on a scale of 0-100, with higher scores indicating that participants were more satisfied with the evaluation. For Hypothesis 1, the predictor variable was calculated by subtracting the response provided from Q2.1 (age of the child when symptoms of autism were noticed) from Q1.10 (age at diagnosis). Responses for Q2.1 that indicated less than 1 year old and were changed to 0 and responses that indicated older than 18 were deleted from the database. This provided one conceptualization of wait time that can include the process of receiving a referral for an evaluation. For Hypothesis 2, Q2.8 represents the predictor variable, the time spent on a waitlist in months. Hypotheses 3, 4, and 7 have predictor variables from Q2.9, Q1.23, and Q2.6, respectively. All predictor variables for these hypotheses are derived from 5-point Likert scales. Higher scores on the predictor variables' Likert scales for Hypotheses 4 and 7 represent a higher degree of that predictor variable (i.e., financial stress and difficulty finding a clinician), while higher ratings of the predictor variable for Hypothesis 3 indicate less of a reasonable wait. Hypothesis 5's predictor variable was collected from Q1.21. This question provides seven possible options for the participant to select ranging from "less than high school" to "doctorate degree." These selections were coded to represent a 7-point Likert scale ordered from lowest education to highest education. The

predictor variable for Hypothesis 6 was gathered from Q3.7. This is a 4-point Likert scale with higher scores indicating longer travel times. See Appendix 1 for the list of questions used in the survey.

Hypotheses 1-3 were aimed to represent different conceptualizations of time spent waiting for a diagnosis and caregivers' perceptions of that wait time. Hypotheses 4-8 were intended to represent barriers faced when seeking out an assessment. Regarding socioeconomic status, many options exist for conceptualizing this variable. Due to the variability of payment methods for an evaluation (e.g., out of pocket, private insurance, Medicaid), financial stress was proposed to best represent financial barriers as opposed to the cost of the evaluation or household income. Therefore, barriers related to SES were related to the variables measuring financial stress and level of education. Additionally, it was hoped that time spent traveling as well as difficulty finding a clinician would be able to capture aspects of rurality that can be the most burdensome for families. Additionally, Hypothesis 8 aimed to capture rurality directly. To create the variable for this hypothesis, the Rural Health Information Hub offers rural data from the National Center for Health Statistics that classifies counties on a 6-point Likert scale for their level of being metropolitan or rural. Higher scores correspond with being more rural. To use this data, the zip codes attained in the data set were converted to their corresponding counties and then the counties were searched within the online rural health database.

Interaction terms were created for the predictors of Hypotheses 9 and 10. For Hypothesis 9, the interaction term contained the predictor variable from Hypothesis 3 (Q2.9) and the predictor variable from Hypothesis 2 (Q2.8). For Hypothesis 10, the interaction term contained the predictor variable from Hypothesis 3 (Q2.9) and a total barrier score. A total barrier score was created to capture the effect of all the barriers combined. Equal weight was given to the

variables used to calculate the total barrier score by setting all variables on the equivalent of a 5-point Likert scale and reversing the level of education variable. Two variables were already from a 5-point Likert scale. The other variables had a formula created to divide the response by the amount of the scale (i.e., 4 or 7) and this number was then be multiplied by 5. In the event that these interaction terms do not significantly add to the model, they were proposed to be dropped. These interaction terms were chosen based on a theoretical understanding of the importance of the perception of the reasonability of the time spent waiting. Appendix 2 displays a data dictionary for reference with definitions of all variables utilized in this study.

Several covariates likely exist in relation to this topic. Therefore, there were eight proposed covariates to be measured: race and ethnicity of the child and caregiver, age of the child at diagnosis, age of the caregiver at their child's diagnosis, and child and parent gender. Due to the limited amount of racially and ethnically diverse participants in the collected sample, it was proposed for that covariate to be transformed into a dichotomous variable to represent "White" and "Non-white." However, the covariates ultimately were not significant within the models and were subsequently dropped.

Descriptive statistics are provided and include descriptives on all variables (e.g., sample size, range, mean, standard deviation, variance, skewness, kurtosis), a correlation matrix between all variables, and descriptive statistics of demographic information about the sample (e.g., age at diagnosis, gender, race, ethnicity, income, education). See Tables 3, 4, and 5 below and Table 6 within the Results section).

Analyses

All participants who did not meet the inclusion criteria or who failed the attention checks were removed. This includes participants who indicated meeting inclusion criteria initially but

Table 3

Descriptive Statistics

	n	Range	Min	Max	Mean	SD	Variance	Skewness	Kurtosis
Caregiver Satisfaction	339	100	0	100	72.13	23.68	560.84	-.92	.68
Time Since Noticing Symptoms	338	16	0	16	2.83	2.64	6.97	1.83	3.63
Months on a Waitlist	337	24	0	24	4.03	3.84	14.74	2.62	9.15
Reasonability of Wait Time	343	4	1	5	2.95	1.37	1.88	.06	-1.24
Financial Stress	342	4	1	5	3.11	1.25	1.56	.04	-1.15
Education	343	6	1	7	3.64	1.41	1.99	.28	-.90
Travel Time	343	3	1	4	1.56	.80	.65	1.31	.87
Difficulty Finding a Clinician	343	4	1	5	2.83	1.26	1.59	-.06	-1.2
Rurality	335	5	1	6	3.03	1.55	2.42	.47	-.84
Combined Barrier Score	343	15.18	5.39	20.57	13.18	3.08	9.46	-.17	-.54

Table 4

Age Descriptive Statistics

	n	Range	Min	Max	Mean	SD	Variance	Skewness	Kurtosis
Caregiver Age at Child's Diagnosis	320	41	22	63	36.47	8.36	69.81	.89	.43
Child Age at Diagnosis	341	15	1	16	5.57	3.40	11.57	.93	.07

Table 5

Descriptive Statistics of Other Demographics

	n	Percentage
Caregiver Gender		
Male	41	11.95%
Female	298	86.88%
Other	3	0.01%
Child Gender		
Male	247	72.01%
Female	92	26.82%
Other	4	1.17%
Caregiver Race		
White/Caucasian	310	90.38%
Black/African America	17	4.96%
Native American/Alaska Native	20	5.83%
Asian	2	0.58%
Native Hawaiian or Other Pacific Islander	2	0.58%
Other	8	2.33%
Child Race		
White/Caucasian	317	92.42%
Black/African America	29	8.45%
Native American/Alaska Native	21	6.12%
Asian	4	1.17%

Table 5 (continued)

Native Hawaiian or Other Pacific Islander	1	0.29%
Other	10	2.91%
Caregiver Ethnicity		
Hispanic/Latino	42	12.24%
Not Hispanic/Latino	286	83.38%
Other	12	3.50%
Child Ethnicity		
Hispanic/Latino	58	16.91%
Not Hispanic/Latino	272	79.30%
Other	10	2.91%
Income		
Less than $25,000	88	25.66%
$25,000 to $34,999	66	19.24%
$35,000 to $49,999	66	19.24%
$50,000 to $74,999	62	18.08%
$75,000 to $99,999	28	8.16%
$100,000 to $149,999	21	6.12%
$150,000 or more	11	3.21%

later responses provided indicated otherwise (i.e., age of child at diagnosis was 18 or older; n=31). A participant's data was deleted for a particular variable for several possible reasons: caregiver age was deleted if caregiver was young and same age as child at diagnosis (e.g., caregiver and child were both 5 years old; n=9), a negative score on time since first noticing symptoms (n=3), or caregiver age at diagnosis was younger than 12 years old (n=6). The final sample size of the dataset that was analyzed was n=345. See Table 3, 4, and 5 for descriptive information regarding the sample. To avoid a large amount of missing data on the travel time variable, those who indicated they did not travel were included within the lowest selection on the Likert scale (i.e., "less than 1 hour"; n=164). Listwise deletion was used for each analyses. For Model 1, the final total sample size after listwise deletion was 322 and for Model 2 it was 329. Therefore, 23 participants were deleted from Model 1, and 16 were deleted from Model 2.

The Statistical Package for the Social Sciences (SPSS) was used for the statistical analyses (IBM Corporation, 2017). Hypotheses 1-10 was analyzed using a hierarchical multiple linear regression, following the data set being evaluated for normality, linearity, and multicollinearity. A multiple linear regression was proposed due to it having the ability to examine predictive relationships between a single outcome variable and multiple predictor variables (Allison, 2012). Specifically, a hierarchical multiple linear regression was proposed due to the ability of this form of multiple regression to analyze the variables in a sequential order based off the researcher's theoretical understanding of their importance in the model (Petrocelli, 2003). In addition to the hierarchical regression, a simultaneous regression was also completed and the differences between the two were observed. Through the use of this analysis, it was aimed to observe the relationship between the outcome variable, caregiver satisfaction of the diagnostic evaluation, and the eight predictor variables.

The results of the multiple linear regression provided correlations between each of the variables (Allison, 2012). These correlation coefficients were interpreted using descriptors of the categorization of their strength such as weak ($r \leq .3$), moderate ($r = .31$ - $.5$), and strong ($r > .5$; Plonsky & Oswald, 2014). However, according to Taylor (1990), an interpretation of statistical significance is needed for the descriptive interpretation to be meaningful. Therefore, multiple *t*-tests were conducted to determine the significance of the individual variables as well as an F-test, which was conducted to determine the significance of the overall model. Cohen (2013) proposed interpretations of effect sizes to be $f^2 = .02$ being a small effect, $f^2 = .15$ being a medium effect, and $f^2 = .35$ being a large effect. Additionally, the change in R^2 between steps and the partial and semi-partial correlations for each variable were reported.

We generally proposed to analyze the data using two hierarchical regression models. Firstly, we proposed to enter the aforementioned covariates into the model. Any covariates that have a significant relationship in the model would be retained within the multiple regression model. Next, the predictor variables would be added into the model. Finally, interaction terms were proposed to further analyze the relationships between the variables. Specifically, two interaction terms were proposed to be tested within the multiple regression models. These interaction terms were "reasonable wait X time spent on a waitlist" and "reasonable wait X total barrier score".

The first hierarchical regression model that was run included three steps that were proposed and described above: first covariates were entered, then the eight predictor variables, then a single interaction term, reasonable wait X time spent on a waitlist. The other interaction term could not be added to this model as the combined barrier variable had not previously been included within the model. Therefore, we proposed to run a second hierarchical regression model. This model was similar to the first model with some exceptions. The second model was proposed to include covariates, then all variables apart from interaction terms with the exception of the barrier variables being replaced with a total barrier score, and then the two interaction terms. The differences between these two models were observed and discussed below.

After the analyses were run, it was discovered that no covariates significantly added to the models, therefore they were all dropped. The hierarchical multiple regression models then were composed of two steps. Additionally, the interaction terms within the second regression model were not significant and were subsequently dropped from this model. This left one hierarchical multiple regression model with two steps (Model 1) and one standard regression model (Model 2). However, as initially discussed in the proposal, a simultaneous regression was

included to describe the observed difference and determine best model fit. This simultaneous regression was represented by the second step of Model 2. Therefore, this step was still reported and described within the results even though the interaction terms were non-significant.

As previously stated, missing data was addressed by listwise deletion for all variables except for the total barrier score. For the total barrier score, the participant's mean score was imputed for instances of less than 25% missing data. If participants had more than 25% of data missing for the variables within the total barrier scale, they would not be included within the analyses. However, no participant fit this criterion therefore no participants were excluded.

Regarding statistical assumptions, there was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values. A visual inspection demonstrated that there was a linear relationship for each partial regression plot and the residuals formed a horizontal band for the plot of studentized residuals. There was independence of residuals as assessed by a Durbin Watson statistic of approximately 2. There was homoscedasticity, as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. The visual inspection found the residuals to be approximately evenly distributed. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1. There were no studentized deleted residuals greater than ±3 standard deviations, no leverage values greater than 0.2, and values for Cook's distance above 1. The assumption of normality was met, as assessed by Q-Q Plot. A visual inspection of this plot found the points to approximately align with the diagonal line.

Results

Correlations

As a part of the hierarchical multiple regression analyses, Pearson's correlation was run for all variables (see Table 6). Statistically significant relationships were observed across multiple variables. Caregiver satisfaction had a small negative correlation with months on a waitlist, $r(329) = -.22$, $p < .001$, a moderate negative correlation with reasonability of wait time, $r(329) = -.36$, $p < .001$, a moderate negative correlation with difficulty finding a clinician, $r(322) = -.32$, $p < .001$, and a small negative correlation with a combined barrier score, $r(329) = -.2$, $p < .001$. Time since noticing symptoms had a small positive correlation with months on a waitlist, $r(329) = .11$, $p < .05$, a small positive correlation with reasonability of wait time, $r(329) = .14$, $p < .05$, a small positive correlation with education, $r(322) = .22$, $p < .001$, and a small negative correlation with travel time, $r(322) = -.12$, $p < .05$. Months on a waitlist had a large positive correlation with reasonability of wait time, $r(329) = .52$, $p < .001$, a small positive correlation with financial stress, $r(322) = .17$, $p < .01$, a moderate positive correlation with difficulty finding a clinician, $r(322) = .32$, $p < .001$, a small positive correlation with rurality, $r(322) = .11$, $p < .05$, and a small positive correlation with a combined barrier score, $r(329) = .22$, $p < .001$. Reasonability of wait time had a small positive correlation with financial stress, $r(322) = .13$, $p < .05$, a moderate positive correlation with difficulty finding a clinician, $r(322) = .49$, $p < .001$, and a small positive correlation with a combined barrier score, $r(329) = .25$, $p < .001$. Financial stress had a small positive correlation with difficulty finding a clinician, $r(322) = .22$, $p < .001$, and a small positive correlation with rurality, $r(322) = .11$, $p < .05$. Education had a small negative correlation with travel time, $r(322) = -.12$, $p < .05$, and a small negative correlation with rurality, $r(322) = -.2$, $p < .001$. Travel time had a small positive correlation with difficulty finding a

Table 6

Correlation Table

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Caregiver Satisfaction	1									
2. Time Since Noticing Symptoms	.06	1								
3. Months on a Waitlist	-.22***	.11*	1							
4. Reasonability of Wait Time	-.36***	.14*	.52***	1						
5. Financial Stress	-.08	-.02	.17**	.13*	1					
6. Education	-.01	.22***	.10	.09	-.09	1				
7. Travel Time	-.10	-.12*	.07	.08	.07	-.12*	1			
8. Difficulty Finding a Clinician	-.32***	.05	.32***	.49***	.22***	-.01	.22***	1		
9. Rurality	.01	-.03	.11*	.002	.11*	-.2***	.14*	.01	1	
10. Combined Barrier Score	-.20***	-.10	.22***	.25***	-	-	-	-	-	1

Note. Sig. 2-tailed *$p < .05$. **$p < .01$. *** $p < .001$

clinician, $r(322) = .22$, $p < .001$, and a small positive correlation with rurality, $r(322) = .14$, $p < .05$.

Hierarchical Multiple Regression Models

A hierarchical multiple regression was run to determine if the addition of interaction terms improved the prediction of caregiver satisfaction over and above length of wait and barrier variables alone. See Table 7 and 8 for full details of each regression model. No covariates significantly added to the model, so they were dropped from both models. The interaction term in the first model was the only interaction to reach statistical significance. Therefore, the interaction terms in the second model were theoretically dropped but still retained within thisresults section to discuss in terms of the simultaneous regression agreed upon within the proposal. Table 7 represents the first model which, in the first step, contains separate variables for barriers (i.e., financial stress, education level, travel time, difficulty finding a clinician, and rurality). In the second step of this model, an interaction term of reasonability of wait X time spent on a waitlist was added, which creates a full model for Model 1.

The first step of Model 1 yielded statistically significant results, $R^2 = .17$, $F(8, 313) = 8.09$, $p < .001$; adjusted $R^2 = .15$. This initial step of Model 1 explained 17% of the variance in caregiver satisfaction and a moderate effect-size ($f^2 = .20$). The full model of wait time variables, barrier variables, and an interaction term (reasonability of wait X time spent on a waitlist) to predict caregiver satisfaction (Model 1, Step 2) was statistically significant, $R^2 = .18$, $F(9, 312) = 7.82$, $p < .001$; adjusted $R^2 = .16$ with a medium effect ($f^2 = .22$). This second step of Model 1 (the full model version of Model 1) explained 18% of the variance in caregiver satisfaction. The addition of the interaction term to the prediction of caregiver satisfaction led to a statistically

Table 7

Multiple Regression Results for Caregiver Satisfaction (Model 1)

	B	*95% CI*		*SE B*	β	R^2	Adjusted R^2	ΔR^2	*F*	ΔF
		LL	*UL*							
Model (Step 1)						.17	.15	.17	8.09***	8.09***
Constant	94.06***	81.31	106.8	6.48						
Time Since Noticing Symptoms	.95*	.01	1.88	.48	.11*					
Months on a Waitlist	-.20	-.95	.54	.38	-.03					
Reasonability of Wait Time	-4.66***	-6.87	-2.44	1.13	-.27***					
Financial Stress	.04	-1.98	2.05	1.02	.00					
Education	-.05	-1.88	1.79	.93	.00					
Travel Time	-.81	-3.99	2.38	1.62	-.03					
Difficulty Finding a Clinician	-3.31**	-5.58	-1.05	1.15	-.18**					
Rurality	.29	-1.32	1.90	.82	.02					
Model (Step 2)						.18	.16	.01	7.82***	4.85*

Table 7 (continued)

Constant	86.7***	72.42	100.97	7.25	
Time Since Noticing Symptoms	.99*	.06	1.92	.47	.11*
Months on a Waitlist	2.29	-.06	4.65	1.20	.37
Reasonability of Wait Time	-2.70	-5.51	.11	1.43	-.16
Financial Stress	.29	-1.73	2.30	1.02	.02
Education	.31	-1.54	2.16	.94	.02
Travel Time	-.88	-4.04	2.29	1.61	-.03
Difficulty Finding a Clinician	-3.57**	-5.83	-1.31	1.15	-.19**
Rurality	.09	-1.52	1.70	.82	.01
Reasonability X Time on Waitlist	-.63*	-1.19	-.07	.29	-.49*

Note. Model = "Enter" method in SPSS Statistics; *B* = unstandardized regression coefficient; *CI* = confidence interval; *LL* = lower limit; *UL* = upper limit; *SE B* = standard error of the coefficient; β = standardized coefficient; R^2 = coefficient of determination; ΔR^2 = R^2 change.

*$p < .05$. **$p < .01$. ***$p < .001$.

Table 8

Multiple Regression Results for Caregiver Satisfaction (Model 2)

	B	*95% CI*		*SE B*	β	R^2	Adjusted R^2	ΔR^2	*F*	ΔF
		LL	*UL*							
Model (Step 1)						.15	.14	.15	14.49***	14.49***
Constant	97.5***	86.12	108.87	5.78						
Time Since Noticing Symptoms	.88	-.04	1.80	.47	.10					
Months on a Waitlist	-.20	-.94	.53	.37	-.03					
Reasonability of Wait Time	-5.73***	-7.79	-3.66	1.05	-.33***					
Combined Barrier Score	-.75	-1.56	.07	.42	-.10					
Model (Step 2)						.17	.15	.01	10.61***	2.57
Constant	86.52***	63.29	109.75	11.81						
Time Since Noticing Symptoms	.95*	.03	1.86	.47	.11*					
Months on a Waitlist	2.01	-.41	4.42	1.23	.33					
Reasonability of Wait Time	-1.66	-9.23	5.91	3.85	-.10					
Combined Barrier Score	-.36	-2.24	1.53	.96	-.05					
Reasonability X Time on Waitlist	-.55	-1.13	.02	.29	-.43					
Reasonability X Total Barrier	-.18	-.76	.40	.30	-.17					

Note. Model = "Enter" method in SPSS Statistics; *B* = unstandardized regression coefficient; *CI* = confidence interval; *LL* = lower limit; *UL* = upper limit; *SE B* = standard error of the coefficient; β = standardized coefficient; R^2 = coefficient of determination; ΔR^2 = R^2 change.

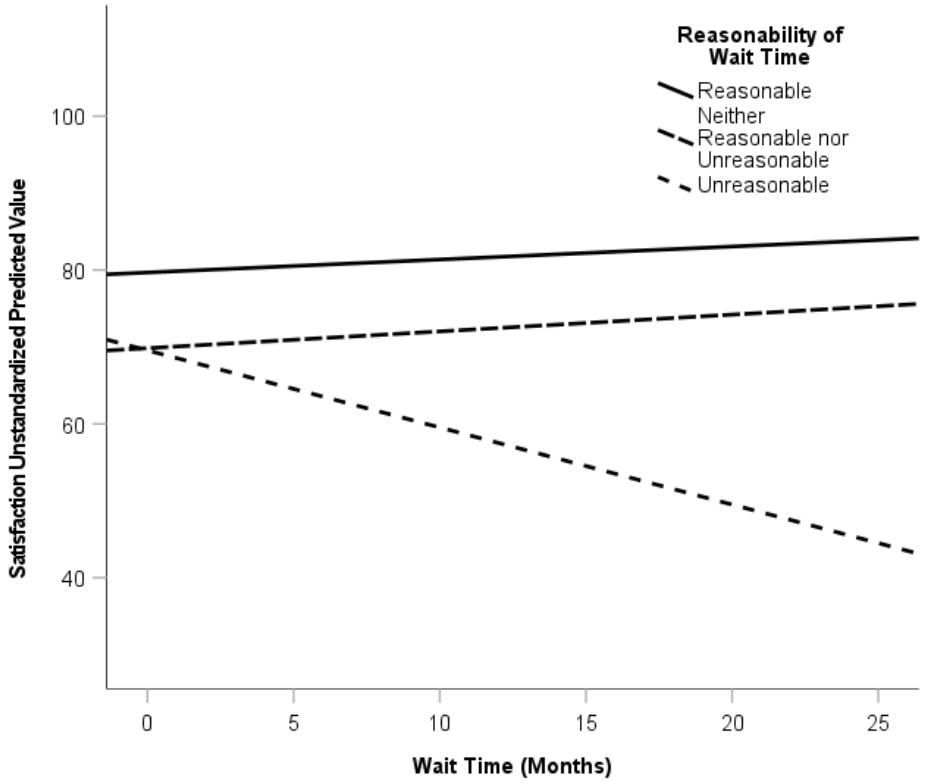
*$p < .05$. **$p < .01$. ***$p < .001$.

significant increase in R^2 of .01, $F(1, 312) = 4.86$, $p < .001$ but with a small effect ($f^2 = .01$). Figure 1 illustrates this interaction and is discussed in more detail below.

While the multiple regression model was statistically significant for predicting caregiver satisfaction within both Step 1 and Step 2, not all variables added to the model to an extent that was statistically significant. Within Step 1, reasonability of wait time (β = -.27, $p < .001$), difficulty finding a clinician (β = -.18, $p < .01$), and time since noticing symptoms (β = .11, $p < .05$) significantly added to the model. Within Step 2, difficulty finding a clinician (β = -.19, $p < .01$), time since noticing symptoms (β = .11, $p < .05$), and the interaction term of reasonability of wait X time spent on a waitlist (β = -.49, $p < .05$) significantly added to the

Figure 1

Significant Interaction Term



model. Table 9 presents the part and partial correlations for this model. Significant findings are discussed in more detail below.

Table 8 represents the second model which, in the first step, contains a combined barrier score in place of separate barrier variables. In the second step of this model, two interaction terms are added (reasonability of wait X time spent on a waitlist and reasonability of wait X combined barrier score), which creates the full model for Model 2.

Regarding statistical assumptions, there was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values. There was independence of residuals. There was homoscedasticity, as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1. There were no studentized deleted residuals greater than ±3 standard deviations, no leverage values greater than 0.2, and values for Cook's distance above 1. The assumption of normality was met, as assessed by Q-Q Plot.

The first step of Model 2 yielded statistically significant results, $R^2 = .15$, $F(4, 324) = 14.49$, $p < .001$; adjusted $R^2 = .14$. This initial step of Model 2 explained 15% of the variance in caregiver satisfaction and a moderate effect-size ($f^2 = .18$). The full model of wait time variables, a combined barrier variable, and two interaction terms to predict caregiver satisfaction (Model 2, Step 2) was statistically significant, $R^2 = .17$, $F(6, 322) = 10.61$, $p < .001$; adjusted $R^2 = .15$, with a medium effect ($f^2 = .20$). This second step of Model 2 (the full model) explained 17% of the variance in caregiver satisfaction. The addition of the interaction term to the prediction of caregiver satisfaction did not lead to a statistically significant increase in R^2 of .01, $F(2, 322) = 2.57$, $p = .08$. Table 10 presents the part and partial correlations for this model. Significant

findings are discussed in more detail below. See Table 11 for outline of the significant findings for each hypothesis.

While the multiple regression model was statistically significant for predicting caregiver satisfaction within both Step 1 and Step 2, not all variables added significantly to the model. Within Step 1, reasonability of wait time ($\beta = -.33$, $p < .001$) statistically significantly added to the model. Within Step 2, time since noticing symptoms ($\beta = .11$, $p < .05$) significantly added to the model.

Regarding Hypothesis 1 (i.e., longer times since first noticing symptoms will be associated with lower satisfaction), the zero-order correlation was not significant, $r(329) = .06$, $p = .3$. This did not support the hypothesis; additionally, when examining results of the hierarchical

Table 9

Part and Partial Correlation Coefficients for Model 1

	Partial	*Part*
Model (Step 1)		
Time Since Noticing Symptoms	.11*	.10*
Months on a Waitlist	-.03	-.03
Reasonability of Wait Time	-.23***	-.21***
Financial Stress	.00	.00
Education	-.00	-.00
Travel Time	-.03	-.03
Difficulty Finding a Clinician	-.16**	-.15**
Rurality	.02	.02
Model (Step 2)		
Time Since Noticing Symptoms	.12*	.11*
Months on a Waitlist	.11	.10
Reasonability of Wait Time	-.11	-.10
Financial Stress	.02	.01
Education	.02	.02
Travel Time	-.03	-.03
Difficulty Finding a Clinician	-.17**	-.16**
Rurality	.01	.01
Reasonability X Time on Waitlist	-.12*	-.11*

*$p < .05$. **$p < .01$. ***$p < .001$.

Table 10

Part and Partial Correlation Coefficients for Model 2

	Partial	*Part*
Model (Step 1)		
Time Since Noticing Symptoms	.10	.10
Months on a Waitlist	-.03	-.03
Reasonability of Wait Time	-.29***	-.28***
Combined Barrier Score	-.10	-.09
Model (Step 2)		
Time Since Noticing Symptoms	.11*	.10*
Months on a Waitlist	.09	.08
Reasonability of Wait Time	-.02	-.02
Combined Barrier Score	-.02	-.02
Reasonability X Time on Waitlist	-.11	-.10
Reasonability X Total Barrier	-.03	-.03

*$p < .05$. **$p < .01$. ***$p < .001$

Table 11

Outline of Findings for Each Hypothesis

Hypothesis	**Conclusion**
H1 (Time since 1st symptoms)	Not supported, significant in opposite direction; small effect size
H2 (Time on wait list)	Supported only by correlation; small effect size
H3 (Reasonability of wait)	Supported by correlation and hierarchical multiple regression; small to moderate effect size
H4 (Financial stress)	Not supported
H5 (Education)	Not supported
H6 (Travel time)	Not supported

Table 11 (continued)

H7 (Difficulty finding clinician)	Supported by correlation and hierarchical multiple regression; small to moderate effect size
H8 (Rurality)	Not supported
H9 (Reasonability X Time on wait list)	Supported by hierarchical multiple regression (Model 1); small effect size
H10 (Reasonability X Total Barrier Score)	Not supported

regression Model 1, the length of time since first noticing symptoms was significantly correlated with caregiver satisfaction for step 1, $t = 2$, $p = .05$, as well as step 2, $t = 2.09$, $p = .04$. Specifically, an increase in 1 year since noticing symptoms was associated with an increase in caregiver satisfaction for step 1 and 2 by .99 points of satisfaction and .95 points of satisfaction, respectively. For Model 2 in the first step, the length of time since first noticing symptoms was not significantly correlated with caregiver satisfaction, $t = 1.89$, $p = .06$. Here, an increase in 1 year since noticing symptoms was associated with an increase in caregiver satisfaction by .88 points of caregiver satisfaction. In the second step of Model 2 (the full model), the length of time since first noticing symptoms was significantly correlated with caregiver satisfaction, $t = 2.03$, $p = .04$. An increase in 1 year since noticing symptoms was associated with an increase in caregiver satisfaction by .95 points of caregiver satisfaction. Across Model 1 and 2 and the steps within these model, the part and partial correlations remained similar (.1 to .12) and were also significant except for Step 1 of Model 2. This suggests that when controlling for other variables, the relationship between the length of time since first noticing symptoms and caregiver satisfaction has a partial correlation between $r_{partial} = .1$ and $r_{partial} = .12$. This indicates that there is a small, positive correlation between the length of time since first noticing symptoms and

caregiver satisfaction when controlling for other variables. While some values were statistically significant, the hypothesis was not supported due to the direction of the effect sizes being opposite of the hypothesis. Taken together, this hypothesis was not supported by the analyses. In fact, significant findings suggest that as the time since noticing symptoms increased, satisfaction generally increased, although the effect of this relationship was rather small.

Regarding Hypothesis 2 (i.e., longer times spent on a waitlist will be associated with lower satisfaction), the zero-order correlation was a statistically significant, small, and negative, $r(329) = -.22$, $p < .001$. This supported the hypothesis. When considering the multiple regression models, the length of time on a waitlist was not significantly correlated with caregiver satisfaction in any model or step. This did not support the hypothesis. The part and partial correlations were also not significant and ranged from $r_{partial} = -.03$ to $r_{partial} = .11$. This is a small, positive and negative correlation between the length of time on a waitlist and caregiver satisfaction when controlling for other variables. This was not significant and did not support the hypothesis. This hypothesis overall was not supported by the analyses. Although there was a small significant correlation in the hypothesized direction, after accounting for other variables within the regression models, no significant effect remained.

Regarding Hypothesis 3 (i.e., less reasonable wait will be associated with lower satisfaction), the zero-order correlation was statistically significant, moderate, and negative, $r(329) = -.36$, $p < .001$. This was both statistically significant and supported that hypothesis as reasonability is measured in the inverse (i.e., a higher score is less reasonable). Within the multiple regression models, the reasonability of wait time was statistically significant and correlated with caregiver satisfaction for the first steps of Model 1 and Model 2, $t = -4.13$, $p < .001$ and $t = -5.46$, $p < .001$. An increase in 1 point of reasonability of wait time (more

unreasonable) is associated with a decrease of 4.66 points of caregiver satisfaction and 5.73 points of caregiver satisfaction for step 1 of Model 1 and 2, respectively. Again, this is statistically significant, and it did support the direction of the hypothesis. The part and partial correlations that were statistically significant for the first steps of Model 1 and 2 ranged from $r_{partial}$ = -.21 to $r_{partial}$ = -.29. This is a small, negative correlation between reasonability of wait time and caregiver satisfaction when controlling for other variables. This was statistically significant and did support the direction of the hypothesis. This hypothesis overall was supported by both the correlation and within the regression models with significant small to moderate effect sizes. It is likely that significance for this variable was not found within either of the full models as this variable was contained within the interaction terms that were added within this step.

Regarding Hypothesis 4 (i.e., higher levels of reported financial stress will be associated with lower satisfaction), the zero-order correlation was not significant, $r(322) = -.08$, $p = .16$. This does not support the hypothesis. This predictor variable was only within the first multiple regression model. Here, financial stress and caregiver satisfaction were not statistically significant within either step of this model, not supporting the hypothesis. The part and partial correlations ranged from $r_{partial}$ = .00 to $r_{partial}$ = .02. These are a small, positive, non-significant correlation between financial stress and caregiver satisfaction when controlling for other variables. This did not support the hypothesis. Overall, this hypothesis was not supported by either the correlation or regression model.

Regarding Hypothesis 5 (i.e., lower levels of reported education will be associated with lower satisfaction), the zero-order correlation was not significant, $r(322) = -.01$, $p = .91$. This did not support the hypothesis. This predictor variable was only within the first multiple regression model. Here, education level and caregiver satisfaction were not statistically significant within

either step of this model, not supporting the hypothesis. The part and partial correlations ranged from $r_{partial}$ = -.00 to $r_{partial}$ = .02. These are a small, positive and negative, non-significant correlation between education level and caregiver satisfaction when controlling for other variables. This did not support the hypothesis. Overall, this hypothesis was not supported by either the correlation or regression model.

Regarding Hypothesis 6 (i.e., longer time spent traveling to receive the evaluation will be associated with lower satisfaction), the zero-order correlation was not significant, $r(322) = -.1$, $p = .08$. This did not support the hypothesis. This predictor variable was only within the first multiple regression model. Here, travel time and caregiver satisfaction were not statistically significant within either step of this model, not supporting the hypothesis. The part and partial correlations were the same for each step, $r_{partial}$ = -.03. These are a small, negative, non-significant correlation between travel time and caregiver satisfaction when controlling for other variables. This did not support the hypothesis. Overall, this hypothesis was not supported by either the correlation or regression model.

Regarding Hypothesis 7 (i.e., higher difficulty finding a clinician will be associated with lower satisfaction), the zero-order correlation was significant, moderate, and negative, $r(322) = -.32$, $p < .001$. This supported the hypothesis. This predictor variable was only within the first multiple regression model. Here, difficulty finding a clinician and caregiver satisfaction were statistically significant within both steps of this model, $t = -2.88$, $p = .004$ and $t = -3.1$, $p = .002$, within step 1 and 2, respectively. This supports the hypothesis. An increase in 1 point of increased difficulty finding a clinician was associated with a decrease of 3.31 points and 3.57 points of decreased caregiver satisfaction in steps 1 and 2 of the model, respectively. The part and partial correlations ranged from $r_{partial}$ = -.15 to $r_{partial}$ = -.17. These are a small, negative,

significant correlations between difficulty finding a clinician and caregiver satisfaction when controlling for other variables. This did support the hypothesis. Taken together, this hypothesis was supported by both the correlation and regression model. There were significant effect sizes that ranged from small to moderate that suggested as there was higher difficulty finding a clinician, caregivers rated more dissatisfaction.

Regarding Hypothesis 8 (i.e., more rural reported locations will be associated with lower caregiver satisfaction), the zero-order correlation was not significant, $r(322) = .01$, $p = .89$. This did not support the hypothesis. This predictor variable was only within the first multiple regression model. Here, rurality and caregiver satisfaction were not statistically significant within either step of this model, not supporting the hypothesis. The part and partial correlations were also not significant and ranged from $r_{partial} = .01$ to $r_{partial} = .02$. This is a small, positive correlation between rurality and caregiver satisfaction when controlling for other variables. This did not support the hypothesis. Overall, this hypothesis was not supported by either the correlation or regression model.

Regarding Hypothesis 9 (i.e., the interaction of a less reasonable wait and more time spent on the waitlist will be associated with lower satisfaction), this is an interaction term that is within the second step of both multiple regression models. Within the second step of Model 1 (full model for Model 1), the reasonability of wait X time on the waitlist and caregiver satisfaction were statistically significant, $t = -2.2$, $p = .03$. An increase in 1 point of reasonability of wait time (more unreasonable) X time on the waitlist is associated with a decrease of .12 points of caregiver satisfaction. However, within the second step of Model 2 (full model of Model 2), these variables were not statistically significant. The hypothesis was supported for Model 1 but not supported for Model 2. The significant part and partial correlations (i.e., from

Model 1), ranged from $r_{partial}$ = -.11 to $r_{partial}$ = -.12. This is a small, negative correlation between reasonability of wait X time on the waitlist and caregiver satisfaction when controlling for other variables. This supported the hypothesis, again for Model 1, but not Model 2. Taken together, there were mixed findings for this hypothesis. The regression Model 1 supported the hypothesis, with significant small effects. However, significant effects were not seen within the second regression model. When analyzing significance between groups of the interaction effect, the contrasts between the reasonable group vs. unreasonable group as well as the neutral group vs. unreasonable group were both significant ($p < .001$).

Regarding Hypothesis 10 (i.e., the interaction of a less reasonable wait and a higher total barrier score will be associated with lower satisfaction), this is an interaction term that is within the second step of the second multiple regression model only. Within Model 2, step 2 (the full model), the reasonability of wait X a combined barrier score and caregiver satisfaction were not statistically significant. This did not support the hypothesis. The part and partial correlations were $r_{partial}$ = -.03. These are a small, negative, non-significant correlation between the reasonability of wait X a combined barrier score and caregiver satisfaction when controlling for other variables. This does not support the hypothesis. This hypothesis overall was not supported by the analyses.

Discussion

The primary purpose of this study was to investigate how factors, such as wait time and societal barriers to an autism diagnostic evaluation, contribute to caregivers' satisfaction with the evaluation. The extant literature on this topic is limited, from outside of the United States, and does not examine the identified barriers simultaneously and directly with caregiver satisfaction. The previous literature on caregiver satisfaction has typically found results that suggest caregivers tend to be more dissatisfied when wait times to get an evaluation are longer (e.g.,

Crane et al., 2016; Eggleston et al., 2019; Howlin & Moore, 1997; McCrimmon & Gray, 2021; Siklos & Kerns, 2007). Additionally, barriers, such as lower SES, have also been related, both directly and indirectly, to lower caregiver satisfaction with the autism diagnostic process (e.g., Goin-Kochel et al., 2006; Hildago et al., 2015). The current study seeks to update the current literature, provide a basis for understanding this topic within the United States, and elaborate upon the existing barriers involved in the diagnostic process when understanding caregiver satisfaction.

Due to the lack of literature that took both sociodemographic barriers and wait time into consideration when assessing caregiver satisfaction, two hierarchical multiple regression models were proposed. These models included different conceptualizations of barriers (i.e., individually vs. combined) as well as different interaction terms. The findings of the current study suggests that the best model to capture the data examines the barrier variables individually. In fact, the combined barrier variable and the interaction terms within the second model did not significantly add to the model. This is likely due to the many barrier variables not reaching statistical significance within the models. This model (Model 1) also had the highest amount of variance in caregiver satisfaction explained by the independent variables and a moderate effect size for all of the variables added within the model.

Previous literature did not use a standard measure of wait time. Therefore, this study sought to address this discrepancy within the conceptualization of wait time by including the two standardly used conceptualizations. Notably, the time since first noticing symptoms of autism to when they received an evaluation was found to be a significant variable within the regression models, however this finding was in the opposite direction of the hypothesis. The findings suggest that more time since noticing symptoms is associated with higher caregiver satisfaction.

Even though this is the opposite of the hypothesized direction, there is a possible explanation of this: caregivers have had more time to process the possibility of their child being autistic. Often, a diagnosis of autism can be highly emotional for caregivers, and taking more time to consider this possibility may lead to more overall satisfaction with the evaluation process and, perhaps, add a sense of relief that could also influence satisfaction in this manner. Additionally, with more time since the symptoms being noticed, caregivers could have more opportunity to gain information about autism. There is more potential time to connect with others that have gone through the diagnostic process and have a child with autism or research more information about autism on the internet. If caregivers engage in this type of searching, it is possible that they are also processing through this diagnosis, as discussed above, and feel more comfortable with the process due to the information they gain. An additional way to conceptualize wait time is the number of months that caregivers had their child on a wait list for an autism evaluation. For this variable, while it did not yield significant findings within the multiple regression models, there was significance between its correlation with caregiver satisfaction. This suggests, that when considered independently from other variables, caregiver satisfaction and months spent on a wait list are negatively related (i.e., fewer months on a waitlist is associated with higher caregiver satisfaction). Opposing the other conceptualization of wait time, this version of wait time was in the expected direction. Notably, the time since first noticing autism symptoms was considerably longer than how long children were on a waitlist (i.e., 2.8 years vs. 4 months, respectively). This indicates that there is a large gap in time between when symptoms of autism are first noticed and when caregivers find a clinician to evaluate their child for autism. There could be a variety of factors that contribute to this delay. Some possible factors include stigma and difficulty navigating the process of finding a clinician for the evaluation, such as medical providers

dismissing concerns of caregivers or uncertainty about how to seek out an evaluation. It is also possible that following the diagnosis of autism, caregivers are able to better identify early autism symptoms after receiving explanation of the symptoms or increasing their knowledge of autism. Then, engaging in retrospective thinking, they are rating when they first noticed symptoms even if they did not realize they were symptoms of autism at the time. These factors together may add to an explanation of why these conceptualizations of wait times have somewhat conflicting findings.

Additionally, the caregiver's perception of the reasonability of the wait time was added to the model. This, though not often included within the existing literature, was an important factor to have within this study. The findings suggested that as reasonability of wait time increases, caregiver satisfaction likewise increases. Across multiple models and methods of analyses (i.e., correlation and multiple regression), the reasonability of the wait was a significant variable, often highly significant (i.e., $p < .001$) with caregiver satisfaction. This variable displayed even more consistent significance than other conceptualizations of wait time, such as months on a wait list and time since noticing first autism symptoms. This suggests that reasonability of wait time is likely a more important and influential factor to account for. This is particularly significant as it is a variable that has been largely unmeasured within the existing literature. Additionally, reasonability of wait time was correlated with several other variables. One barrier variable it was significantly correlated with was financial stress, so that as financial stress increased, reasonability of wait time decreased. This could suggest that those who have more financial difficulties have more difficulty accessing assessment services within a reasonable time frame. This was consistent with the existing literature. Reasonability of wait time was also significantly correlated with the two other conceptualizations of wait time. In particular, there was a large

effect between reasonability of wait time and time on a wait list. This indicated that as more months went by after getting on a waitlist, the reasonability of that wait decreased which is consistent with the present literature. Another important significant correlation to note is between difficulty finding a clinician and the reasonability of wait time. This was a highly significant correlation with an effect size that bordered on large which suggested that as the reasonability of wait decreased, the difficulty of finding a clinician increased. This was expected based off the current literature. This also points to the importance of caregiver perception within this literature as both of these variables are significant through the analyses completed and are more based on the perception of the caregiver than other reported variables, such as wait time and travel time.

We hypothesized that barriers which caregivers may face when seeking an autism evaluation may influence their satisfaction with the evaluation process. This was especially true for the barrier of perceived difficulty finding a clinician to conduct the evaluation. This barrier was found to be a significant variable both within the first regression model and as a correlation with caregiver satisfaction. As difficulty finding a clinician decreased, satisfaction with the autism diagnostic process increased, which fit with the hypothesized direction of this relationship. Additionally, while this was the only barrier variable that on its own was significant, it also was highly significant with several other barrier variables such as financial stress and travel time as well as reasonability of wait and months on a wait list. This suggests that difficulty finding a clinician has an association with barriers previously found within the literature as well as an association with wait time variables.

Several barrier variables did not reach significance within the model or as a correlation with caregiver satisfaction. These variables include financial stress, education level, travel time, and rurality. While these barriers may not be significant as hypothesized, they still provide

valuable information and conclusions. It is possible that within this data set, these variables are not the best measure of barriers that caregivers may face when seeking an autism evaluation even though these are barriers typically found within the literature. It appears that within this study, difficulty finding a clinician may better represent how these barriers influence caregiver satisfaction, as previously discussed. Additionally, travel time was measured in a manner that did not allow for much variance and in a way that created a positive skew within the variable (i.e., more lower travel times reported). This may influence the results of the lack of significance within the analyses.

A combined barrier variable was also proposed to be measured within the second multiple regression model. Ultimately, this variable did not significantly add to this model and only was significant through correlation with caregiver satisfaction. However, this could be a result of other barrier variables adding to this significant relationship, such as difficulty finding a clinician. Altogether, it is suggested that barrier variables be reported individually to see their distinctive influence, instead of an aggregated variable.

Finally, interaction terms were proposed to understand how an interaction between the reasonability of wait time and other variables influenced caregiver satisfaction. Only one interaction term was significant, and this was only within the first model: reasonability X time on a wait list. Figure 1 offers a plot of this interaction term. For this figure, reasonability of wait time was separated into three groups for ease of interpretation: those who found the wait to be reasonable (i.e., ratings of a 1 or 2), those who were neutral about reasonability (rating of 3), and those who found the wait time to be unreasonable (ratings of a 4 or 5). The slope for reasonable group was .17, for the neither reasonable nor unreasonable group is .22, and for the unreasonable group is -1. This interaction suggests that when the wait time was rated as reasonable, the

number of months waited did not appear to be a significant factor for this group as it related to reported caregiver satisfaction. Caregiver satisfaction was generally highest in the reasonable group. Similarly, when the wait time was rated as neutral (i.e., neither reasonable nor unreasonable), the number of months waited did not appear to be a significant factor for this group as it related to reported caregiver satisfaction. However, when participants rated the wait time as unreasonable, caregiver satisfaction decreased as caregivers waited more months for an evaluation. This created an interaction effect. Additionally, the unreasonable group generally rated caregiver satisfaction the lowest. In general, those who deemed the wait to be reasonable were more satisfied with the diagnostic process, regardless of the amount of time they waited. However, those who deemed the wait to be unreasonable were generally less satisfied and this dissatisfaction increased with the more months spent waiting for an evaluation. These results have important implications and support the significance of this finding. This suggests that reasonability is an important factor that must be taken into consideration. These findings imply that, provided the perception of the wait was judged to be reasonable, caregivers were ultimately more satisfied with the overall process.

When considering the appropriateness of this interaction term within the model, it significantly adds to the variance explained within the model. Therefore, it should be retained and considered in the overall model and with the interaction term in the model, this explains the largest amount of variance in caregiver satisfaction. Upon reflection of the importance of this interaction term overall, considerations must be provided for reasoning as to why it was significant in one model and not the other. The primary difference between these two models is that Model 2 contains a combined barrier variable instead of the barriers being represented separately. This is likely the reason for the differing significance of this interaction term between

the two models. The individual contribution of the barrier variables is a better representation of the data and allows for the significance of the interaction term in Model 1. A combined barrier variable dilutes the effects of the individual barrier variables, as seen in Model 2. It is likely that the relationship between these specific barrier variables and this interaction term aided in creating the significance observed within Model 1. Of consideration as well is the novel understanding this interaction term provides as this furthers our understanding of what influences caregiver satisfaction within the autism diagnostic process. With this interaction term, we can further support the importance of reasonability and a caregiver perception of the wait time and the process. Overall, we find that Hypothesis 9 was supported as there was a significant interaction when participants found the wait time to be unreasonable.

Implications, Limitations, and Future Directions

One of the main objectives of this study was to add to the current literature on the topic of caregiver satisfaction with the autism diagnostic process. With this addition to the current literature, the goal is to increase knowledge surrounding this topic. Specifically, this study increases the information available to the field and the public about the issues facing caregivers who are navigating the autism diagnostic process for their children. It also provides evidence of experiences that negatively impact caregiver satisfaction in hopes of urging the reduction of these factors. A step in the process of reducing barriers is understanding what those barriers are, which it is the hope that this study provides a foundation for that understanding. Additionally, this study can provide data to testify to the experiences of caregivers within the United States, a population which has yet to be explored in depth within this line of research. We hope that through the information provided within this study, changes can be made within the autism diagnostic process to best support children and their families to navigate this process. Changes

occurring are of high importance as they can reduce the age of identification of autism and help caregivers move forward after having their child evaluated for autism and doing so would help achieve better outcomes for children with autism (e.g., Moh & Magiati, 2012; Osborne et al., 2008; Webb et al., 2014).

Several limitations occurred within this study. One such limitation is the nature of the data collected. That is, caregivers were asked to recall information about an event that could have occurred many years ago. The reliance on retrospective data creates room for errors to occur with reporting. This type of data collected can lack accuracy and is open to respondents misremembering events. Therefore, the data collected is likely only an estimation of what occurred and may not represent the true events and surrounding factors. However, it should be noted that most studies that were conducted on this and related topics rely on similar types of data and it is likely that the data collected for this study is of a similar accuracy to that of these other studies.

Another limitation that arose was the lack of evaluation of the method of the evaluation (i.e., in person vs. online). The field of online evaluations or evaluations that have a virtual component is an expanding area, especially in light of the COVID-19 pandemic. New tools for autism assessment are being validated that do not require a family to leave their house, provided they have an internet connection. While at the time of collecting this data, the resources for online autism assessment were more limited, the access to these tools and information about their validity has greatly expanded in the years following the data collection for this study. It is reasonable to conclude that this has altered the domain of the autism diagnostic process and changed how families are accessing these evaluations. Likely, this has also changed the barriers to, wait times for, and satisfaction with the autism diagnostic process.

Further considering limitations with the data that was collected, it is important to note that the sample collected had a limited variety of racial and ethnic differences. Specifically, the sample was largely non-Hispanic, white and was not representative of the general population of the United States. This is of particular importance to discuss due to the varied experiences that are likely to occur between caregivers of different races and ethnicities. The literature has previously supported those who are racial or ethnic minorities can experience lower satisfaction with the process and longer delays in receiving an autism diagnosis. Those experiences were largely not captured within this study.

Another consideration about the demographics of this sample is that most caregivers were female and most children diagnosed with autism were male. This outcome is to be expected due to women being more likely to provide care to their children than other family members (Sharma et al., 2016) and children diagnosed with autism are more likely to be male (Loomes et al., 2017). While the gender demographics of this study's sample is not surprising, it is important to gather the experiences of individuals that may not represent the standard experience (e.g., male caregivers, female autistic children, those who are gender minorities).

Lastly, the study utilized a correlational design, which limits the conclusions and inferences that could be made from the findings of this study. Also, the current study examined only a limited number of factors. It is without question that there are many more factors that could be involved that contribute to caregiver satisfaction with the autism diagnostic process. It is illogical to assume that one study could include all factors that impact a caregiver's reaction to their child being diagnosed with autism and the process that occurred to reach that diagnosis. Several possible factors that should be researched further could include clinician characteristics,

further information about the process within the diagnostic evaluation (e.g., type of testing, length of testing, involvement of caregiver), and caregiver preferences.

When considering next steps for this line of research, several possibilities arise. One such line of consideration would be to focus on the identified importance of caregiver perceptions with the autism diagnostic process, such as further examining how reasonability and difficulty finding a clinician influence other factors related to caregivers' reactions to this process. Also, it would be important to examine other variables more within caregivers' reactions to the diagnostic process (such as distress, relief, frustration, etc.). Teasing apart reactions to the diagnosis versus reactions to elements of the process is another area to examine. When considering the findings of this study, we suggest an implementation of a process that would guide or help explain the diagnostic process to caregivers. It is clear that difficulty with finding a clinician can relate to dissatisfaction. Therefore, clarifying this process is of high importance. The findings suggest that, while waiting longer for a diagnosis of autism is typically associated with lower caregiver satisfaction, that these are not the most important elements to consider. In fact, it is possible that more time to prepare for and process the possibility of an autism diagnosis could be beneficial for some families. Instead, what is needed is assistance with navigating this process. Clear guidelines or personalized help could assist families in understanding the process, therefore making the wait (while still longer than anyone wants) more reasonable while simultaneously reducing the difficulties families face when attempting to find a clinician. Through this, caregiver satisfaction could increase which, in turn, could create lower levels of stress and mental health concerns as well as a quicker receipt of intervention services for the child. By finding and implementing ways of increasing caregiver satisfaction, this is offering the opportunity of providing better outcomes for children with autism.

References

Abbott, M., Bernard, P., & Forge, J. (2013). Communicating a diagnosis of Autism Spectrum Disorder-a qualitative study of parents' experiences. *Clinical Child Psychology and Psychiatry*, *18*(3), 370-382.

Allison, P. D. (2012). *Multiple regression: A primer*. Thousand Oaks, CA: Pine Forge Press.

American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders (3rd ed.)*. American Psychiatric Publishing.

American Psychiatric Association (APA). (1987). *Diagnostic and Statistical Manual of Mental Disorders, 3rd edition revised (DSM-III-R)*. Washington, DC: American Psychiatric Publishing.

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (5th ed.).* American Psychiatric Publishing.

American Psychiatric Association (2022). *Diagnostic and statistical manual of mental disorders 5th edition, text revision (DSM-5-TR).* American Psychiatric Publishing.

Andersson, G. W., Miniscalco, C., & Gillberg, C. (2014). Preschoolers assessed for autism: Parent and teacher experiences of the diagnostic process. *Research in Developmental Disabilities*, *35*(12), 3392-3402.

Antezana, L., Scarpa, A., Valdespino, A., Albright, J., & Richey, J. A. (2017). Rural trends in diagnosis and services for autism spectrum disorder. *Frontiers in Psychology*, *8*, 590.

Bent, C. A., Barbaro, J., & Dissanayake, C. (2020). Parents' experiences of the service pathway to an autism diagnosis for their child: What predicts an early diagnosis in Australia?. *Research in Developmental Disabilities*, *103*, 103689.

Bivarchi, F. A., Kehyayan, V., & Al-Kohji, S. M. (2021). Barriers to the early detection and intervention of children with autism spectrum disorders: A literature. *Journal of Nursing Education and Practice*, *11*(11).

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, *50*(3), 184-198.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, *17*(4), 208-215.

Brian, J. A., Zwaigenbaum, L., & Ip, A. (2019). Standards of diagnostic assessment for autism spectrum disorder. *Paediatrics & Child Health*, *24*(7), 444-451.

Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders*, *45*(10), 3244-3254.

Centers for Disease Control and Prevention. (2011). *Survey of pathways to diagnosis and services*. State and Local Area Integrated Telephone Survey. Retrieved July 3, 2022, from http://www.cdc.gov/nchs/slaits/spds.htm

Chawarska, K., Paul, R., Klin, A., Hannigen, S., Dichtel, L. E., & Volkmar, F. (2007). Parental recognition of developmental problems in toddlers with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *37*(1), 62-72.

Cohen, J. (2013). *Statistical power analysis for the behavioral sciences*. Academic Press.

Cohen, P., & Hesselbart, C. S. (1993). Demographic factors in the use of children's mental health services. *American Journal of Public Health*, *83*(1), 49-52.

Constantino, J. N., & Gruber, C. P. (2012). *Social Responsiveness Scale, Second Edition (SRS-2)*. Western Psychological Services.

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*(2), 153-162.

Da Paz, N. S., Siegel, B., Coccia, M. A., & Epel, E. S. (2018). Acceptance or despair? Maternal adjustment to having a child diagnosed with autism. *Journal of Autism and Developmental Disorders*, *48*(6), 1971-1981.

Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuiseppi, C., Nicholas, J. S., ... & Schieve, L. A. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a US cross-sectional study. *PloS one*, *5*(7), e11551.

Edwards, N. M., Kaiser, E., & Stapel-Wax, J. L. (2021). Investigating a "Wait and See" Mindset Among Pediatric Health Care Providers: Missed Opportunities to Refer Toddlers With Autism Spectrum Disorder to Part C Early Intervention. *Infants & Young Children*, *34*(4), 284-305.

Eggleston, M. J., Thabrew, H., Frampton, C. M., Eggleston, K. H., & Hennig, S. C. (2019). Obtaining an autism spectrum disorder diagnosis and supports: New Zealand parents' experiences. *Research in Autism Spectrum Disorders*, *62*, 18-25.

Farooq, A., & Ahmed, S. (2020). Sociocultural Barriers to Early Diagnosis of Autism Spectrum Disorder. *Life and Science*, *1*(4), 6-6.

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*, 175-191.

Fountain, C., King, M. D., & Bearman, P. S. (2011). Age of diagnosis for autism: individual and community factors across 10 birth cohorts. *Journal of Epidemiology & Community Health*, *65*(6), 503-510.

Gholipour, K., Ghiasi, A., Shahrokhi, H., Dadashi, Z., Javanmard, S., Tabatabaei, S. H., & Iezadi, S. (2022). Perceptions of the Professionals and Parents of Children with Autism Spectrum Disorders About Autism Services; A Qualitative Study. *Journal of Autism and Developmental Disorders*, 1-14.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis?. *Autism*, *10*(5), 439-451.

Gona, J. K., Newton, C. R., Rimba, K. K., Mapenzi, R., Kihara, M., Vijver, F. V., & Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *Rural and Remote Health*, *16*(2), 3517.

Gordon-Lipkin, E., Foster, J., & Peacock, G. (2016). Whittling down the wait time: exploring models to minimize the delay from initial concern to diagnosis and treatment of autism spectrum disorder. *Pediatric Clinics*, *63*(5), 851-859.

Green, J. G., McLaughlin, K. A., Alegría, M., Costello, E. J., Gruber, M. J., Hoagwood, K., ... & Kessler, R. C. (2013). School mental health resources and adolescent mental health service use. *Journal of the American Academy of Child & Adolescent Psychiatry*, *52*(5), 501-510.

Hastings, R. P., & Symes, M. D. (2002). Early intensive behavioral intervention for children with autism: Parental therapeutic self-efficacy. *Research in Developmental Disabilities*, *23*(5), 332-341.

Hedges, S. H., Shea, V., & Mesibov, G. B. (2018). Age-Related Issues in the Assessment of Autism Spectrum Disorder. *Assessment of Autism Spectrum Disorder*, *130*.

Hidalgo, N. J., McIntyre, L. L., & McWhirter, E. H. (2015). Sociodemographic differences in parental satisfaction with an autism spectrum disorder diagnosis. *Journal of Intellectual and Developmental Disability*, *40*(2), 147-155.

Hodges, H., Fealko, C., & Soares, N. (2020). Autism spectrum disorder: definition, epidemiology, causes, and clinical evaluation. *Translational Pediatrics*, *9*(1), S55.

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

Hyman, S. L., Levy, S. E., & Myers, S. M. (2020) Council on children with disabilities: Section on developmental and behavioral pediatrics. *Pediatrics, 145*(1). https://doi.org/10.1542/peds.2019-3447

IBM Corporation (2017). *IBM SPSS Statistics for Windows* (Version 25.0). IBM Corporation. https://www.ibm.com/analytics/spss-statistics-software

Jashar, D. T., Fein, D., Berry, L. N., Burke, J. D., Miller, L. E., Barton, M. L., & Dumont-Mathieu, T. (2019). Parental perceptions of a comprehensive diagnostic evaluation for toddlers at risk for autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *49*(5), 1763-1777.

Johnson, C. P. (2007). Myers SM; American Academy of Pediatrics Council on Children With Disabilities. Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, *120*(5), 1183-1215.

Johnson, N. L., Krueger, W., Jilek, E., & Haglund, K. (2020). Conversations With Health Care Providers and Parents Before Autism Diagnosis: A Qualitative Study. *Journal of Pediatric Health Care*, *34*(5), 453-461.

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

Koegel, L. K., Koegel, R. L., Ashbaugh, K., & Bradshaw, J. (2014). The importance of early identification and intervention for children with or at risk for autism spectrum disorders. *International Journal of Speech-Language Pathology*, *16*(1), 50-56.

Konstantareas, M. M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry*, *30*(3), 459-470.

Lappé, M., Lau, L., Dudovitz, R. N., Nelson, B. B., Karp, E. A., & Kuo, A. A. (2018). The diagnostic odyssey of autism spectrum disorder. *Pediatrics*, *141*(4), S272-S279.

Le Couteur, A. (2003). *National Autism Plan for Children (NAPC): Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autsim spectrum disorders*. National Autistic Society.

Lee, G. K., Lopata, C., Volker, M. A., Thomeer, M. L., Nida, R. E., Toomey, J. A., ... & Smerbeck, A. M. (2009). Health-related quality of life of parents of children with high-functioning autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *24*(4), 227-239.

Leff, P. T., & Walizer, E. H. (1992). The uncommon wisdom of parents at the moment of diagnosis. *Family Systems Medicine*, *10*(2), 147.

Locke, J., Ibanez, L. V., Posner, E., Frederick, L., Carpentier, P., & Stone, W. L. (2020). Parent perceptions about communicating with providers regarding early autism concerns. *Pediatrics*, *145*(1), S72-S80.

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*(6), 466-474.

Lord, C., & Bishop, S. L. (2010). Autism Spectrum Disorders: Diagnosis, Prevalence, and Services for Children and Families. *Society for Research in Child Development*, *24*(2).

Lord, C., Rutter, M., DiLavore, P.C., Risi, S., Gotham, K., & Bishop, S. L. (2012). *Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) Manual (Part I): Modules 1-4*. Western Psychological Services.

Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., ... & Shaw, K. A. (2023). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020. *MMWR Surveillance Summaries*, *72*(2), 1.

Makino, A., Hartman, L., King, G., Wong, P. Y., & Penner, M. (2021). Parent experiences of autism spectrum disorder diagnosis: A scoping review. *Review Journal of Autism and Developmental Disorders*, *8*(3), 267-284.

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism, 8*(4), 387–407. https://doi.org/10.1177/1362361304045213

Mandell, D. S., & Palmer, R. (2005). Differences among states in the identification of autistic spectrum disorders. *Archives of Pediatrics & Adolescent Medicine*, *159*(3), 266-269.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., ... & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, *99*(3), 493-498.

McCrimmon, A. W., & Gray, S. M. (2021). A systematic review of factors relating to parental satisfaction with the diagnostic process for autism spectrum disorder. *Review Journal of Autism and Developmental Disorders*, *8*(3), 334-349.

Mello, M. P., Goldman, S. E., Urbano, R. C., & Hodapp, R. M. (2016). Services for children with autism spectrum disorder: Comparing rural and non-rural communities. *Education and Training in Autism and Developmental Disabilities*, *51*(4), 355-365.

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *6*(1), 293-303.

Murphy, M. A., & Ruble, L. A. (2012). A comparative study of rurality and urbanicity on access to and satisfaction with services for children with autism spectrum disorders. *Rural Special Education Quarterly*, *31*(3), 3-11.

National Research Council. (2001). Educating children with autism. In C. Lord & J. P. McGee (Eds.), *Committee on Educational Interventions for Children with Autism* (pp. 211–229). Washington, DC: National Academy Press.

Nissenbaum, M. S., Tollefson, N., & Reese, R. M. (2002). The interpretative conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities*, *17*(1), 30-43.

Osborne, L., McHugh, A., Saunders, L., & Reed, J. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(6), 1092–1103.

Osborne, L. A., & Reed, P. (2010). Stress and self-perceived parenting behaviors of parents of children with autistic spectrum conditions. *Research in Autism Spectrum Disorders*, *4*(3), 405-414.

Oswald, D. P., Haworth, S. M., Mackenzie, B. K., & Willis, J. H. (2017). Parental report of the diagnostic process and outcome: ASD compared with other developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, *32*(2), 152-160.

Pattison, E., Ure, A., Mittiga, S. R., Williams, K., & Freeman, N. C. (2021). The feedback session of an autism assessment: a scoping review of clinical practice guideline recommendations. *Journal of Autism and Developmental Disorders*, *52*(4), 1-20.

Penner, M., Anagnostou, E., Andoni, L. Y., & Ungar, W. J. (2018). Systematic review of clinical guidance documents for autism spectrum disorder diagnostic assessment in select regions. *Autism*, *22*(5), 517-527.

Perry, A., Condillac, R. A., & Freeman, N. L. (2002). Best practices and practical strategies for assessment and diagnosis of autism. *Journal on Developmental Disabilities*, *9*(2), 61-75.

Petrocelli, J. V. (2003). Hierarchical multiple regression in counseling research: Common problems and possible remedies. *Measurement and Evaluation in Counseling and Development*, *36*(1), 9-22.

Plonsky, L., & Oswald, F. L. (2014). How big is “big”? Interpreting effect sizes in L2 research. *Language Learning*, *64*(4), 878-912.

Quine, L., & Pahl, J. (1986). First diagnosis of severe mental handicap: characteristics of unsatisfactory encounters between doctors and parents. *Social Science & Medicine*, *22*(1), 53-62.

Reed, P., & Osborne, L. A. (2012). Diagnostic practice and its impacts on parental health and child behaviour problems in autism spectrum disorders. *Archives of Disease in Childhood*, *97*(10), 927-931.

Remington, B., Hastings, R. P., Kovshoff, H., Degli Espinosa, F., Jahr, E., Brown, T., ... & Ward, N. (2007). Early intensive behavioral intervention: Outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation*, *112*(6), 418-438.

Rivard, M., Lépine, A., Mercier, C., & Morin, M. (2015). Quality determinants of services for parents of young children with autism spectrum disorders. *Journal of Child and Family Studies*, *24*(8), 2388-2397.

Robins, D. L., Fein, D., & Barton, M. (2009). *Modified Checklist for Autism in Toddlers, Revised, with Follow-up (M-CHAT-R/F)*. Self-published.

Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: from Kanner to DSM-III to DSM-5 and beyond. *Journal of Autism and Developmental Disorders*, *51*(12), 4253-4270.

Rutter, M. (2005). Incidence of autism spectrum disorders: changes over time and their meaning. *Acta Paediatrica*, *94*(1), 2-15.

Rutter, M., Le Couteur, A., & Lord, C. (2003). *Autism Diagnostic Interview – Revised, Manual*. Western Psychological Services.

Ryan, S., & Salisbury, H. (2012). 'You know what boys are like': pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice*, *62*(598), e378-e383.

Sansosti, F. J., Lavik, K. B., & Sansosti, J. M. (2012). Family experiences through the autism diagnostic process. *Focus on Autism and Other Developmental Disabilities*, *27*(2), 81-92.

Schopler, E., Van Bourgondien, M. E., Wellman, G. J., & Love, S. R. (2010). *Childhood Autism Rating Scale – 2nd Edition.* Western Psychological Services.

Shah, K. (2001). What do medical students know about autism?. *Autism*, *5*(2), 127-133.

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*(1), 7.

Shaw, K. A., Maenner, M. J., & Baio, J. (2020). Early identification of autism spectrum disorder among children aged 4 years—Early Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2016. *MMWR Surveillance Summaries*, *69*(3), 1.

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, *28*(1), 9-22.

Singh, R. L., Moody, E. J., Rigles, B., & Smith, E. B. (2019). What it takes to raise children with autism in a rural state. *Advances in Neurodevelopmental Disorders*, *3*(1), 17-28.

Skellern, C., Mcdowell, M., & Schluter, P. (2005). Diagnosis of autistic spectrum disorders in Queensland: Variations in practice. *Journal of Paediatrics and Child Health, 41*, 413-8. https://doi.org/10.1111/j.1440-1754.2005.00667.x.

Slade, E. (2003). The relationship between school characteristics and the availability of mental health and related health services in middle and high schools in the United States. *The Journal of Behavioral Health Services & Research*, *30*(4), 382-392.

Smith-Young, J., Chafe, R., & Audas, R. (2020). “Managing the wait”: Parents’ experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with autism spectrum disorder. *Health Services Insights*, *13*.

Strasser, R. (2003). Rural health around the world: challenges and solutions. *Family Practice*, *20*(4), 457-463.

Taylor, R. (1990). Interpretation of the correlation coefficient: a basic review. *Journal of Diagnostic Medical Sonography*, *6*(1), 35-39.

Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M. (2012). The association of autism diagnosis with socioeconomic status. *Autism*, *16*(2), 201-213.

Vassos, E., Agerbo, E., Mors, O., & Pedersen, C. B. (2016). Urban–rural differences in incidence rates of psychiatric disorders in Denmark. *The British Journal of Psychiatry*, *208*(5), 435-440.

Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., & State, M. (2014). Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *53*(2), 237-257.

Wan, Y., Hu, Q., Li, T., Jiang, L., Du, Y., Feng, L., ... & Li, C. (2013). Prevalence of autism spectrum disorders among children in China: a systematic review. *Shanghai Archives of Psychiatry*, *25*(2), 70.

Ward, S. L., Sullivan, K. A., & Gilmore, L. (2016). Practitioner Perceptions of the Assessment and Diagnosis of Autism in Australia. *Australian Psychologist, 51*(4), 272-279. https://doi.org/10.1111/ap.12211

Webb, S. J., Jones, E. J., Kelly, J., & Dawson, G. (2014). The motivation for very early intervention for infants at high risk for autism spectrum disorders. *International Journal of Speech-Language Pathology*, *16*(1), 36-42.

Whitaker, P. (2002). Supporting families of preschool children with autism: What parents want and what helps. *Autism*, *6*(4), 411-426.

White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review*, *29*(3), 216–229.

Williams, J. G., Higgins, J. P., & Brayne, C. E. (2006). Systematic review of prevalence studies of autism spectrum disorders. *Archives of Disease in Childhood*, *91*(1), 8-15.

Woolley, H., Stein, A., Forrest, G. C., & Baum, J. D. (1989). Imparting the diagnosis of life threatening illness in children. *British Medical Journal*, *298*(6688), 1623-1626.

Zuckerman, K. E., Lindly, O. J., & Sinche, B. K. (2015). Parental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. *The Journal of Pediatrics*, *166*(6), 1431-1439.

Zuckerman, K. E., Sinche, B., Mejia, A., Cobian, M., Becker, T., & Nicolaidis, C. (2014). Latino parents' perspectives on barriers to autism diagnosis. *Academic Pediatrics*, *14*(3), 301-308.

Appendix 1

Q1.1 Before you proceed to the survey, please complete the CAPTCHA below.

Q1.2 **Informed Consent to Participate** Dear Caregiver: We are conducting a research study designed to evaluate experiences and satisfaction with the autism diagnostic process. As a caregiver of a child who was diagnosed with autism spectrum disorder (ASD)/Asperger's syndrome before the age of 18, you are invited to complete a web-based questionnaire regarding your experience with the evaluation process of your child. This survey is expected to take approximately 15-20 minutes to complete. You will be asked questions regarding your demographic information, the evaluation process (e.g., how the testing was completed), and the feedback process (i.e., how you were informed about the diagnosis). We appreciate your time and responses, as these will give us a better understanding of caregiver's experiences and satisfaction with the autism diagnostic process.
PARTICIPATION: Your participation in this survey is completely voluntary and anonymous. You may refuse to take part in the research or exit the survey at any time without penalty. You are free to decline to answer any particular question you do not wish to answer for any reason.
BENEFITS: Upon completion of the survey, you may enter a drawing for a $50 Amazon gift card (odds of winning are 1 in 25). RISKS: The possible risks or discomforts of the study are minimal. Some participants may feel distressed when answering questions about their child.
CONFIDENTIALITY: Your answers will be collected using Qualtrics, where data will be stored in a password-protected electronic format. Qualtrics does not collect identifying information such as your name or email address (except where discussed above), and therefore, your responses will remain anonymous. No one will be able to identify you or your answers, and no one will know whether or not you participated in the study. Results from this study may be presented at professional meetings or published in professional publications. However, responses are anonymous and reported in a group format.
CONTACT:
If you have questions at any time about the study or the procedures, you may contact Dr. Robert Rieske at riesrobe@isu.edu or via phone at 208-282-4192.
If you feel you have not been treated according to the descriptions in this form, that your rights as a research participant have not been honored during the course of this project, or you have any questions, concerns, or complaints that you wish to address with someone other than the investigator, you may contact the ISU Human Subjects Committee at humsubj@isu.edu or by calling (208) 393-2179.
ELECTRONIC CONSENT: Please select your choice below. You may print a copy of this consent form for your records. Clicking on the "Agree" button indicates that You have read the above information

- You voluntarily agree to participate
- You are 18 years of age or older
- You are a caregiver of at least one child that was diagnosed with autism spectrum disorder (ASD) or Asperger's syndrome prior to age of 18 years
- You have been present at/part of the autism evaluation process
- You are fluent in written English

- You are located in the United States of America or US territories

  ○ Agree

  ○ Disagree

Q1.3 Are you 18 years of age or older?

○ Yes

○ No

Q1.4 Are you fluent in written English?

○ Yes

○ No

Q1.5 Are you a caregiver of a child who was diagnosed with Autism/Asperger's syndrome/ASD?

○ Yes

○ No

Q1.6
If you are a caregiver of more than one child that was diagnosed with autism/Asperger's syndrome/ASD, please answer the following questions thinking about your 1st experience with autism evaluation.

Q1.7 **Were you present at/part of the diagnostic evaluation process?** (This may include but is not limited to some of the following activities: bringing child for the evaluation, communicating with the clinician, observing the testing, completing questionnaires, receiving the child's diagnosis, reading the evaluation report.)

○ Yes

○ No

Q1.8 Was the child's diagnostic evaluation completed within the United States or US territories?

- ○ Yes
- ○ No

Q1.9 What year was the diagnostic evaluation completed?

_____

Q1.10 How old was the child at the time of receiving the autism diagnosis? (in years)

Q1.11 What is your child's gender?

- ○ Male
- ○ Female
- ○ Other, please specify: _____

Q1.12 What is your child's race? (Check all that apply)

- ☐ White/Caucasian
- ☐ Black or African-American
- ☐ Native American or Alaska Native
- ☐ Asian
- ☐ Hawaiian Native or other Pacific Islander
- ☐ Other, please specify: _____

Q1.13 What is your child's ethnicity?

- ○ Hispanic or Latino
- ○ Not Hispanic or Latino
- ○ Other, please specify: _____

Q1.14 What is your relationship to your child

- ○ Biological Mother
- ○ Biological Father
- ○ Adoptive/Foster Mother
- ○ Adoptive/Foster Father
- ○ Stepmother
- ○ Stepfather
- ○ Other, please specify: _____

Q1.15 What is your gender?

- ○ Male
- ○ Female
- ○ Other, please specify: _____

Q1.16 Which race(s) do you identify with? (Check all that apply)

- ☐ White/Caucasian
- ☐ Black or African-American
- ☐ Native American or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other, please specify: _____

Q1.17 Which ethnicity do you most identify with?

- ○ Hispanic or Latino
- ○ Not Hispanic or Latino
- ○ Other, please specify: _____

Q1.19
For the following questions, think back to the time in which you received your child's diagnosis.

Q1.20 How old were you **at the time of receiving your child's diagnosis?**
_____

Q1.21 What was the highest degree or level of education you had completed **at the time of receiving your child's diagnosis?**

- ○ Less than high school
- ○ High school graduate
- ○ Some college
- ○ 2-year degree
- ○ 4-year degree
- ○ Professional degree (e.g., D.C.;M.D.;D.M.A.;D.V.M.;Pharm.D.)
- ○ Doctorate (e.g., PhD)

Q1.22 What was your total household income before taxes **at the time of receiving your child's diagnosis?**

- ○ Less than $25,000
- ○ $25,000 to $34,999
- ○ $35,000 to $49,999
- ○ $50,000 to $74,999
- ○ $75,000 to $99,999

- ○ $100,000 to $149,999
- ○ $150,000 or more

Q1.23 How often were finances a stressor for you **at the time of receiving your child's diagnosis?**

- ○ Never
- ○ Sometimes
- ○ About half the time
- ○ Most of the time
- ○ Always

Q1.24 Including yourself and all children, how many people lived in your household **at the time of receiving your child's diagnosis?**

_____

Q1.25 What was your home ZIP code **at the time of receiving your child's diagnosis?**

_____

Q2.1 At what age (in years) did you first notice symptoms of autism in your child?

- ○ Before 1
- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ 7
- ○ 8

- ○ 9
- ○ 10
- ○ 11
- ○ 12
- ○ 13
- ○ 14
- ○ 15
- ○ 16
- ○ 17
- ○ 18+

Q2.6 How difficult was it to find a clinician who would complete the evaluation?

- ○ Extremely easy
- ○ Somewhat easy
- ○ Neither easy nor difficult
- ○ Somewhat difficult
- ○ Extremely difficult

Q2.8 From the time you first contacted the clinician, how many months did you have to wait for the evaluation? _____

Q2.9 Do you believe that the wait time for the diagnostic evaluation was reasonable?

- ○ Strongly agree
- ○ Somewhat agree
- ○ Neither agree nor disagree

○ Somewhat disagree

○ Strongly disagree

Q3.1
The following questions will be asking about the autism evaluation that you completed with your child. We encourage you to refer back to the assessment report or other sources of information (e.g., notes taken during the evaluation) if possible. Doing so can make completion of the survey easier and help with recollection.

Q3.6 Did you have to travel for the evaluation outside of your immediate living area?

○ Yes

○ No

Q3.7 How long did the travel for the evaluation take you?

○ Less than 1 hour

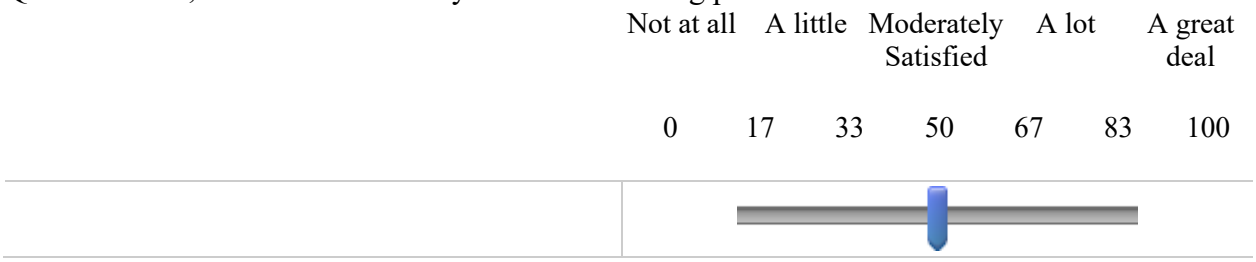
○ 1-2 hours

○ 3-4 hours

○ 5+ hours

Q3.8
Now, we will be asking you about the testing portion of your evaluation. This may include an interview with you or your child, filling out rating forms about your child, testing of your child, etc. This <u>does not</u> include the "Feedback Session" in which you received your child's diagnosis after testing. We will ask questions about the "Feedback Session" later.

Q3.19 Overall, how satisfied were you with the testing process?



Q5.9 Do you have any additional information about your experience with the autism evaluation process (including pre-evaluation, testing, feedback, and post-evaluation) that you would like to share with us?

_____

_____
_____
_____
_____

Q6.1
Thank you for your completing our survey! We appreciate your time and insight. To enter the raffle for one of the $50 Amazon gift cards, please click on the link below. The link will redirect you to a different website where you will be prompted to type your email address. Doing so allows us to keep your identity anonymous by not directly associating your email address with your responses on this survey.

For more resources about autism, feel free to visit the following websites:
https://nationalautismassociation.org
https://autisticadvocacy.org
https://www.autism-society.org
https://www.autismspeaks.org

Appendix 2

Variable Name	Origin Item	Definition and Additional Information
Caregiver Satisfaction	Q3.19	How satisfied a caregiver was with the autism evaluation process on a scale of 0-100 with 100 being "a great deal".
Time Since Noticing Symptoms	Q1.10-Q2.1	How long since the caregiver first noticed autism symptoms to when the child received their autism diagnosis. Reported in years. Calculated by subtracting the age of the child when symptoms of autism were noticed) from the age at diagnosis.
Time on Wait List	Q2.8	How long the child was on a wait list for an autism evaluation. Reported in months.
Reasonability of Wait Time	Q2.9	How reasonable the caregiver rated the wait for an evaluation. Rated on a 5-point Likert scale with 5 being the least reasonable.
Financial Stress	Q1.23	How often the caregiver reported finances being a stressor at the time of evaluation. Rated on a 5-point Likert scale with 5 being "always".
Education	Q1.21	The highest degree of education a caregiver received. Participants selected a response of type of degree which was then coded to represent a 7-point Likert scale with higher values equivalent to more education.
Travel Time	Q3.6, Q3.7	How long caregivers reported traveling to receive an evaluation for their child. Participants first selected whether they traveled outside of their immediate living area. If they selected yes, they then selected how long (in hours) they traveled from 4 options ranging from less than an hour to 5+ hours.
Difficulty Finding a Clinician	Q2.6	Caregiver's perception of how difficult it was to find a clinician who would complete an evaluation for their child. This was rated on a 5-point Likert scale with 5 being "extremely difficult".
Rurality	Q1.25	How rural their living location was based off their ZIP code at the time of the evaluation. The process for creating this code is outlined in Hypotheses section. Codes were based on a a 6-point Likert scale with higher scores corresponding with being more rural.
Combined Barrier Score	N/A	The sum of all the barrier variables after each variable was given equal weight and the inverse of education was used.
Interaction: Time on a Wait List	N/A	An interaction term that included reasonability of wait time X time on a wait list.
Interaction: Total Barrier	N/A	An interaction term that included reasonability of wait time X the combined barrier score.