Understanding Barriers to Healthcare for Children with Autism Spectrum Disorder: A Preliminary Measure Validation Study

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Abstract

Autism spectrum disorder (ASD) is associated with a variety of physical, mental, and behavioral healthcare needs. However, parents of autistic children consistently report difficulty accessing necessary services, and no instrument has been validated to assess and quantify these barriers for autistic children. The current study aims to adapt and validate the Barriers to Care Questionnaire (BCQ), a pre-existing measure of barriers to healthcare for children with specific healthcare needs, for families of autistic children. The BCQ and theoretically related measures were collected from 242 parents (117 parents of autistic children, 125 parents of non-autistic children). Cronbach's alpha statistics (ranging from 0.87 to 0.96 for BCQ subscales) provide evidence of reliability for the BCQ. The BCQ subscales were correlated with unmet treatment need, treatment experiences, and theoretically related variables at the child, parent, and family level, providing evidence of convergent validity. Correlations were of low magnitude with theoretically unrelated variables (parent personality and socially desirable responding), suggesting preliminary evidence of discriminant validity. Additionally, the BCQ subscales predicted a significant amount of variance in unmet need and treatment experiences over and above other predictors for autistic youth, indicating incremental validity. Parents of autistic children reported significantly more barriers to care across all subscales of the BCQ than parents of non-autistic children, and the highest average item score was on the "skills" subscale, which measures difficulties with navigating the healthcare system. Results support that the BCQ can be used among autistic youth, and suggest the critical need for family-centered supports and provider education in order to ameliorate barriers to healthcare for autistic children.

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General Audience Abstract

Autism spectrum disorder (ASD) is related to many physical, mental, and behavioral healthcare needs. However, parents of autistic children state that it is often hard to receive healthcare when their child needs it. No questionnaire exists to measure barriers that make getting healthcare harder for autistic children. Our study adapted the Barriers to Care Questionnaire (BCQ) for families of autistic children. The BCQ and related questionnaires were filled out by 242 parents (117 parents of autistic children, 125 parents of non-autistic children). The BCQ reliably and consistently measured barriers to care in these groups. The BCQ subscales were associated with unmet treatment need, treatment experiences, and other related variables at the child, parent, and family level. The questionnaire was less strongly related to variables that we would not expect to be associated with barriers to care, like personality and social desirability. Also, the BCQ subscales predicted healthcare experiences even when accounting for other factors that might impact access to care. Parents of autistic children reported more barriers to care on all subscales of the BCQ than parents of non-autistic children, and the highest average item score was on the "skills" subscale, which measures difficulties with navigating the healthcare system. Results show that the BCQ can be used among autistic youth, and suggest the need for family-centered supports and provider education in order to improve barriers to healthcare for autistic children.

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Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social communication difficulties as well as restrictive and repetitive behaviors (Diagnostic and Statistical Manual of Mental Disorders, 5th edition [DSM-5]). Although autism was first recognized by our diagnostic system in the DSM-III in 1980, it was originally conceptualized as a rare childhood disorder. However, in recent decades, reported prevalence rates of ASD diagnoses have increased rapidly, with the most current Centers for Disease Control rates estimating that 1 in 54 children are on the autism spectrum (Maenner et al., 2020). Given this steady increase in ASD prevalence rates, understanding how to best serve autistic children and their families has become a critical public health priority.

Healthcare Needs in ASD

Autistic individuals experience a wide variety of healthcare needs throughout their lifespan, and timely service delivery is critical when considering care utilization in ASD. A preponderance of evidence suggests that early identification and intervention improve outcomes for autistic children (e.g. Zwaigenbaum et al., 2015a; Zwaigenbaum et al., 2015b). However, despite the importance of early identification and treatment, many families are not able to access these services at all or in a timely manner, perhaps because early diagnostic assessment and intervention approaches are often time- and cost-intensive. ASD is typically suspected by parents prior to their child's second birthday (Herlihy, Knoch, Vibert, & Fein, 2015), but the average age of diagnosis exceeds four years (Maenner et al., 2020). The gap between first parental concern and diagnosis is even more pronounced in families from rural areas, families of low socioeconomic status, and non-White identified families (Mandell, Novak, & Zubritsky, 2005; Mandell, Listerud, Levy, & Pinto-Martin, 2002). Age of service entry is also impacted by

demographic factors; one study found that children from households with a primary language other than English entered classroom-based services later (Nguyen et al., 2016). This phenomenon speaks to a broader problem for families of autistic children: barriers to services are widespread and are sometimes insurmountable.

In addition to the need for autism-specific evaluation and intervention, autistic children frequently experience a number of medical and psychiatric co-occurring diagnoses. The majority of autistic children and adolescents experience at least one co-occurring mental health condition, such as an anxiety disorder, attention deficit/hyperactivity disorder (ADHD), and externalizing problems such as oppositional defiant disorder (Simonoff, Pickles, Charman, Chandler, Loucas, & Baird, 2008; van Steensel, Bögels, & de Bruin, 2013). Additionally, about one-third of autistic individuals also have an intellectual disability (Maenner et al., 2020). Furthermore, autistic people are likely to experience significantly more physical health issues than non-autistic people. In particular, autistic individuals have high rates of co-occurring gastrointestinal issues, epilepsy, sleep problems, and metabolic problems, among other concerns (Bauman, 2010).

Given the need for ASD-related services, as well as the wide array of health issues for which they are at risk, autistic individuals often need to utilize a significant amount of healthcare. Research has estimated that autistic children attend roughly twice as many primary care medical appointments as their non-autistic counterparts, and that they attend an average of 2.2 psychiatric visits annually, compared to 0.3 in children without ASD (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). In a study of emergency department (ED) utilization, autistic adolescents had higher ED costs than adolescents with intellectual disability alone or a non-autistic comparison group, and frequently presented to the ED with psychiatric concerns (Hand, Boan, Bradley, Charles, & Carpenter, 2019). Furthermore, autistic children attend substantially

more specialty appointments than non-autistic children, including visits for speech and occupational therapy, social skills training, and psychotherapy (Cummings et al., 2016).

Access to Healthcare in Autism

Despite the clearly increased need for mental and physical healthcare services for autistic children, parents frequently report difficulty in accessing these services. A 2014 analysis of national survey data found that 55% of parents of autistic children reported challenges in accessing services, which was greater than the proportion of parents of children with other developmental disabilities or mental health conditions (Vohra, Madhavan, Sambamoorthi & St Peter, 2014). Similarly, children with developmental disabilities are significantly less likely than children with physical disabilities to have access to services such as a medical home, healthcare transition services, and community-based services (Cheak-Zamora & Thullen, 2017). This result is repeatedly found in the literature; Chiri and Warfield (2012) found that nearly 18% of parents of autistic children reported that their children had unmet needs in therapy or mental health domains; these families experienced obstacles so significant that they ultimately resulted in services being entirely inaccessible. Again, the authors found that families of autistic children reported significantly more difficulty than families of children with other specific healthcare needs. In a similar finding, when examining national survey data, Benevides, Carretta and Lane (2016) found that autistic children were 1.4 times more likely to have an unmet need for therapy services than children with other specific healthcare needs.

Unfortunately, families from racial or ethnic minority-identifying backgrounds, of low socioeconomic status (SES), and from rural communities are likely to report greater barriers to services and less service utilization. In one study of North Carolina families, lower SES households, racial and ethnic minority-identifying families, and those from non-metropolitan

residences reported less service use (Thomas, Ellis, McLaurin, Daniels, & Morrisey, 2007). In addition, using national survey data, Liptak et al. found that Black and Latinx families had decreased access to services (Liptak et al., 2008). This holds true in qualitative interviews as well; parents of Latinx children also report poor access to diagnostic services as a result of a variety of factors, which are reviewed below (Zuckerman, Sinche, Mejia, Cobian, Becker, & Nicolaidis, 2013). Additionally, a scoping review found that racial disparities in access to medical care for autistic children were present in the majority of studies reviewed (Bishop-Fitzpatrick & Kind, 2017).

Lower SES families are also less likely to have access to services (Liptak et al., 2008). In an open-ended survey format, parents from lower SES households reported structural barriers to receiving healthcare for their children (Pickard & Ingersoll, 2016). In this study, lower SES was associated with increased likelihood of reporting scheduling conflicts and level of autism service knowledge as barriers to care. Interestingly, parents of lower and higher SES reported cost as a barrier at similar rates. Other demographic variables, such as geographic location, are also likely to play a role in barriers to access. Families in rural areas report having diminished access to diagnostic and intervention services, resulting in a longer time-to-diagnosis and less identification of ASD overall (Antezana, Scarpa, Valdespino, Albright & Richey, 2017). Rural families are likely to have difficulty finding providers within feasible traveling distance, which may reflect one of the most significant barriers for this group.

Approaches to Measuring Healthcare Access and Barriers to Care

Despite the clear evidence of difficulty in accessing care, and parental report of systemic barriers to healthcare utilization, little is known about what specific barriers families face in their attempts to access care for their children. Research in this field has predominantly been gathered

using one of two methods: large, national survey cohorts and open-ended/qualitative surveys/interviews (see Table 1 for a summary of key measurement approaches in the extant literature). Each of these methods have their advantages.

First, national survey research has the significant advantage of rigorous data collection from large, nationally representative samples (see Table 1). Most frequently, this research has utilized epidemiological survey datasets such as the National Survey of Children with Special Healthcare Needs, which covers a wide range of topics for children with a variety of healthcare needs (e.g. Chiri & Warfield, 2012). These surveys typically ask caregivers about whether they are able to access needed care. However, they do not allow for families to share detailed and nuanced information about what barriers have prevented access (e.g. Benevides, Carretta, & Lane, 2016; Skinner & Slifkin, 2007).

Second, open-ended and qualitative research allows for families to provide specific details about their healthcare experiences which can guide future research and policy efforts (See Table 1). Studies using these methods have identified several barriers that families have reported when accessing healthcare for their autistic children. In general, parents report that the service delivery system is difficult to navigate, and they identify finances, lack of information and long waitlists as major barriers to service use (Pickard & Ingersoll, 2016). In the context of community mental health, parents expressed in qualitative interviews that a lack of access to specialized autism service providers is a barrier to adequate care, as are frequent changes in eligibility criteria for services (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2012). Additionally, parents of autistic children are more likely to be told that their child might "grow out of" their symptoms as opposed to children with other developmental disabilities (Oswald,

Haworth, Mackenzie, & Willis, 2017), which may delay diagnosis and subsequent enrollment in services.

Families from traditionally marginalized groups tend to report additional structural problems that serve as barriers to care. For example, parents of low SES are more likely to report that transportation issues and their work schedules prevent them from accessing care (Pickard & Ingersoll, 2016). Furthermore, in a study of Black identifying female caregivers of autistic children, several specific barriers emerged. Participants reported provider-level factors such as healthcare providers not taking their concerns seriously, racism and racial bias, and poor interactions between providers and caregivers. Caregivers also reported custody issues and community stigma as barriers to receiving services (Dababnah, Shaia, Campion, & Nichols, 2018). In a focus group study of Latinx identifying parents, similar barriers of community stigma and provider dismissal of concerns were reported, as well as difficulty accessing care due to financial concerns, language barriers, and a confusing and slow diagnostic process (Zuckerman et al., 2014).

Relatedly, similar qualitative research has examined the healthcare experiences of autistic adults, which may be instructive when considering what specific barriers families and children face in accessing care. Raymaker and colleagues (2017) developed a measure to investigate barriers to healthcare for autistic adults. They found that autistic adults experience greater barriers to care than non-autistic adults. The most prominent barriers that autistic individuals cited were fear or anxiety, difficulties with information processing, concerns about cost, and sensory and communication issues. In a qualitative study, Dern and Sappok (2016) generated a similar list of healthcare barriers for autistic adults, and noted that sensory and communication issues were particularly problematic barriers. Furthermore, Nicolaidis and colleagues (2015)

interviewed autistic adults as well as providers and found that provider-level factors, such as accessible communication, and system-level factors, such as navigating a complex healthcare system, also played a role in the healthcare experiences of autistic adults. Autistic adults also report difficulty accessing care for mental health services, with one significant barrier being provider-level problems such as lack of autism knowledge (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2019).

Despite the strengths of the existing literature in this area (see Table 1), neither epidemiological survey datasets nor existing qualitative surveys/interviews offers an opportunity for families to provide detailed, quantitative, standardized self-report regarding the barriers they experience when seeking care for their child. Although several questionnaires exist for measuring barriers to care, most are designed for adult populations or have not been validated in a sample of caregivers of autistic children. As a result, a clear picture has yet to emerge regarding which specific healthcare barriers are most problematic. The development of a valid and psychometrically sound, open-access, and free caregiver-report measure would allow for easier replication of findings across studies, which could in turn clarify our understanding of barriers to ASD care and guide future approaches to minimize such barriers.

Barriers to Care Questionnaire

One measure that has previously been used to evaluate barriers to care for children and families is the Barriers to Care Questionnaire (BCQ, Seid, Sobo, Gelhard, & Varni 2004). The BCQ is a 39-item questionnaire that was designed to measure factors that interfere with the receipt of healthcare for children with special healthcare needs. The BCQ was developed within an ecological theoretical model of healthcare, suggesting that certain child, family, provider, and system-level factors play a role in healthcare access and quality (e.g. Aday, 1994; American

Academy of Pediatrics, 1999; Kuang, Johnson, Schetzina, Kozinetz, & Wood, D. L., 2017). Therefore, the measure considers that barriers to receiving care can occur at any of these levels (Seid et al., 2004).

The BCQ consists of five subscales: (1) skills (e.g. "providers speak in a way that is too technical or medical"), (2) marginalization (e.g., "getting the provider to listen to you"), (3) expectations (e.g. "worrying that providers will not do what is right for your child"), (4) knowledge/beliefs (e.g. "providers that have different ideas about mental health than you do"), and (5) pragmatics (e.g. "the cost of appointments"). Item development for the measure occurred after the authors held a number of focus groups with English and Spanish speaking families of children with chronic health conditions. It was originally validated with children at a rheumatology clinic as well as a hematology/oncology clinic, with criterion validity and interitem correlations used as the chief validation strategies. The measure has since been validated for use in children with asthma (Seid et al., 2009). However, the questionnaire has not been tested for use in an autism population to date, and thus may not cover the unique challenges facing families of autistic children. Therefore, the current study aims to validate the use of an expanded form of the BCQ among caregivers of autistic and non-autistic youth (see Table 3 for original and expanded items).

To apply the BCQ to caregivers of youth with and without ASD, the expanded version will contain additional content identified as relevant for the autistic community from the prior qualitative research in this area (see Table 2 for original and added BCQ items). For example, items related to stigma and difficulty navigating the service system were added, as these are consistently identified as barriers by parents in the existing research (e.g. Dababnah et al., 2018; Zuckerman et al., 2014). In addition, an item related to sensory difficulties was added as this has

been reported as a barrier to healthcare by autistic adults (Raymaker et al., 2017). Finally, existing BCQ items related to marginalization and health insurance problems were expanded to reflect the variety of potential challenges in these areas for parents of autistic children. As a critical aspect of psychometric validation, the expanded form of the BCQ will be validated against theoretically related indicators, as described below (see also Table 3). Indicators are considered at multiple ecological levels, including family-level factors, caregiver factors, and child factors, consistent with ecological perspectives on healthcare access (e.g. Aday, 1994; American Academy of Pediatrics, 1999; Kuang, 2017).

Construct Validity: Correlates of Barriers to Care

Socio-demographic factors. Although little is known about the specific barriers to care that families find most problematic, there is a burgeoning body of evidence regarding factors that are likely to be associated with experiencing more difficulties accessing care. As discussed above, a variety of demographic variables are associated with barriers to care. Parents who identify with racial or ethnic minority identities tend to experience more difficulty accessing services than White parents, and families of low SES also experience greater barriers. Families living in geographically isolated areas also report more difficulty accessing services.

Family-level factors. There is additional evidence in the literature describing the association between barriers to care and family functioning. A survey of parents on a waitlist for government-funded applied behavioral analysis services found that family quality of life was significantly positively correlated with local opportunities for their health needs to be met. Conversely, there was a significant negative correlation between family quality of life and having unmet disability-related healthcare needs (Jones, Bremer, & Lloyd, 2017). For children with a range of developmental disabilities, receipt of family-centered care is a strong predictor of

family quality of life (Davis & Gavidia-Payne, 2009), which may suggest that lack of such care is associated with lower family quality of life. Furthermore, in a survey of White and Latinx caregivers of autistic children, unmet service needs were associated with higher levels of family burden, even when controlling for ethnicity, child behavior problems, and other variables (Lopez, Reed, & Magaña, 2019).

Caregiver factors.

Parental psychopathology. Additional literature supports an association between parent psychopathology and barriers to care. The literature clearly supports an association between having a child with autism in general and increased levels of parental mental health difficulties (Piven et al., 1991; Hastings, Kovshoff, Ward, Degli Espinosa, Brown, & Remington, 2005; Machado Jr., Celestino, Serra, Caron & Pondé, 2016). However, this is particularly pronounced in parents who also have difficulty accessing care for their children. In a study of unmet service needs among transition-age adolescents, parental anxiety was significantly correlated with unmet care needs (Taylor & Henninger, 2015). Additionally, a qualitative U.K. study of mothers of autistic children with co-occurring mental health conditions found that managing their child's mental health concerns led to feelings of "aloneness" in navigating care systems, and all of the mothers reported that they had waited too long to receive care for their child (Jackson, Keville, & Ludlow, 2020). In addition to these findings, it is well established in the literature that parent anxiety and depression decrease after children receive services (Tarver et al., 2019). Therefore, it is likely that difficulty accessing services is associated with higher parental mental health concerns.

Parent personality. Although barriers to care are clearly associated with a number of parental factors, there are also constructs that we would not expect to be highly related to

difficulty accessing care. One such construct is parent personality. The five-factor personality structure supported by much of the personality literature, known as the "Big Five", includes the following traits: open-mindedness, conscientiousness, extraversion, agreeableness, and neuroticism or negative emotionality. These personality characteristics are considered relatively stable over time (Conley, 1985; McCrae & Costa, 1994), and any changes in personality traits are not generally associated with adverse life events (Cobb-Clark & Schurer, 2012). Thus, it is unlikely that barriers to care, which represent system- and provider-level challenges, are related strongly to parental personality traits. Therefore, we consider parent personality in this sample with the goal of demonstrating discriminant validity (e.g., showing that the BCQ subscales are only weakly or moderately correlated with personality).

Parent stress. Unlike parent psychopathology and family factors, research on parental stress and barriers to care is somewhat mixed. Some studies and reviews have found that families with higher levels of stress are more likely to access services (Thomas et al., 2007; Wilson, Hamilton, Whelan, & Pilkington, 2018). However, other research has suggested a different association; one study found that that encountering barriers to care in the months after a child's autism diagnosis was associated with increased maternal stress over time (Petrongolo, 2014). Another study found that parents of autistic children identified attaining services as one of their top ten sources of stress, although other concerns such as child behavior, the future, education, and relationships were bigger stressors (Tehee, Honan, & Hevey, 2009). Additionally, for parents of autistic girls, receiving fewer services have been associated with higher levels of parent stress (Zamora, Harley, Green, Smith & Kipke, 2014). Furthermore, meta-analytic research indicates that receiving autism services is associated with a decrease in parenting stress, as well as a decrease in child disruptive behavior (Tarver et al., 2019). Although the literature

suggests that an association between exists access to care and parent stress, the direction of the association is not yet clear.

In addition to overall parent stress, financial stress is also an important construct to consider when examining access to care. Factors such as income and insurance status are predictive of barriers (e.g., Thomas et al., 2007); however, it can be difficult to generalize income indicators across household sizes, geographic locations, and so on. Therefore, the construct of financial stress allows families to self-report on whether they are able to cover their expenses and whether they have difficulty making ends meet. Combined with income data, financial stress information helps to provide a clearer picture of SES.

Parental autism knowledge. At least one study has suggested that higher levels of autism service knowledge may be associated with lower barriers to care (Pickard & Ingersoll, 2016). This is consistent with the idea that the autism service delivery system is complex and can be difficult to navigate, and many parents report that challenges with this system act as a barrier to care (e.g. Zuckerman et al., 2014). Therefore, increased autism knowledge may lead to smoother interactions with the service delivery system, and ultimately lead to fewer barriers to care overall.

Socially desirable responding. As an additional measure of discriminant validity, we will consider socially desirable responding. Social desirability bias refers to an individual's tendency to answer items based on what they perceive to be the most "desirable" response, rather than their true opinion or perception of a particular item (Grimm, 2010). Given that barriers to care are not likely to reflect poorly on the individual when reported, it is predicted that social desirability will not be strongly correlated with barriers to care.

Child-level factors.

Adverse childhood experiences. Research has suggested that children who are exposed to adverse childhood experiences (ACEs) have higher unmet healthcare needs (Berg, Shiu, Feinstein, Msall, & Acharya, 2018). ACEs encompass a wide variety of neighborhood and family-level factors, including financial strain, discrimination, neighborhood violence, parental divorce, incarceration, death, domestic violence, substance abuse, and mental illness (Berg et al., 2018). The authors found that autistic children with 1-2 ACES and children with 3 or more ACEs were likely to have more unmet needs than children without any ACEs. Given that family conflict, parental mental health difficulties, and financial hardship are all classified as ACEs, the results of this study suggest that high levels of barriers to care are likely to be associated with these variables.

Child psychopathology. When considering service utilization, it is also important to consider child-specific factors that may impact a child's treatment needs. For example, autistic children who require more support or who have more co-occurring problems may be likely to require a greater overall number of services. In turn, greater overall need may leave more room for unmet need; a study of transition-age autistic youth found that more severe behavior problems were associated with greater unmet need (Taylor & Henninger, 2015). Furthermore, parents of autistic children with co-occurring psychiatric diagnoses are more likely to report unmet need than parents of autistic children without co-occurring psychiatric diagnoses. (Zablotsky, Pringle, Colpe, Kogan, Rice, & Blumberg, 2015). Therefore, it will be important to account for autism symptom severity and co-occurring problems when investigating the association between unmet treatment need and barriers to care.

Aims of the Current Study

Given the limitations of the current strategies that are used to measure barriers to care, the current study aimed to validate the use of a barriers to care questionnaire in a sample of parents of autistic children. Validating the measure will be useful for future research aiming to minimize barriers to care, as well as for use in clinical contexts such as case management. We aim to achieve this overarching goal by administering the survey to parents of autistic and non-autistic children with the following four specific aims.

Aim 1: We examined reliability of the BCQ and the proposed subscales using internal consistency analyses and inter-item correlations.

Aim 2: For construct validity, we evaluated convergent and discriminant validity associations between barriers to care subscales and the aforementioned factors proposed as construct validity indicators based on prior research in this area. These factors consist of variables at multiple ecological levels, including demographic factors, family and parent-level factors, and child-level factors.

Aim 3: For incremental validity, we examined whether BCQ subscales predict key indicator variables (treatment experiences/unmet need), even when controlling for the influence of other theoretically related indicators.

Aim 4: Fourth, we investigated group differences in parent-reported barriers to care for autistic and non-autistic children. The results of the questionnaire were then used to gain a preliminary understanding of the most problematic barriers reported by parents of autistic children.

Method

Participants

Participants were 242 parents, including 117 parents of autistic children and 125 parents of non-autistic children ages 2-17 (*M*=9.28, SD=4.57). Parent and child demographic characteristics were collected, in addition to mental health history information. Exclusion criteria included not living in the United States and parent not being comfortable reading and responding in English. Psychiatric conditions, other neurodevelopmental disorders (e.g. ADHD), and physical health conditions were not exclusionary for either group in order to maximize generalizability of the results. Consistent with previous literature, most autistic children had at least one co-occurring condition, with the most common diagnoses being ADHD (58%), intellectual disability (23%) and learning disability (21%). In the non-autistic group, the most frequently reported psychiatric diagnoses were ADHD (6%) and generalized anxiety disorder (6%).

Procedure

The study was completed as an online survey administered using Qualtrics survey software. Participants were recruited through Prolific, an online survey recruitment platform which allows surveys to be advertised to specific groups. Crowdsourcing platforms have been shown to yield high quality, replicable data with low rates of missingness, particularly for research related to parenting and children (Buhrmester, Kwang, & Gosling, 2016; Schleider & Weisz, 2015). These samples tend to yield higher rates of child mental health concerns than other convenience samples, which is beneficial for research with clinical populations (Jensen-Doss, Salim Patel, Casline, Mora Ringle, & Timpano, 2021). Furthermore, Prolific specifically has

been shown to have more diverse, honest and valid samples than Amazon's Mechanical Turk, another well-known crowdsourcing platform (Peer, Brandimarte, Samat, & Acquisti, 2017).

We first conducted a brief prescreening study that assessed for a range of demographic and mental health concerns, wherein participants endorsed whether they had children, how old their children were, and whether their child had certain diagnoses including autism spectrum disorder. The prescreening survey included validity items (to ensure that participants were attending to the questions) and items asking about a range of diagnoses (e.g., asking parents whether their child had any of a list of 8 different diagnoses), to prevent participants from invalid responding (e.g., to prevent participants from selecting autism in order to access the full study, as the specific purpose of the prescreening study was not apparent). Only participants who passed all attention check items and who endorsed having an autistic child in the prescreening study were invited to participate in the full study in the autism group, whereas participants who passed attention check items and endorsed having a child without autism were eligible for the non-autistic comparison group.

For the full study, all participants completed an informed consent form prior to beginning the survey. The survey took an average of 39 minutes to complete (see Table 3 for full survey contents). Participants were compensated $7 for their time. A debriefing form was available at the end of the questionnaire providing online mental health resources for families. To ensure valid responding, we included 4 attention check items throughout the survey (2 multiple choice and 2 free response items), and participants were excluded from analysis if they failed any of these items. In addition, we required re-captcha verification and designed the survey so that it could only be accessed one time per participant, using the 'prevent ballot box stuffing' setting on

Qualtrics. Lastly, participants whose responses in the full survey did not match their responses on the prescreening survey were excluded from analysis due to invalid responding.

Barriers to Care Measure

Barriers to Care Questionnaire (BCQ; Seid et al., 2004). The BCQ is described in detail above. The modified version for the current study consists of 65 items regarding various problems families may face in accessing healthcare for their autistic child. Higher scores on the measure and in each subscale (skills, marginalization, expectations, knowledge/beliefs and pragmatics) are associated with more barriers to care. See Table 2 for the full measure, including original and added items.

Family-Level Factor Measures

Beach Center Family Quality of Life Scale (FQOL; Hoffman et al., 2006). The FQOL is a 25-item measure of family quality of life that was originally developed for use with families including a child with a disability. The FQOL includes five subscales: family interaction (e.g. "My family enjoys spending time together"; α=0.90), parenting (e.g. "Family members help the children learn to be independent"; α=0.87), emotional well-being (e.g. "my family has the support we need to relieve stress"; α=0.82), physical/material well-being (e.g. "my family has a way to take care of our expenses"; α=0.86) and disability-related support ("my family member with special needs has support to make progress at home"; α=0.82). Caregivers were asked to rate each item on a scale from 1 (*very dissatisfied)* to 5 (*very satisfied)*. Higher scores on the measure indicate higher FQOL. For the current study, families had the option to select "Not applicable" for the disability-related items.

Financial Stress Questionnaire (FSQ; Fast Track Project.) The FSQ is a 9-item measure of financial stress. Seven of the items inquire about affordability of items such as

clothing, food, and medical care (e.g. "We have enough money to afford the kind of clothing we should have"). Respondents were asked to rate the items on a scale from 1 (*Strongly Agree*) to 5 (*Strongly Disagree*). These items were summed to a total score, with higher scores indicating more financial stress (α=0.93). The last two items inquire about difficulty with paying bills and having enough money to make ends meet over the last twelve months. These two items are reported separately from the sum score.

Parent-Level Factor Measures

Inventory for Depressive and Anxiety Symptoms – Second Edition (IDAS-II; Watson et al., 2012). The IDAS-II assesses a range of internalizing symptom domains. The current study uses the IDAS-II Dysphoria subscale. The Dysphoria subscale consists of 10 items and assesses symptoms of depression and generalized anxiety (e.g. "felt depressed"; "found myself worrying all the time"). Participants were asked to rate how much they experienced each symptom on a scale of 1 (*Not at all*) to 5 (*Extremely*). Higher levels on the IDAS-II Dysphoria scale indicate more symptoms of depression and generalized anxiety. Cronbach's alpha for this measure was 0.95 in the current study.

Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1994.) The PSS is a well-established measure of perceived stress that was administered to caregivers in the present study. The scale consists of 10 items relating to various aspects of stress (e.g. "In the last month, how often have you felt nervous and "stressed"?). Participants are asked to rate each item on a scale of 0 (*Never*) to 4 (*Very Often*). Higher scores on this measure indicate higher levels of perceived stress. Cronbach's alpha for the PSS was 0.91 in the current study.

Big-Five Inventory, Second Edition – Extra Short Form (BFI-2-XS; Soto & John, 2017). The BFI-2-XS is a 15-item measure of personality traits. The measure includes three

items for each of the big five personality traits: openness ("is original, comes up with new ideas"; α=0.52), conscientiousness (e.g. "is reliable, can always be counted on"; α=0.71), extraversion (e.g. "is dominant, acts like a leader"; α=0.64), agreeableness (e.g. "is compassionate, has a soft heart"; α=0.55) and neuroticism (e.g. "worries a lot"; α=0.80). Participants were asked to rate each item on a scale from 1 (*Disagree Strongly*) to 5 (*Agree Strongly*). Higher scores in each trait domain correspond to higher levels of that trait.

Autism Awareness Scale (AAS; Gillespie-Lynch et al., 2015). The AAS is a scale developed by Gillespie-Lynch et al. (2015) as part of a measure of autism knowledge and stigma. The 13-item scale consists of items such as "With the proper treatment, most children outgrow autism spectrum disorder" and "Autism is more frequently diagnosed in males than females". Participants were asked to rate each item on a five-point scale from Strongly Disagree to Strongly Agree, with false items being reverse scored. Higher scores on the measure indicate more awareness and knowledge of autism; coefficient alpha for the AAS was 0.84.

Socially Desirable Responding Set, Five items (SDRS-5; Hays, Hayashi & Stewart, 1989). The SDRS-5 is a 5-item scale of social desirability which is intended to briefly measure socially desirable responding (e.g. "I sometimes feel resentful when I don't get my way"). Respondents were asked to rate each item on a five-point scale ranging from Definitely True to Definitely False. The extreme socially desirable response (e.g., "Definitely False" to the example item above) is scored a 1, and all other responses are scored a 0. Higher scores on the measure indicate more socially desirable responding. Coefficient alpha for the SDRS-5 was 0.71.

Child-Level Factor Measures

Pediatric Quality of Life Inventory – Short Form (PedsQL-SF; Varni, 1998). The PedsQL-SF is a 15-item measure of pediatric health-related quality of life. The measure includes

subscales for physical functioning (e.g. “participating in active play or exercise”; α = 0.89), emotional functioning (e.g. “feeling afraid or scared”; α=0.87), social functioning (e.g. “playing with other children”; α=0.83), and school functioning (e.g. “missing school because of not feeling well”; α=0.82). Parents were asked to report how much of a problem each item is on a scale from 0 (*Never*) to 4 (*Almost always*). Scores are then transformed to a 0 to 100 scale, with 0 converting to 100, 1 to 75, and so on. Higher scores on the transformed scale indicate better health-related quality of life. A total score (α=0.94) is calculated from the average of the subscale scores. Of note, the PedsQL was used as a measure of construct validity during the original development of the BCQ (Seid et al., 2004).

Unmet Need Scale. Our measurement strategy for operationalizing unmet treatment need is based on the method used by Lopez et al. (2019). Parents were provided a list of 10 common types of services for children with ASD and asked to specify whether they received enough of the service, received the service but not enough of it, did not receive the service but needed it, or did not receive the service and did not need it. The types of services included in the Lopez et al. paper were: speech therapy, occupational therapy, physical therapy, psychological services, social/recreational activities, respite services, and intensive autism therapy. We have added three additional service areas: primary care services, specialty medical care, and psychiatry. Each service type was scored on a 0-2 scale; items received a 1 if the parent reported receiving an insufficient amount of the service and a 2 if they reported not receiving the service at all despite need. Therefore, total scores can range from 0 to 20, with higher scores indicating more unmet need (α=0.92).

Treatment experiences. Parents were also asked about treatment experiences on a brief, 3-item measure which inquired about whether the parent felt that, overall, the child had unmet

treatment needs, whether they were satisfied with their child's healthcare experiences, and whether the healthcare system had worked well for them. Parents were asked to answer on a 7 point scale ranging from "*Strongly Disagree*" to "*Strongly Agree*". The unmet need item was reverse coded and then the three items were summed to create an overall score for treatment experiences, with higher scores indicating more positive experiences (α=0.72.)

Adverse Child Experience Questionnaire (ACE; Felitti et al., 1998). The ACE questionnaire is a yes/no measure which assesses ten adverse childhood events. Parents were asked whether their children have experienced any of the following ten events during childhood: physical abuse, emotional abuse, sexual abuse, physical neglect, emotional neglect, parental divorce, witnessing intimate partner violence, or a household member who experienced incarceration, mental illness or substance use. Scores can range from 0 to 10 based on how many ACEs are endorsed (α=0.87).

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). The SDQ is a 25-item behavioral screening questionnaire which measures a variety of positive and negative child behaviors. Caregivers were asked to rate each item as "Not True", "Somewhat True" or "Certainly True". The SDQ consists of five subscales: emotional problems (e.g. "many worries"), conduct problems (e.g. "often loses temper"), hyperactivity (e.g. "restless, overactive, cannot stay still for long"), peer problems (e.g. "picked on or bullied by other children" and prosocial (e.g. "shares readily with other children"). The measure yields an internalizing scale (α=0.72), which is the sum of the emotional and peer problems scales, and an externalizing scale (α=0.69), which is the sum of conduct problems and hyperactivity. The total problems scale is the sum of the internalizing and externalizing scales (α = 0.80).

Autism Spectrum Quotient (AQ10; Allison, Auyeung, & Baron-Cohen, 2012). The AQ10 is a short screening measure used to identify autism symptoms (e.g. "S/he doesn't know how to keep a conversation going with his/her peers). Parents were asked to rate each item on a scale from "Definitely Agree" to "Definitely Disagree". The measure is scored dichotomously, such that each autistic trait is scored as one point, regardless of the distinction between "Slightly Agree" and "Definitely Agree". For the current study, the AQ10 was used to investigate whether BCQ scores predict treatment experiences and unmet treatment need over and above child autistic traits. Coefficient alpha for the AQ10 was 0.82.

Analytic Plan

For preliminary analyses, demographic factors were reported in the autistic and non-autistic groups, with group differences considered using independent samples t-tests for continuous variables and Chi-square for categorical or nominal variables. Additionally, descriptive analyses regarding means and standard deviations for relevant scales in the autistic and non-autistic groups were calculated. Correlational analyses were also conducted between indicator variables.

Our first substantive aim was to examine the reliability of the BCQ by calculating internal consistencies for the overall scale and each subscale. In addition, inter-item correlations among the items within each subscale were examined, to ensure that all items within a subscale were sufficiently correlated with one another (i.e., values $\geq$.20 at minimum) while not being redundant (i.e., values $\geq$.90) . Item response frequencies were also considered, in order to understand whether any items were not endorsed by a significant portion of the sample. Finally, correlations among each of the subscales were also conducted. These analyses are considered within the full sample, and within the autistic and non-autistic groups separately.

Second, we investigated the construct validity of the BCQ by examining how BCQ subscales related to demographic and family-, parent-, and child-level factors (see Table 3 for a complete list of validity-related measures). Convergent validity was examined by relating the BCQ subscales to measures of similar, highly related constructs (e.g., treatment experiences/unmet need). Convergent validity was further considered by relating the BCQ subscales to indicators of constructs that should be related to access to care, whereas discriminant validity was considered by assessing how the BCQ subscales correlate with constructs where we would not expect as strong of an association (e.g., parent personality; social desirability). For all of these analyses, Pearson correlations between the BCQ scales and indicators were conducted. For demographic factors, MANOVA and correlational analyses were used. These analyses were conducted in the full sample, and separately within the autistic and non-autistic groups where possible.

Third, for incremental validity, we used hierarchical regression analysis to determine whether the BCQ subscales predicted children's treatment experiences and unmet need over and above other key indicators of these constructs (child autistic traits, child behavior problems, family income, parent race/ethnicity, and geographic status). We conducted one hierarchical regression for treatment experiences and one for unmet need. In step one of the regression, we included child autistic traits, child behavior problems, family income, parent race/ethnicity, and geographic status, as these are thought to be key indicators of treatment experiences/unmet need. In step two, we added the five BCQ subscales. Changes in R-squared were used to examine whether each step explained additional variance, and the significance and magnitude of the coefficients were used to quantify the association between the BCQ subscales and the outcome

variables. These analyses are reported in the full sample and separately within the autistic and non-autistic groups.

Fourth and finally, we conducted MANOVA analysis to examine response differences on the BCQ subscales between parents of autistic and non-autistic children. This allowed us to investigate whether parents of autistic children reported more barriers to care on the BCQ. Follow-up MANCOVA was then used to examine group differences on the BCQ while accounting for demographic differences between the groups.

Statistical Power

The study was designed to detect a medium to large effect size in multiple regression (for our primary analysis of incremental validity of the BCQ) and in group comparison tests (comparing autistic and non-autistic groups on the BCQ). Previous literature has found a small to medium-large effect size when comparing unmet treatments needs in autism versus other healthcare needs (Chiri & Warfield, 2012; Benevides et al., 2016; Chen et al., 2010). However, our study compares children with ASD to a general population sample, rather than children with other specific healthcare needs. Therefore, we predicted that effect sizes in this study would range from medium to large. Post-hoc power analyses confirm that our sample was sufficiently powered for regression analyses to detect a medium effect size (i.e., $\beta = 0.15$) in the full sample, and a medium-large effect size (i.e. $\beta=0.35$) in the separate group analyses, as well as to detect a medium-large group difference (i.e., Cohen's d of .4) in group comparison analyses (Soper, 2021).

Results

Descriptive Statistics

Descriptive statistics of the autistic and non-autistic groups are presented in Table 4. Groups did not differ on parental or child age. Significantly more respondents (parents) in the autistic group were female. Additionally, significantly more children in the autistic group were male, which is consistent with higher reported prevalence of autism diagnoses among males (Maenner et al., 2020). There were also significant demographic differences between the groups, with the autistic group having significantly more White children, lower parental education, and lower annual household income.

Table 5 presents group differences between the autistic and non-autistic groups on primary study variables. There were significant differences in parent stress, dysphoria, and personality between the groups, such that parents of autistic children had higher stress and dysphoria, as well as lower self-reported open-mindedness, conscientiousness, extraversion, and agreeableness, and higher negative emotionality. Parents of autistic children also reported that their children had significantly more autistic traits, behavior difficulties, and lower quality of life than parents of non-autistic children. Family quality of life was also lower in the autistic group across all domains. Parents of autistic children also reported significantly more financial stress and less positive experiences with their child's care. However, there were no significant group differences on unmet treatment need between the autistic and non-autistic groups.

Correlational Analyses

Correlations between main study variables in the sample as a whole (excluding correlations with the BCQ, which are discussed in detail below) are presented in Table 6. The majority of main study variables are correlated as expected. Treatment experiences were

correlated with nearly all child, parent, and family level variables, except for parent autism knowledge, although their correlation with parent personality variables was low to moderate (*r* ranging from .16 to -.33.) Unmet need was moderately correlated with child ACEs (*r*=.28) and slightly correlated with child QOL (*r*=-.14), child externalizing difficulties (*r*=-.14), the FQOL family subscale (*r*=-.13) and emotions subscale (*r*=-.14), and parent autism knowledge (*r*=-.17).

Additionally, correlation analyses for the non-autistic and autistic groups separately are presented in Supplemental Tables 1 and 2. In the autistic group, unmet need was correlated with child ACES (*r*=.53), child QOL (*r*=-.20), child autism traits (*r*=-.33), parent autism knowledge (*r*=-.38), parent agreeableness (*r*=-.39), parent stress (*r*=.10), and several subscales of the FQOL scale. Treatment experiences among parents of autistic children were correlated with child QOL (*r*=.25), internalizing difficulties (*r*=-.21), all subscales of the FQOL scale, and several parental characteristics (negative emotionality, stress, financial stress, and dysphoria). Child ACEs had correlations of stronger magnitude with other variables in the autistic group than the non-autistic group, and internalizing difficulties had stronger magnitudes of correlations in the non-autistic group. The pattern of the remaining correlations was similar across groups.

Reliability Analyses and Item Frequencies

To investigate reliability of the BCQ, we calculated internal consistency of the measure overall as well as each subscale, and also examined inter-item correlations among the items of each subscale. Cronbach's alpha was high for all subscales: 0.93 for skills (0.92 for autistic, 0.91 for non-autistic), 0.96 for marginalization (0.95 for autistic, 0.94 for non-autistic), 0.92 for expectations (0.88 for autistic, 0.89 for non-autistic), 0.91 for knowledge (0.90 for autistic, 0.87 for non-autistic), 0.90 for pragmatics (0.89 for autistic, 0.87 for non-autistic), and 0.98 for the total score (0.98 for autistic, 0.97 for non-autistic).

In order to preliminarily investigate whether any items were not highly related to their subscale, or whether any items may be redundant, inter-item correlations were analyzed for all subscales. Inter-item correlation tables are presented in Supplemental Tables 3-7. There were no items that correlated greater than 0.9, so no items were removed for redundancy. Furthermore, only one item correlated with any other items in its group at less than 0.2: "having to wait too long in the waiting room" from the pragmatics subscale had low correlation with transportation and health insurance items, but was correlated more strongly with all other items from the subscale and thus was not removed. Additionally, inter-item correlations separated by group are presented in Supplemental Tables 8-12.

Item frequencies were examined and are presented in Tables 7-11. All items were endorsed by participants in both groups, so no items were removed because of lack of response. Parents of autistic children endorsed the highest levels of difficulty in: "knowing how to make the healthcare system work for me" (mean score 3.01 on 5-point scale), "knowing whether services will work for my child" (mean score 2.99), "lack of communication between different parts of the healthcare system" (mean score 3.03), "having to manage household responsibilities" (mean score 3.09), and "meeting the needs of other family members" (mean score 3.07). Furthermore, correlations among subscales are presented in Table 12 for the full sample and Table 13 for the autistic and non-autistic groups.

Construct Validity (Convergent and Discriminant Validity)

Convergent validity. Construct validity was investigated using correlations between the BCQ subscales and identified convergent and discriminant variables, presented for the full sample in Table 14. For convergent validity, we examined associations between the BCQ subscales and child ACEs, child and family QOL, parent stress and depression/anxiety, family

financial stress, parent autism awareness, unmet treatment need, and treatment experiences. Unmet need was positively correlated with all BCQ subscales in the full sample, and treatment experiences were negatively correlated with all BCQ subscales with moderate to strong magnitude. Consistent with our hypotheses, all BCQ subscales were significantly positively correlated with child ACEs, such that more adverse events were associated with more barriers to care, with correlation coefficients for the subscales ranging from 0.49 to 0.58. Child QOL was negatively correlated with all BCQ subscales, with correlations ranging from -0.47 to -0.56. All family QOL subscales were also negatively associated with the BCQ subscales, indicating that higher family quality of life was associated with fewer barriers to care (*r* ranging from -.26 to -.57). Autism knowledge was also negatively correlated with barriers to care, such that parents with more autism knowledge reported fewer barriers, although the magnitude of the correlation ranged from *r*=-.17 for the expectations subscale to *r*=-.33 for the marginalization subscale. Parent stress (*r* ranging from .33 to .47) and dysphoria (*r* ranging from .38 to .51) were significantly positively correlated with all subscales of the BCQ. Financial stress was significantly positively correlated with all of the BCQ subscales as well (*r* ranging from .31 to .40). Therefore, convergent validity for the BCQ with theoretically related constructs is supported by these analyses, as the majority of these associations were of at least moderate magnitude and in theoretically expected directions

Additionally, correlations for the separate autistic and non-autistic groups are presented in Table 15. The pattern of correlational results largely remains the same in the autistic-only group as in the full sample. Specifically, all subscales were significantly and positively correlated with child ACEs and internalizing problems, as well as parent stress, financial stress, and dysphoria. All BCQ subscales were significantly negatively correlated with family FQOL,

parenting FQOL, physical FQOL, child total QOL, and parent autism knowledge. Treatment experiences and unmet need were both correlated with all five subscales on the BCQ in the autism-only group as well. These findings provide further evidence for convergent validity of the BCQ specifically for the autistic group.

Relations with socio-demographic factors. The BCQ subscales were also investigated in relation to socio-demographic factors. In the full sample, MANOVA analyses with all of the BCQ subscales entered simultaneously showed no significant main effect of caregiver race (White versus non-White; $F(5,192)=1.90$, $p=.10$), child race (White versus non-White; $F(5,189)=2.08$, $p=.07$), caregiver sex (male versus female; $F(5,189)=1.26$, $p=.28$), or child sex (male versus female; $F(5,192)=.59$, $p=.71$). There was a significant main effect of rurality on the BCQ subscales ($F(5,192)=2.77$, $p=.019$), with tests of between subjects effects showing that caregivers who endorsed living in rural settings reported the lowest level of barriers to care on all subscales for their children. The association between the BCQ subscales and continuous demographic factors were investigated using correlations. Years of parent education was significantly negatively correlated with the BCQ subscales (skills $r=-.23$; marginalization $r=-.30$; knowledge $r=-.26$; pragmatic $r=-.29$; expectations $r=-.21$). Household income and parent age were not associated with the BCQ subscales. Child age was significantly but weakly correlated with the pragmatics subscale ($r=-.13$). The majority of associations could not be validly examined separately within the autistic group, given low numbers of participants who endorsed select demographic categories (e.g., low n for non-White participants, rural participants, etc.).

Discriminant validity. Our main discriminant variables were parent personality and parent social desirability (see Table 14). There were some correlations between parent personality and BCQ subscales, although the magnitude of the correlations ranged from low to

moderate, consistent with our hypothesized associations. Extraversion correlated with three BCQ subscales, with correlation magnitude ranging from -.14 to -.20. Open mindedness correlated with four BCQ subscales, with correlations ranging from -.19 to -.21. The remaining personality variables were correlated with all BCQ subscales, with correlation coefficients ranging from -.14 for agreeableness and the skills subscale to -.40 for parent conscientiousness and the expectations subscale. In the full sample, social desirability was significantly correlated with four of the BCQ subscales, but these correlations were of relatively low magnitude (*r* ranging from -.23 for pragmatics to -.34 for marginalization). This provides initial evidence of discriminant validity, as these correlations were low in magnitude and weaker than the associations with our convergent variables.

Results for the autistic and non-autistic groups alone are presented in Table 15. In the autism group, parent extraversion and parent open-mindedness were not correlated with any subscale of the BCQ. The remaining personality variables had a similar pattern of correlations to the full sample. Overall, this pattern further supports additional discrimination between parent personality and barriers to care in the ASD group in particular. Regarding social desirability, there were only two significant correlations, which were low in magnitude (r=-.21 for knowledge/beliefs and r=-.30 for marginalization). Overall, there were fewer significant associations with discriminant variables in the autistic group than the full sample. Therefore, taken together, these results offer additional support for discriminant validity specifically in the autistic group.

Incremental Validity

We used hierarchical regression analysis to determine whether the BCQ subscales predicted children's unmet treatment need or treatment experiences over and above the proposed other key

indicator variables, which included child autistic traits, child behavior problems, family income, parent race/ethnicity, and geographic status. Hierarchical regression analyses for the full sample are presented in Table 16. In the full sample, neither step one nor step two of the regression model was significantly predictive of unmet need. However, regarding treatment experiences, both step one and step two were significantly predictive, and there was a significant change in R^2 between steps one and two (R^2 change = 0.16, $p<.001$). The only significant individual predictor of treatment experiences in step one was child externalizing symptoms (β =-.19); in step two, the only significant predictor of treatment experiences was the BCQ expectations subscale (β =-.38).

We also conducted hierarchical regression analyses for the autistic and non-autistic group separately to understand whether there were differential patterns of association specifically for the autistic group, presented in Table 17. In the autistic group analysis, unmet need and treatment experiences were both predicted by the hierarchical regression analyses. For unmet need, R^2 from the child-level and demographic predictors was .18; however, in step two (with the BCQ subscales included) R^2 was .35, representing a significant change in R^2 of .17. The only individual variables which emerged as significant in either step of the regression were child internalizing (β=-.32) and the marginalization subscale of the BCQ (β=.73), such that higher levels of marginalization experiences were associated with more unmet need for autistic children. For treatment experiences as the dependent variable, R^2 was significant for both steps of the hierarchical regression. In step one, parent race and rurality were the only significant predictors (β = -.26 and .31, respectively). In step two, externalizing symptoms were significant (β = -.26) and the BCQ skills subscale was also a significant predictor of treatment experiences (β=-.49) such that higher levels of barriers to care related to skills (e.g., "providers speak in a way that is too technical or medical"; "knowing what type of services to look for") were

associated with worse treatment experiences for autistic youth. There was a significant R^2 change of .15 when including the BCQ subscales in the regression analysis. In the non-autistic group, unmet need was not predicted by either step of the regression analysis. Step two of the model was significant for treatment experiences (R^2=.27), although no individual predictors emerged as significant.

Group Differences

MANOVA analyses were used to evaluate group differences on the BCQ subscales between autistic and non-autistic children. There was a significant main effect of group (F(65, 192)=9.20, p<.001), and post-hoc Bonferroni corrected comparisons showed that all five subscales were significantly different between the families of autistic and non-autistic children (p<.001 for all subscales), indicating more barriers to care in all domains for the autistic group. Since the subscales had different numbers of items, Table 18 presents the average item score by subscale for the ASD and non-ASD group for ease of interpretation. On the BCQ overall, the average item score for the children with ASD was 2.43, while for the non-ASD group the average score was 1.80, on a scale ranging from 1 (*never*) to 5 (*almost always*). Because there were significant demographic differences between the groups, a follow-up MANCOVA was conducted to examine whether group differences on the BCQ remained significant when controlling for parent and child gender, child race/ethnicity, parent years of education, family income, and rural/nonrural geographic status. Even when controlling for these demographic group differences, there was a significant main effect of group (F(5, 167)=8.73, p<.001), and all BCQ subscales were significantly higher (indicating more barriers) for the autistic group than for the non-autistic group (Bonferroni-corrected comparisons p<.001 for all subscales).

Discussion

The results of the current study provide preliminary support for use of a measure of barriers to healthcare for families of autistic children. In addition, parent responses in the present study offer new insights regarding what barriers families of autistic and non-autistic children face when seeking healthcare and services, and which of these barriers are most frequently problematic. Taken together, findings of the present study highlight the need for decreasing barriers to services for families of autistic children, in addition to providing initial support for a tool which can measure such barriers.

Psychometric Properties of the BCQ

Reliability. This study offers preliminary evidence that the Barriers to Care Questionnaire is a reliable measure in the context of autism, expanding upon its initial use in the context of children with medical concerns such as asthma (Seid et al., 2004; Seid et al., 2009). Our reliability analysis suggests strong internal consistency of the BCQ overall, as well as each subscale of the measure. Given that the measure aims to capture a multifaceted concept such as barriers to care, this finding of strong internal consistencies provides good evidence for the reliability of this scale. Relatedly, inter-item correlations show that items were all significantly correlated with the other items in their scale at a magnitude of at least 0.20 (with one exception noted above), but none were correlated at greater than 0.90. Therefore, while items in the same subscale were related to each other, they were not redundant in the barriers to care that were being measured.

Convergent validity. A main aim of this study was to establish the validity of the BCQ in measuring barriers to care. We aimed to establish convergent, divergent and incremental validity of the measure. With respect to convergent validity, correlational analyses demonstrate

that the BCQ is associated with theoretically related constructs as hypothesized, and that these patterns of correlations are present specifically in the autistic group. ACEs were highly related to all five subscales of the BCQ in the overall sample as well as in the autistic group, showing that children with higher levels of adversity experience more barriers to healthcare, consistent with Berg et al. (2018). Child QOL was negatively associated with all subscales, indicating that more barriers to care were associated with lower child QOL in the full sample and in the autism group. This is consistent with the original BCQ validation study, which also found that the measure was negatively associated with child quality of life (Seid et al., 2004). At the parent level, parent stress and dysphoria were positively associated with barriers to care, and autism knowledge was negatively correlated with barriers. Family QOL was also negatively related to the BCQ, with the family, parenting, and physical subscales being particularly associated with barriers to care. Additionally, family financial stress was associated to barriers, with somewhat lower magnitude of correlations than FQOL. Notably, parent education, a key indicator of socioeconomic status, also showed the expected negative association with barriers to care, such that parents with higher education reported fewer barriers. In contrast, rurality was negatively associated with barriers to care, such that families living in rural settings reported fewer barriers to care. Future research should use an objective measure of rurality (e.g. zip code) as well as collect data from more diverse samples of autistic youth. Overall, the majority of the hypothesized associations with the BCQ scales were present, which provides strong evidence for convergent validity of this measure with theoretically related indicators.

Discriminant validity. There is preliminary support for discriminant validity of the measure as well. Although some parent personality factors were associated with barriers to care, others were not related to the BCQ subscales and the strength of associations were weaker than

the relations between the BCQ with the convergent validity indicators described above. However, conscientiousness, negative emotionality and agreeableness did have moderate associations with barriers to care. Although these associations were not specifically hypothesized, there are several potential explanations for these findings. Given the relationship between negative emotionality and stress/dysphoria, it is reasonable that negative emotionality would be associated with barriers to care given that both stress and dysphoria are correlated with barriers. Furthermore, agreeableness was negatively associated with barriers, indicating that parents who reported higher levels of friendliness and compassion experienced fewer barriers. This finding could indicate reporting differences, such that those high in agreeableness are likely to be more reluctant to report barriers that may reflect poorly on others. Alternatively, agreeableness could be protective against experiencing barriers as it may be associated with high levels of patience in navigating the healthcare system. Similarly, conscientiousness was negatively associated with barriers to healthcare. Given that accessing healthcare often requires consistent appointments and contact with providers, parents who are naturally more conscientious may find these structural barriers less difficult to navigate.

Despite some parent personality traits being associated with reported barriers to healthcare, other personality traits were not associated, which provides evidence for discriminant validity. In the full sample, extraversion was slightly associated with four of the BCQ subscales (correlations ranging from -.14 to -.20); however, in the autism group, extraversion was not significantly correlated with any subscale of the BCQ. A similar pattern was observed with parent open mindedness, and social desirability was associated with only two subscales of the BCQ in the autism-only group. Therefore, although there were some slight to moderate correlations with some discriminant variables, other variables were not associated with the BCQ.

These findings suggest preliminary evidence of discriminant validity, although further work in this area is indicated.

Incremental validity. Incremental validity was investigated using hierarchical regression analyses to determine whether the BCQ subscales predicted unmet treatment need and treatment experiences over and above demographic and child level factors. Both unmet need and treatment experiences had a significant amount of variance explained by the BCQ subscales for the autistic group, providing evidence for incremental validity in this population. For unmet need, the BCQ marginalization subscale emerged as significantly predictive. The marginalization subscale contains a number of items related to being judged by aspects of one's identity as well as specific concerns about provider and staff attitudes. Therefore, this finding may indicate that experiencing stigma or negative attitudes from providers is associated with unmet treatment needs. This highlights the critical need for quality training in interpersonal communication skills as well as diversity, equity, and inclusion for providers. With regard to the treatment experiences model, the BCQ skills subscale was a significant predictor. The skills subscale includes items related to knowing what services to look for and navigating the healthcare system broadly. This finding therefore underscores the need for supports to assist families in navigating the system (for a review of several family-centered support interventions, see Russa, Matthews, & Owen-DeSchryver, 2015). In the overall sample, the regression model was significant only for treatment experiences and not for unmet need. This is likely due to the highly right-skewed distribution for unmet need in the non-ASD group, with 58.87% of parents in the non-ASD group reporting no unmet needs (compared to 15.32% in the ASD group). It may be important to consider additional factors that may be impacting unmet need and treatment experiences that are not captured by the BCQ or demographic or child-level factors.

Group Differences in Barriers to Care

Parents of autistic children reported significantly more barriers on all subscales, even when accounting for demographic group differences, which confirms our hypothesis that this measure would detect more barriers to care for autistic children than non-autistic children. This is consistent with previous research which finds that autistic children face high levels of barriers to healthcare (Vohra et al., 2014; Cheak-Zamora & Thullen, 2017). Furthermore, this finding of increased barriers for parents of autistic children highlights the critical need for interventions that may increase access to services for families of autistic children.

Regarding the frequency of experiencing distinct types of barriers to accessing care, the autistic group endorsed the highest levels of the following items as barriers: "(difficulties) knowing how to make the healthcare system work for me", "(difficulties) knowing whether services will work for my child", "lack of communication between different parts of the healthcare system", "(difficulties) having to manage household responsibilities", and "(difficulties) meeting the needs of other family members", which spanned the skills, expectations, and pragmatics subscales. There are significant clinical and policy implications of these barriers. Several of them may be addressed by providing parents with education regarding the healthcare system. Given that accessing healthcare can be extremely complicated and difficult, families may benefit from patient-centered education on navigating the healthcare system, as well as information regarding evidence based practice, from general practitioners, family navigators, or public health campaigns (e.g., Russa, Matthews, & Owen-DeSchryver, 2015; Roth et al., 2016; Graybill et al., 2016). In the long term, our findings highlight the critical need for structural changes to the healthcare system to improve accessibility. Furthermore, the frequent endorsement of other household responsibilities as a barrier highlights the importance of

adequate respite services for families in order to decrease the burden of accessing healthcare (Whitmore, 2016). Although the items listed here had the highest mean rating, most barriers included in the BCQ are experienced at least some of the time by families. Therefore, it is critical that future research carefully consider the barriers assessed here in order to understand how they may be effectively ameliorated.

Limitations

Although this study provides evidence for use of the BCQ in an ASD sample, these results should be considered within the context of several limitations. First, although our study was powered for the analyses presented here, the sample size was not large enough to allow for more advanced psychometric analyses such as factor analytic strategies. Future studies with larger samples investigating the factor structure of this measure will be critical in understanding whether the BCQ scales (defined by the original Seid et al. paper [2004] and expanded upon in the present study), which were conceptually developed, are confirmed empirically by factor analysis. Furthermore, it is important to note that this study included predominantly White identifying individuals, and participants were required to be comfortable reading and responding in English. This may have resulted in artificially low scores on the marginalization subscale, particularly items related to marginalization based on race, ethnicity, or language use. As such, it is critical that future research investigate measures such as this one specifically in underrepresented groups. An additional potential limitation was the use of unmet treatment need as a key outcome variable. Although this measure was predicted by the BCQ in the autistic group, the highly skewed distribution of the measure in the non-autistic group resulted in insignificant results for the full sample. Our results suggest that while unmet need is likely an appropriate measure for the autistic group, it may have been less useful or appropriate for the

sample as a whole. Additional research in this field can consider how the BCQ relates to other meaningful indicators of healthcare access and utilization (E.g., annual appointments attended, frequency of losing patients to follow up, elapsed time from diagnosis to entry into services, availability and insurance coverage of providers in area, and so on).

Implications and Future Directions

The present study has several important implications. First, the results presented here suggest that this measure may be useful for investigating barriers to healthcare and services, and that it may be particularly appropriate for autistic children. The use of such a measure will allow researchers, clinicians, and policymakers to improve their understanding of the barriers that families face when accessing care, and who in turn can advocate for policy changes which may mitigate many of these barriers. Specifically, the most frequently endorsed items, if replicated, may provide evidence in favor of the use of family supports such as family navigator programs and respite services. Additionally, the finding that child ACEs and family quality of life are highly related to barriers to care suggests that family-focused intervention strategies may have the potential to improve accessibility of services.

There are several important future directions for this line of research. Regarding psychometric research, future studies should investigate a larger and more diverse sample of parents in order to conduct advanced psychometric analyses. Additionally, the development of a short form of this scale may also be useful, as the current 65-item form may be burdensome for families to fill out in its entirety in real world clinical settings. It may also be beneficial to develop other formats of administration for this measure, such as child- or clinician-report and interview forms, in order to obtain perspectives on barriers to care from other stakeholders. In addition to further psychometric research, future work in the area of care accessibility should

investigate potential intervention strategies to facilitate access to care. Such intervention research has the potential to impact policy decisions and improve access to services for families of autistic children.

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Tables

Table 1

Summary of Access and Barriers to Care Research Strategies

Measurement Strategy	Authors	Data	Sample	Findings
National Survey Cohorts	Chiri & Warfield, 2012	2005-2006 NS-CSHCN	ASD	Families of children with ASD at higher risk for unmet need; report provider lack of skills as a barrier
	Benevides, Carretta, & Lane, 2016	2005-2006 and 2009-2010 NS-CSHCN	ASD	Factors associated with unmet therapy need included: not having a well-child visit; female gender; lack of insurance; greater functional limitation
	Skinner & Slifkin, 2007	2000-2002 NS-CSHCN	SHCN	Rural families of children with SHCN (not ASD specifically) face more barriers of transportation and not having a provider in the area
	Lindly, Chavez & Zuckerman, 2016	2009-2010 NS-CSHCN	I/DD including ASD	Unmet need associated with adverse family employment and financial impacts
	Zuckerman, Lindly, Bethell, & Kuhlthau, 2014	2009-2010 NS-CSHCN	SHCN, SCHN+ASD, SCHN+ Functional Limitation	SHCN+ASD had high rates of adverse family impacts
	Vohra, Madhavan, Sambamoorthi, & St Peter, 2013	2009-2010 NS-CSHCN	ASD	Families of children with ASD at higher risk for barriers to services, lack of care source, inadequate insurance coverage, adverse family impacts than children with other SHCN
	Montes & Halterman, 2011	2005-2006 NS-CSHCN	SHCN without ASD, ASD	Black parents of children with SHCN and with ASD less likely to report family-centered care than White parents
	Berg, Shiu, Feinstein, Msall, & Acahrya, 2018	2011-2012 National Survey of Children's Health	ASD	Children with family ACEs had a later age of diagnosis and entry into services
	Cheak-Zamora & Thullen, 2017	2009-2010 NS-CSHCN	DD	Children with DD have less access to medical home, adequate insurance, and community services than other SHCN
	Liptak et al., 2008	2003-2004 National Survey of Children's Health	ASD	Black, Latinx, and poor children had less access to services
Open Ended or Qualitative Data	Galpin, Barratt, Ashcroft, Greathead, Kenny, & Pellicano, 2018	Surveys of parent well-being and semi-structured follow-up interviews	ASD with co-occuring ID	Existing support does not meet families' needs; parents report a need for family-centered services
	Pickard & Ingersoll, 2016*	Qualitative and quantitative data from open- and close-ended survey	ASD	ASD service knowledge partially mediates the relationship between SES and service use; low SES parents reported structural barriers and lack of information about service availability
	Dababnah, Shaia, Campion, & Nichols, 2018	interviews	Black children with ASD	Black mothers report providers ignoring early concerns, racial bias, legal/custody issues, and denial/shame as barriers to diagnosis
	Zuckerman, Sinche, Mejia, Cobian, Becker, & Nicolaidis, 2014	focus groups and qualitative interviews	Latinx children with ASD	Parents reported barriers to diagnosis such as low levels of ASD information; disability stigma; poverty; language barriers; dismissal of concerns
	Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor	qualitative interviews	ASD	Parents reported that lack of access to ASD service providers and frequent changes in service eligibility are barriers to community mental healthcare
Survey Study	Oswald, Haworth, Mackenzie, & Willis, 2017	large survey	ASD	parents of children with ASD more likely to report that providers de-emphasize child's early symptoms

Note. NS-CSHCN = National Survey of Children with Special Healthcare Needs. SCHN = special healthcare needs. DD= developmental disability. I/DD= intellectual or developmental disability.

Table 2
Original and Added BCQ items.

Skills	• Knowing how to make the healthcare system work for you • Providers not fluent in your language • Providers speak in a way that is too technical or medical • Getting referrals to specialists or therapists • Understanding provider recommendations • Having enough information about how the health care system works • Needing to be more 'savvy' or knowledgeable about getting services • Getting enough help with paperwork or forms • **Knowing what type of services to look for** • **Knowing where to go for services** • **Knowing whether services are covered by your health insurance** • **Knowing whether services are necessary for your child** • **Knowing whether services will work for your child**
Marginalization	• Feeling like providers are trying to give as little service as possible • Feeling like the health care system is trying to give as little service as possible • Impatient providers • Intimidating providers • Rude office staff • Uncaring office staff • Getting the provider to listen to you • Getting your questions answered • Not knowing what to expect from one visit to the next • Being judged on your appearance • Providers rushing you and your child through the visit • Being judged on your accent • **Being judged on your race or ethnicity** • **Being judged on where you live** • **Being judged on your parenting skills** • **Being judged on your gender** • **Being judged on your speaking ability** • **Being judged on another aspect of your identity** • **Providers judging your child's behavior** • **Worrying that accessing services will make people think differently about you** • **Worrying that accessing services will make other kids think differently about your child**

Expectations	• Offices that are not child-friendly • Mistakes made by providers • Worrying that providers will not do what is right for your child • Providers treating the symptoms without finding out the root cause • Getting a thorough evaluation • Lack of communication between my child's providers and other specialists in the health care system • Lack of communication between different parts of the health care system • **Providers not explaining their decision making** • **Offices that do not meet your child's sensory needs**
Knowledge and Beliefs	• Disagreeing with the provider's recommendations • Providers not believing in home or traditional treatments • Providers giving you instructions or recommendations that seem wrong • Providers that have different ideas about mental health than you do • **Providers that have different ideas about what your child's needs mean than you do** • **Providers not listening to your concerns or ideas** • **Conflicting recommendations from different service providers**
Pragmatics	• Getting hold of the provider's office or clinic by phone • Having to wait too many days for an appointment • Getting care after hours or on the weekends • Having to take care of household responsibilities • Having to take time off work • Meeting the needs of other family members • The cost of appointments • **Having transportation to the provider's office** • **Services not being covered by your health insurance** • **Finding providers in your area** • **Not having health insurance** • **Not having childcare for your other children** • **Your child not being able to get the diagnosis that fits them best** • **Your child not having the diagnosis they need to access services**

Note. Bolded items were added to the original BCQ in order to capture ASD-specific difficulties with seeking care. Items were added into the subscale where they are expected to correlate most strongly.

Table 3
Summary of Proposed Validity Measures

Purpose of Measure	Measure Name	Measure Construct	Number of Items
Convergent Validity	Unmet Need Scale (Lopez et al., 2019)	Unmet Need	10
	Treatment Experiences Scale	Treatment Experiences	3
	Pediatric Quality of Life Inventory, Short Form (PedsQL-SF)	Health-related Quality of Life	15
	Beach Center Family Quality of Life Scale (FQOL)	Family Quality of Life	25
	Perceived Stress Scale (PSS)	Parent Stress	10
	Inventory of Depression and Anxiety Symptoms, Second Edition, Dysphoria Subscale	Parent Depression/Anxiety	10
	Adverse Childhood Experiences Questionnaire (ACE)	Child ACEs	10
	Financial Stress Questionnaire (FSQ)	Financial Stress	9
	Autism Awareness Scale (AAS)	Parent Autism Awareness	13
Discriminant Validity	Big Five Inventory, Second Edition, Extra Short Form (BFI-2-XS)	Parent Personality	15
Incremental Validity	Strengths and Difficulties Questionnaire (SDQ)	Child Behavior Problems	25
	Autism Spectrum Quotient – 10 (AQ10)	Child ASD Symptom Severity	10

Table 4
Demographic Variables

Variable	*n*	Non-ASD n=125 *M (SD) or %*	*n*	ASD n=117 *M (SD) or %*	Group Comparison *p*-value
Parental age	125	37.78 (8.23)	117	36.87 (6.84)	.35
Parental gender	125		117		
Male	71	56.8%	35	29.9%	<.001***
Female	54	43.2%	79	67.5%	
Non-Binary	0	0.00%	3	2.6%	
Child age	124	9.28 (4.57)	117	8.58 (4.13)	.22
Child gender	124		117		
Male	67	54.0%	83	71.0%	.008**
Female	57	46.0%	34	29.0%	
Child race/ethnicity	125		117		
White	88	70.4%	97	82.9%	.012*
Black	17	13.6%	11	9.4%	
Asian or Asian American	11	8.8%	1	0.9%	
Latino or Hispanic	10	8.0%	10	8.5%	
Native Hawaiian or Pacific Islander	0	0.0%	1	0.9%	
Bi- or multiracial	6	4.8%	5	4.3%	
Parental Education	125	16.7 (2.26)	117	15.4 (2.64)	<.001***
Annual family income (USD)	108	91652.76 (60666.34)	108	74250.00 (41011.73)	.014*
Geographic location	125		116		
Urban	42	33.6%	60	51.7%	.85
Suburban	66	52.8%	42	36.2%	
Rural	17	15.2%	14	12.1%	

Note. Group differences were analyzed using t-tests for continuous variables and Chi-square tests for nominal/ordinal variables. Some parents selected multiple race/ethnicity options to best represent their child's identity. Chi-square values were calculated based on dichotomous variables (white vs. non-white, rural vs. non-rural) due to low power. Chi-square significance values represent exact, 2-sided p-values. Parents were given the option to select a gender identity other than male or female for their children but in all cases parents selected male or female gender. *p≤0.05, **p≤0.01, ***p≤0.001.

Table 5
Sample Characteristics

Variable	Non-ASD n=125 *n*	Non-ASD n=125 *M (SD) or %*	ASD n=117 *n*	ASD n=117 *M (SD) or %*	Group Comparison *p*-value
Parent Characteristics					
Autism Knowledge	125	36.04(6.45)	114	36.75(9.10)	.49
PSS Parent Stress	123	13.31(8.95)	114	19.58(7.06)	<.001
IDAS Parent Dysphoria	121	17.90(9.41)	114	26.40(9.77)	<.001
Personality Traits					
Open Mindedness	124	11.59(2.30)	117	10.63(2.57)	.003
Conscientiousness	125	11.98(2.87)	117	9.90(2.90)	<.001
Extraversion	124	9.08(3.11)	115	8.15(2.77)	.015
Agreeableness	124	11.72(2.46)	117	10.97(2.40)	.019
Negative Emotionality	125	7.08(3.47)	117	9.21(3.06)	<.001
Child Characteristics					
Quality of Life	123	83.77(15.14)	109	55.21(19.53)	<.001
Physical	124	89.19(16.83)	114	62.81(26.72)	<.001
Emotional	124	78.93(19.72)	112	52.40(21.36)	<.001
Social	124	87.57(17.44)	116	54.96(25.04)	<.001
School	125	77.73(23.18)	117	47.58(24.44)	<.001
Autism Traits	111	2.47(2.18)	108	6.81(2.38)	<.001
Behavior Difficulties	119	8.44(2.69)	108	12.85(2.82)	<.001
Internalizing	122	3.12(1.22)	115	5.66(1.98)	<.001
Externalizing	122	5.34(1.85)	110	7.21(1.65)	<.001
Family Characteristics					
Family Quality of Life					
Family	122	26.15(3.35)	116	22.95(4.70)	<.001
Parenting	122	26.04(3.32)	115	22.95(4.44)	<.001
Emotional	125	16.48(2.79)	117	14.09(3.60)	<.001
Physical	121	22.12(2.92)	109	19.12(4.32)	<.001
Financial Stress	124	14.80(6.22)	115	19.28(6.95)	<.001
Unmet Treatment Need	124	4.69(7.09)	111	5.55(4.50)	.26
Treatment Experiences	125	17.10(3.08)	117	13.66(3.94)	<.001

Note. *p≤0.05, **p≤0.01, ***p≤0.001. PSS = Perceived Stress Scale. IDAS = Inventory of depression and anxiety symptoms.

Table 6
Pearson Correlations Among Primary Study Variables

	Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1.	Child ACEs	---																			
2.	Child QOL Total	**-.52****	---																		
3.	Child Internalizing Difficulties	.37**	**-.69****	---																	
4.	Child Externalizing Difficulties	.08	-.39**	**.50****	---																
5.	Child Autism Traits	.14*	**-.50****	**.61****	**.58****	---															
6.	FQOL Family	**-.46****	**.42****	**-.42****	-.31**	-.30**	---														
7.	FQOL Parenting	**-.45****	**.44****	**-.47****	-.31**	-.35**	**.85****	---													
8.	FQOL Physical	**-.54****	**.47****	**-.41****	-.26**	-.30**	**.68****	**.72****	---												
9.	FQOL Emotional	-.27**	.35**	-.37**	-.35**	-.37**	**.71****	**.74****	**.65****	---											
10.	Parent Autism Knowledge	-.30**	.15*	-.03	.12	.17*	.24**	.26**	.28**	-.01	---										
11.	Parent Extraversion	-.07	.15*	-.24**	-.25**	-.27**	.22**	.24**	.24**	.33**	-.15*	---									
12.	Parent Agreeableness	-.33**	.22**	-.17**	-.17**	-.17*	.38**	.36**	.28**	.30**	.21**	.20**	---								
13.	Parent Conscientiousness	**-.40****	**.45****	**-.42****	**-.40****	-.31**	**.43****	**.50****	**.45****	.36**	.07	.31**	.39**	---							
14.	Parent Negative Emotionality	.35**	-.39**	.39**	**.41****	.29**	**-.43****	**-.45****	**-.40****	**-.49****	.12	**-.42****	-.32**	**-.60****	---						
15.	Parent Open Mindedness	-.22**	.27**	-.26**	-.18**	-.18**	.29**	.28**	.21**	.19**	.31**	.21**	.33**	.21**	-.21**	---					
16.	Parent Stress	**.44****	**-.50****	**.46****	**.44****	.32**	**-.59****	**-.58****	**-.56****	**-.61****	-.01	**-.40****	-.37**	**-.63****	**.78****	-.21**	---				
17.	Parent Financial Stress	35**	-.39**	.35**	.24**	.30**	-.39**	**-.41****	**-.64****	**-.49****	-.04	-.30**	-.12	-.33**	.31**	-.19**	**.52****	---			
18.	Parent Dysphoria	**.48****	**-.56****	**.53****	.39**	.30**	**-.55****	**-.57****	**-.55****	**-.54****	-.12	-.26**	-.32**	**-.61****	**.73****	-.22**	**.81****	-.38**	---		
19.	Unmet Need	.28**	-.14*	-.02	-.14*	-.10	-.13*	-.09	-.14*	-.10	-.17*	.02	-.09	.07	-.08	.01	.01	-.05	.08	---	
20.	Treatment Experiences	-.28**	**.45****	**-.41****	-.30**	-.34**	**.43****	-.43**	**.47****	**.45****	-.02	.16*	.30**	.27**	-.33**	.13*	**-.42****	**.42****	-.36**	-.14*	---
21.	Social Desirability	-.23**	.29**	-.23**	-.16*	-.12	.31	.35**	.28**	.28**	.19**	.07	**.54****	.32**	-.28**	.19**	-.31**	.01	-.30**	.01	.27**

Note. *p ≤ 0.05, **p ≤ 0.01. Correlations greater than or equal to 0.4 are bolded.

Table 7
Skills Subscale Frequencies

Skills	M (SD) Autism	M (SD) Non-Autism	Valid N	% Never	% Almost Never	%Sometimes	%Often	%Almost Always
1. Knowing how to make HCS work	3.01 (1.27)	2.46 (1.19)	115 / 123	13.9 / 26.0	22.6 / 27.6	27.8 / 27.6	20.0 / 12.2	15.7 / 6.5
2. Providers not fluent in language	1.93 (1.27)	1.39 (0.86)	117 / 124	59.0 / 79.0	9.4 / 8.9	15.4 / 8.1	12.0 / 2.4	4.3 / 1.6
3. Providers speak too technically	2.32 (1.28)	1.56 (0.80)	117 / 123	39.3 / 61.0	15.4 / 24.4	23.1 / 12.2	17.9 / 2.4	4.3 / 0.0
4. Getting referrals	2.89 (1.26)	1.87 (1.04)	117 / 124	17.1 / 47.6	20.5 / 28.2	31.6 / 16.1	17.9 / 5.6	12.8 / 2.4
5. Understanding recommendations	2.53 (1.33)	1.96 (1.16)	116 / 123	31.9 / 48.0	18.1 / 24.4	22.4 / 16.3	19.8 / 6.5	7.8 / 4.9
6. Having enough info about HCS	2.81 (1.27)	2.37 (1.27)	116 / 123	21.6 / 30.9	17.2 / 29.3	29.3 / 22.0	22.4 / 8.1	9.5 / 9.8
7. Needing to be more knowledgeable	2.91 (1.31)	2.10 (1.06)	117 / 123	20.5 / 35.8	15.4 / 31.7	29.1 / 22.0	22.2 / 8.1	12.8 / 2.4
8. Getting help with paperwork	2.61 (1.24)	2.05 (1.22)	117 / 124	24.8 / 45.2	23.1 / 25.0	24.8 / 16.1	21.4 / 7.3	6.0 / 6.5
9. Knowing what type of services to look for	2.85 (1.28)	2.21 (1.33)	117 / 124	23.9 / 40.3	10.3 / 27.4	30.8 / 13.7	27.4 / 8.1	7.7 / 10.5
10. Knowing where to go for services	2.51 (1.26)	2.02 (1.38)	115 / 125	30.4 / 53.6	18.3 / 18.4	26.1 / 12.0	20.0 / 4.0	5.2 / 12.0
11. Knowing whether services are covered	2.96 (1.27)	2.28 (1.15)	116 / 124	17.2 / 32.3	16.4 / 26.6	34.5 / 25.8	17.2 / 11.3	14.7 / 4.0
12. Knowing whether services are necessary	2.78 (1.16)	2.07 (1.24)	116 / 122	16.4 / 44.3	24.1 / 25.4	31.9 / 16.4	20.7 / 6.6	6.9 / 7.4
13. Knowing whether services will work	2.99 (1.17)	1.98 (1.16)	117 / 123	15.4 / 47.2	12.8 / 24.4	38.5 / 17.1	23.9 / 6.5	9.4 / 4.9

Note. HCS = healthcare system.

Table 8
Expectations Subscale Frequencies

Expectations	M (SD) Autism	M (SD) Non-Autism	Valid N	% Never	% Almost Never	%Sometimes	%Often	%Almost Always
1. Offices not child friendly	2.44 (1.25)	1.54 (0.80)	116 / 123	31.9 / 62.6	18.1 / 24.4	31.9 / 9.8	10.3 / 3.3	7.8 / 0.0
2. Mistakes by providers	2.39 (1.08)	1.75 (0.83)	115 / 122	26.1 / 45.9	27.8 / 36.9	27.8 / 14.8	17.4 / 1.6	0.9 / 0.8
3. Worrying that providers will not do what is right	2.83 (1.12)	1.97 (1.06)	117 / 125	16.2 / 41.6	18.8 / 32.8	35.9 / 16.0	23.9 / 6.4	5.1 / 3.2
4. Treating symptoms, not cause	2.62 (1.24)	1.98 (1.13)	115 / 124	26.1 / 46.0	17.4 / 25.8	32.2 / 16.1	17.4 / 8.9	7.0 / 3.2
5. Getting a thorough evaluation	2.94 (1.15)	2.13 (1.21)	116 / 125	14.7 / 39.2	18.1 / 29.6	32.8 / 17.6	27.6 / 6.4	6.9 / 7.2
6. Lack of communication between provider and other specialists	2.93 (1.25)	1.81 (0.92)	116 /124	16.4 / 48.4	20.7 / 26.6	27.6 / 20.2	24.1 / 4.8	11.2 / 0.0
7. Lack of communication between parts of HCS	3.03 (1.25)	2.02 (1.05)	116 / 125	14.7 / 42.4	19.8 / 24.0	26.7 / 24.0	25.9 / 8.8	12.9 / 0.8
8. Not explaining decision making	2.50 (1.15)	1.73 (0.96)	116 / 124	26.7 / 54.0	20.7 / 25.8	30.2 / 13.7	20.7 / 5.6	1.7 / 0.8
9. Not meeting child's sensory needs	2.27 (1.22)	1.45 (0.82)	115 / 125	37.4 / 72.8	20.0 / 12.0	26.1 / 13.6	11.3 / 0.8	5.2 / 0.8

Note. HCS = healthcare system.

Table 9
Knowledge Subscale Frequencies.

Knowledge	M (SD) Autism	M (SD) Non-Autism	Valid N	% Never	% Almost Never	%Sometimes	%Often	%Almost Always
1. Disagreeing with recommendations	2.62 (1.12)	1.64 (0.80)	117 / 124	23.1 / 54.8	15.4 / 28.2	42.7 / 15.2	14.5 / 1.6	4.3 / 0.0
2. Providers not believing in traditional/home tx	2.30 (1.21)	1.79 (1.09)	116 / 124	36.2 / 54.4	20.7 / 24.2	22.4 / 12.1	18.1 / 4.8	2.6 / 4.0
3. Instructions/ Recommendations seem wrong	2.33 (1.19)	1.65 (0.94)	116 / 124	32.8 / 59.7	23.3 / 22.6	26.7 / 12.9	12.9 / 3.2	4.3 / 1.6
4. Providers have different ideas about MH	2.58 (1.25)	1.62 (0.99)	117 / 124	28.2 / 63.7	17.1 / 19.4	29.1 / 10.5	19.7 / 4.0	6.0 / 2.4
5. Providers have different ideas about child needs	2.65 (1.20)	1.72 (1.00)	116 / 124	22.4 / 57.3	21.6 / 21.8	31.9 / 15.3	17.2 / 3.2	6.9 / 2.4
6. Providers not listening to concerns / ideas	2.48 (1.19)	1.73 (0.96)	117 / 124	27.4 / 53.2	23.9 / 27.4	16.5 / 13.7	17.9 / 4.0	4.3 / 1.6
7. Conflicting recommendations from diff providers	2.46 (1.13)	1.74 (0.99)	116 / 125	27.6 / 53.6	20.7 / 28.8	32.8 / 10.4	16.4 / 4.8	2.6 / 2.4

Note. Tx = treatment. MH= mental health. Diff = different.

Table 10
Pragmatic Subscale Frequencies

Pragmatics	M (SD) Autism	M (SD) Non-Autism	Valid N	% Never	% Almost Never	%Sometimes	%Often	%Almost Always
1. Getting hold of office by phone	2.71 (1.33)	2.09 (1.18)	117 / 124	24.8 / 37.9	20.5 / 34.7	24.8 / 16.1	18.8 / 3.2	11.1 / 8.1
2. Having to wait too long for apt	2.96 (1.25)	2.18 (1.12)	116 / 125	16.4 / 35.2	19.0 / 27.2	29.3 / 25.6	23.3 / 8.0	12.1 / 4.0
3. Getting care after hours/ weekends	2.82 (1.41)	2.25 (1.21)	117 / 123	24.8 / 34.1	17.9 / 28.5	24.8 / 22.8	15.4 / 7.3	17.1 / 7.3
4. Household responsibilities	3.09 (1.11)	2.38 (1.25)	117 / 125	12.8 / 32.0	9.4 / 23.2	42.7 / 28.8	25.6 / 7.2	9.4 / 8.8
5. Taking time off work	2.77 (1.27)	2.07 (1.01)	115 / 123	21.7 / 37.4	19.1 / 27.6	29.6 / 27.6	20.0 / 5.7	9.6 / 1.6
6. Having to wait too long in waiting room	2.85 (1.08)	2.58 (1.18)	117 / 124	12.8 / 21.8	19.7 / 26.6	44.4 / 29.8	15.4 / 15.3	7.7 / 6.5
7.Meeting the needs of other family members	3.07 (1.20)	2.47 (1.20)	117 / 122	12.0 / 25.4	18.8 / 28.7	33.3 / 27.0	22.2 / 11.5	13.7 / 7.4
8. The cost of appointments	2.73 (1.30)	2.09 (1.15)	117 / 124	24.8 / 41.9	16.2 / 22.6	31.6 / 24.2	16.2 / 7.3	11.1 / 4.0
9. Transportation	2.18 (1.37)	1.72 (1.33)	115 / 124	49.6 / 71.8	12.2 / 8.9	15.7 / 4.8	15.7 / 4.8	7.0 / 9.7
10. Services not covered	2.80 (1.26)	1.81 (0.93)	117 / 124	21.4 / 48.4	17.1 / 27.4	30.8 / 18.5	21.4 / 5.6	9.4 / 0.0
11. Finding providers in your area	2.84 (1.32)	2.01 (1.24)	115 / 125	22.6 / 48.0	17.4 / 24.8	23.5 / 12.0	26.1 / 8.8	10.4 / 6.4
12. No health insurance	1.88 (1.17)	1.40 (0.83)	116 / 125	56.0 / 76.0	15.5 / 12.8	16.4 / 8.0	8.6 / 1.6	3.4 / 1.6
13. No childcare	2.26 (1.29)	1.42 (0.80)	117 / 124	43.6 / 74.2	12.0 / 12.1	23.9 / 12.1	16.2 / .8	4.3 / 0.8
14. Not getting diagnosis that fits best	2.32 (1.21)	1.48 (0.85)	117 / 124	33.3 / 71.0	25.6 / 14.5	19.7 / 11.3	17.9 / 2.4	3.4 / 0.8
15. Not having diagnosis needed for services	2.43 (1.24)	1.57 (0.92)	116 / 125	31.9 / 64.8	22.4 / 20.0	19.0 / 10.4	24.1 / 3.2	2.6 / 1.6

Note. Apt = appointment.

Table 11
Marginalization Subscale Frequencies

Marginalization	M (SD) Autism	M (SD) Non-Autism	Valid N	% Never	% Almost Never	%Sometimes	%Often	%Almost Always
1. Feeling like providers are trying to give as little service as possible	2.61 (1.23)	1.92 (1.04)	116 / 125	24.1 / 44.8	20.7 / 28.8	33.6 / 18.4	12.9 / 5.6	8.6 / 2.4
2. Feeling like HCS is giving as little service as possible	2.87 (1.32)	1.98 (0.98)	116 / 124	20.7 / 38.7	18.1 / 34.7	27.6 / 17.7	20.7 / 8.1	12.9 / 0.8
3. Impatient providers	2.51 (1.28)	1.75 (0.96)	116 / 123	31.0 / 51.2	17.2 / 31.7	29.3 / 8.9	14.7 / 7.3	7.8 / 0.8
4. Intimidating providers	2.21 (1.17)	1.70 (0.90)	114 / 123	36.0 / 53.7	26.3 / 28.5	22.8 / 12.2	10.5 / 5.7	4.4 / 0.0
5. Rude staff	2.56 (1.21)	1.92 (1.00)	116 / 124	28.4 / 43.5	15.5 / 29.8	31.0 / 19.4	21.6 / 5.6	3.4 / 1.6
6. Uncaring staff	2.42 (1.08)	1.82 (0.98)	115 / 124	27.0 / 48.4	20.9 / 29.8	37.4 / 13.7	13.0 / 7.3	1.7 / 0.8
7. Getting provider to listen to you	2.76 (1.25)	2.28 (1.32)	115 / 123	19.1 / 37.8	26.1 / 24.4	23.5 / 21.1	22.6 / 6.5	8.7 / 10.6
8. Getting your questions answered	2.72 (1.12)	2.34 (1.35)	116 / 123	16.4 / 35.8	25.0 / 26.8	34.5 / 16.3	18.1 / 9.8	6.0 / 11.4
9. Not know what to expect	2.75 (1.24)	1.75 (0.96)	116 / 124	21.6 / 52.4	21.6 / 27.4	23.3 / 14.5	27.6 / 4.0	6.0 / 1.6
10. Judged on appearance	2.28 (1.37)	1.45 (0.91)	116 / 125	44.8 / 75.2	14.7 / 12.0	15.5 / 7.2	18.1 / 4.0	6.9 / 1.6
11. Rushed through visit	2.79 (1.24)	1.77 (1.04)	116 / 124	19.0 / 55.6	22.4 / 21.8	28.4 / 15.3	20.7 / 4.8	9.5 / 2.4
12. Judged on accent	1.94 (1.27)	1.29 (0.80)	115 / 123	59.1 / 83.7	8.7 / 9.8	13.9 / 1.6	15.7 / 3.3	2.6 / 1.6
13. Judged on race or ethnicity	1.91 (1.19)	1.32 (0.73)	116 / 124	56.9 / 79.8	9.5 / 11.3	22.4 / 5.6	7.8 / 3.2	3.4 / 0.0
14. Judged on where you live	1.91 (1.25)	1.30 (0.70)	116 / 125	59.5 / 80.8	10.3 / 10.4	11.2 / 6.4	17.2 / 2.4	1.7 / 0.0
15. Judged on parenting skills	2.30 (1.24)	1.44 (0.78)	115 / 124	36.5 / 71.8	20.0 / 15.3	25.2 / 10.5	13.0 / 2.4	5.2 / 0.0
16. Judged on gender	1.93 (1.28)	1.28 (0.66)	116 / 123	58.6 / 80.5	9.5 / 13.0	18.1 / 4.1	7.8 / 2.4	6.0 / 0.0
17. Judged on speaking ability	2.07 (1.33)	1.26 (0.65)	117 / 125	55.6 / 82.4	6.8 / 12.0	17.1 / 4.0	16.2 / 0.8	4.3 / 0.8
18. Judged on another aspect of identity	2.19 (1.33)	1.31 (0.69)	117 / 124	48.7 / 78.2	8.5 / 14.5	23.9 / 5.6	12.8 / 0.8	6.0 / 0.8
19. Judging child's behaviors	2.62 (1.23)	1.63 (0.94)	115 / 123	26.1 / 61.8	15.7 / 20.3	35.7 / 12.2	15.7 / 4.9	7.0 / 0.8
20. Worrying accessing services will make people see you differently	2.27 (1.28)	1.51 (0.85)	115 / 125	43.5 / 68.0	11.3 / 16.8	22.6 / 11.2	20.0 / 4.0	2.6 / 0.0
21. Worrying accessing services will make people see your child differently	2.52 (1.27)	1.50 (0.80)	117 / 123	31.6 / 66.7	15.4 / 19.5	27.4 / 12.2	20.5 / 0.8	5.1 / 0.8

Note. HCS= healthcare system.

Table 12
Correlations between BCQ Subscales, Full Sample

	Skills	Pragmatics	Expect	Knowledge
Skills	---			
Pragmatics	.84	---		
Expectations	.71	.81	---	
Knowledge	.69	.77	.84	---
Marginalization	.77	.84	.86	.83

Note. BCQ= barriers to care questionnaire. All correlations are statistically significant (p<.001 for all).

Table 13
Correlations between BCQ Subscales by Group

	Skills	Pragmatics	Expect	Knowledge	Marginalization
Skills	---	.78	.58	.55	.60
Pragmatics	.85	---	.74	.67	.75
Expectations	.73	.79	---	.81	.84
Knowledge	.70	.77	.80	---	.79
Marginalization	.83	.86	.82	.80	---

Note. BCQ= barriers to care questionnaire. All correlations are statistically significant (p<.001 for all). Correlations for autistic group fall below diagonal and correlations for non-autistic group fall above diagonal.

Table 14
Correlations with Barriers to Care Questionnaire in Full Sample

Variable	Skills	Marginalization	Expectations	Knowledge	Pragmatics
Key Outcome Variables					
Unmet Need	.23***	.19**	.13*	.18**	.21**
Treatment Experiences	**-.43*** **	**-.45*** **	**-.55*** **	**-.49*** **	**-.45*** **
Child-Level Factors					
ACEs	**.53*** **	**.58*** **	**.49*** **	**.51*** **	**.53*** **
QOL Total	**-.47*** **	**-.51*** **	**-.52*** **	**-.56*** **	**-.53*** **
Internalizing Difficulties	.38***	**.44*** **	**.44*** **	**.44*** **	**.40*** **
Externalizing Difficulties	.08	.17*	.27***	.15*	.20**
Autism Traits	.14*	.21**	.33***	.27***	.18**
Parent-Level Factors					
Autism Knowledge	-.24***	-.33***	-.17**	-.30***	-.26***
Perceived Stress	.33***	**.45*** **	**.47*** **	**.42*** **	**.47*** **
Dysphoria	.38***	**.51*** **	**.49*** **	**.45*** **	**.49*** **
Family-Level Factors					
FQOL Family	-.36***	**-.49*** **	**-.48*** **	**-.45*** **	**-.46*** **
FQOL Parenting	**-.42*** **	**-.53*** **	**-.54*** **	**-.49*** **	**-.45*** **
FQOL Physical	**-.41*** **	**-.50*** **	**-.57*** **	**-.50*** **	**-.51*** **
FQOL Emotional	-.26***	-.32***	**-.42*** **	-.31***	-.30***
Financial Stress	.32***	.32***	**.40*** **	.31***	**.40*** **
Discriminant Variables					
Parent Extraversion	-.06	-.14*	-.20**	-.15*	-.16*
Parent Agreeableness	-.14*	-.31***	-.29***	-.26***	-.27***
Parent Conscientiousness	-.30***	-.39***	**-.40*** **	-.35***	**-.42*** **
Parent Negative Emotionality	.21**	.32***	.33***	.26***	.32***
Parent Open Mindedness	-.07	-.21**	-.19**	-.22***	-.19**
Parent Social Desirability	-.11	-.34**	-.30***	-.29***	-.23***

Note. ACEs = adverse childhood experiences. QOL = quality of life. FQOL = family quality of life. *p≤0.05, **p≤0.01, ***p≤0.001. Correlations greater than or equal to .4 are bolded.

Table 15
Barriers to Care Questionnaire Correlations with Main Study Variables in ASD and Non-ASD groups.

Variable	Skills	Marginalization	Expectations	Knowledge	Pragmatics
Key Outcome Variables					
Unmet Need	.34*** / .14	**.43*** / -.03	.25* / .02	.35*** / .05	.38*** / .09
Treatment Experiences	-.37*** / -.25**	-.30*** / -.39***	**-.42*** / -.43***	-.31*** / **-.45***	-.30** / -.37***
Child-Level Factors					
ACEs	**.62*** / .07	**.66*** / .03	**.50*** / .07	**.56*** / -.02	**.62*** / .02
QOL Total	**-.43*** / -.19*	**-.46*** / -.18	-.39*** / -.26**	**-.51*** / -.25**	**-.49*** / -.25**
Internalizing Difficulties	.24* / .12	.24* / .26**	.20* / .23	.25** / .22*	.22* / .16
Externalizing Difficulties	-.12 / -.11	-.05 / .01	.05 / .06	-.13 / -.01	.04 / -.01
Autism Traits	-.35*** / .08	-.35*** / .24*	-.13 / .17	-.20* / .20*	-.32*** / .05
Parent-Level Factors					
Perceived Stress	**.41*** / .08	**.45*** / .30***	**.53*** / .23*	**.42*** / .21*	**.51*** / .27*
Dysphoria	**.44*** / .05	**.49*** / .32***	**.46*** / .27**	**.40*** / .25**	**.54*** / .22*
Autism Knowledge	-.34*** / -.17	**-.43*** / -.30***	-.21* / -.24**	**-.40*** / -.27**	**-.41*** / -.19*
Family-Level Factors					
FQOL Family	**-.42*** / -.01	**-.43*** / -.31**	**-.47*** / -.23*	**-.41*** / -.21	**-.46*** / -.20*
FQOL Parenting	**-.48*** / -.07	**-.51*** / -.32***	**-.51*** / -.32***	**-.45*** / -.28**	**-.43*** / -.23**
FQOL Physical	**-.40*** / -.17	**-.41*** / -.39***	**-.54*** / -.35***	**-.43*** / -.36***	**-.45*** / -.36***
FQOL Emotional	-.21* / -.06	-.18 / -.23*	-.37*** / -.22*	-.19* / -.18*	-.18 / -.20*
Financial Stress	.26*** / .17	.25* / .19*	**.43*** / .13	.26** / .12	.35*** / .26**
Discriminant Variables					
Parent Extraversion	-.01 / .01	-.07 / -.11	-.18 / -.10	-.12 / -.07	-.07 / -.14
Parent Agreeableness	-.26** / .09	**-.40*** / -.12	-.29** / -.19*	-.28** / -.13	-.34*** / -.10
Parent Conscientiousness	-.33*** / -.06	-.33*** / -.26**	-.32*** / -.26**	-.26** / -.21*	**-.41*** / -.26**
Parent Negative Emotionality	.27** / -.04	.25** / .21*	.28** / .17	.18 / .12	.30** / .16
Parent Open Mindedness	-.08 / .12	-.13 / -.17	-.06 / -.18	-.15 / -.15	-.18 / -.04
Parent Social Desirability	-.15 / .02	-.30** / -.32***	-.17 / -.35***	-.21* / -.29***	-.17 / -.20*

Note. Correlations before the / are for the ASD group and correlations after the / are for non-ASD group. Correlations greater than or equal to 0.40 are bolded. *p≤0.05, **p≤0.01, ***p≤0.001. ACEs = adverse childhood experiences. QOL = quality of life. FQOL = family quality of life.

Table 16
Hierarchical Regression Model, Full Sample

Variable	**Unmet Need** n=153		**Treatment Experiences** n=157	
Step one R^2	.03		**.19*****	
	b (SE)	β	b (SE)	β
Parent Race	-.75 (1.36)	-.05	-.53 (.80)	-.05
Child Autistic Traits	-.22 (.22)	-.12	-.12 (.13)	-.09
Child Externalizing	-12 (.32)	-.04	**-.37 (.19)**	**-.19***
Child Internalizing	.04 (.36)	.01	-.38 (.21)	-.19
Family Income	.00 (.00)	-.08	-.00 (.00)	-.02
Rural Status	-.15 (1.48)	-.01	1.40 (.86)	.12
Step two R^2	.09		**.35*****	
R^2 Change	.06		**.16*****	
	b (SE)	β	b (SE)	β
Parent Race	-.87 (1.35)	-.05	-.19 (.74)	-.02
Child Autistic Traits	-.17 (.23)	-.09	-.07 (.12)	-.05
Child Externalizing	-.03 (.34)	-.01	-.33 (.18)	-.17
Child Internalizing	-.33 (.37)	-.11	-.12 (.20)	-.06
Family Income	.00 (.00)	-.08	.00 (.00)	-.04
Rural Status	.86 (1.50)	.05	.56 (.81)	.05
BCQ Subscales				
Skills	.11 (.08)	.21	-.06 (.04)	-.18
Marginalization	.04 (.07)	.10	.02 (.04)	.10
Knowledge	.13 (.15)	.13	-.10 (.08)	-.15
Pragmatics	.00 (.11)	.01	.05 (.06)	.15
Expectations	-.14 (.14)	-.18	**-.20 (.08)**	**-.38***

Note. BCQ = Barriers to Care Questionnaire. *p≤0.05, **p≤0.01, ***p≤0.001

Table 17
Hierarchical Regression Model by Group

	ASD				**Non-ASD**			
	Unmet Need		**Treatment Experiences**		**Unmet Need**		**Treatment Experiences**	
Variable	n=70		n=73		n= 83		n=84	
Step one R^2	**.18***		**.22***		.08		.04	
	b (SE)	β	b (SE)	β	b (SE)	β	b (SE)	β
Parent Race	2.04 (1.58)	.16	**-3.03 (1.37)**	**-.26***	-2.22 (2.00)	-.12	.80 (.88)	.10
Child Autistic Traits	-.45 (.27)	-.21	-.18 (.23)	-.09	-.32 (.44)	-.10	.14 (.19)	.10
Child Externalizing	-.01 (.33)	-.00	-.46 (.29)	-.19	-.71 (.56)	-.16	.05 (.24)	.03
Child Internalizing	-.45 (.30)	-.19	-.07 (.26)	.03	.43 (.88)	.07	-.57 (.39)	-.21
Family Income	.00 (.00)	.02	.00 (.00)	-.21	.00 (.00)	-0.05	.00 (.00)	-.03
Rural Status	-3.02 (1.58)	-.23	**3.50 (1.33)**	**.31***	2.25 (2.42)	.11	.09 (1.07)	.01
Step two R^2	**.35***		**.38****		.12		**.27***	
R^2 Change	**.17***		**.15****		.04		**.23*****	
	b (SE)	β	b (SE)	β	b (SE)	β	b (SE)	β
Parent Race	1.70 (1.51)	.13	-1.98 (1.30)	-.17	-1.35 (2.10)	-.08	.99 (.82)	.13
Child Autistic Traits	-.15 (.29)	-.07	-.15 (.24)	-.08	-.28 (.46)	-.08	.09 (.18)	.06
Child Externalizing	-.04 (.34)	.02	**-.63 (.29)**	**-.26***	-.53 (.60)	-.12	.17 (.23)	.09
Child Internalizing	**-.75 (.30)**	**-.32***	.14 (.26)	.06	.54 (.93)	.08	-.24 (.37)	-.09
Family Income	.00 (.00)	-.04	.00 (.00)	-.18	.00 (.00)	-.05	.00 (.00)	-.03
Rural Status	-2.29 (1.56)	-.18	2.26 (1.31)	.20	3.07 (2.50)	.15	.20 (.98)	.02
BCQ Subscales								
Skills	-.07 (.09)	-.19	**-.17 (.08)**	**-.49***	.14 (.12)	.21	.06 (.05)	.20
Marginalization	**.19 (.07)**	**.73****	.02 (.06)	.10	-.14 (.14)	-.25	.04 (.05)	.16
Knowledge	.07 (.14)	.10	-.08 (.12)	-.13	.27 (.28)	.19	-.19 (.11)	-.30
Pragmatics	.02 (.12)	.06	.17 (.10)	.47	-.00 (.16)	-.00	-.04 (.06)	-.11
Expectations	-.22 (.13)	-.38	-.18 (.11)	-.33	-.05 (.27)	-.04	-.18 (.11)	-.37

Note. *p≤0.05, **p≤0.01, ***p≤0.001. BCQ = Barriers to Care Questionnaire.

Table 18
Average item score by subscale.

	Autism	Non-Autism
Skills	2.68	2.00
Marginalization	2.33	1.63
Knowledge	2.57	1.67
Pragmatics	2.58	1.95
Expectations	2.64	1.79
Total	2.43	1.80

Note. Item scale ranged from 1 (*Never*) to 5 (*Almost Always*).

Appendix A: Supplemental Materials

Supplemental Table 1
Pearson correlations Among Primary Study Variables – ASD Only

	Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1.	Child ACEs	---																			
2.	Child QOL Total	**-.42****	---																		
3.	Child Internalizing Difficulties	.16	**-.57****	---																	
4.	Child Externalizing Difficulties	-.24*	-.05	.19	---																
5.	Child Autism Traits	**-.44****	.01	.21*	.32**	---															
6.	FQOL Family	**-.45****	.25**	-.24**	-.10	.06	---														
7.	FQOL Parenting	**-.45****	.24*	-.26**	-.03	.09	**.85****	---													
8.	FQOL Physical	**-.56****	.37**	-.20*	-.02	.03	**.63****	**.67****	---												
9.	FQOL Emotional	-.13	.04	-.14	-.19*	-.14	**.67****	**.67****	**.56****	---											
10.	Parent Autism Knowledge	**-.54****	.31**	.02	.18	**.45****	.30**	.30**	.31**	-.13	---										
11.	Parent Extraversion	.09	.02	-.17	-.16	-.36**	.13	.15	.10	.30**	-.21*	---									
12.	Parent Agreeableness	**-.41****	.22*	-.04	-.07	.03	.37**	.33**	.29**	.26**	.27**	.17	---								
13.	Parent Conscientiousness	**-.41****	.36**	-.17	-.10	.06	.33**	**.40****	.37**	.18	.14	.05	.29**	---							
14.	Parent Negative Emotionality	.29**	-.20*	.23*	.24*	.07	-.39**	-.37**	-.37**	**-.46****	.17	-.31**	-.24**	**-.46****	---						
15.	Parent Open Mindedness	-.21*	.22*	-.11	.01	.12	.14	.10	.08	.07	.29**	.18	.21*	.07	-.12	---					
16.	Parent Stress	**.45****	-.37**	.29**	.18	.00	**-.58****	**-.53****	**-.54****	**-.59****	-.08	-.15	-.38**	**-.50****	**.76****	-.13	---				
17.	Parent Financial Stress	.27**	-.33**	.18	.08	.10	-.36**	-.36**	**-.57****	**-.49****	.08	-.09	-.06	-.22*	.34**	-.13	**.51****	---			
18.	Parent Dysphoria	**.48****	**-.48****	.39**	.17	-.07	**-.54****	**-.52****	**-.55****	**-.43****	-.22*	-.07	-.32**	**-.54****	**.66****	-.18	**.77****	.33**	---		
19.	Unmet Need	**.53****	-.20*	-.15	-.15	-.33**	-.27**	-.28**	-.25**	-.13	-.38**	-.03	-.39**	.04	.07	-.17	.10**	.03	.18	---	
20.	Treatment Experiences	-.08	.25**	-.21*	-.18	-.10	.32**	.31**	.30**	**.42****	-.18	.13	.26**	.11	-.29**	-.04	-.39**	-.38**	-.21*	-.21*	---
21.	Social Desirability	-.30**	.28**	-.10	.06	.15	.20*	.26**	.23*	.13	.30**	-.06	**.47****	.21*	-.07	.08	-.17	-.01	-.20*	-.25**	.12

Note. *p ≤ 0.05, **p ≤ 0.01. ACEs = adverse childhood experiences. QOL = quality of life. FQOL = family quality of life. Correlations greater than or equal to 0.4 are bolded.

Supplemental Table 2
Pearson correlations Among Primary Study Variables – Non-ASD Only

	Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1.	Child ACEs	---																			
2.	Child QOL Total	-.23**	---																		
3.	Child Internalizing Difficulties	.10	-.35**	---																	
4.	Child Externalizing Difficulties	-.01	-.21*	**.48****	---																
5.	Child Autism Traits	.11	-.21*	**.51****	.36**	---															
6.	FQOL Family	-.15	.29**	-.31**	-.26**	-.29**	---														
7.	FQOL Parenting	-.13	.36**	**-.49****	-.34**	**-.44****	**.78****	---													
8.	FQOL Physical	-.17	.25**	-.35**	-.19*	-.18	**.62****	**.68****	---												
9.	FQOL Emotional	-.20*	.36**	-.34**	-.24**	-.26**	**.70****	**.75****	**.66****	---											
10.	Parent Autism Knowledge	.01	.14	-.26**	.01*	-.18	.23*	.31**	.36**	.22*	---										
11.	Parent Extraversion	-.18*	.10	-.21*	-.21*	-.12	.23*	.26**	.33**	.31**	-.07	---									
12.	Parent Agreeableness	-.18	.14	-.23*	-.17	-.22*	.34**	.35**	.19*	.30**	.16	.19*	---								
13.	Parent Conscientiousness	-.14	.31**	**-.47****	**-.45****	-.27**	.37**	**.48****	.37**	.39**	.02	**.46****	**.44****	---							
14.	Parent Negative Emotionality	.25**	-.32**	.38**	.36**	.12	-.35**	**-.41****	-.28**	**-.41****	.06	**-.46****	-.32**	**-.62****	---						
15.	Parent Open Mindedness	-.05	.14	-.33**	-.23*	-.30**	.38**	**.40****	.26**	.22*	.38**	.20*	**.41****	.24**	-.19*	---					
16.	Parent Stress	.25**	**-.40****	**.40****	**.42****	.15	**-.52****	**-.53****	**-.48****	**-.55****	.01	**-.51****	-.32**	**-.65****	**.76****	-.17	---				
17.	Parent Financial Stress	.25**	-.15	.21*	.12	.10	-.22*	-.30**	**-.62****	-.34**	-.25**	**-.43****	-.08	-.27**	.16	-.14	**.42****	---			
18.	Parent Dysphoria	.22*	**-.40****	**.43****	.32**	.10	**-.40****	**-.48****	-.38**	**-.51****	-.05	-.36**	-.25**	**-.57****	**.74****	-.12	**.81****	.25**	---		
19.	Unmet Need	.07	-.10	-.04	-.22*	-.12	.00	.07	-.03	-.06	-.02	.05	.09	.14	-.20*	.15	-.06	.03	-.01	---	
20.	Treatment Experiences	-.18*	.26**	-.19*	-.04	-.06	.34**	.34**	**.46****	.25**	.30**	.08	.28**	.17	-.16	.17	-.24**	-.24**	-.25**	-.08	---
21.	Social Desirability	-.06	.23*	-.26**	-.19*	-.14	.39**	**.40****	.25**	.34**	.13	.13	**.58****	.35**	-.35**	.24**	-.33**	.07	-.31**	.15	.34**

Note. *p ≤ 0.05, **p ≤ 0.01. ACEs = adverse childhood experiences. QOL = quality of life. FQOL = family quality of life. Correlations greater than or equal to 0.4 are bolded.

Supplemental Table 3
Skills Inter- item Correlations – Full Sample

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Knowing how to make HCS work	---											
2. Providers not fluent in language	.32	---										
3. Providers speak too technically	.34	.68	---									
4. Getting referrals	.44	.50	.55	---								
5. Understanding recommendations	.48	.46	.51	.55	---							
6. Having enough info about HCS	.55	.36	.39	.54	.71	---						
7. Needing to be more knowledgeable	.52	.40	.49	.61	.59	.65	---					
8. Getting help with paperwork	.50	.50	.49	.53	.63	.61	.54	---				
9. Knowing what type of services to look for	.49	.32	.33	.53	.57	.65	.56	.56	---			
10. Knowing where to go for services	.44	.32	.32	.55	.60	.61	.51	.59	.77	---		
11. Knowing whether services are covered	.43	.25	.33	.46	.46	.52	.56	.44	.54	.52	---	
12. Knowing whether services are necessary	.46	.31	.34	.49	.53	.56	.47	.48	.70	.70	.58	---
13. Knowing whether services will work	.42	.29	.31	.52	.51	.53	.53	.47	.72	.63	.58	.76

Note. HCS = healthcare system. All correlations significant at $p<.001$ level.

Supplemental Table 4
Expectations Interitem Correlations, Full Sample

Variable	1	2	3	4	5	6	7	8	9
1. Offices not child friendly	---								
2. Mistakes by providers	.60	---							
3. Worrying that providers will not do what is right	.48	.62	---						
4. Treating symptoms, not cause	.45	.60	.66	---					
5. Getting a thorough evaluation	.43	.51	.49	.43	---				
6. Lack of communication between provider and other specialists	.56	.62	.60	.56	.60	---			
7. Lack of communication between parts of HCS	.54	.65	.59	.58	.66	.85	---		
8. Not explaining decision making	.46	.51	.60	.57	.46	.59	.57	---	
9. Not meeting child's sensory needs	.54	.51	.50	.46	.43	.45	.50	.53	---

Note. HCS= healthcare system. All correlations significant at $p<.001$ level.

Supplemental Table 5
Pragmatics Interitem Correlations, Full Sample

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Getting hold of office by phone	---													
2. Having to wait too long for apt	.53	---												
3. Getting care after hours/ weekends	.43	.63	---											
4. Household responsibilities	.51	.47	.39	---										
5. Taking time off work	.43	.41	.34	.46	---									
6. Having to wait too long in waiting room	.42	.44	.33	.42	.38	---								
7.Meeting the needs of other family members	.58	.43	.37	.68	.46	.43	---							
8. The cost of appointments	.46	.39	.30	.36	.51	.32	.48	---						
9. Transportation	.46	.25	.29	.36	.34	.14	.46	.36	---					
10. Services not covered	.31	.47	.29	.34	.39	.25	.29	.47	.27	---				
11. Finding providers in your area	.42	.35	.32	.50	.30	.28	.49	.32	.47	.46	---			
12. No health insurance	.35	.38	.26	.25	.34	.18	.24	.43	.39	.45	.32	---		
13. No childcare	.38	.41	.29	.40	.42	.24	.36	.35	.42	.45	.36	.54	---	
14. Not getting diagnosis that fits best	.38	.45	.34	.46	.42	.30	.36	.38	.37	.58	.39	.50	.59	---
15. Not having diagnosis needed for services	.44	.43	.31	.44	.39	.32	.40	.38	.40	.56	.48	.54	.56	.75

Note. Apt = appointment. All correlations are significant at $p<.001$ level.

Supplemental Table 6
Knowledge Interitem Correlations, Full Sample

Variable	1	2	3	4	5	6	
1. Disagreeing with recommendations		---					
2. Providers not believing in traditional/home treatment		.48	---				
3. Instructions/ Recommendations seem wrong		.71	.50	---			
4. Providers have different ideas about mental health		.66	.56	.68	---		
5. Providers have different ideas about child needs		.66	.46	.59	.72	---	
6. Providers not listening to concerns / ideas		.68	.55	.65	.64	.63	---
7. Conflicting recommendations from different providers		.54	.45	.63	.62	.63	.61

Note. All correlations significant at $p<.001$ level.

Supplemental Table 7
Marginalization Interitem Correlations, Full Sample

	Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1.	Feeling like providers are trying to give as little service as possible	---																			
2.	Feeling like HCS is giving as little service as possible	.77	---																		
3.	Impatient providers	.65	.67	---																	
4.	Intimidating providers	.63	.61	.66	---																
5.	Rude staff	.59	.60	.61	.61	---															
6.	Uncaring staff	.67	.62	.67	.70	.81	---														
7.	Getting provider to listen to you	.55	.51	.43	.45	.45	.46	---													
8.	Getting your questions answered	.41	.37	.29	.32	.31	.37	.69	---												
9.	Not know what to expect	.68	.69	.68	.60	.56	.63	.50	.40	---											
10.	Judged on appearance	.52	.52	.56	.70	.61	.60	.46	.39	.56	---										
11.	Rushed through visit	.65	.62	.69	.56	.61	.68	.43	.34	.70	.59	---									
12.	Judged on accent	.37	.37	.43	.57	.49	.44	.33	.23	.47	.72	.47	---								
13.	Judged on race or ethnicity	.32	.42	.42	.54	.48	.44	.37	.22	.43	.69	.43	.74	---							
14.	Judged on where you live	.43	.43	.48	.57	.53	.50	.42	.25	.48	.71	.49	.79	.80	---						
15.	Judged on parenting skills	.46	.50	.50	.55	.51	.52	.44	.32	.53	.70	.60	.52	.59	.55	---					
16.	Judged on gender	.37	.39	.45	.52	.43	.44	.42	.27	.50	.64	.44	.62	.62	.69	.63	---				
17.	Judged on speaking ability	.41	.48	.51	.57	.54	.47	.38	.22	.48	.69	.54	.80	.78	.82	.58	.66	---			
18.	Judged on another aspect of identity	.45	.49	.50	.55	.54	.52	.45	.30	.52	.74	.56	.70	.73	.70	.63	.72	.79	---		
19.	Judging child's behaviors	.59	.60	.59	.55	.59	.61	.55	.46	.65	.62	.59	.44	.51	.52	.66	.58	.51	.61	---	
20.	Worrying accessing services will make people see you differently	.40	.41	.46	.52	.48	.47	.38	.25	.49	.57	.49	.61	.59	.65	.49	.56	.66	.62	.48	---
21.	Worrying accessing services will make people see child differently	.46	.49	.49	.51	.44	.43	.35	.30	.52	.54	.52	.54	.54	.59	.47	.47	.63	.55	.53	.75

Note. HCS = healthcare system. All correlations significant at $p<.001$ level.

Supplemental Table 8
Skills Interitem Correlations by Group

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Knowing how to make HCS work	---	.08	**.21**	**.33**	**.52**	**.58**	**.44**	**.52**	**.45**	**.42**	**.43**	**.46**	**.43**
2. Providers not fluent in language	**.41**	---	**.50**	**.47**	**.27**	**.23**	.17	**.36**	.17	**.25**	.11	**.22**	**.23**
3. Providers speak too technically	**.34**	**.69**	---	**.42**	**.28**	**.24**	**.26**	**.25**	.11	.10	.16	**.22**	.10
4. Getting referrals	**.46**	**.44**	**.51**	---	**.50**	**.49**	**.44**	**.46**	**.49**	**.48**	**.23**	**.44**	**.43**
5. Understanding recommendations	**.39**	**.52**	**.59**	**.52**	---	**.80**	**.55**	**.56**	**.57**	**.56**	**.32**	**.54**	**.55**
6. Having enough info about HCS	**.49**	**.40**	**.44**	**.55**	**.60**	---	**.60**	**.59**	**.63**	**.61**	**.46**	**.59**	**.55**
7. Needing to be more knowledgeable	**.53**	**.45**	**.52**	**.62**	**.58**	**.67**	---	**.49**	**.45**	**.37**	**.42**	**.44**	**.43**
8. Getting help with paperwork	**.42**	**.56**	**.59**	**.53**	**.67**	**.59**	**.52**	---	**.56**	**.59**	**.41**	**.56**	**.50**
9. Knowing what type of services to look for	**.46**	**.36**	**.39**	**.49**	**.53**	**.65**	**.59**	**.50**	---	**.87**	**.43**	**.75**	**.77**
10. Knowing where to go for services	**.42**	**.34**	**.42**	**.58**	**.61**	**.59**	**.60**	**.56**	**.64**	---	**.40**	**.81**	**.75**
11. Knowing whether services are covered	**.36**	**.26**	**.33**	**.53**	**.52**	**.54**	**.59**	**.39**	**.59**	**.61**	---	**.49**	**.45**
12. Knowing whether services are necessary	**.39**	**.29**	**.32**	**.44**	**.46**	**.48**	**.40**	**.31**	**.60**	**.54**	**.61**	---	**.79**
13. Knowing whether services will work	**.31**	**.21**	**.27**	**.42**	**.39**	**.46**	**.48**	**.35**	**.62**	**.46**	**.63**	**.68**	---

Note. HCS = healthcare system. Correlations for autistic group fall below diagonal and correlations for non-autistic group fall above diagonal. Correlations significant at .05 level are bolded.

Supplemental Table 9
Expectations Interitem Correlations

Variable	1	2	3	4	5	6	7	8	9
1. Offices not child friendly	---	**.58**	**.48**	**.43**	**.31**	**.48**	**.49**	**.39**	**.60**
2. Mistakes by providers	**.53**	---	**.66**	**.66**	**.43**	**.63**	**.60**	**.50**	**.43**
3. Worrying that providers will not do what is right	**.34**	**.51**	---	**.68**	**.34**	**.57**	**.57**	**.60**	**.44**
4. Treating symptoms, not cause	**.37**	**.49**	**.59**	---	**.34**	**.60**	**.55**	**.64**	**.37**
5. Getting a thorough evaluation	**.38**	**.48**	**.51**	**.41**	---	**.47**	**.46**	**.34**	**.32**
6. Lack of communication between provider and other specialists	**.46**	**.52**	**.49**	**.46**	**.59**	---	**.83**	**.54**	**.40**
7. Lack of communication between parts of HCS	**.43**	**.61**	**.48**	**.52**	**.51**	**.80**	---	**.54**	**.43**
8. Not explaining decision making	**.37**	**.41**	**.49**	**.43**	**.44**	**.50**	**.47**	---	**.56**
9. Not meeting child's sensory needs	**.40**	**.44**	**.41**	**.44**	**.38**	**.31**	**.41**	**.41**	---

Note. HCS = healthcare system. Correlations for autistic group fall below diagonal and correlations for non-autistic group fall above diagonal. Correlations significant at .05 level are bolded.

Supplemental Table 10
Knowledge Interitem Correlations

Variable	1	2	3	4	5	6	7
1. Disagreeing with recommendations	---	**.34**	**.60**	**.46**	**.56**	**.55**	**.41**
2. Providers not believing in traditional/home tx	**.49**	---	**.39**	**.46**	**.33**	**.42**	**.36**
3. Instructions/ Recommendations seem wrong	**.72**	**.52**	---	**.64**	**.58**	**.57**	**.54**
4. Providers have different ideas about MH	**.65**	**.58**	**.63**	---	**.74**	**.63**	**.69**
5. Providers have different ideas about child needs	**.61**	**.49**	**.50**	**.62**	---	**.57**	**.73**
6. Providers not listening to concerns / ideas	**.66**	**.60**	**.64**	**.56**	**.59**	---	**.56**
7. Conflicting recommendations from diff providers	**.50**	**.46**	**.63**	**.46**	**.46**	**.57**	---

Note. HCS = healthcare system. Correlations for autistic group fall below diagonal and correlations for non-autistic group fall above diagonal. Correlations significant at .05 level are bolded.

Supplemental Table 11

Pragmatics Subscale Interitem Correlations

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Getting hold of office by phone	---	**.44**	**.41**	**.46**	**.25**	**.47**	**.62**	**.32**	**.24**	**.20**	**.35**	.14	.11	**.26**	**.32**
2. Having to wait too long for appointment	**.53**	---	**.54**	**.52**	**.36**	**.45**	**.43**	**.30**	.06	**.39**	**.21**	**.28**	**.25**	**.36**	**.33**
3. Getting care after hours/ weekends	**.39**	**.67**	---	**.38**	**.38**	**.27**	**.34**	.17	.15	**.25**	.17	.09	.14	.13	.14
4. Household responsibilities	**.49**	**.32**	**.33**	---	**.48**	**.49**	**.72**	**.30**	**.23**	**.28**	**.47**	**.21**	**.35**	**.46**	**.46**
5. Taking time off work	**.49**	**.34**	**.24**	**.36**	---	**.38**	**.40**	**.31**	**.23**	**.45**	**.24**	**.19**	**.43**	**.47**	**.40**
6. Having to wait too long in waiting room	**.34**	**.40**	**.35**	**.29**	**.36**	---	**.42**	**.22**	.07	**.26**	**.27**	**.20**	**.25**	**.30**	**.33**
7.Meeting the needs of other family members	**.49**	**.33**	**.33**	**.59**	**.43**	**.39**	---	**.46**	**.43**	**.33**	**.50**	**.19**	**.22**	**.31**	**.33**
8. The cost of appointments	**.51**	**.38**	**.32**	**.33**	**.59**	**.38**	**.43**	---	**.33**	**.47**	**.22**	**.42**	**.26**	**.35**	**.37**
9. Transportation	**.63**	**.35**	**.36**	**.45**	**.39**	.17	**.44**	**.34**	---	**.19**	**.51**	.18	**.19**	.15	**.26**
10. Services not covered	**.26**	**.41**	**.34**	**.24**	**.23**	**.20**	.14	**.38**	**.25**	---	**.21**	**.40**	**.39**	**.58**	**.52**
11. Finding providers in your area	**.40**	**.34**	**.36**	**.45**	**.22**	**.24**	**.39**	**.30**	**.38**	**.52**	---	**.25**	**.23**	**.27**	**.38**
12. No health insurance	**.43**	**.38**	**.31**	**.19**	**.37**	.12	**.21**	**.39**	**.53**	**.40**	**.29**	---	**.51**	**.54**	**.49**
13. No childcare	**.45**	**.39**	**.29**	**.34**	**.31**	**.20**	**.35**	**.30**	**.53**	**.34**	**.33**	**.50**	---	**.66**	**.59**
14. Not getting diagnosis that fits best	**.37**	**.39**	**.38**	**.36**	**.28**	**.27**	**.29**	**.30**	**.47**	**.47**	**.35**	**.42**	**.47**	---	**.86**
15. Not having diagnosis needed for services	**.44**	**.39**	**.33**	**.31**	**.26**	**.29**	**.36**	**.28**	**.47**	**.46**	**.45**	**.50**	**.45**	**.63**	---

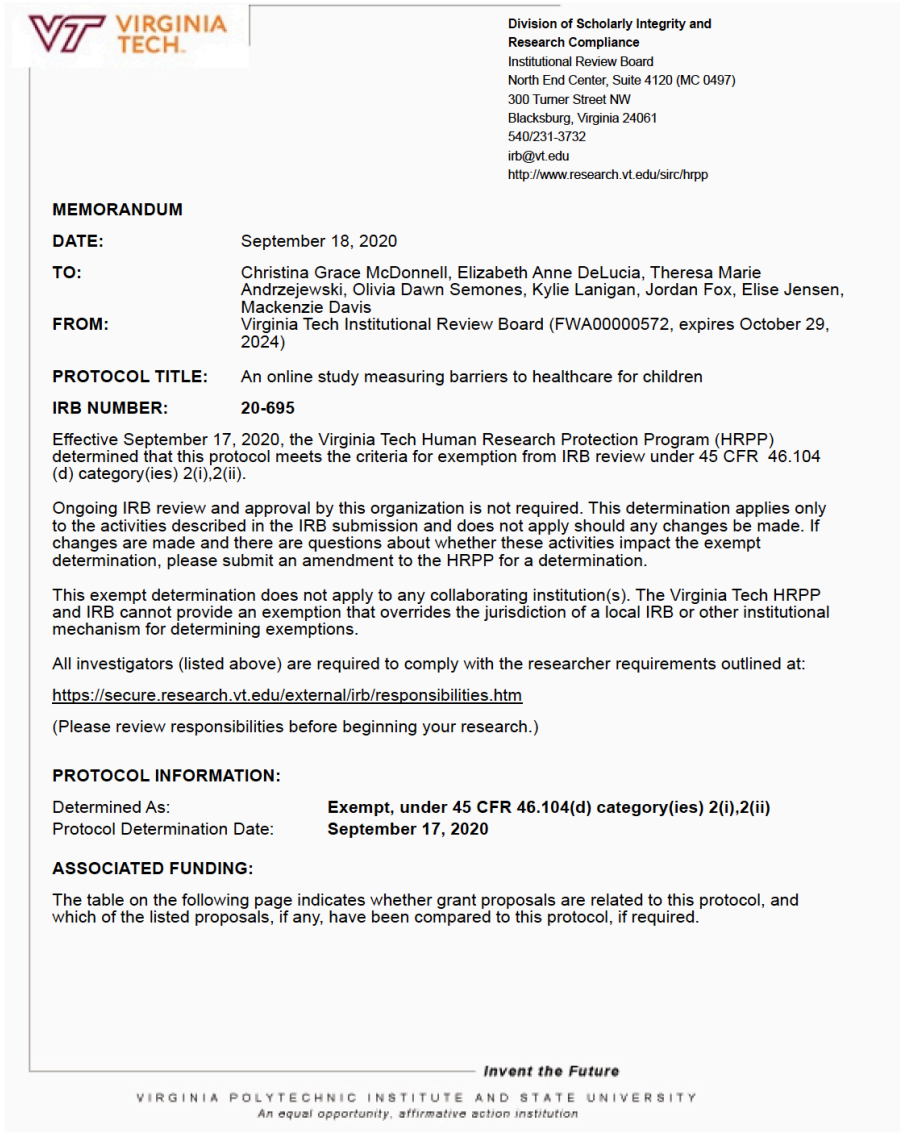
Note. Correlations for autistic group fall below diagonal and correlations for non-autistic group fall above diagonal. Correlations significant at .05 level are bolded.

Supplemental Table 12
Marginalization Subscale Interitem Correlations

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
1.Feeling like providers are trying to give as little service as possible	---	**.82**	**.67**	**.64**	**.56**	**.63**	**.51**	**.35**	**.58**	**.47**	**.59**	**.27**	**.24**	**.36**	**.24**	**.27**	**.33**	**.46**	**.51**	**.41**	**.43**
2. Feeling like HCS is giving as little service as possible	**.70**	---	**.66**	**.60**	**.51**	**.56**	**.44**	**.27**	**.56**	**.49**	**.64**	**.37**	**.33**	**.40**	**.27**	**.34**	**.39**	**.39**	**.49**	**.29**	**.35**
3. Impatient providers	**.58**	**.61**	---	**.71**	**.61**	**.68**	**.34**	**.25**	**.62**	**.47**	**.58**	**.37**	**.38**	**.42**	**.25**	**.36**	**.32**	**.36**	**.51**	**.34**	**.34**
4. Intimidating providers	**.58**	**.55**	**.59**	---	**.65**	**.75**	**.37**	**.26**	**.61**	**.66**	**.56**	**.54**	**.53**	**.57**	**.42**	**.44**	**.47**	**.46**	**.56**	**.54**	**.59**
5. Rude staff	**.55**	**.59**	**.54**	**.53**	---	**.86**	**.32**	**.25**	**.56**	**.62**	**.58**	**.46**	**.52**	**.59**	**.43**	**.35**	**.50**	**.47**	**.51**	**.41**	**.41**
6. Uncaring staff	**.65**	**.59**	**.61**	**.63**	**.75**	---	**.35**	**.34**	**.62**	**.60**	**.59**	**.40**	**.47**	**.55**	**.33**	**.28**	**.39**	**.47**	**.54**	**.40**	**.42**
7. Getting provider to listen to you	**.55**	**.54**	**.47**	**.49**	**.52**	**.52**	---	**.74**	**.41**	**.36**	**.34**	**.19**	**.29**	**.30**	**.22**	**.21**	**.24**	**.33**	**.51**	**.35**	**.32**
8. Getting your questions answered	**.45**	**.41**	**.29**	**.35**	**.32**	**.35**	**.60**	---	**.33**	**.27**	**.27**	.16	**.19**	**.24**	.14	.12	.15	**.21**	**.32**	**.24**	**.24**
9. Not know what to expect	**.69**	**.68**	**.64**	**.54**	**.47**	**.57**	**.55**	**.43**	---	**.48**	**.66**	**.34**	**.45**	**.41**	**.36**	**.31**	**.34**	**.40**	**.52**	**.41**	**.38**
10. Judged on appearance	**.47**	**.44**	**.41**	**.70**	**.54**	**.54**	**.50**	**.46**	**.50**	---	**.49**	**.66**	**.71**	**.75**	**.60**	**.53**	**.67**	**.71**	**.63**	**.52**	**.57**
11. Rushed through visit	**.62**	**.50**	**.68**	**.50**	**.56**	**.69**	**.45**	**.37**	**.62**	**.55**	---	**.36**	**.35**	**.47**	**.49**	**.39**	**.45**	**.46**	**.51**	**.32**	**.35**
12. Judged on accent	**.34**	**.26**	**.38**	**.54**	**.43**	**.40**	**.38**	**.24**	**.42**	**.70**	**.42**	---	**.76**	**.76**	**.55**	**.61**	**.84**	**.66**	**.35**	**.43**	**.46**
13. Judged on race or ethnicity	**.26**	**.37**	**.35**	**.50**	**.38**	**.35**	**.40**	**.20**	**.31**	**.64**	**.35**	**.69**	---	**.82**	**.60**	**.62**	**.73**	**.62**	**.49**	**.47**	**.49**
14. Judged on where you live	**.39**	**.34**	**.43**	**.54**	**.45**	**.42**	**.47**	**.23**	**.41**	**.66**	**.42**	**.78**	**.77**	---	**.57**	**.61**	**.77**	**.70**	**.46**	**.47**	**.52**
15. Judged on parenting skills	**.48**	**.48**	**.51**	**.57**	**.48**	**.55**	**.57**	**.42**	**.47**	**.68**	**.55**	**.42**	**.51**	**.47**	---	**.63**	**.61**	**.58**	**.58**	**.43**	**.49**
16. Judged on gender	**.33**	**.31**	**.41**	**.52**	**.40**	**.46**	**.52**	**.36**	**.48**	**.62**	**.37**	**.58**	**.57**	**.67**	**.57**	---	**.63**	**.65**	**.45**	**.43**	**.47**
17. Judged on speaking ability	**.36**	**.41**	**.49**	**.58**	**.50**	**.45**	**.43**	**.23**	**.41**	**.65**	**.49**	**.76**	**.77**	**.82**	**.48**	**.62**	---	**.78**	**.42**	**.51**	**.55**
18. Judged on another aspect of identity	**.36**	**.42**	**.46**	**.55**	**.51**	**.48**	**.51**	**.33**	**.44**	**.69**	**.49**	**.67**	**.72**	**.65**	**.55**	**.69**	**.75**	---	**.52**	**.54**	**.54**
19. Judging child's behaviors	**.56**	**.55**	**.55**	**.48**	**.56**	**.59**	**.55**	**.57**	**.61**	**.52**	**.50**	**.38**	**.43**	**.46**	**.60**	**.57**	**.44**	**.55**	---	**.42**	**.51**
20. Worrying accessing services will make people see you differently	**.29**	**.35**	**.42**	**.45**	**.44**	**.44**	**.35**	**.23**	**.41**	**.53**	**.48**	**.64**	**.59**	**.68**	**.40**	**.54**	**.60**	**.57**	**.39**	---	**.83**
21. Worrying accessing services will make people see child differently	**.37**	**.42**	**.44**	**.40**	**.34**	**.33**	**.31**	**.31**	**.43**	**.41**	**.45**	**.48**	**.48**	**.55**	**.30**	**.36**	**.57**	**.44**	**.38**	**.65**	---

Note. HCS = healthcare system. Correlations for autistic group fall below diagonal and correlations for non-autistic group fall above diagonal. Correlations significant at .05 level are bolded.

Appendix B: IRB Approval Letter



VIRGINIA TECH

Division of Scholarly Integrity and Research Compliance
Institutional Review Board
North End Center, Suite 4120 (MC 0497)
300 Turner Street NW
Blacksburg, Virginia 24061
540/231-3732
irb@vt.edu
http://www.research.vt.edu/sirc/hrpp

MEMORANDUM

DATE: September 18, 2020

TO: Christina Grace McDonnell, Elizabeth Anne DeLucia, Theresa Marie Andrzejewski, Olivia Dawn Semones, Kylie Lanigan, Jordan Fox, Elise Jensen, Mackenzie Davis

FROM: Virginia Tech Institutional Review Board (FWA00000572, expires October 29, 2024)

PROTOCOL TITLE: An online study measuring barriers to healthcare for children

IRB NUMBER: **20-695**

Effective September 17, 2020, the Virginia Tech Human Research Protection Program (HRPP) determined that this protocol meets the criteria for exemption from IRB review under 45 CFR 46.104 (d) category(ies) 2(i),2(ii).

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit an amendment to the HRPP for a determination.

This exempt determination does not apply to any collaborating institution(s). The Virginia Tech HRPP and IRB cannot provide an exemption that overrides the jurisdiction of a local IRB or other institutional mechanism for determining exemptions.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

https://secure.research.vt.edu/external/irb/responsibilities.htm

(Please review responsibilities before beginning your research.)

PROTOCOL INFORMATION:

Determined As: **Exempt, under 45 CFR 46.104(d) category(ies) 2(i),2(ii)**
Protocol Determination Date: **September 17, 2020**

ASSOCIATED FUNDING:

The table on the following page indicates whether grant proposals are related to this protocol, and which of the listed proposals, if any, have been compared to this protocol, if required.