

**Client-Level Barriers to Successful Utilization of Telehealth
for Clients with Autism Spectrum Disorder**

Dissertation

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By

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Abstract

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and repetitive, restricted behaviors, with a current estimated prevalence of 1:54. Individuals with ASD typically benefit from a range of medical, psychological, and other services due to impairments caused by ASD as well as high rates of comorbid conditions. Despite this increased need, individuals with ASD and their families often report significant difficulty accessing services, an issue which is compounded for some groups including minoritized racial groups and people living in rural areas. The current study sought to identify challenges faced by clients with ASD and their families when attempting to access behavioral health services via telehealth within the context of the COVID-19 pandemic. Specific research questions were: (1) What are the most common challenges faced by clients with ASD and their families when attempting to access telehealth services? (2) What are the most problematic barriers (i.e., barriers most associated with being unable to access telehealth) faced by clients with ASD and their families when attempting access telehealth services? and (3) Which demographic groups (e.g., race, age, comorbidities) are least likely to be able to access telehealth?

Data were extracted from client records of a multi-site provider of developmental disability (DD) services in Ohio following Institutional Review Board (IRB) approval. Results of our analyses suggest that the most common challenges faced by clients with

ASD and their families were issues related to client behavior, including client inattention, client noncompliance, and need for in-person support. In regard to ability versus inability to access telehealth services, need for in-person support was found to be related to decreased likelihood of receiving telehealth services, and client inattention was found to be related to increased likelihood of receiving telehealth services. Demographic groups most likely to experience difficulty accessing telehealth services were African American/Black clients and clients with a language disorder.

Results of the current study re-iterate challenges identified in previous studies on healthcare access for clients with ASD and their families, including issues related to behavior and communication difficulties. They also highlight the effects of race on access to services, with minoritized racial groups consistently being found to experience increased challenges in accessing healthcare. While future research should further study these effects on additional samples and outside of the context of COVID-19, the current results provide information on where interventions designed to increase access to behavioral health services may be most efficiently targeted. Possible solutions to address identified issues are discussed.

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Field of Study

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Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and repetitive, restricted behaviors (American Psychiatric Association, 2013). Current estimates suggest a prevalence rate of 1:54 American children, with a 4:1 male to female ratio (Centers for Disease Control and Prevention, 2020). A significant number of individuals with ASD have at least one comorbid condition, with the most common being seizures, multisystem disorders (e.g., gastrointestinal disorders, auditory disorders and infections), and psychiatric disorders (e.g., anxiety disorders, obsessive compulsive disorder [OCD], oppositional defiant disorder [ODD] attention deficit and hyperactivity disorder (ADHD; Doshi-Velez et al., 2014; Joshi et al., 2010, Brookman-Frazee et al., 2009; Brookman-Frazee et al., 2018). Due to the lifelong, pervasive nature of ASD, support and services often involve a wide range of professions, including speech therapy, medicine, occupational therapy, psychology, and special education (CDC, 2019). The required breadth and intensity of services contribute to an estimated increase in annual cost of care in excess of \$17,000 as compared to typically developing children (Lavelle et al., 2014). The cost of supporting adults with ASD can be even higher, contributing to an estimated lifetime cost of over \$2 million per individual (Buescher et al., 2014). This cost of care illustrates the level and complexity of care often required by people with ASD in order to promote maximum independence and quality of life. Unfortunately, this increased need for care is often not

met with adequate resources for providing such care. In the 2002 Surgeon General's report on health of persons with intellectual disability (ID), it is highlighted that individuals with ID report poorer access to care, including difficulties finding, accessing, and traveling to care (Office of the Surgeon General, 2002). While not all individuals with ASD have ID, this report was an early acknowledgement of the healthcare disparities faced by individuals with developmental disabilities (DD), and later research would expand this finding to focus more specifically on healthcare access for individuals with ASD.

Medical Care and ASD

Core features of ASD such as communication difficulties, sensory sensitivities, and difficulty with changes in routine often complicate the process of accessing medical care. Parents of children with ASD have reported significant barriers to accessing healthcare services for their children, citing difficulties with provider communication, limited provider knowledge about ASD, and feeling unheard (Boshoff et al., 2021). When attempting to access medical care, parents of children with ASD have reported that they often have to explain ASD to their medical providers but that providers do not always appear to value parent input (Muskat et al. 2016; Nicholas et al., 2016; Russell & McCloskey, 2016). Parents have also reported that, when giving instructions or explaining medical procedures, medical providers commonly use language that is difficult for their children with ASD to understand, leading to confusion and frustration for their children (Brown & Brown, 2014; Muskat et al., 2015; Nicholas et al. 2016). When medical providers are unfamiliar with ASD, parents reported that providers seem

to view meltdowns or sensory sensitivity as bad behavior, leading to criticisms of parenting skills and have led to the use of intrusive strategies such as physical restraint (Brown & Brown, 2014; Stein Duker et al. 2017).

Adults with ASD report even more difficulty accessing services than children, despite higher need (Turcotte et al. 2016). Specific barriers include difficulties with sensory discomfort, completing paperwork, sitting in the waiting room, communicating with staff, and misinterpretation of behaviors by staff (Stein Duker et al., 2019). Adults with ASD living with family have been found to report decreased service use, higher unmet need, and increased obstacles to accessing services compared to adults with ASD not living independently or in a supported living facility (Dudley et al., 2019). Correlates of increased service access for adults with ASD include comorbid mental health conditions and adaptive behavior deficits with members of minoritized racial and ethnic groups and adults with higher levels of problem behaviors experiencing increased challenges accessing services (Taylor et al., 2015). Similar to reports from parents of children with ASD, a survey of primary care physicians identified lack of training in providing service to adults with ASD as a significant barrier to healthcare access (Bruder et al. 2012). This is consistent with other, broader research demonstrating a lack of physician education on developmental disabilities (Holder et al., 2009; Symons et al., 2009) and significant barriers to care for adults with developmental disabilities (Prokup et al., 2018). Despite calls to actions and various proposed models for increased disability-related education—including ASD-specific education (Havercamp et al., 2016)—in the medical field, these barriers appear to persist (Bowen et al., 2020).

Independent Living and ASD

Greater independence (e.g., employment, independent residence) is typically associated with higher objective and subjective quality of life measures for adults with ASD (Bishop-Fitzpatrick et al., 2016). Despite this, only about 17% of young adults with ASD have lived independently, lower than rates seen for young adults with intellectual disability, learning disability, or emotional disturbance (Anderson et al., 2014). The same study suggested that correlates of increased likelihood of independent living included being White, having better communication skills and functional skills, and having a higher household income. Adults with ASD often experience lower proficiency with daily living skills than would be predicted based solely on their cognitive ability, demonstrating the need for support related to increasing daily living skill (Bal et al., 2015). However, adults with ASD and their families report difficulty accessing supports related to employment and residential living (Graetz, 2010).

Caregiver Support and ASD

Caregivers of children with ASD report higher stress levels than caregivers of typically developing children or children with other disabilities such as Down syndrome (Dabrowska & Pisula, 2010; Li et al., 2018) as well as lower relationship satisfaction (Sim et al., 2016). Specific behavioral factors associated with increased caregiver stress include high rates of behavior problems (Lecavalier et al., 2006) and periodic increases in restricted and repetitive behaviors (Harrop et al., 2006). Parents of children with ASD reported that more stressful than tasks related to direct support for their child are tasks related to advocacy (Shepherd et al., 2018), which includes navigating the numerous

barriers to accessing medical care (Parker & Killian, 2020). Specific expressed needs of parents of children with ASD included needing more information and guidance, assistance finding providers and navigating the healthcare system, and emotional support (Derguy et al., 2015). Among racial and ethnic minorities, these stress levels are often even higher due to the effects of the intersectionality of their child having a disability and being part of a minoritized group. These parents reported increased difficulty navigating the system, lack of community support and understanding, prejudice from providers, and language barriers (Iadarola et al., 2019). Interventions such as mindfulness-based therapy and parent support groups have been shown to be somewhat effective for reducing parent stress and improving parenting style in parents of children with ASD (Rutherford et al., 2019). Involving caregivers in the therapy process with their children through parent-mediated therapy has also been found to decrease caregiver stress (Turner-Brown et al., 2019).

Behavioral Health Services and ASD

Access to behavioral health services is a particularly important issue for individuals with ASD and their families. Primary care physicians have more difficulty finding mental health providers for their patients than other specialist providers (Cunningham, 2009). Between 1997 and 2010, unmet need for behavioral health services rose from 4.3 million to 7.2 million (Roll et al., 2013). As of 2008, only 63% of counties in the United States had a facility that provided outpatient mental health treatment for children and adolescents, and fewer than half of U.S. counties had a facility with any special programs for youth with severe emotional disturbance (Cummings et al., 2013).

Current numbers are likely to be even lower considering the decreases in mental health funding since 2008 (Honberg et al., 2011; National Alliance on Mental Health, 2015). In some states, over half of counties are without a psychologist or psychiatrist (Summers-Gabr, 2020). Presence of a mental health provider is only one factor impacting access to care, however, as a significant number of people report exceptional difficulty finding a mental health provider that accepts their insurance, more so than for other specialty providers (National Alliance on Mental Health, 2018).

Psychotherapy and Intervention

Especially important for best long-term outcomes are early intervention services, typically defined as services received before the age of 3 years old (Hyman et al., 2020). While early intervention services typically include behavioral therapy such as therapies based in applied behavior analysis (e.g., ABA) as well as therapies from allied fields such as occupational therapy and speech therapy, psychotherapy has also been found to be beneficial for older individuals with ASD, especially those with comorbid mental health conditions (Ruberman, 2002). Research into specific therapeutic techniques has demonstrated that a variety of approaches can be beneficial for individuals with ASD. Cognitive behavioral therapy (CBT) has been found to be effective for improving interaction with peers (Wood et al., 2020), anxiety symptoms (Driscoll et al., 2020; Hunsche & Kerns, 2019; Murphy et al., 2017; Perihan et al., 2020), obsessive-compulsive symptoms (Hamatani et al., 2020; Vause et al., 2020), and depressive symptoms (McGillivray et al., 2014; Sizoo & Kuiper, 2017). Though research on other therapeutic techniques is more limited, mindfulness-based therapy (Spek et al., 2013), person-

centered therapy (Murphy et al., 2017), and acceptance and commitment therapy (ACT; Byrne & O'Mahony, 2020; Pahnke et al., 2019) have also been found to be beneficial for reducing anxious and depressive symptoms and improving daily living skills in individuals with ASD.

Appropriately trained specialists are necessary for treatment, as modifications to traditional psychotherapy are often needed when working with individuals with ASD. Such considerations may include changes to the therapy itself—such as increased use of written and visual information, reduced complexity and abstractness of language, creation of clear and consistent expectations of boundaries, involvement of a caregiver, allowance for breaks, and incorporation of special interests—as well as changes to the therapy setting, including lowered lighting and reduced noise (National Institute for Health Care Guidance [NICE], 2021). Clients with ASD may also need support with additional skills including social interaction, emotion recognition, expression of emotions, and management of problem behaviors prior to and while addressing co-occurring mental health problems (Walters et al., 2016). For trauma-focused CBT (TF-CBT), common adaptations to therapeutic techniques for individuals with ASD include increased length of treatment, shortened session length, increased psychoeducation, and increased focus on emotion recognition and regulation (Stack & Lucyshyn, 2019). When treating symptoms of OCD with CBT, common modifications include increased psychoeducation and greater involvement of caregivers, and incorporation of visual session materials (Jone & Jassi, 2020). For treatment of anxiety with CBT, adaptations such as increased use of visual and concrete session materials, increased parent participation, and incorporation of

child interests (Moree & Davis, 2010), though some research has suggested that a separate form of CBT may be more beneficial when treating anxiety in individuals with ASD than modifications to existing CBT protocols (Wood et al., 2009). In particular, these ASD-specific forms of CBT typically incorporate more focus on ASD-specific goals such as practicing perspective-taking, friendship skills training, and self-help skills (Sze & Wood, 2008). Adults with ASD have also reported that written communication and clearly structured sessions are helpful modifications (Lipinski et al., 2019).

Diagnostic Assessment

The average age of ASD diagnosis is around four years old, despite parents of children with ASD often beginning to notice atypical development in their child between 15 and 22 months of age (Johnson & Myers, 2007; Zuckerman et al., 2015). In several subgroups, the average age of diagnosis is even higher—over 5 years old for Black children (Constantino et al., 2020) and approximately 7 years old for children living in rural areas (Shattuck et al., 2009). The delay in diagnosis for these groups is not surprising given other research on healthcare disparities. People who live in remote areas tend to report both lower access to health-related services and poorer health as well as being more likely to forgo healthcare (Towne, 2017). Despite organized efforts such as those by the National Health Service Corps—a loan repayment program for healthcare providers practicing in areas of high need—only 9% of physicians practice in rural areas (Council of State Governments, 2011), whereas 19% of the population lives in rural areas (Ratcliffe et al., 2016). As of December 31, 2020, 3,409 rural counties were designated as Mental Health Professional Shortage Areas by the Health Resource Services

Administration (HRSA), meaning they lack sufficient mental health providers (e.g., psychiatrists, psychologists, licensed mental health counselors) to meet base need (HRSA, 2020). The Council of State Governments (CGS) estimates that 49% of new physicians, 54% of new dentists, and 71% of new psychiatrists need to practice in non-metropolitan areas to meet recommended provider-to-population ratios (CGS, 2011). For behavioral health services, estimates suggest that 20,000 more psychologists are needed to meet current unmet need (Markit, 2018). However, healthcare in remote areas appears to be headed in the opposite direction as cuts to Medicare and Medicaid have resulted in rising amounts of rural hospital closures, including 98 hospital closures in rural areas between 2010 and 2019 (Bauerlein, 2014; Seigel, 2019).

Previous research has also demonstrated disparities in healthcare access and quality for racial and ethnic minorities, resulting in higher mortality rates and rates of illness (US Department of Health and Human Services, 1985). Despite reports on these disparities, such as The Institute of Medicine's *Unequal Treatment*, Black-White and Hispanic-White disparities in access to mental health services increased between 2004 and 2012 (Cook et al., 2017). Black patients have also been shown to be less likely than White patients to receive follow-up care following inpatient psychiatric treatment (Carson et al., 2014). As recently as 2019, the National Healthcare Quality and Disparities Report showed continued disparities in access to behavioral and mental healthcare services for racial and ethnic minorities (US Department of Health and Human Services, 2019). A survey of Black patients suggested that reasons for unmet mental

healthcare needs included feelings of stigma, fear of discrimination, and minimization of symptoms by professionals (Alang, 2019).

In addition to these barriers, the delay between first concerns and diagnosis is further fueled by a shortage of specialized providers, causing a wait time of 12 months or more for initial assessment (Chiri & Warfield, 2012; Dawson & Bernier, 2013; Gordon-Lipkin et al., 2016; Siklos & Kerns, 2007). Previous research has found that over 80% of counties in the United States lack ASD-specific diagnostic resources, meaning that families are often required to travel a significant distance to receive a diagnosis (Ning et al., 2019). Even when mental health providers exist, they may not be qualified to diagnose ASD in individuals with cooccurring mental health disorders or to address mental health disorders when comorbid with ASD and other developmental disabilities. In the absence of these specialized providers, diagnosis may often fall on professionals who may not have the adequate training. As many as 70% of people with ASD experience at least once cooccurring mental health disorder (Dominick et al. 2007; Leyfer et al. 2006). These additional diagnoses can include conditions such as anxiety disorders, major depressive disorder, schizophrenia, psychosis, OCD, tic disorders, attention deficit hyperactivity disorder, bipolar disorder, language impairment, catatonia, eating disorders, hoarding, borderline personality disorder, and oppositional defiant disorder (Mannion et al. 2014; Matson & Goldin, 2013). People with DD, including ASD, are also more likely to experience abuse and other trauma likely to lead to the development of post-traumatic stress disorder (PTSD; Kerns et al., 2015). These high rates of comorbidities are complicate the diagnostic process as symptoms of these disorders can overlap with

symptoms of ASD. For example, care must be taken to distinguish symptoms of anxiety, trauma, or obsessive thoughts from those of ASD (Kerns, 2012; Wood & Gadow, 2010). Similarly, a diagnosis of ASD or other developmental disability can cause comorbidities to be more likely to be missed due to diagnostic overshadowing, a phenomenon where symptoms of cooccurring mental illness are misattributed to ASD (Reiss et al., 1982; Simonoff et al., 2008). For these reasons, people with DD need access not only to mental health professionals, but mental health professionals who specialize in DD.

Telehealth Services

As early as the 1800s, healthcare professionals began to question how technology such as the telephone might be used to provide health services available without requiring professionals and clients to be in the same room (Nesbitt, 2012). Since that time, telehealth has grown substantially, though significant variance in definitions, practices, regulation, and coverage by insurance companies remains (American Psychological Association, 2020). “Telemedicine”—meaning “healing at a distance”—was officially coined in the 1970s (Strehle & Shabde, 2006). The World Health Organization (WHO) uses the following definition (WHO, 1997):

The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities. (p. 10)

The Health Resources Services Administration (HRSA) defines telehealth as “the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration” (HRSA, 2019). In their 2009 report, the WHO noted that some make a distinction between “telehealth” and “telemedicine,” with the former being a broader term and the latter referring specifically to services provided by physicians; however, these terms are often used interchangeably (WHO, 2009). The current study will primarily use the term “telehealth” to focus on the provision of behavioral health services, including mental health services.

Currently, psychological telehealth services are most commonly provided via telephone or video conference (Luxton, Pruitt, & Osenbach, 2014). Methods of therapy span the range of therapies utilized during in-person therapy, including cognitive behavioral therapy (CBT), acceptance and commitment therapy (ACT), dialectical behavior therapy (DBT), and mindfulness (Larsen et al., 2019). A recent meta-analysis found evidence supporting small to medium effects for depression, anxiety, substance abuse, and general mental health interventions provided via telehealth (Bennett et al., 2020). Previous research also demonstrates shorter hospital stays for children presenting to rural hospitals with anxiety, depression, self-harm, or suicidality when telehealth behavioral health services were available (Fairchild et al., 2020).

Telehealth and ASD

Telehealth can be useful for clients with ASD as well. Feedback from parents of clients with ASD has suggested that they believe telehealth is an acceptable and effective

way to receive services and as well as being more accessible than services offered in a clinic setting, both in terms of cost and physical accessibility. This is especially true for clients who are from low income families and/or who live in rural areas (Little et al., 2018).

Medical Services.

Though ASD-specific research on psychiatric services provided through telehealth is limited, they have been found to be an effective way to reach clients with developmental disabilities (DD) for medication management and mental health evaluation, especially those in rural areas (Gentile et al., 2018; Szeftel et al., 2012). Other research studies have suggested telehealth for primary care appointments have shown benefits for pediatric clients with DD and their families, including increased client cooperation, slower appointment pace, and lower reported client and family stress levels (Langkamp et al., 2015). However, some patients may have more difficulty with accessing medical services via telehealth, including those who are actively suicidal and those who require physical examination, and it may be more difficult for providers to communicate effectively, build rapport, and acquire certain types of information such as embarrassing side effects or reports of sexual abuse, especially if more people are involved in the appointment to facilitate telehealth (Szeftel et al., 2011).

Independent Living.

While research on telehealth and independent living is extremely limited for individuals for ASD specifically, telehealth services have been used to offer more independence for clients with intellectual disability (ID) living in integrated community

settings (Taber-Doughty et al., 2010). Rather than requiring staff in the home, technology such as cameras, phones, computers, and sensors can be used to provide remote support (Tassé, Wagner, & Kim, 2020). Video prompting and modeling via iPad have also been used to teach new independent living skills (Kellems et al., 2018; Cullen et al., 2017) and even vocational skills (Cavkaytar et al., 2017) to young adults with DD. Technology has also been used to facilitate self-prompting for adults with DD, with results suggesting effectiveness for improving proficiency with daily living skills (Cullen & Alber-Morgan, 2015). One of the few studies exploring telehealth and independent living skills in younger children with DD also demonstrated positive results for self-monitoring via technology (Jimenez-Gomez et al., 2021).

Diagnostic Assessment.

Some psychological assessments, including gold-standard assessments for ASD, have been attempted via telehealth with encouraging results, but more data on this are needed to fully understand how this method of administration compares to in-person administration (Alfuraydan et al., 2020; Goldstein et al., 2017; Reese et al., 2013). While assessment via standard live video conference or recorded videos is most common, specific interfaces for administration of measures such as the Autism Diagnostic Observation Schedule--Second Edition (ADOS-2) have also been created that allow the assessor and client to interact with the measure in unique ways (e.g., showing pictures on-screen, integrated scoring). A few studies evaluated the use of one of these specialized interfaces for adult ASD assessment, with positive results (Schutte et al., 2015; Parmanto et al., 2013). One example of assessment via recorded video is the Naturalistic

Observation Diagnostic Assessment (NODA) for ASD, which involves a developmental interview as well as guided home videos recorded in the following settings -- (1) family meal time, (2) playtime with others, (3) playtime alone, and (4) parent concerns (Smith et al., 2017). Other research has suggested that parent-facilitated infant ASD screening may also be able to be provided via telehealth (Talbot et al., 2020) as well as screenings for toddlers (Dahiya et al., 2020). These studies also utilized live video conferencing as well as mobile application. In addition to providing promising results on efficacy, studies that solicit parent feedback from these types of screenings have suggested that they are generally a positive experience for parents (Corona et al., 2021). Encouraging results have also been found for telehealth assessment of common comorbidities such as language disorders (Sutherland et al., 2019).

Intervention and Therapies.

Research has also suggested that behavioral therapies, such as those based in applied behavior analysis (ABA), may be provided effectively via telehealth (Marino et al., 2020; Neely et al., 2021). Research has suggested that many clients with ASD can transition to telehealth ABA services from in-person services while maintaining rate of progress (Pollard et al., 2021). A recent review of existing data on ABA-based intervention for clients with ASD provided via telehealth reported generally favorable results, though they noted that these results should be interpreted with caution as overall quality of related research was low (Ferguson et al., 2019). Existing research on functional communication training via telehealth found a reduction in problem behavior

(Lindgren et al., 2020; Wacker et al., 2013) and some evidence for reduced resurgence of problem behavior (Suess et al., 2020).

Evidence has also been found supporting the efficacy of psychotherapy through telehealth, though this is more limited. Previous research has suggested that cognitive behavioral therapy for symptoms of anxiety in clients with ASD may be able to be effectively administered via telehealth (Kalvin et al., 2021; Hepburn et al., 2016). Other research has provided evidence for successful telehealth implementation of acceptance and commitment therapy for clients with ASD (Cameron et al., 2020). Telehealth interventions focused on social emotional skills have also been evaluated, preliminary results have suggested both feasibility and efficacy (Tang et al., 2021).

Parent Support and Training.

Parents of clients can also benefit from virtual service provision, as parent training in methods such as ABA can be presented via telehealth (Fisher et al., 2020; Benson et al., 2018; Lindgren et al., 2015). These studies have shown that parent training provided in this method can be highly effective and produce clinically significant improvements in targets such as communication and self-injurious behavior. For example, one study found that significant improvements in social communication could be made by providing training in the Early Start Denver Model (ESDM) to parents via telehealth (Vismara et al., 2018). Telehealth services may also be useful for training parents to teach self-care skills to their children with ASD (Boutain et al., 2020).

Telehealth has also been utilized to train new providers in specific assessments and interventions from a distance with encouraging results (Vismara et al., 2009). Feasibility

research on parent training via telehealth suggests high treatment fidelity by clinicians, high rates of treatment completion, and clinically significant improvements in treatment outcomes (Bears et al., 2018). While the most common type of telehealth parent training is provided to the parent directly from a provider, there are also self-directed parent training options, where the parent interacts directly with the information without provider facilitation. However, research on this type of training has suggested significantly lower completion rates and knowledge gains than in provider-led trainings (Ingersoll et al., 2017).

Challenges with Telehealth.

Much of the focus on telehealth centers around its ability to overcome barriers to care, but virtual service provision is not without challenges of its own. The COVID-19 pandemic led to increased need for physically-distanced service provision, which highlighted barriers faced by patients attempting to access this method of service. Practitioners often must navigate issues with technology such as comfort with the telehealth interface and unstable provider internet connection (Lee et al., 2015). Between 19 and 42 million individuals are without access to broadband internet service (Busby & Tanberk, 2021), a necessary prerequisite for most methods of telehealth delivery. In light of the pandemic, the federal government designated some resources to meet this need, including the Keep Americans Connected Pledge (Federal Communications Commission [FCC], 2020) and the CARES Act (FCC, 2020; USDA, 2020). However, the funding designated for increasing broadband access was just 0.125% of the total amount needed (Giorgi, 2020), and initiatives for expansion of telehealth services focused on assumed

adequate broadband access (FCC, 2020), leaving millions of Americans without broadband connectivity.

Even when clients can access telehealth, difficulties remain. Some studies have documented that clients reported feeling disconnected from telehealth providers via phone and indicate concerns about privacy, as clients often lacked a completely private place to participate in telehealth (Jubelt et al., 2015). Providing services via telehealth also created unique ethical considerations, such as concerns with information security and HIPAA compliance (Pollard et al., 2017). Providers must ensure that video conferences and other methods of electronic data exchange are protected from hackers and other potential data breaches. Previous research on client barriers to telehealth parent training for parents of children with DD indicates difficulties at the client level including limited experience with the telehealth interface (e.g., Zoom), lack of an appropriate device, poor visibility, distracting environment, and engagement in dangerous behavior (Lerman et al., 2020). Focus group research suggests that parents of children with ASD receiving in-person early intervention services indicated a preference for in-person services and did not feel confident in the efficacy of telehealth services as a sole treatment model (Yang et al., 2020). Parents of clients with ASD completing self-directed telehealth parent training have reported difficulties with stress in the home, technology barriers, and lack of time as challenges to participating in telehealth services (Ingersoll et al., 2017).

Contribution to Knowledge

Preliminary data on effects of the COVID-19 pandemic on individuals with ASD and their families have suggested increased stress and problem behaviors as well as loss

of skills, largely due to reduced access to support services and therapies, highlighting the need for effective alternative methods of service provision for clients with ASD (White et al., 2021). However, much of the current telehealth research focuses on typically developing clients, provider-level barriers, and efficacy of specific interventions. To provide telehealth services to clients with ASD and their families most effectively, more research is needed on client-level barriers in this specific population. It is possible that many of these barriers are consistent with what has been observed in the general population and studies on specific interventions, but there are likely to be additional barriers that exclusively or disproportionately affect this population. Identification of these unique challenges is important for effectively targeting quality improvement initiatives and assisting clients with ASD in successfully accessing telehealth services when in-person services are inconvenient or impossible.

Research Questions

1. What are the most common challenges faced by clients with ASD and their families when attempting to access telehealth services?
2. What are the most problematic barriers (i.e., barriers most associated with being unable to access telehealth) faced by clients with ASD and their families when attempting access telehealth services?
 - a. It is predicted that race, age, access to necessary technology (e.g., computer, tablet), location (e.g., rural, urban, suburban), median household incomes, urbanicity, presence of ADHD or a disruptive behavior disorder, and presence of client problem behaviors (e.g.,

inattention, aggression, noncompliance) will be associated with ability/inability to participate in telehealth.

3. Which demographic groups (e.g., race, age, comorbidities) are least likely to be able to access telehealth?

Method

Context

Data were collected through a retrospective review of client records in collaboration with Empower Behavioral Health and Intervention (Empower), a multi-site provider of DD and ASD services in Ohio. The author was completing a predoctoral internship at Empower at the time of data collection, and the current research was approved and supported by Empower leadership.

There is no age minimum or maximum on clients accepted by Empower, but they typically do not serve clients for court-mandated services or clients who have a severe mental illness such as a personality disorder or schizophrenia. The majority of clients have ASD or another developmental disability. They are contracted to provide services utilizing private insurance, Medicaid, and Franklin County Board of DD funding. Empower behavioral health staff includes social workers, mental health counselors, licensed psychologists, board certified behavior analysts (BCBAs), psychology assistants, and registered behavior technicians. During most of the time period of interest (March 2020 to March 2021), Empower was known as Haugland Therapy Services and provided behavioral health services (e.g., counseling, case management, behavioral therapy, diagnostic assessment) as well as occupational, physical, and speech therapies across multiple locations, which included an outpatient behavioral health clinic and early intervention center in Columbus, OH, branch outpatient locations in Lancaster, Sandusky,

and Athens, and in-home services. They also contracted with all locations of Haugland Learning Center, a school for children with ASD and other developmental disabilities, to provide behavioral health services within the school setting. During the COVID-19 pandemic, many of these locations temporarily closed for in-person services, which made it necessary for clients to move to telehealth services if possible.

Variables

Demographic Information

Information related to client characteristics, family and home factors, and cultural considerations (*see Appendix A*) was collected from electronic client records to identify factors associated with success or difficulty with utilization of telehealth services.

Demographic information fell into three broad categories—*Client information* (e.g., IQ and adaptive behavior, age, recorded diagnoses), *Home & Family* (e.g., number of children in the home, rural/urban/suburban residence), and *Values & Cultural Considerations* (e.g., race, ethnicity, religion, language(s) spoken). As standard measures of SES such as family income are not frequently recorded in Empower client records, a partial proxy for SES was created by using median home values. Median home values were calculated using the American Community Survey 2019 report of household income in the past 12 months, which is the most recent survey household income available through the United States Census Bureau. Reported median incomes for family households were used as all participants in the study met the United States Census Bureau definition of “family” household--one adult and at least one child or dependent. Urbanicity was calculated based on the United States Department of Agriculture's

(USDA) rural-urban commuting area (RUCA) codes, which use zip codes to provide a categorization of metropolitan, micropolitan, small town, or rural. These categories are further broken down into subcategories by distance from a metropolitan center, but the broad four categories were used for the current analysis as there was not enough variance in subcategories among study participants to add meaningful information.

The USDA defines “metropolitan” as an area containing a core urban area of at least 50,000 residents, “micropolitan” as an area containing an urban core with 10,000-49,999 residents, “small town” as an area with 2,500 to 9,999 residents, and “rural” as an area with fewer than 2,500 residents (USDA, 2020).

Evaluation of Barriers and Challenges

For the purposes of this study, “challenges” are defined as any reported factors that made receipt of telehealth services more difficult but may or may not have prevented access to telehealth entirely. “Barriers” are defined as reported difficulties that prevented success with telehealth services. Any challenges expressed (i.e., noted in client records or reported by providers) by clients and their families when attempting to access telehealth services were recorded. For ease of data collection, likely barriers were identified based on previous research and informal interview with practicing clinicians and categorized in manner designed to mirror the demographic categories: *Technology* (e.g., internet access, availability of appropriate devices), *Client Factors* (e.g., support level, language skills), *Home & Family* (e.g., availability of childcare for other children in the home, availability of supportive adult), *Values & Cultural Considerations* (e.g., ESL/limited English, acceptance of value of teletherapy), and *Other* (e.g., indicated barriers that do not fall into

predetermined categories, such as provider-level barriers). A list of predicted barriers is provided in *Appendix A*, though this list was not intended to be exhaustive. These categorizations were used for the purposes of organization and were not included in the provider survey or analyses.

Utilization of Telehealth

Based on information noted in records—and interviews with providers when necessary—clients were categorized as one of the following – 1a) unable to use telehealth, not attempted; 1b) attempted telehealth, unsuccessful; 2) able to successfully use telehealth. One participant who could not easily be categorized into one of these groups was excluded from analyses.

Because the number of sessions and amount of progress necessary to determine whether telehealth is appropriate and/or successful can widely between participants, the categorization was based on the care team’s plans and predictions regarding likelihood of continuation of telehealth services at the time of data collection rather than a set number of completed telehealth sessions. Participants in **Group 1a** were those for whom no telehealth sessions were conducted. **Group 1b** included participants who participated in at least one telehealth session but discontinued telehealth services due to difficulties experienced. **Group 2** included participants who, at the time of data collection, were participating in ongoing telehealth services and, as determined by their care team, were making sufficient progress as to justify continuation of these services indefinitely or who participated in telehealth services until services were no longer needed or agency locations were reopened for in-person services.

Participants

Any Empower client with ASD who was offered telehealth as a method of service provision for ongoing behavioral health services (e.g., psychotherapy, behavioral therapy) from March 2020 through March 2021 was eligible for inclusion. Clients were excluded from data analysis if they did not have a recorded diagnosis of ASD in their chart or if their status with telehealth was pending (e.g., it was, at the time of data collection, unclear whether telehealth services were a good fit for the client). One-hundred-sixty-two clients were initially identified as being potential participants, of whom nine were excluded for not having a documented diagnosis of ASD and one was excluded for a pending telehealth status. This resulted in a final sample of 154 participants.

The average age of the sample was 13.14 years ($SD=6.61$) with a range of 3-61 years. The sample was 78.6% male, 19.5% female, and 1.9% other or unspecified gender. The racial breakdown was as follows: 50% White, 24% Black, 1.3% Asian or Pacific Islander, 6.5% Multiracial, 3.9% Other, and 14.8% missing/unknown. The ethnic breakdown was as follows: 5.2% Hispanic/Latinx, 76.6% Not Hispanic/Latinx, and 18.2% missing/unknown (*Table 1*). Participants had a variety of comorbidities recorded in their charts, with the most common being attention-deficit/hyperactivity disorder (ADHD). Others included intellectual disability (ID), oppositional defiant disorder (ODD), major depressive disorder (MDD), posttraumatic stress disorder (PTSD), intermittent explosive disorder (IED), obsessive compulsive disorder (OCD), generalized

anxiety disorder (GAD), and a language/communication disorder (i.e., documented language or communication disorder in electronic record). Rates of most comorbid disorders (*Table 1*) in the current sample were lower than rates found in previous research (Brookman-Frazee et al., 2018; Simonoff et al., 2008). Possible reasons for this discrepancy will be explored in the Discussion. All participants were receiving either counseling/psychotherapy or behavioral therapy or consultation, provided by a psychology assistant, counselor, social worker, or BCBA (*Table 2*). Although previous research has reported associations between race and income and race and urbanicity, no statistically significant relationship was found between race and urbanicity ($G^2[15] = 23.404, p = .076$). Black/African American participants had an average median household income of \$15,700 less than White participants based on zip code ($p=.008, CI [-27271.91, -4269.851]$). See *Variables* section for details of how median household income and urbanicity were calculated.

Table 1
Sample Demographics

Average Age in Years (SD)		13.14 (6.61)
Group		Percentage of Sample
Gender		
Male		78.6
Female		19.5
Other/Unspecified		1.9
Race		
White/Caucasian		50
Black/African American		24
Asian/Pacific Islander		1.3
Native American		0
Multiracial		6.5
Other		3.9
Unspecified		14.8

Ethnicity	
Hispanic/Latinx	5.2
Not Hispanic/Latinx	76.6
Unspecified	18.2
Comorbidities	
ADHD	22.73
ID	1.90
ODD	2.60
MDD	3.90
GAD	5.84
PTSD	1.95
IED	1.30
OCD	1.30
Language/Communication Disorder	57.80

Table 2
Services Received

Group	Percentage of Sample
Primary Provider	
Psychology Assistant	1.9
BCBA	51.3
Counselor/Social Worker	46.8
Primary Service Received	
Counseling/Psychotherapy	44.8
Behavioral Therapy/Consultation	51.3
Multiple Services	3.9

Procedure

Behavioral health providers at Empower were sent a survey (See *Appendix B* for email script and *Appendix C* for survey questions) asking for information on access to telehealth for clients with ASD served between March 2020 and March 2021.

Additionally, a list of clients receiving services during the relevant time period was gathered by running a service history report through Empower’s electronic record system Carelogic. This allowed for follow-up with providers and supervisors on eligible clients

for whom survey data was not initially provided. Demographic information was collected via review of electronic records. Information on access to telehealth services and difficulties experienced was gathered either directly from the client's provider via the aforementioned online survey or from a review of client records, depending on whether their provider during the relevant time period was employed by Empower at the time of data collection. For clients whose provider was not employed by Empower at the time of data collection, access to telehealth and challenges experiences was assessed via review of notes for relevant services, as determined by billing codes, as well as a review of memos to chart, session notes, and consultation with the case supervisor. Billing codes allow for differentiation between types of services as well as whether the service was provided in-person or via telehealth, and challenges experienced were often indicated in memos to chart (e.g., "client's parent declined telehealth services due to need for in-person support") or session notes (e.g., "client repeatedly turned off camera," "no progress was able to be made due to client inattention").

Coding

Specific coding instructions can be found in *Appendix E*. The author extracted relevant information from client records and the provider survey, deidentified the data, and entered it into the dataset according to these coding instructions. A second coder independently followed the same procedure to extract, code, and enter data for 17% of the participants to check for coding reliability, which resulted in 96% agreement in coding. Cohen's kappa could not be calculated due to unequal numbers of categories between variables (i.e., some variables had 2 categories, and some had more) as

calculation of Cohen's kappa requires that all variables have the same number of categories.

IRB Review

This research was approved as "exempt" by the Ohio State University's Institutional Review Board (IRB; *See Appendix D*) and granted a HIPAA privacy waiver because data were collected through review of records, the data accessed were available to the researcher and secondary coder through daily job duties, and clients and their families were not contacted for data collection.

Privacy and Confidentiality

Because protected health information was accessed during the records review, extra caution was taken to ensure privacy and confidentiality of client information in accordance with the HIPAA Privacy Rule (U.S. Department of Health & Human Services, 2017). Only information directly relevant to the research questions was collected, and protected health information (PHI) will not be reused or disclosed to any other person or entity, except as required by law or for authorized oversight of the research project. Data were stored digitally and protected by password. In order to comply with HIPAA regulations, while PHI was accessed during data collection, no identifiable information was recorded for data analysis. Data extracted from records and the provider survey were deidentified before entering them into the dataset. Information such as birth date and zip code was transformed into an alternate form (e.g., age, United States Department of Agriculture's rural-urban commuting area [RUCA] codes) before being recorded for data analysis. Client records were only accessed by study personnel

who had access to the records as part of their daily job duties (i.e., the author and second coder, who were both employed by Empower at the time of data collection).

Statistical Analyses

Analyses were completed using SPSS software version 26. Pairwise deletion was used for missing data. Percentages of missing data for each demographic variable can be found in *Table 1*. Logistic regression was used for research questions 2 and 3. Logistic regression is used for comparisons of groups when the outcome variable is categorical rather than continuous, and it can accommodate both categorical and continuous predictor variables. It results in odds ratios, which provide an estimate of the likelihood of a certain outcome given a certain exposure (Szumilas, 2015). Stepwise logistic regression enters dependent variables one at a time to allow for evaluation of how each contributes to model fit and removes variables that are not statistically significantly associated with the independent variables, calculating odds ratios only for variables in the final model. This allows for identification of which variables in a group are significantly associated with the independent variable. Maximum likelihood (G^2) was used to assess for statistical significance, as this statistic is preferable for smaller sample size and, unlike the Wald statistic, does not require the log likelihood ratio be quadratic in shape (Meeker & Escobar, 1995). The 10:1 ratio often used for logistic regression (Peduzzi et al., 1995) suggested a needed sample size of approximately $N=150$ participants for statistical stability.

Assumption Checks and Multicollinearity Analyses

In order to use logistic regression, entries must be independent (e.g., no duplicate entries or repeated measures; Stoltzfus, 2011), which is true for the cases used in the current analyses. Logistic regression also requires that there are no strong outliers as determined by residuals (Stoltzfus, 2011), which is also true for the cases used in the current analyses. Caution is recommended when including variables that are highly correlated in the final model, as doing so may inflate standard errors for beta coefficients (i.e., odds ratios; Stoltzfus, 2011). Checks for multicollinearity were run in two ways—by running correlations between predictor variables and by calculating the variance inflation factor (VIF) for predictor variables. No correlations indicative of multicollinearity ($r > .7$) were found for predictor variables in the final models (inattention and reported need for in-person support [$r = -.018$; $p = .820$], race and language disorder [$r = .172$, $p = .033$], race and urbanicity [$r = -.142$, $p = .079$], language disorder and urbanicity [$r = -.019$, $p = .816$]), and no VIFs indicative of multicollinearity ($VIF > 10$) were found for predictor variables included in the final model (inattention [$VIF = 1.079$], need for in-person support [$VIF = 1.036$], race [$VIF = 2.524$], language disorder [$VIF = 1.155$], urbanicity [$VIF = 1.109$]).

Research Question 1

What are the most common challenges faced by clients with ASD and their families when attempting to access telehealth services?

Identifying the most common challenges faced by families is the first step to being able to address these challenges. Once the most common issues have been identified, interventions can be implemented to mediate those challenges and increase

access to telehealth for clients with ASD and their families. Focusing on the most common challenges allows for more efficient and effective implementation of intervention and supports. Simple frequencies were generated to evaluate the most common challenges across participants in all groups, regardless of access to telehealth services. All expressed challenges were included in this analysis in order to identify challenges that appeared most frequently across groups.

Research Question 2

What are the most problematic barriers (i.e., barriers most associated with being unable to access telehealth) faced by clients with ASD and their families when attempting access telehealth services?

Identification of most problematic barriers (i.e., those most likely to prevent clients and their families from being able to access telehealth services at all) is, again, crucial for efficient and effective intervention efforts as these barriers make the difference in whether clients are able to access services or must go without. Forward logistic regression was used to explore the relationships between indicated barriers and success with telehealth to identify the most cumbersome barriers to successful utilization of telehealth (i.e., those most associated with inability to successfully access telehealth services). For this analysis, telehealth access (e.g., yes or no) was entered as the outcome variable, and expressed challenges experienced when attempting to access telehealth (e.g., difficulty with internet access, disruptive child behavior) were entered as categorical predictor variables (see *Results* for list of all entered variables). Logistic regression allowed for calculation of the odds of difficulty accessing telehealth given a

particular identified challenge (e.g., internet difficulties, client inattention) and identification of barriers predictive of telehealth inaccessibility (i.e., expressed barriers statistically significantly more common for clients who were not able to access telehealth services versus those who were). For these analyses, Groups 1a (telehealth never initiated) and 1b (telehealth initiated but discontinued) were collapsed as *N* of Group 1b was not sufficient to analyze the groups separately. Challenges expressed by those who were not able to access telehealth and by those who were able to access telehealth were compared to identify which challenges were statistically significantly more common in the “unable to access telehealth” group and were, therefore, not just challenges, but barriers to accessing services.

Research Question 3

Which demographic groups (e.g., race, age, comorbidities) are least likely to be able to access telehealth?

Forward logistic regression was used to explore the relationship between demographic information and success with telehealth to identify the most relevant demographic variables associated with successful utilization of telehealth. For this analysis, telehealth access (e.g., yes or no) was the outcome variable, and demographic groups (e.g., race, ethnicity, urbanicity of residence) were entered as the predictor variables (see *Results* for list of all variables entered). This analysis allowed for calculation of odds of difficulty accessing telehealth given membership in a particular demographic group (e.g., race, median home income) and identified which demographic variables were most predictive of difficulty accessing telehealth services. This analysis

was important to identify particular demographic groups most likely to face obstacles when attempting to access telehealth services in order to focus supports on those groups. Groups 1a (telehealth never initiated) and 1b (telehealth initiated but discontinued) were collapsed as *N* of Group 1b was not sufficient to analyze the groups separately.

Results

Research Question 1

What are the most common challenges faced by clients with ASD and their families when attempting to access telehealth services?

Research question 1 sought to determine which challenges were most frequently faced across groups—regardless of whether clients were ultimately able to participate in telehealth services. Identification of these challenges allows for a more specific focus of interventions to improve quality of telehealth services by highlighting issues commonly faced by clients and their families.

Frequency analyses determined that the most common client-level difficulties reported were client attention (25.32%), need for in-person support (22.08%), and client noncompliance (20.80%) (see Table 3). “Client attention” refers to difficulty attending to the screen and to instruction during telehealth sessions to a degree that interfered with sessions. “Need for in-person support” includes clients for whom either their primary behavioral health provider or electronic record indicated that the client needed a one-on-one provider with them in person in order to participate in therapy or that they would have been significantly more successful with telehealth if they would have had in-person support. While the reason for this need was not always delineated, reported reasons were exclusively related to behavioral issues such as noncompliance and inattention. Parents may have felt they lacked the time or expertise needed to manage these behaviors on their

own. “Client noncompliance” included refusal to participate in telehealth sessions, as demonstrated by behaviors such as turning off the camera, eloping from the instruction space, or refusal to follow instruction or answer questions. “Internet access” (15.58%) included issues such as clients not having access to fast enough internet speeds to facilitate video conferencing, issues with bandwidth (e.g., slow internet speed due to multiple members of the household needing internet access at one time), and difficulty with sessions freezing or disconnecting. “Parent declined services” (13.00%) indicates that the client’s caregiver reported they did not want to receive telehealth services. While the reason for this decline was not always reported, some indicated reasons were feeling overwhelmed, not feeling a need for services, or feeling that telehealth services would not be a good fit for their child. “Client aggression” (7.79%) included physical or verbal aggression that interfered with the session such as verbal threats, throwing objects, or attempted destruction of the device used for telehealth. “Parent did not return attempts to contact” (6.50%) indicates that caregivers did not return phone calls, letters, or emails from the provider agency regarding initiation of telehealth services following shut down of in-person services. “Caregiver work schedule” (6.49%) includes clients whose caregivers expressed that their work schedule made it difficult to schedule or participate in telehealth sessions. Difficulty with “access to appropriate technology” (5.84%) includes clients who did not have devices appropriate for participating telehealth sessions (e.g., client could only participate in telehealth via a smartphone, but the screen was too small to see presented stimuli). “Lack of childcare” (5.84%) includes clients for whom need for childcare for other children in the home made telehealth sessions difficult or

impossible (e.g., other children interrupted telehealth sessions, caregiver had to attend to other children and could not support client during telehealth sessions). “Caregiver comfort with telehealth” (2.56%) includes clients whose caregivers were uncertain about the benefit of telehealth either in general or for their child specifically. “Language barrier” (0.60%) included clients who had difficulty participating in telehealth because they or their caregivers did not speak English fluently. The “other” category (7.79%) included difficulties accessing telehealth that did not fall into other categories such as inconsistent session attendance.

Table 3

Frequency of Reported Challenges to Accessing Telehealth Services

Challenge	Percentage of sample
Client attention	25.32
Client noncompliance	20.80
Internet access	15.58
Need for in-person support	14.38
Parent declined services	13.00
Client aggression	7.79
Parent did not respond to attempts to contact	6.50
Caregiver work schedule	6.49
Access to appropriate technology	5.84
Lack of childcare	5.84
Caregiver comfort with telehealth	2.56
Language barrier	0.60
Other	7.79

Research Question 2

What are the most problematic barriers (i.e., barriers most associated with being unable to access telehealth) faced by clients with ASD and their families when attempting access telehealth services?

The identification of these barriers is crucial for efficiently targeting supports to increase access to telehealth services because it allows for focused implementation of intervention efforts on most impactful barriers rather than broad, nonspecific intervention. It also allows for the narrowing of the focus of intervention from challenges that cause some difficulty but don't necessarily prevent access altogether (e.g., those identified in research question 1) to factors that prevent clients from being able to access telehealth services at all. For this question, it was predicted that a number of variables such as client behavior (e.g., inattention, aggression, noncompliance) and access to reliable, high speed internet would be associated with likelihood of accessing telehealth services. However, following forward stepwise logistic regression to compare reported challenges in Group 1 (unable to access telehealth) to reported challenges in Group 2 (able to access telehealth), only two barrier variables were determined to have a statistically significant relationship with likelihood of access to telehealth. Client difficulties with attention were associated with decreased odds of difficulty receiving telehealth (OR = 0.383, $p = .017$, CI [0.174, 0.841]) while need for in-person support was associated with increased odds of difficulty receiving telehealth (OR = 3.965, $p = .012$, CI [1.352, 11.629]).

Variables not found to be statistically significant are presented in *Table 4*. Several variables hypothesized by the author to be associated with decreased likelihood of access to services (e.g., client aggression, internet access, client noncompliance) were not found to be statistically significantly associated with access to services

Table 4
Nonsignificant Reported Challenges to Accessing Telehealth Services

Challenge	Score Statistic	<i>df</i>	<i>p</i> -value
Client noncompliance	.606	1	.436
Internet access	.005	1	.944
Client aggression	1.187	1	.276
Caregiver work schedule	.530	1	.467
Access to appropriate technology	.478	1	.489
Lack of childcare	1.462	1	.227
Caregiver comfort with telehealth	.138	1	.710
Language barrier	1.124	1	.289
Other	.003	1	.955

Research Question 3

Which demographic groups (e.g., race, age, comorbidities) are least likely to be able to access telehealth?

Identification of demographic groups most likely to experience challenges accessing telehealth is, again, important for being able to target interventions and support toward groups most in need of that support. It was predicted that demographics commonly associated with low access to healthcare (e.g., race, ethnicity, urbanicity of residence, and SES [proxied in the current study by average median household income by zip code], and severity of disability) would be associated with lower access to telehealth services.

Client race ($G^2[5] = 15.249, p = .009$), presence of a language disorder ($G^2[1] = 11.544, p = .001$), and urbanicity of residence ($G^2[3] = 14.734, p = .002$) were found to predict likelihood of difficulties accessing telehealth. More specifically, Black/African American clients ($OR = 3.414, p = 0.29, CI [1.312, 10.300]$) and clients with a language disorder ($OR = 3.099, p = .001, CI [1.592, 6.031]$) were more likely to have difficulty with telehealth access. Clients living in micropolitan areas ($OR = 0.125, p = .009, CI [0.27, .589]$) were less likely to have difficulty accessing telehealth services.

Demographic variables found nonsignificant are listed *Table 7*. To further explore these relationships, logistic regression was run between race and reported challenges as well as language disorder and reported challenges, and no statistically significant associations were found (*Table 5 and 6*). Though the Maximum Likelihood statistic (G^2) was used for all analyses, when it was significant for a variable at the overall level but no statistical significance was found at the categorical level (e.g., for “race” overall, but not between any racial categories), the Wald statistic was used to clarify statistical significance.

Table 5
Race and Reported Challenges

Challenge	G^2	<i>df</i>	<i>p</i> -value
Internet access	8.206	5	.145
Client attention	16.248	5	.006 [†]
Client aggression	2.722	5	.743
Client noncompliance	6.511	5	.260
Childcare	4.474	5	.483
Caregiver work schedule	9.300	5	.098
Caregiver comfort with telehealth	2.553	5	.768
Language barrier	1.393	5	.925
Lack of appropriate technology	10.658	5	.059
Need for in-person support	3.852	5	.571
Other	5.752	5	.331

Note: [†]Wald statistic was nonsignificant, as was *p*-value for each race category

Table 6
Language Disorder and Reported Challenges

Challenge	G ²	df	p-value
Internet access	.261	1	.610
Client attention	.000	1	.998
Client aggression	.320	1	.571
Client noncompliance	.370	1	.543
Childcare	.688	1	.407
Caregiver work schedule	5.387	1	.020 [†]
Caregiver comfort with telehealth	.529	1	.467
Language barrier	1.101	1	.294
Lack of appropriate technology	.316	1	.574
Need for in-person support	2.449	1	.118
Other	1.672	1	.196

Note: [†]Wald statistic was nonsignificant.

Table 7
Nonsignificant Demographic Variables

Challenge	Score Statistic	df	p-value
Gender	5.409	2	.067
Disruptive disorder	.965	1	.326
Attention-deficit/hyperactivity disorder	2.330	1	.127
ASD social communication severity	2.431	3	.488
ASD repetitive, restricted behavior severity	3.595	3	.309
ID diagnosis	1.125	1	.289
Number of children	1.631	1	.202
Number of adults	2.067	1	.150
Ethnicity	5.552	2	.062
Religion	4.123	5	.532
Age	3.275	1	.072
Median income	.128	1	.721

Discussion

While use of telehealth services dates back decades, the need for physically-distanced care during the COVID-19 pandemic increased focus on and use of telehealth services, resulting in a substantial expansion of telehealth services by providers and insurance companies. Even as providers are able to return to in-person services, it is likely that this forced expansion of services will have a lasting impact on service provision, due to factors such as decreased cost of care for telehealth services (Camden & Silva, 2021; Lindgren, 2016) and difficulties experienced by families when attempting to access in-person services. Existing literature on telehealth services focused primarily on the general population, clients with developmental disabilities broadly, and the efficacy of specific interventions. The current study sought to fill existing gaps in research and knowledge surrounding challenges faced by clients with ASD and their families when attempting to access telehealth services. Our hope is that this information can be used in the future to provide guidance for interventions focused on improving access to telehealth services for people with ASD and their families.

The first research question sought to identify most common challenges faced by clients with ASD and their families when attempting to access telehealth services, regardless of whether those challenges prevented them from accessing telehealth services entirely. In order to improve access to services, it is important to first identify the most common difficulties. Without knowing this information, interventions seeking to improve

access will necessarily need to be broad and indiscriminate, leading to inefficient and potentially ineffective interventions. Results from the current study found that the top three reported difficulties across groups were related to client behavior—need for in-person support, client inattention, and client noncompliance—and a clinically significant proportion of the sample (13%) did not participate in telehealth services because caregivers declined outright these telehealth services. While reasons for caregiver decline of telehealth services were not always reported, stated reasons included: (1) feeling overwhelmed by COVID-19-related changes, (2) feeling no need for direct services, and (3) feeling their child was not appropriate for telehealth services due to behavioral concerns. These findings align with previous research demonstrating behavioral barriers to accessing healthcare services (Brown & Brown, 2014; Stein Duker et al., 2017) and suggest that interventions to improve access to telehealth services should focus some attention on managing client behavior, which may include addressing basic prerequisite skills for telehealth services (e.g., sitting and attending to a screen, following directions, on-task behaviors) and education for parents on managing problem behaviors during sessions, though more research is needed to evaluate efficacy of such interventions.

Previous research on parent training focused on behavior management has shown positive results, both when implemented in person and via telehealth, suggesting that this strategy could be effectively implemented to address behaviors identified as causing most difficulty with telehealth services. Specifically, parent training has been demonstrated effective for increasing joint engagement (Kasari et al., 2015) and joint attention (Rocha et al., 2007; Vismara et al., 2013), decreasing disruptive behaviors (Bearss et al., 2013),

and teaching guided compliance skills to parents (Spiegel et al., 2016). While the details of many parent training methods are study-specific, some manualized programs and techniques for parent education and training have also been developed and evaluated. For example, previous research has shown that parent child interaction therapy (PCIT) is effective for reducing externalizing symptoms, including symptoms associated with ADHD, as well as noncompliance (Vetter, 2018). Manualized parent training programs such as Stepping Stones Triple P have shown effectiveness for reducing disruptive behavior, as measured by parent ratings (Roux et al., 2013). Balance, a parent training program designed to be implemented by BCBA's, has been shown to reduce problem behavior and increase cooperativeness with tasks (Ruppel et al., 2021). COMPASS for Hope (C-HOPE), an eight-week manualized parent training program designed for implementation via telehealth or in-person, has shown effectiveness for reducing problem behavior and parent stress (Kuravackel et al., 2018). Parent training appears to be effective at addressing problem behaviors regardless of cognitive level or ASD severity level (Lecavalier et al., 2017; Vetter, 2018).

In addition, providers may consider changing the format of telehealth sessions to involve activities that are more fun and engaging for clients. While research on game- or play-based teletherapy for clients with ASD is sparse, there is research demonstrating effectiveness of incidental versus more structured teaching via telehealth (Neely et al., 2019) as well as naturalistic teaching via telehealth (D'Agostino, 2020). Other research has shown that play-based therapy delivered via telehealth is effective for individuals with Prader-Willi (Dimitropoulos, 2017). Although research on incorporation into

telehealth is limited, interventions could include video-game-like elements such a virtual reality, which has been shown effective for improving understanding of facial expressions (Cheng & Ye, 2010; Deriso et al., 2012; Stichter et al., 2014), emotion recognition (Serret et al., 2014), joint attention (Bernardini et al., 2014), social engagement (Lahiri et al., 2013), sharing and comforting behaviors (Gal et al., 2009). Robotics could also potentially be included, as robot-mediated therapy has been shown effective in interventions targeted toward improvement of emotion labeling (Costa et al., 2014), imitation of facial expressions (Mazzei et al., 2012), social orienting (Bekele et al., 2013), joint attention (Duquette et al., 2008; Feng et al., 2013; Warren et al., 2015), and collaborative play (Wainer et al., 2014). Some research shows that, compared to therapist-delivered interventions, intervention delivered by tablet may result in shorter session lengths, higher engagement, lower levels of challenging behavior, and more on-task behavior (Lee et al., 2015).

A clinically significant portion of the sample reported difficulties with internet access (e.g., internet speed, bandwidth). This was predicted given that the Federal Communication Commission (FCC) estimates that 14.5 million Americans and 328,000 Ohioans are without access to high speed internet (FCC, 2020) and other estimates place the number as high as 42 million Americans and 1,404,448 Ohioans (Busby et al., 2021). Importantly, neither of these estimates include people who live in areas with high-speed internet access but who cannot afford the service. People who cannot access broadband internet service often rely on mobile data via smartphones (Perrin, 2021). However, access to mobile data is also limited in rural areas, and mobile data speeds typically do

not meet the standards set by the Federal Communications Commission for “adequate” speed (Strover, 2018). Hence, using cellular service and a smart phone or device may not be an adequate alternative for accessing telehealth services for people without broadband internet. Issues with internet access may be partially mitigated by offering alternatives to live video conferencing sessions. Prerecorded video modeling and video feedback have been demonstrated to be effective for improving vocational skills (English et al., 2017), generalization of social interaction skills (Jones et al., 2014), imitation (Cardon et al., 2011), communication (Plavnick & Ferren, 2011), independent living skills (Johnson et al., 2013), and emotion recognition (Akmanoglu, 2015). Computer- and tablet-mediated interventions such as app- and video game-based interventions have shown effectiveness for improving communication (Law et al., 2018; Stephenson, 2016), social interaction and understanding of social relationships (Birtwell et al., 2019), emotion recognition (Abirached et al., 2011; Bekele et al., 2013), attention to tasks (Bar-Haim et al., 2011), joint attention (Bernardini et al., 2014) and vocational skills (Strickland et al., 2013).

The second research question sought to aid in further refining the focus of potential interventions by identifying barriers most likely to prevent clients from being able to access telehealth services altogether. This information is important for prioritizing the focus of interventions designed to mitigate challenges with telehealth in order to improve access for clients facing the most cumbersome barriers. In the current study, issues with client inattention and urbanicity were two variables significantly associated with ability to access telehealth services, with client inattention and residence in a micropolitan area having a positive relationship with receipt of services. The latter

finding was not predicted, as access as resources necessary for telehealth access such as high-speed internet diminish outside of urban centers (Busby et al., 2021; FCC, 2020), which one would expect to make access to telehealth services more challenging.

However, the small OR may not be clinically significant. It is probable that, with a larger sample size, one would see a statistically and clinically significant negative relationship for those living in a small town or rural area, as the current sample included 3.2% “small town” participants and 0% “rural” participants.

The positive association between client inattention and access to telehealth services was also not predicted, though there are several possible explanations. It is possible that parents of children with attention difficulties found more need for telehealth services than parents of children without significant attention difficulties when the alternative was no services, as it was for a time during the COVID-19 pandemic, due to need for behavior management and engaging activities. It is also possible that this result is an artifact of the way information was reported by providers and documented in electronic records. For example, it is possible that clients who were not able to receive telehealth services also experienced significant difficulties with inattention but that other, more significant challenges, were the ones documented in charts and reported by providers.

By identifying demographic variables most associated with significant difficulties accessing telehealth services, interventions aimed at improving access can be designed to target certain demographic groups, most likely to experience the more significant barriers. This information enables interventions to be crafted to address specific needs of

these groups, hopefully, resulting in increased access. Results of the current study suggest that race—specifically being African American/Black—and having a language disorder put clients at increased risk of not being able to access telehealth services.

Increased challenges with telehealth among Black/African American participants aligns with previous research on disparities in healthcare access by race (Fortney & Tassé, 2021; Nelson, 2002; US Department of Health and Human Services, 2019). African American/Black individuals consistently experience poorer access to care and, as a result, poorer health outcomes (Nelson, 2002; US Department of Health and Human Services, 2019). Findings from the current study suggest that further research is needed on the intersectionality of race and disability and that more work is needed to address racial disparities in healthcare and reduce systemic bias, as offering services via telehealth does not appear to sufficiently mitigate racial disparities in care. Previous research on racial disparities in health and healthcare has identified structural and interpersonal racism, including provider bias (Blair et al., 2013; Paradies et al., 2014), as major factors (Shaver et al., 2012), leading to poorer mental and physical health (Paradies et al., 2015) for people who are African American/ Black. This has recently been highlighted by research on the disproportionate effect of COVID-19 on African American/ Black communities identified relevant factors such as higher likelihood of being “essential workers” and, therefore, increased exposure to the public/risk of infection (CDC, 2021), increased likelihood of preexisting secondary health issues (Lovelace, 2020), higher likelihood of having a low income (Semega et al., 2019), decreased access to medical care and healthy, fresh food (Sampson, 2003), increased

exposure to pollutants and toxins (Laster, 2020), and increased homelessness (U.S. Department of Housing and Urban Development, 2020).

During the COVID-19 pandemic, African American/Black workers with disabilities were more likely than other groups to experience job loss (National Disability Institute, 2020). This highlights the unique experience of the intersectionality of being both a member of a minoritized racial or ethnic group and disabled, which is more complex than just a simple additive effect of multiple disadvantages (Stuart, 2006). As early as 1968, it was noted that African American/Black children with disabilities were more likely than White children with disabilities to be to be educated in a segregated setting (Dunn, 1968). This pattern continues, with African American/Black students with disabilities being significantly more likely than White students with disabilities to be educated in the regular classroom settings for less than 80% of the day (U.S. Department of Education, 2020). African American/Black students with a disability are also more likely to be suspended than White students with a disability (Krezmien et al., 2007). Despite the disproportionate representation of African American/Black students with disabilities in segregated educational settings, research has suggested that, when factors such as SES and academic achievement are controlled for, African American/Black students are less likely than comparable White students to be identified by their school district as having a disability and are therefore less likely to receive appropriate educational supports (Morgan et al., 2017). This effect persists beyond the classroom as well, with research having demonstrated that African American/Black individuals with disabilities report lower income and higher rates of poverty than either White individuals

with a disability or nondisabled African American/Black individuals (Maroto et al., 2019; National Disability Institute, 2019). People who are both members of a minoritized racial or ethnic group and disabled have also reported higher levels of harassment in the workplace (Shaw et al., 2012). Although the issues of systemic and interpersonal racism are likely to play a significant role in disparities in access to telehealth services, more research is needed to confirm this prediction and identify specific mechanisms that drive the disparity, especially within the intersection of minoritized racial identities and disability.

The impact of a language disorder on access to telehealth services is also expected given past research highlighting communication as a common barrier experienced by individuals with ASD when attempting to access healthcare services (Brown & Brown, 2014; Muskat et al., 2015; Nicholas et al. 2016). Difficulties with communication are consistently rated among the top challenges faced when attempting to access healthcare services, and past research has suggested that this may only be exacerbated when providing services via telehealth (Szeftel et al., 2011). To address this issue, providers could receive more training in communication, especially communication with individuals with a language disorder. This may include taking more time for appointments and explanations, providing more comprehension checks, reducing language level, and increasing use of visual supports. Parent training focused on building communication skills may also be a helpful addition to improve communication during telehealth sessions, as this type of intervention has shown to be potentially effective in the past (Akemoglu et al., 2020).

Limitations and Future Directions

Because much of the data for this study was collected retrospectively from client medical/school records, it was dependent on the thoroughness of the documentation in electronic charts of relevant variables. The level of detail in documentation varied among clients, which meant that some relevant information such as reasons for decline of telehealth services was limited for some clients. Future studies could collect data and solicit more detailed information about challenges experienced and reasons for decline of services directly from families at the time of service. For example, providers could request information about reasons for hesitancy to initiate telehealth services at the time of decline and, at the end of telehealth sessions, make note of any issues (e.g., challenging behavior, unreliable internet connection) that arose during the session and the degree to which they impacted the session. Similarly, information on comorbid mental health conditions such as ADHD and MDD was only available when this information was documented in the chart. Because follow up with families was not allowed under HIPAA privacy waiver, it is not possible to know whether there were comorbidities that had been diagnosed but not documented in the record for some clients. This may be a possible explanation for the lower-than-expected rate of comorbidities (e.g., ADHD, ID, MDD, GAD) observed in the current sample as compared to previous research on comorbidities in ASD. It is also possible that families already connected to educational and behavioral health services under a current diagnosis may feel less pressure or need to get their child evaluated for additional diagnoses. Future studies could include obtaining written informed consent from participants to permit follow up interviews or surveys,

which would allow the researchers to collect additional documentation (e.g., reports from past psychological evaluations) directly from families or conduct screening or full developmental evaluations (e.g., mental health assessment, cognitive testing, etc.) for participants to confirm current diagnoses and undiagnosed or unreported comorbidities.

Collecting and analyzing research data from a single point of service has the potential to introduce bias due to influence from agency policy and resources. This may limit our ability to generalize the findings and conclusions. For example, this agency's guidance from lead administrators was to provide telehealth services to every client who requested it, despite challenges, unless the level of obstacles made sessions impossible or nearly impossible. This was important to the agency as, due to COVID-19 making most in-person services unsafe, the alternative at the time was no services. This commitment to provision of telehealth services may not be representative of other agencies and clinics providing similar services and may have influenced the degree to which certain challenges were significantly associated with likelihood of receiving services. Variables that may have prevented clients from receiving services elsewhere may not have had the same effect for clients in the current sample. These findings should be replicated on additional samples. Future studies could be improved by recruiting participants from multiple sites with varying policies and guidance for telehealth services.

Logistic regression results in odd ratios, which are a form of effect size measurement, are highly context-specific. Because of this, there are no standard benchmarks for what size odds ratio is clinically meaningful, as what may be a practically insignificant change in odds in one situation may be groundbreaking in

another. This subjectivity creates somewhat of a limitation when using this analysis method. For the purposes of the current study, because the negative effects of not receiving services are so great, it was argued that a relatively small change in odds is likely to have clinically relevant consequences, especially when exploring the difference between receiving services or not.

Because household income typically was not recorded in client records, median household income from zip code of residence was used as a proxy for SES. Zip codes were used to find median household income using the US Census Bureau's publicly available datasets. This method has been used as a proxy in the absence of data on individual household income for over a decade (Krieger, 1997); however, recent research suggests it provides an imperfect estimation of individual SES measures (Moss et al., 2021). The same study suggests that income estimates based on zip code rather than county data provide the best estimates of individual SES but that the error in estimation may be enough to obscure associations between SES and health-related outcome variables. While information in the current study is still useful for understanding the influence of neighborhood on telehealth access, future studies could more accurately account for individual SES by collecting actual household incomes of participants, as well as parent education levels.

Conclusion

With the COVID-19 pandemic, came a unique opportunity to study behavioral health services delivered through telehealth. Due to the severity of the pandemic and resulting mitigation protocols and restrictions, the alternative to telehealth services was

typically no services, so clients and providers were highly motivated to attempt service provision through telehealth. This provided a larger than typical subject pool with which barriers to receipt of telehealth services could be explored. It also provided an environment in which the motivation to provide or receive telehealth services was so high that the most impactful challenges and barriers could more easily be identified, as lower-level challenges that may have been a reason for discontinuation of services in a typical environment were more likely to be ignored or worked through in the pandemic environment and therefore not be reported as a barrier to receipt of services. The current study adds to previous research demonstrating persistent barriers in access to telehealth services for clients with ASD and their families, reiterating the impact of core and associated features of ASD, need for alterations to typical methods and techniques, difficulties with communication, and the influence of race and rurality on disparities in access to healthcare. This highlights the need for continued work to make all behavioral health services more accessible to all clients with ASD and their families, regardless of support needs, race, or location of residence.

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Appendix A: Variables for Data Collection

Demographics	
Client Information	
Age	
Gender	
Diagnoses	
ASD severity level	
ID severity level	
Sensorimotor impairment	
Language disorder	
Comorbidities	
Type of provider	
Location of provider	
Type of service received	
Race	
Ethnicity	
Home & Family	
Number of children in the home	
Number of adults caregivers in the home	
Urbanicity	
Median home values	
Values & Cultural Considerations	
Religion	

Country of origin	
Language(s) spoken	

Evaluation of Barriers	
Technology	
Internet access	
Devices available for telehealth	
Client Factors	
Client behavior	
Language barrier	
Sensorimotor impairment	
Need for in-person support	
Home & Family	
Childcare for other children in the home	
Availability of appropriate adult for support	
Values & Cultural Considerations	
Comfort with telehealth	
Other	
Provider-level barriers (e.g., provider comfort with telehealth interface, provider internet access)	
Parent declined services	
Parent did not respond to attempts to contact	

Appendix B: Email Script

Hello,

As promised, now that I have received IRB approval, I am requesting help gathering data for my dissertation research. Below is the link to a very brief **survey regarding clients served between March 2020 and March 2021**, which is intended to identify clients who will be included in my review of records. All clients for whom **ongoing behavioral health services** (e.g., counseling, behavioral therapy) **via telehealth** were *considered* during this time frame should be included in your responses, regardless of whether they ended up receiving telehealth services. This should **not** include clients who were/are *only* receiving speech therapy, occupational therapy, and/or physical therapy through Empower.

I would appreciate your responses as soon as you are able, as I am hoping to complete the records review before our switch to Central Reach. I appreciate that everyone is very busy, so I have kept the survey as brief as possible. Please let me know if you have any questions.

(Survey Link)

Appendix C: Provider Survey

Dissertation Data

Start of Block: Block 1

This survey will ask you about your clients for whom ongoing behavioral health services via telehealth were **considered or offered**. Only clients served between March 2020 and March 2021 should be included.

You should complete one survey for each client for whom telehealth was considered as an option, *even if the client ultimately did not receive any telehealth services*.

End of Block: Block 1

Start of Block: Default Question Block

Q12 Your primary role

- Psychologist
- Psychology Assistant
- Counselor or Social Worker
- BCBA/Behavior Consultant
- Speech Therapist/Speech Therapy Assistant
- Occupational Therapist/Occupational Therapy Assistant
- Physical Therapist/Physical Therapy Assistant

Skip To: Q13 If Your primary role = Speech Therapist/Speech Therapy Assistant

Skip To: Q13 If Your primary role = Occupational Therapist/Occupational Therapy Assistant

Skip To: Q13 If Your primary role = Physical Therapist/Physical Therapy Assistant

Q11 Your name

Q1 Client's name

Q14 What ongoing service were/are you providing (or attempting to provide) to the client via telehealth?

Counseling/Psychotherapy

Behavioral Therapy

Other _____

Q2 Service Location (your primary location at the time you were serving the client and/or the location where the client would have received services had they been in-person)

- AIC
- Athens
- Lancaster
- Billingsley
- In-home
- HLC East
- HLC New Market
- Other _____

Q3 Did the client receive telehealth services?

- No, the family and/or care team did not think the client would be successful with telehealth.
 - Yes, but sessions were discontinued due to difficulties.
 - Yes, and telehealth services are ongoing OR sessions continued until goals were met or it was possible to return to in-person services.
 - Yes, but started recently and not sure yet if telehealth is a good fit.
 - Other _____
-

Display This Question:

If Did the client receive telehealth services? = No, the family and/or care team did not think the client would be successful with telehealth.

Q4 What barriers prevented the client from attempting telehealth services? Please add additional detail when possible.

This response should focus on barriers experienced by *the client and their family* (e.g., the client did not have high speed internet, the client could not attend to the computer),

not the provider (e.g., the provider did not have high speed internet, the provider was unsure how to provide the service via telehealth).

- Client Internet access or speed _____
- Client behavior (please be specific) _____
- Lack of childcare for other children

- Caregiver work schedule _____
- Caregiver comfort with telehealth services

- Language barrier _____
- Lack of appropriate technology

- Other _____

Display This Question:

If Did the client receive telehealth services? = Yes, but sessions were discontinued due to difficulties.

Q6 What barriers caused the client to discontinue telehealth services? Please add additional detail when possible.

This response should focus on barriers experienced by *the client and their family* (e.g., the client did not have high speed internet, the client could not attend to the computer),

not the provider (e.g., the provider did not have high speed internet, the provider was unsure how to provide the service via telehealth).

Client Internet access or speed

Client behavior (please be specific)

Lack of childcare for other children

Caregiver work schedule _____

Caregiver comfort with telehealth services

Language barrier _____

Lack of appropriate technology

Other _____

Q9 What, if any, additional challenges affected the client's participation in or success with telehealth (even if these challenges did not make telehealth services impossible)?

This may include challenges faced by the provider as well as challenges faced by the client and their family.

Display This Question:

If Your primary role = Speech Therapist/Speech Therapy Assistant

Or Your primary role = Occupational Therapist/Occupational Therapy Assistant

Or Your primary role = Physical Therapist/Physical Therapy Assistant

Q13 Thank you for your time! This survey is only for behavioral health services.

End of Block: Default Question Block

Appendix D: IRB Approval Letter

Study Determined Exempt for #2021E0432

OR IRB Info <IRBInfo@osu.edu>

Mon 4/26/2021 2:26 PM

To: Tasse, Marc <tasse.1@osu.edu>

Cc: Fortney, Stoni <fortney.69@osu.edu>



THE OHIO STATE UNIVERSITY

Practices

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04/26/2021

Study Number: 2021E0432

Study Title: Client-Level Barriers to Successful Utilization of Telehealth for Clients with Autism Spectrum Disorder

Principal investigator: Marc Tasse

Date of determination: 04/26/2021

Qualifying exempt category: #4b

Dear Marc Tasse,

The Office of Responsible Research Practices has determined the above referenced project exempt from IRB review. In addition, the Ohio State University HIPAA Privacy Board granted the project a full waiver of HIPAA authorization by expedited review, according to 45 CFR 164.512.

Administrative Note:

- As the university moves to a staged approach to restarting research activities, refer to Human Subjects Guidance and FAQs. If after reviewing this information and working through your college you have additional questions, please direct emails to research@osu.edu.

Please note the following about this determination:

- Retain a copy of this correspondence for your records.
- Only the Ohio State staff and students named on the application are approved as Ohio State investigators and/or key personnel for this study.
- Privacy Board approval does not guarantee access to the desired records: additional permissions, rules, regulations, and/or reporting may apply-please contact the
- steward(s) of the desired records for information.

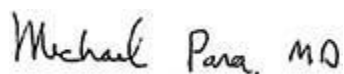
The Ohio State University Wexner Medical Center controls access to its patient information for research purposes. You must obtain approval to access OSUMC patient information from the department of Medical Information Management. Please see <https://www.medctr.ohio-state.edu/Departments/MIM/Resources/Research.aspx>. For questions, call 614-366-6690.

- Simple changes to personnel that do not require changes to materials can be
 - submitted for review and approval through Buck-IRB. No other changes may be made to exempt research (e.g., to recruitment procedures, advertisements, instruments, protocol, etc.). If changes are needed, a new application for exemption must be submitted for review and approval prior to implementing the changes.
 - Records relating to the research (including signed consent forms) must be retained and available for audit for at least 5 years after the study is closed. For more
 - information, see university policies, [Institutional Data](#) and [Research Data](#).
- It is the responsibility of the investigators to promptly report events that may represent unanticipated problems involving risks to subjects or others.

This determination is issued under The Ohio State University's OHRP Federalwide Assurance #00006378. Human research protection program policies, procedures, and guidance can be found on the [ORRP website](#).

Please feel free to contact the Office of Responsible Research Practices with any questions or concerns.

Jacob Stoddard
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 (614) 292-0526



Michael Para, MD

Chair, HIPAA Privacy Board

Appendix E: Coding Instructions

Median Family Income

1. Go to: Census - Table Results
2. Select the appropriate ZTCA under “Geo.” ZTCA is not always the same as zip (though it usually is), so be sure to check the converter document.
3. To reduce the amount of data, you can remove all selections except “family” under the “columns” tab on the far right of the table.
4. The number that should be entered is the **median income** (not mean) for **families** (not households).

Urbanicity Designation

1. Look up address using FFIEC Geocoding System
2. Locate the State-County-Tract FIPS Code in the OH RUCA codes files
 - a. Should be entered all as one number with no spaces or decimals
3. Data should entered as one of the following collapsed groups: metropolitan (coded as 1 -- RUCA codes 1-3), micropolitan (coded as 2 -- RUCA codes 4-6), small town (coded as 3 -- RUCA codes 7-9), or rural (coded as 4 -- RUCA code 10)

Other Variables

Provider Type (Psychologist = 1, Psychology assistant = 2, Counselor/Social Worker = 3, BCBA/Behavior Consultant = 4)

Primary Service (Counseling/Psychotherapy = 1, Behavior consultation/ABA = 2, Other = 3)

Provider Location (AIC = 1, Athens = 2, Lancaster = 3, Billingsley = 4, In-home = 5, HLC East = 6, HLC New Market = 7, Other = 8, Sandusky = 9, Zanesville = 10)

Gender (1 = Male, 2 = Female, 3 = Other/Unspecified)

ASD diagnosis (1 = yes, 2= no)

ID diagnosis (1 = yes, 2 = no)

ID severity (1 = mild, 2 = moderate, 3 = severe/profound)

BARRIERS TO TELEHEALTH FOR CLIENTS WITH ASD

Sensorimotor impairment (Blind, Deaf/hard of hearing, motor impairment) (1 = yes, no = 2)

Language impairment (Recorded communication disorder diagnosis) (1 = yes, 2 = no)

Race (1 = White/Caucasian, 2 = Black/African American, 3 = Asian/Pacific Islander, 5 = Native American, 6 = Multiracial)

Rural/Urban Designation (1 = Metropolitan, 2 = Micropolitan, 3 = Small Town, 4 = Rural)

Ethnicity (1 = Hispanic/Latinx, 2 = Not Hispanic/Latinx)

Religion (1 = Christian, 2 = Muslim, 3 = Jewish, 4 = Hindu, 5 = Other/None)

Access to telehealth (1 = Was not able to receive telehealth services, 2 = Received some telehealth services but services were discontinued, 3 = Successfully received telehealth services until no longer needed, 4 = Success with telehealth pending)

All barriers and challenges coded as 1 = yes, 2 = no

All missing data coded as 99