

Serving Individuals with Autism Spectrum Disorder in the Age of COVID-19: Special  
Considerations for Rural Families

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### **Abstract**

This position paper explores the needs of rural families of children, adolescents, and adults with autism spectrum disorder (ASD) during the age of COVID-19. Prior to COVID-19, a rich literature portrays elevated stress in families of individuals with ASD and health and socioeconomic disparities for rural and underserved populations. These disparities have only been exacerbated due to COVID-19 and subsequent lockdowns and economic turmoil. Academic and adaptive skills training has been particularly impacted due to school closures, with parents tasked with taking up the reins. Our goals for this paper focus on special considerations for rural families regarding (a) neurobiological and developmental impacts of stressful experiences like COVID-19, (b) delineation of the impacts on individuals with ASD and other comorbid and related conditions, and (c) education and intervention needs during these times. Finally, we offer suggestions for future care during pandemic events, including recommendations for improving service delivery under such conditions.

**Keywords:** Autism spectrum disorder, COVID-19, Families, Pandemic, Rural

The COVID-19 pandemic has disrupted families of children with autism spectrum disorder (ASD) in multiple ways, including physical and mental health, academic and treatment progress, and economic stability (Figure 1). There is a well-established literature base demonstrating that, even during typical times, many parents of individuals with ASD report increased stress levels relative to parents of typically-developing (TD) children and parents of children with other developmental disabilities (e.g., Davis & Carter, 2008; Estes et al., 2009; Ingersoll & Hambrick, 2011). The stress levels of families is likely at an all-time high due to the recent pandemic. Primarily characterized by deficits in social-communication, restricted and repetitive behaviors and interests, and sensory atypicalities (APA, 2013), many individuals with ASD exhibit a variety of associated challenges. These include difficulties with executive function, emotion regulation, feeding and sleep disturbance, self-injurious behavior, aggression, seizure disorders, comorbid psychiatric conditions, and elopement, among others (Ming et al., 2008). Together, these primary and secondary symptoms are thought to increase parental burden and stress response in many cases (Stuart & McGrew, 2009). Moreover, families in rural areas and those from traditionally underserved groups receive less support in managing these difficulties due to a lack of available services (Hoogsteen & Woodgate, 2013; Mello et al., 2016; Skinner & Slifkin, 2007) or difficulty accessing services. The current paper explores impacts of stressful experiences like COVID-19, how these experiences affect individuals with ASD and other comorbid and related conditions, and education and intervention needs of families during these times, all with a specific focus on rural and underserved populations.

Measures taken in response to COVID-19 (e.g., lockdowns, educational adjustments, alterations in intervention services, general disruption of routines) likely increased stress for many families of individuals with ASD and further exacerbated stress in rural families.

Additionally, the U.S. Centers for Disease Control and Prevention (CDC) lists individuals with developmental and behavioral disorders, including ASD, and individuals in rural communities as two groups that should take extra safety precautions with respect to COVID-19 (CDC, 2020).

Moreover, data indicate that individuals from minority populations have been impacted disproportionately by the COVID-19 pandemic in a variety of ways (Fortuna et al., 2020). Yet, lacking social and financial safeguards in the U.S. and many parts of the world can make adherence to health and safety recommendations incredibly challenging for those less advantaged (e.g., Chukwuorji & Iorfa, 2020), further compounding stress and health risks.

Global pandemics aside, families in rural areas face a number of challenges and are subject to a variety of health-related disparities (e.g., Maenner et al., 2009; Mandell et al., 2005). Families in rural areas are subject to high rates of poverty (e.g., Beale, 2004) and food insecurity (e.g., Ramadurai et al., 2012), and limited access to health information (Ramírez et al., 2017) and reliable high-speed internet (Tsami et al., 2019), among other challenges. Rural health disparities are often attributed to a variety of factors, including dearth of healthcare providers in rural areas (Bureau of Health Workforce/HRSA, 2020; Skinner & Slifkin, 2007) or insufficient geographic proximity (Mello et al., 2016). For example, living in rural settings has been tied to delayed ASD diagnosis (Mandell et al., 2005), fewer available ASD service providers (Drahota et al., 2020), and limited access to specialized education services (Murphy & Ruble, 2012; Pennington et al., 2009). Individuals with ASD from ethnic or racial minority groups are also subject to a variety of disparities, including delays in first evaluations (Maenner et al., 2020), elevated rates of misdiagnosis (Mandell et al., 2007), differences in the types of special education services received (St. Amant et al., 2018), and disparities in specialty healthcare utilization (Broder-Fingert et al., 2013). Because the number of providers with specialist training in rural areas is

insufficient (Murphy & Ruble, 2012; Singh et al., 2019), caregivers might experience elevated burden and stress (Iadorola et al., 2019). Also, intervention services and opportunities for respite can be significantly limited (Hoogsteen & Woodgate, 2013; Mello et al., 2016). These barriers can result in limited implementation of intervention for rural families (Mello et al., 2016).

Despite these challenges, individuals from rural and underserved communities possess a number of strengths that deserve mention. These include traits like high levels of spirituality (Isaacs et al., 2019), close family and community ties (Parra-Cardona et al., 2006), and strong work ethic (Raffaelli & Wiley, 2012), among others. Moreover, while formal support networks may have come to a halt during the pandemic, families living in rural areas often report leaning more on informal sources, such as extended family and neighbors (Raffaelli & Wiley, 2012). Nevertheless, we surmise that, unfortunately, these resiliency factors have been put to the test with obstacles likely magnified during the COVID-19 pandemic. Here, we focus on the potential impact of COVID-19 on rural areas and provide recommendations for families, service providers, and researchers in the advent of future pandemics (see Tables 1 and 2).

### **Potential Neural and Developmental Impacts of COVID-19**

Dynamic changes in cognitive, social, and neurobiological development are hallmark features of childhood and adolescence (Fischer, 2008). Adverse life events, such as exposure to natural disasters, poverty, and neglect, increase stress and decrease mental health in children, significantly altering development in the sympathetic nervous system and the hypothalamic-pituitary-adrenal axis via neuroendocrine responses culminating in increased cortisol levels (McLaughlin et al., 2013). Due to their unpredictability and prolonged duration, the social ramifications of the COVID-19 pandemic constitute an adverse life event (Fofana et al., 2020), which may alter the course of children's and adolescents' brain development via deprivation,

decreasing neural specialization and pruning. The social ramifications of the COVID-19 pandemic have been especially deleterious for families of youth with other risk factors (e.g., ASD), geographical isolation, or family financial precarity, increasing stress and ASD symptomatology (e.g., less prosocial behavior; Brown et al., 2020; Nonweiler et al., 2020), both of which are associated with abnormal brain development (Gunnar et al., 2009; Khundrakpam et al., 2017). Thus, disruptions to brain development resulting from the social ramifications of the COVID-19 pandemic may affect long-term clinical outcomes in rural and underserved youth with ASD, further limiting this already-disadvantaged population.

In addition to its ramifications for brain development, the COVID-19 pandemic may also entail ramifications for cognitive development. Impairments in executive function, a set of cognitive processes necessary for control of behavior that includes inhibition, working memory, and cognitive flexibility, are characteristic of children and adolescents with ASD (Hill et al., 2004) and may also be present in their parents (Hughes et al., 1997). Daily disruptions due to COVID-19 represent an additional tax on the already-strained executive functions of youth with ASD and their parents, which may further negatively affect their adaptive behavior (Gilotty et al., 2002). Moreover, executive functioning impairments may increase susceptibility to the psychological effects of the COVID-19 pandemic via immature emotion regulation (Zhou, 2020). These demands on executive function tied to the COVID-19 pandemic may have compounded the already heightened demands on executive function for rural and underserved youth with ASD and their families (due to financial challenges, geographical isolation, and sparsity of support services), potentially worsening the effects of executive function deficits on their cognitive development.

### *Infancy to Adolescence*

Healthy early childhood development is contingent upon caregivers who provide the structure and sustenance necessary to meet milestones across developmental domains; yet, routine interruptions can be particularly disruptive to secure caregiver attachments that are critical for adaptive outcomes (Boldt, 2014). Additionally, infants are adept at perceiving emotional cues and parental stress (Waters et al., 2017) likely to be exacerbated by COVID-19 as rural families face increased economic insecurity and health concerns (Hirko et al., 2020). With physical and social distancing mandates, young children will experience limited opportunities for exploration—an essential skill for establishing a foundation for independent learning and generating cognitive flexibility (Kogan, 2013), a component of executive function impaired in ASD (van Eylen et al., 2011). Infants in rural and disadvantaged environments and young children at elevated risk for ASD already demonstrate deficits in these areas (see Tacke et al., 2015; St. John et al., 2016). Thus, this is of critical developmental concern during the pandemic.

For early school-age children, issues related to school closings are likely to be some of the largest pandemic-related impacts. Exposure to structured educational environments promote strong regulatory abilities (e.g., maintaining attention, turn-taking, activity-switching; Bull et al., 2008). Moreover, predictability and routine tend to be particularly helpful for children with ASD (e.g., Stoppelbein et al., 2016). With stay-at-home mandates in many locations, classrooms have shifted to remote instruction, which relies on technological skills of the child and caregiver and advanced regulatory abilities of the child to focus on instruction in a less-structured home environment with fewer opportunities for peer play-based learning. Because rural populations are already more vulnerable to behavioral disorders and cognitive and attention issues (Tine, 2017), rural children may be more adversely affected by school closings than their urban and suburban peers. Even with support and structure, children with ASD often struggle to transition into a

traditional school setting (Fontil et al., 2019), and the unstructured nature of school and home routines may adversely limit progress on goals (see below for more discussion on school closings).

The period of middle childhood and adolescence involves a balancing act between risk and reward related to slow brain maturation within cognitive or cool regulation areas (e.g., prefrontal cortex) that is insufficient relative to increased maturation of affective or hot reward (e.g., ventral striatum and subcortical regions; Casey et al., 2008). Children with ASD often exhibit additional executive function impairments during adolescence (O’Hearn et al., 2008; Rosenthal et al., 2013), making this period particularly vulnerable to scholastic and intervention disruptions. Evidence of more immediate impacts on youth with ASD and their families following pandemic disruptions and extended interruptions continues to emerge (e.g., White et al., 2021), including in rural areas (McFayden et al., 2021). Yet, time will tell if there are long-term, sustained impacts on progress that disproportionately affect children with ASD across ages in rural or disadvantaged settings.

### ***Adherence to Pandemic Health Needs***

Provision of publicly- and privately-administered in-person health care services frequently used by children with ASD and their families have been curtailed by limitations on face-to-face interactions. Given that fewer such services are available to children with ASD located in rural locales (Antezana et al., 2017; Mello et al., 2016), restrictions on provision of these services have the potential to be particularly deleterious, widening service gaps between them and their non-rural counterparts. Moreover, there are special challenges to helping children with ASD understand the shift in societal “pandemic rules” that impact children across contexts (school, home, stores). Although specialists, educators, and advocates were quick to produce

resources for families, these challenges are further exacerbated for certain populations with comorbid medical or other neurodevelopmental disorders. Explanations of the pandemic may be overly complex for the approximately 28-51% of children with ASD who also have a comorbid intellectual disability or borderline cognitive ability (Tonnsen et al., 2016).

Yet, ensuring that individuals with ASD understand the basic health concerns and adhere to guidelines is critical, as children and adults with developmental disabilities are approximately twice as likely to die from COVID-19 (Turk et al., 2020). Health behaviors in the pandemic require diligent and frequent hand washing, physical distancing, and wearing a mask in public. These health behaviors may be challenging for individuals with ASD who struggle with hygiene (Matson et al., 2012), appropriate physical space (Kennedy & Adolphs, 2014), or have sensory sensitivities that can be aggravated (Neil et al., 2016).

In addition to these behaviorally-based challenges, there are other risks for children who are medically fragile or immunocompromised. For instance, there is a high prevalence of seizures, gastrointestinal issues, and metabolic issues in children with ASD (Bauman, 2010). Importantly, children with ASD are more prone to inflammation (e.g., gastrointestinal issues, allergies, asthma; Goines & Van de Water, 2010), suggesting that children with ASD are more likely to be immunocompromised, and poverty can lead to immune system dysregulation during childhood (Schmeer & Yoon, 2016). Being immunocompromised is considered a severe COVID-19 risk factor for children and adults (Hageman, 2020). Thus, it is increasingly important for children who are medically fragile or susceptible to illness to maintain strict safety and hygiene measures despite additional burden on families. Unfortunately, there is often poor access to safety equipment and healthcare, as well as ASD support services, in rural or impoverished areas (Caldwell et al., 2016; McBain et al., 2020).

## **Education and Intervention in the Age of COVID-19**

### **Special Education Services in the Age of COVID-19**

The provision of educational services for students with disabilities varies considerably across countries, with diverse philosophies and contexts shaping special education practice. However, all developed countries and many developing countries mandate provision of services to children with special educational needs (Rix et al., 2013). Internationally, frameworks such as the World Declaration on Education for All and Article 24 of the United Nations Convention on Rights of Persons with Disabilities emphasize that children with disabilities have a universal right to education and specialized services (United Nations Educational, Scientific and Cultural Organization, 2002; Quinn, 2009).

Local educational agencies may find it particularly challenging to provide these services to students with ASD during pandemic-caused school closures. In countries that have reopened schools under modified conditions, students with disabilities and special educational needs have been encouraged and allowed to attend school in person rather than remotely (National Principles for School Education, 2020). Some countries have implemented temporary legislative changes to special education policies, such as the United Kingdom, which specifies that local authorities use “reasonable endeavors” to provide special education services (United Kingdom Department for Education, 2020). In contrast, special education policies such as Australia’s Disabilities Standards for Education (Commonwealth of Australia, 2005) and the United States’ Individuals with Disabilities in Education Act (IDEA, 2004) have not been officially modified or suspended, though schools have flexibility in determining how services are delivered (U.S. Department of Education [USDOE], 2020b). For example, in the case of school closures in the United States, if a school continues to provide educational opportunities to students in general

education, schools must also provide equal access and opportunities to students with disabilities as mandated by IDEA, including the provision of a free and appropriate education, and, to the greatest extent possible, the special education and related services specified in the student's individualized education program (IEP; USDOE, 2020b). If the school district is unable to provide services remotely, the child is entitled to compensatory services once school resumes (USDOE, 2020b).

For infants and toddlers with or at risk for ASD and their families, services in the United States are typically provided under IDEA Part C and occur in natural environments, such as families' homes, childcare programs, or other community settings (IDEA, 2004). Owing to COVID-19, states' Part C systems shifted to remote service delivery to limit in-person interactions (Early Childhood Technical Assistance [ECTA] Center, 2020). Similar to guidance put forth for school-based services under IDEA Part B, USDOE (2020b) provided guidance that, in the event of program closures, the provision of Part C services is not required (USDOE, 2020b). Upon reopening, the Individualized Family Service Plan (IFSP) team must determine any necessary changes to the IFSP and whether a need exists for compensatory services (USDOE, 2020b). If a program remains open but services cannot be provided because of particular circumstances (e.g., person infected with COVID-19), accommodations must be made to continue service provision (USDOE, 2020b). In addition, the 45-day timeline for the initial evaluation and IFSP meeting remains, with an option to develop an interim IFSP if necessary (USDOE, 2020a).

Given the need for many students with ASD to receive intensive, individualized instruction and support, Part B services provided remotely during school closures may be insufficient, and school districts have little guidance on how to provide these services effectively,

with the onus of instruction likely falling on caregivers. Whereas online learning and service delivery certainly have value, they also have limitations. Because many children with ASD receive a number of support services within early childcare and school settings (Wei et al., 2014), limitations on in-person attendance have, in turn, limited provision of these services. Compared to their White peers, Hispanic and indigenous children are less likely to be diagnosed with ASD in school settings (Sullivan, 2013), and Hispanic children diagnosed with ASD receive smaller doses of speech-language and occupational therapy in school settings (Irvin et al., 2012), making them even more vulnerable to the loss of these services. Rural schools face even more challenges, and geographic barriers limit access to resources and infrastructure even under typical conditions (Ashburner et al., 2016). Such schools may also lack staff with specific expertise in working with students with ASD, with many schools relying on outside consultants (Anderson et al., 2017), which may not be feasible for underserved and under-resourced schools in these extraordinary circumstances.

In contrast to Part B services, the transition to remote service delivery under Part C should not require a major shift in approach, aside from delivery method. Because Part C services should already be family centered and facilitate caregiver-implemented intervention (Division for Early Childhood [DEC], 2014; IDEA, 2004; Workgroup on Principles and Practices in Natural Environments, 2008), the direct approach of caregiver support (rather than working directly with children) remains consistent; however, challenges to remote service delivery exist.

### **Adaptations to Education and Service Provision**

Although remote service provision has removed some access barriers particularly onerous for rural families, such as extended travel necessary to receive services in person (Antezana et

al., 2017; Mello et al., 2016), technological barriers have been introduced, such as the need for internet-connected devices and sufficient bandwidth. Moreover, educators, service providers, and caregivers must be familiarized with novel platforms and techniques necessary for remote service delivery (Ashburner et al., 2016; Iacono et al., 2016).

Although caregivers of individuals with ASD are largely open to trying remote service provision (Hepburn et al., 2016; Iacono et al., 2016), this shift in response to COVID-19 has, in large part, entailed replacement rather than supplementation of face-to-face contact, the latter of which is preferred by service providers and families (Ashburner et al., 2016). Currently, evidence concerning the efficacy of remote implementation of educational and support services for individuals with ASD and their families is scant, given that remote implementation of many such services was relatively limited prior to COVID-19 (see Simacek et al., 2020 for a review of telehealth services for families of children with ASD between 2014 and January 2020). Existing evidence from parent-mediated interventions indicates that therapist-assisted telehealth interventions can improve language and social skills in children with ASD, as well as caregivers' use of effective strategies supporting development of these skills (e.g., Ingersoll et al., 2016; Vismara et al., 2013). Both case studies and systematic analyses indicate that caregiver-mediated service provision using telehealth approaches may improve clinical outcomes in individuals with ASD (Bearss et al., 2018; Ferguson et al., 2019; Sutherland et al., 2019).

During these stressful times, family-centered practice, a key component of intervention services under Part C, can foster caregiver capacity, self-efficacy and, ultimately, child outcomes (Dunst et al., 2007, 2008; Trivette et al., 2010). When intervention services are family centered, they address the family's priorities and concerns and focus on support to the caregivers to, in turn, support the individual within the family's everyday routines. Given the stressors of this

global pandemic and families spending more time in their households, it is arguably evermore important to consider family centeredness when providing educational and intervention services to individuals with ASD of all ages. Family systems theory (Kerr & Bowen, 1988) and ecological systems theory (Bronfenbrenner, 1994) drive the idea of the individual with ASD as part of a greater unit influenced by those in their environment. Family-centered approaches to intervention address family functioning and the individual's environment, both of which influence the individual's overall functioning. By taking a family-centered approach to services, caregivers can receive the individualized level of support needed to successfully support the individual with ASD and their family as a whole.

### **Family Management Challenges and Family-Centered Strategies During Stay-At-Home Orders**

The challenges caregivers in rural or underserved areas face in managing education and therapy for their children during crisis are not new in many respects, but rather are an intensified version of the challenges they face under typical circumstances. Beyond preexisting limits on the availability of specialized services in rural areas (e.g., Drahota et al., 2020), disruptions in associated education and health systems can cause additional hardships. For example, the abrupt discontinuation of various childcare arrangements, combined with continued or increased work demands for caregivers, has created situations that require immediate attention. In such cases, interventionists may have seen their roles shift from supporting child development and education to promoting the long-term mental health of the entire household.

One adaptive approach during stay-at-home orders has been for parents to focus on specific, limited, and attainable maintenance goals for the at-home environment. Additionally, individualized support for parents engaged in their children's intervention and education has

been correlated with increased parental self-efficacy and reduction in stress levels (Keen et al., 2010), particularly important in a crisis situation.

When parental resources are limited (e.g., a single parent providing care for a child with a developmental disability and a sibling), directing goals toward the needs of the child with lower developmental age may be appropriate. In practice, this might mean lowering the expectations for all children in the home temporarily and focusing, instead, on maintenance of attained skills. The child with lower developmental age is likely to require more support for skill maintenance in this type of situation. For example, in a case study of ABA delivery under stay-at-home orders (degli Espinosa et al., 2020) the authors suggested that adjusting short-term therapy goals to account for the resources of the family unit in its entirety (e.g., presence of adults other than the primary caregiver, as well as children of varying ages) mitigates short-term burnout for parents, allowing for reasonable levels of parental satisfaction to be maintained over longer periods. We encourage caregivers and professionals to recognize that social isolation is an extreme situation that requires adjustment not only to education and service delivery methods, but also to intervention goals and individual expectations, for the duration of, and possibly even past, formal isolation requirements.

To maintain healthy family ecosystems during social isolation, early adjustments to individual and cumulative schedules are critical. In reframing individual and family schedules, case studies (degli Espinosa et al., 2020; Simacek et al, 2020) have found it practicable to, first, focus on maximizing sleep time for all family members as a step toward maintaining long-term physical health (for adolescents, a temporary shift of circadian rhythms may need to be taken into account; Tarokh et al., 2019). The waking hours should be structured to allow for frequent changes in the types of activities to maintain levels of child motivation and caregiver self-

efficacy. When in a situation of prolonged increased contact with caregivers, children of all ages can become ‘apprentices’ in learning developmentally-appropriate self-care and life skills. Learning to apply meta-cognitive skills in everyday life (e.g., preparing a workspace or resources for projects, allocating time, working backwards from specific long-term goals) is one of many important and necessary life skills particularly relevant during this time.

Depending on the age and cognitive abilities of the child, it may be possible to supplement or even increase tutoring and therapeutic engagement via programs delivered remotely, the number and range of which have increased drastically during stay-at-home orders. Use of these programs, however, is governed by the developmental age of the child. Older children, whose goals are usually geared toward enhancing executive control and planning (Jacobson et al., 2011), may benefit from online engagement and content delivery. Younger children, who benefit primarily from sensory and direct engagement experiences (e.g. tactile feedback during language therapy; Pieretti et al., 2015), may refuse online participation or require intense concurrent parental engagement. Nevertheless, access to various online learning communities has increased manifold during stay-at-home: educational programming ranging from physical education (martial arts, ballet), to music, to specialized early and gifted education (summer camps with such institutions as Art of Problem Solving, Institute for Educational Advancement, Duke Talent Identification Program, Johns Hopkins Center for Talented Youth). The learning communities that were only accessible in large metropolitan areas prior to stay-at-home are now available online to youth around the world. However, difficulties in obtaining broadband internet access remain a challenge for rural areas (e.g., Tsami et al., 2019).

### **Recommendations for Future Waves of COVID-19 and Other Pandemics**

Modifications and adaptations to service delivery, telehealth, and research opportunities for rural families have always been important, but never more so than in the age of COVID-19 and beyond. Whereas professionals have advocated for changes over the years (e.g., making intervention available online; e.g., Lindgren et al., 2016), such suggestions were rarely implemented on a large scale. We align the challenges and barriers for families from rural and underserved communities with a collection of recommendations for providers and professionals within Table 1 and for educators and families within Table 2, further outlined within the family context below.

--- Place Tables 1 and 2 about here---

### **Adaptations to Service Delivery**

First, online opportunities for fostering social connections and engaging in community initiatives (via internet) may mitigate stress, loneliness, and feelings of uncertainty and anxiety in individuals with ASD. Second, changing service delivery to online formats involves plans and decisions at the infrastructural, theoretical, ethical, personnel, and practical levels, among others. Training and support should be administered to service providers and caregivers to aid in continuity of sessions without major disruption. Third, given the resistance to change and rigidity of routines in individuals with ASD, protocols should be developed for introducing and establishing new service platforms (e.g., online treatment), as well as adhering to in-person safety measures (e.g., physical distancing, mask use). Fourth, during times of physical distancing, perhaps the biggest challenge and change would be for individuals with ASD who need one-to-one support or struggle with physical boundaries (e.g., inappropriate touching or proximity). Fifth, change in educational practices for individuals with ASD will be necessary. Different forms of instruction, assessment, and evaluation for measuring educational outcomes

need to be implemented, and immersion/transition plans and modifications should be available for students with disabilities. Finally, there must be an established process for teaching the new social and interpersonal rules and routines (e.g., physical distancing). Adequately preparing individuals with ASD and their families for any transitions related to future pandemics is critical. Pertinent to rural and underserved communities, the resources must be communicated across multiple modalities (e.g., online, print, broadcast) to ensure communication to all families, including those with limited internet access. Public or community organizations (e.g., local libraries, recreation centers) can be leveraged as a portal for families to use internet access, and phone and text-based options can also be utilized for care and consultations.

### ***Improvements in Telepractice***

Telehealth modalities can be synchronous (i.e., real-time care through telephone or live audio-video interaction) or asynchronous (i.e., messages or data collected at one time point and interpreted or responded to at a later time). Professionals are faced with a major challenge during the COVID-19 pandemic. Most are accustomed to in-person interactions with individuals with ASD, sometimes on a one-to-one basis. However, the physical distancing during the pandemic is forcing clinicians and educators into roles they might not have otherwise assumed. Like the individuals they work with, many professionals might not be ready for this transition right away. Hence, to support this transition to remote service delivery, the right systems must be in place to implement telepractice in a seamless and impactful way, such as platforms that are user-friendly and require lower bandwidths. In addition, detailed professional training to shift to the new system should be ready and available. Moreover, broader use of telepractice would depend on several factors, including accessibility for families, particularly those from rural and underserved areas. Availability of devices, such as laptops or smartphones, along with robust internet

connectivity, are all going to play a role in developing the infrastructure needed for widespread telepractice. For certain therapies, availability of health insurance coverage and other third-party payer agreements for telepractice services is another important and potentially limiting factor. Obstacles related to insurance coverage and payments need to be identified and resolved quickly before people can rely on this service. Some of the medical insurance agencies, public and private, are considering this on a temporary basis (Mehrota et al., 2020); however, we argue that it should be considered for long-term use.

### **Adaptations to Research Infrastructure and Procedures**

COVID-19 significantly impacted and stalled human subjects ASD research (Amaral & de Vries, 2020) due to safety concerns and necessary preventive measures (e.g., physical distancing). Research labs continuing with projects or re-starting studies encountered many methodological issues and were often forced to make considerable modifications (e.g., adapting surveys to an online format). Such changes increased the variability and heterogeneity in research (Lourenco & Tasimi, 2020). Moving from experimental settings to home settings resulted in multiple uncertainties and may have increased risk for participants and jeopardized research quality. On the other hand, individuals with ASD and their caregivers might prefer participating in research from home (Aman & Pearson, 2020), and such settings provide a better representation of real life for families, supporting an easier translation of research to community practice. Participants and families living in rural areas face additional infrastructural issues including internet access and speed that might require data collection via alternate procedures (e.g., telephone rather than internet), introduce limitations on generalizability and replicability of results, and restrict the types of data collected (e.g., inability to collect neuroimaging data).

Research efforts should prepare additional validity metrics to empirically examine possible effects of setting or pandemic research modifications that can guide future practices.

### **Conclusion**

The slow development of knowledge about COVID-19 complicates our ability to provide validated recommendations, and the true lasting effects of the virus and its impacts remain to be seen. Despite tremendous efforts from scientists around the world, it could be many years before we fully understand how the virus is transmitted and are able to totally eradicate or manage COVID-19 and its variants. For individuals with ASD, this may mean several months of uncertainty and ongoing shifts in preventative public health measures, academic and treatment services, and even the home environment. The lack of stable “pandemic rules” can be frustrating for individuals with ASD who may not understand the reasons for the changes. Although various measures can be implemented to prevent stagnation of educational and therapeutic goals during and after limited in-person support services, these changes are far from perfect and often leave families scrambling and in incredibly challenging situations, particularly disadvantaging rural families. Although the long-term impacts of COVID-19 remain to be seen and many predictions speculative, current trends suggest that uncertainty surrounding COVID-19 may continue for quite some time. Professionals who work with these families must seize the opportunity of COVID-19 to adapt, adjust, innovate, and harness strengths and resiliency in order to best serve families during these unprecedented circumstances. Our recommendations serve to provide scope and a foundation as a developmental guide for future catastrophic events in order to protect these vulnerable individuals.

### **Table 1**

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*Provider and professional recommendations for addressing challenges, barriers, and health disparities in rural communities*

Challenges and barriers	Recommendations for providers and professionals
Lack of reliable high-speed internet	<p>Use of public radio and television</p> <p>Tollfree telephone hotlines</p> <p>Platforms that are user-friendly, require lower bandwidths (e.g., phone over video)</p> <p>Consider availability of devices (laptops, tablets, smartphones)</p>
Limited access to health information	<p>Use of free apps and websites</p> <p>Engagement with community health workers (paid and volunteer)</p>
High rates of poverty	<p>Address insurance coverage and payments for telehealth early in process</p> <p>Address family-level outcomes, in addition to child-level outcomes, to support the entire family (e.g., connecting families to local resources)</p>
Elevated caregiver burden and stress	<p>Structured websites and forums providing information on stress reduction</p> <p>Tollfree telephone hotlines for 24/7 support</p> <p>Use a caregiver-implemented intervention approach to support caregivers' use of strategies during time between sessions or visits</p> <p>Connect families to local respite resources</p>
Health disparities	Recommendations for providers and professionals
Lack of healthcare providers within geographic proximity	<p>Clinician rotations in rural areas (e.g., one day per week/month there)</p> <p>Incentives for clinicians to practice in rural areas</p> <p>Establishment of mobile clinics</p> <p>Building virtual professional communities to connect providers working in rural areas</p>
Delayed ASD diagnosis	<p>Telehealth applications that could aid ASD diagnosis</p> <p>More communication with local pediatricians and/or primary health centers about screening for autism</p>

	Organizing screening and diagnostic opportunities for autism in rural communities
	Partnering with early childhood professionals to support identification of early red flags for ASD and next steps when concerns are present
Lack of specialist training in rural communities	Professional training for new service delivery options Utilize a cascading coaching model Organizing training workshops and inviting candidates from rural communities to attend
Limited implementation of intervention	For those requiring 1:1 treatment, establish physical markers, use plexiglass separators, inventive use of large outdoor spaces Develop mechanisms for asynchronous therapy
Adaptations to service delivery	Adapting to online format: training and support for service providers and families Use as training opportunity for trainees Document success (and failures) and decisions for revision Introduce variable service platforms (e.g., online, safety measures) early
Increase in mental health issues following social isolation	Providers check in with clients via phone Development of peer-to-peer networks that connect via phone, internet, or in-person with safety protocols

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**Table 2**

*Recommendations for addressing educational disparities for educators and families in rural communities*

Barrier	Educator recommendations <sup>a</sup>	Family recommendations <sup>b</sup>
Schedule concerns	Provide a predictable schedule to students (daily, weekly, etc.)	Provide structure and predictable daily routines
	Provide parents with resources (e.g., visual schedules, social narratives, token economies); May require developing templates for immersion/transition plans	Use visual supports/schedules with visual timers or “first, then” boards to help with transitions
	Communicate with families any changes or disruptions	Communicate with educators to address schedule problems (e.g., adherence, transitions)
	Include time for physical activities and exercise, as well as regular calming activities and breaks	Be prepared to accommodate breaks (e.g., assemble activity bins or plan different exercise activities)
Instruction needs	Prepare for different forms of instruction, assessment, evaluation; Consider use of public radio and television	Offer children a choice of instructional activities
	Provide concrete instructions for all online or home-based activities	Provide a dedicated area for school work with minimal distractions
	Sharing (and sanitizing) educational tools	Connect with another family to share tools
	Allow opportunities for student choice in instructional activities	Implement positive reinforcement systems (e.g., token economies)
	Programs to place teachers in high-need rural areas (e.g., Teach for America)	
	Incentives for teachers to work in rural areas	
Socialization needs	Schedule physically-distanced check-ins with students	Provide regular opportunities for safe socializing with family, neighbors, or friends
	Use social narratives to explain new routines or situations	Connect with other families to serve as a peer (and parent) network

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<sup>a</sup> See Nowell et al., 2020

<sup>b</sup> See Hume et al., 2020

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