


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

Rural Special Education Quarterly
2023, Vol. 42(2) 105–118
© Hammill Institute on Disabilities 2023
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/87568705231167440
journals.sagepub.com/home/rsq


Theodore S. Tomeny, PhD¹, Caitlin M. Hudac, PhD¹, Evie A. Malaia, PhD¹ ,
Laura M. Morett, PhD¹, Kimberly R. Tomeny, PhD¹, Laci Watkins, PhD¹,
and Rajesh K. Kana, PhD¹

Abstract

This position paper explores the needs of rural families of children, adolescents, and adults with autism spectrum disorder (ASD) during the COVID-19 pandemic. Prior to COVID-19, literature portrays elevated stress in families of individuals with ASD and health and socioeconomic disparities for rural and underserved populations. These disparities were exacerbated due to COVID-19 and subsequent lockdowns and economic turmoil. Academic and adaptive skills training were particularly impacted due to school closures, with parents tasked with taking some responsibility for training these skills. Our goals for this article 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 special education

The COVID-19 pandemic disrupted the lives of families of children with autism spectrum disorder (ASD) in multiple ways, including physical and mental health, academic and treatment progress, and economic stability (see 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 were likely at an all-time high due to the recent pandemic. Primarily characterized by deficits in social-communication skills, restricted and repetitive behaviors and interests, and sensory atypicalities (American Psychiatric Association [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 indicators are thought to increase the parental burden and stress response (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. This article explores (a) the impacts of stressful experiences like COVID-19; (b) how these experiences affect individuals with ASD and other comorbid and related conditions; and (c) the 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 for rural families. In addition, the U.S. Centers for Disease Control and Prevention (CDC) listed individuals with developmental and behavioral disorders,

¹The University of Alabama, Tuscaloosa, USA

Corresponding Author:

Theodore S. Tomeny, Department of Psychology, The University of Alabama, Box 870348, Tuscaloosa, AL 35487, USA.
Email: tstomeny@ua.edu

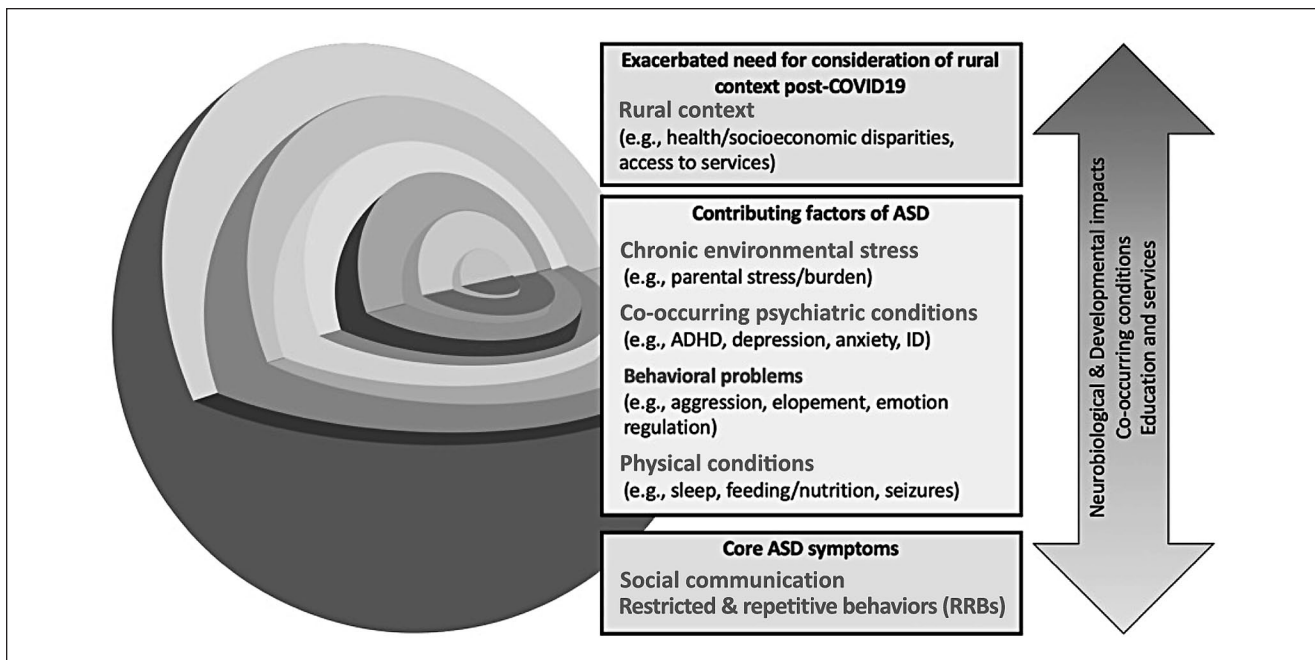


Figure 1. Conceptual Framework of Factors Affecting Rural ASD Communities Post-COVID-19.
Note. ASD = autism spectrum disorder.

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 were impacted disproportionately by the COVID-19 pandemic in a variety of ways (Fortuna et al., 2020). Yet, lacking social and financial safeguards in the United States 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), food insecurity (e.g., Ramadurai et al., 2012), limited access to health information (Ramírez et al., 2017), unreliable high-speed internet (Tsami et al., 2019), and other challenges. Rural health disparities are often attributed to a variety of factors, including a dearth of health care providers in rural areas (Bureau of Health Workforce/Health Resources and Services Administration [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 (Iadarola 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 the limited implementation of interventions 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 a strong work ethic (Raffaelli & Wiley, 2013). Moreover, while formal support networks may have come to a halt during the pandemic, families living in rural areas often report support from informal sources, such as extended family and neighbors (Raffaelli & Wiley, 2013). Nevertheless, we surmise that, unfortunately, these traits were put to the test with obstacles likely magnified during the COVID-19 pandemic. Here, we focus on the 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).

Table 1. Provider and Professional Recommendations for Addressing Challenges and Barriers.

Challenges, barriers, & health disparities	Recommendations for providers and professionals
Challenges & barriers	
Lack of reliable high-speed internet	Use of public radio and television Toll-free telephone hotlines Platforms that are user-friendly, require lower bandwidths (e.g., phone over video) Consider availability of devices (laptops, tablets, smartphones)
Limited access to health information	Use of free apps and websites Engagement with community health workers (paid and volunteer)
High rates of poverty	Address insurance coverage and payments for telehealth early in process Address family-level outcomes, in addition to child-level outcomes, to support the entire family (e.g., connecting families to local resources)
Elevated caregiver burden and stress	Structured websites and forums providing information on stress reduction Toll-free telephone hotlines for 24/7 support Use a caregiver-implemented intervention approach to support caregivers' use of strategies during time between sessions or visits Connect families to local respite resources
Health disparities	
Lack of health care providers within geographic proximity	Clinician rotations in rural areas (e.g., 1 day per week/month there) Incentives for clinicians to practice in rural areas Establishment of mobile clinics Building virtual professional communities to connect providers working in rural areas
Delayed ASD diagnosis	Telehealth applications that could aid ASD diagnosis More communication with local pediatricians and/or primary health centers about screening for autism 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
Increase in mental health issues following social isolation	Introduce variable service platforms (e.g., online, safety measures) early Providers check in with clients via phone Development of peer-to-peer networks that connect via phone, internet, or in-person with safety protocols

Note. ASD = autism spectrum disorder.

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). This in turn may impact physical growth, metabolic function, the thyroid, and potentially reproduction. The unpredictability and lengthiness of the 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. These social ramifications have been especially deleterious for families of youth with other risk factors (e.g., ASD), geographical isolation, family

Table 2. Recommendations for Addressing Educational Disparities.

Barrier	Educator recommendations ^a	Family recommendations ^b
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)	
Socialization needs	Incentives for teachers to work in rural areas	
	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

^aSee Nowell et al. (2020). ^bSee Hume et al. (2020).

financial precarity, increasing stress, and ASD symptomatology (e.g., less prosocial behavior; Brown et al., 2020; Nonweiler et al., 2020), 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 ramifications for brain development, the COVID-19 pandemic may also have implications 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, 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). The demands on executive function tied to the

COVID-19 pandemic may compound the already heightened demands on executive function for rural and underserved youth with ASD and their families (i.e., 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 et al., 2014). In addition, 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), also a component of executive function impaired in individuals with ASD (van Eylen et al., 2011).

Infants in rural and disadvantaged environments and young children at elevated risk of ASD already demonstrate deficits in these areas (see St. John et al., 2016; Tacke et al., 2015). Thus, a 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 promotes strong regulatory abilities (e.g., maintaining attention, turn-taking, and 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 shifted to remote instruction, which relies on the 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 the school and home routines may adversely limit progress on goals.

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 for children with ASD and their families was curtailed by limitations of face-to-face interactions. Given that children with ASD in rural areas have limited access to services, (Antezana et al., 2017; Mello et al., 2016), their academic and social skills may lag behind their peers in more urban areas who have better access to educational and therapeutic services. 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 approximately 28% to 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). A pandemic like COVID-19 requires diligence in health-related behaviors like hand washing, social distancing, and wearing a mask. These health behaviors may be challenging for individuals with ASD who struggle with hygiene (Matson et al., 2012) and appropriate physical space (Kennedy & Adolphs, 2014), or have sensory sensitivities that can be aggravated (Neil et al., 2016).

In addition to 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 the 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 During the COVID-19 Pandemic

Special Education Services and 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 the 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 (Quinn, 2009; United

Nations Educational, Scientific and Cultural Organization [UNESCO], 2002).

Local educational agencies likely found challenges to providing these services to students with ASD during pandemic-caused school closures. In countries that reopened schools under modified conditions, students with disabilities and special education were encouraged and allowed to attend school in person rather than remotely (Australian Department of Education, Skills, and Employment, 2020). Some countries implemented temporary legislative changes to special education policies, such as the United Kingdom, which specified 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 U.S. Individuals with Disabilities Education Improvement Act (IDEA, 2004) were not officially modified or suspended, though schools had flexibility in determining how services were delivered (U.S. Department of Education [USDOE], 2020b). For example, in the case of school closures in the United States, if a school continued to provide educational opportunities to students in general education, schools must have also provided equal access and opportunities to students with disabilities as mandated by IDEA, including the provision of 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 was unable to provide services remotely, the child is entitled to compensatory services once school resumed (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, child care 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 was not required (USDOE, 2020b). Upon reopening, the Individualized Family Service Plan (IFSP) team was to determine any necessary changes to the IFSP and whether a need existed for compensatory services (USDOE, 2020b). If a program remained open but services cannot be provided because of particular circumstances (e.g., person infected with COVID-19), accommodations must have been made to continue service provision (USDOE, 2020b). In addition, the 45-day timeline for the initial evaluation and IFSP meeting remained, 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 have been insufficient, and school districts had little guidance on how to provide these services effectively, with the onus of instruction likely falling on caregivers. Moreover, because many children with ASD receive support services within early child care and school settings (Wei et al., 2014), limitations on in-person attendance limit the provision of these services. Compared with 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 therapies in school settings (Irvin et al., 2012), possibly 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 have required 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 a lack of internet-connected devices and insufficient 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 before COVID-19 (see Simacek et al., 2021). 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 for 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 the global pandemic and families spending more time in their households, it is arguably even more important to consider family-centeredness when providing education 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 crises 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 child care arrangements, combined with continued or increased work demands for caregivers, created situations that required 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 was for parents to focus on specific, limited, and attainable maintenance goals for the at-home environment. In addition, 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), practitioners may have to prioritize goals for caregivers to work on in the home environment. In practice, this could mean focusing on the maintenance of attained skills. For example, in a case study of ABA service 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., the 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., 2021) have found it practical 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 metacognitive skills in everyday life (e.g., preparing a workspace or resources for projects, allocating time, working backward from specific long-term goals) is one of many important and necessary life skills particularly relevant during these new times.

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 increased drastically during stay-at-home orders. The 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 increased during stay-at-home (e.g., educational programming for physical education [martial arts, ballet], music, and specialized early and gifted education [summer camps with such institutions as Art of Problem Solving, Institute for Educational Advancement, Duke Talent Identification Program, and 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. While 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.

Adaptations to Service Delivery

First, online opportunities for fostering social connections and engaging in community initiatives (via the 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 the 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 and 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, a 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 and 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.

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 were faced with a major challenge during the COVID-19 pandemic. Most were accustomed to in-person interactions with individuals with ASD, sometimes on a one-to-one basis. However, physical distancing during the pandemic forced 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 immediate transition. 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 a new/different system should be ready and available. Moreover, the 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, will play a role in developing the infrastructure needed for widespread telepractice. For certain therapies, the 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 before people can rely on these services. Some of the medical insurance agencies, public and private, have considered this on a temporary basis (Mehrotra 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 participant 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 the 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 complicated 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 years 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, current trends suggest that uncertainty surrounding COVID-19 may continue for quite some time. Professionals who work with families of individuals with ASD must seize the opportunity of COVID-19 to adapt, adjust, innovate, and harness strengths and resiliency to

best serve families during these unprecedented circumstances. Our recommendations serve to provide the scope and a foundation as a developmental guide for future catastrophic events to protect individuals with ASD.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Evie A. Malaia  <https://orcid.org/0000-0002-4700-0257>

References

- Aman, M. G., & Pearson, D. A. (2020). Challenges for child and adolescent psychiatric research in the era of COVID-19. *Journal of Child and Adolescent Psychopharmacology*, *30*(5), 280–284. <https://doi.org/10.1089/cap.2020.0081>
- Amaral, D. G., & de Vries, P. J. (2020). COVID-19 and autism research: Perspectives from around the globe. *Autism Research*, *13*(6), 844–869. <https://doi.org/10.1002/aur.2329>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- Anderson, C. M., Martin, R. J., & Haynes, R. D. (2017). Supporting students with autism spectrum disorder in rural schools. In K. D. Michael & J. P. Jameson (Eds.), *Handbook of rural school mental health* (pp. 213–230). Springer.
- Antezana, L., Scarpa, A., Valdespino, A., Albright, J., & Richey, J. A. (2017). Rural trends in diagnosis and services for autism spectrum disorder. *Frontiers in Psychology*, *8*, Article 590. <https://doi.org/10.3389/fpsyg.2017.00590>
- Ashburner, J., Vickerstaff, S., Beetge, J., & Copley, J. (2016). Remote versus face-to-face delivery of early intervention programs for children with autism spectrum disorders: Perceptions of rural families and service providers. *Research in Autism Spectrum Disorders*, *23*, 1–14. <https://doi.org/10.1016/j.rasd.2015.11.011>
- Australian Department of Education, Skills, and Employment. (2020). *COVID-19 Support for students with disability*. <https://www.dese.gov.au/covid-19/schools/support-students-disability>
- Bauman, M. L. (2010). Medical comorbidities in autism: Challenges to diagnosis and treatment. *Neurotherapeutics*, *7*(3), 320–327. <https://doi.org/10.1016/j.nurt.2010.06.001>
- Beale, C. L. (2004). Anatomy of nonmetro high-poverty areas: Common in plight, distinctive in nature. *Amber Waves*, *2*, 21–27. <https://doi.org/10.22004/ag.econ.131783>
- Bearss, K., Burrell, T. L., Challa, S. A., Postorino, V., Gillespie, S. E., Crooks, C., & Seahill, L. (2018). Feasibility of parent training via telehealth for children with autism spectrum disorder and disruptive behavior: A demonstration pilot. *Journal*

- of Autism and Developmental Disorders, 48(4), 1020–1030. <https://doi.org/10.1007/s10803-017-3363-2>
- Boldt, L. J., Kochanska, G., Yoon, J. E., & Koenig Nordling, J. (2014). Children's attachment to both parents from toddler age to middle childhood: Links to adaptive and maladaptive outcomes. *Attachment & Human Development, 16*(3), 211–229. <https://doi.org/10.1080/14616734.2014.889181>
- Broder-Fingert, S., Shui, A., Pulcini, C. D., Kurowski, D., & Perrin, J. M. (2013). Racial and ethnic differences in subspecialty service use by children with autism. *Pediatrics, 132*(1), 94–100. <https://doi.org/10.1542/peds.2012-3886>
- Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husen & T. N. Postlethwaite (Eds.), *International encyclopedia of education* (Vol. 3, 2nd ed., pp. 1643–1647). Elsevier.
- Brown, S. M., Doom, J. R., Lechuga-Peña, S., Watamura, S. E., & Koppels, T. (2020). Stress and parenting during the global COVID-19 pandemic. *Child Abuse & Neglect, 110*(Pt 2), Article 104699. <https://doi.org/10.1016/j.chiabu.2020.104699>
- Bull, R., Espy, K. A., & Wiebe, S. A. (2008). Short-term memory, working memory, and executive functioning in preschoolers: Longitudinal predictors of mathematical achievement at age 7 years. *Developmental Neuropsychology, 33*(3), 205–228. <https://doi.org/10.1080/87565640801982312>
- Bureau of Health Workforce/Health Resources and Services Administration. (2020). *Designated health professional shortage area: Third quarter of fiscal year 2020 designated HPSA quarterly summary*. <https://data.hrsa.gov/Default/GenerateHPSAQuarterlyReport>
- Caldwell, J. T., Ford, C. L., Wallace, S. P., Wang, M. C., & Takahashi, L. M. (2016). Intersection of living in a rural versus urban area and race/ethnicity in explaining access to health care in the United States. *American Journal of Public Health, 106*(8), 1463–1469. <https://doi.org/10.2105/AJPH.2016.303212>
- Casey, B. J., Getz, S., & Galvan, A. (2008). The adolescent brain. *Developmental Review, 28*(1), 62–77. <https://doi.org/10.1016/j.dr.2007.08.003>
- Centers for Disease Control and Prevention. (2020). *Coronavirus disease 2019 (COVID-19): People at increased risk*. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/index.html>
- Chukwuorji, J. C., & Iorfa, S. K. (2020). Commentary on the coronavirus pandemic: Nigeria. *Psychological Trauma: Theory, Research, Practice, and Policy, 12*(S1), S188–S190. <https://doi.org/10.1037/tra0000786>
- Commonwealth of Australia. (2005). *Disability standards for education 2005*. <https://docs.education.gov.au/node/16354>
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*(7), 1278–1291. <https://doi.org/10.1007/s10803-007-0512-z>
- degli Espinosa, F., Metko, A., Raimondi, M., Impenna, M., & Scognamiglio, E. (2020). A model of support for families of children with autism living in the COVID-19 lockdown: Lessons from Italy. *Behavior Analysis in Practice, 13*(3), 550–558. <https://doi.org/10.1007/s40617-020-00438-7>
- Division for Early Childhood. (2014). *DEC recommended practices in early intervention/early childhood special education*. <http://www.dec-sped.org/recommendedpractices>
- Drahota, A., Sadler, R., Hippensteel, C., Ingersoll, B., & Bishop, L. (2020). Service deserts and service oases: Utilizing geographic information systems to evaluate service availability for individuals with autism spectrum disorder. *Autism, 24*(8), 2008–2020. <https://doi.org/10.1177/1362361320931265>
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered help giving practices research. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 370–378. <https://doi.org/10.1002/mrdd.20176>
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2008). *Research synthesis and meta-analysis of studies of family-centered practices*. Winterberry Press.
- Early Childhood Technical Assistance (ECTA) Center. (2020). *Coronavirus disease (COVID-19)*. <https://ectacenter.org/topics/disaster/coronavirus.asp>
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism, 13*(4), 375–387. <https://doi.org/10.1177/1362361309105658>
- Ferguson, J., Craig, E. A., & Dounavi, K. (2019). Telehealth as a model for providing behaviour analytic interventions to individuals with autism spectrum disorder: A systematic review. *Journal of Autism and Developmental Disorders, 49*(2), 582–616. <https://doi.org/10.1007/s10803-018-3724-5>
- Fischer, K. W. (2008). Dynamic cycles of cognitive and brain development: Measuring growth in mind, brain, and education. In A. M. Battro, K. W. Fischer, & P. Léna (Eds.), *The educated brain* (pp. 127–150). Cambridge University Press. <https://doi.org/10.1017/CBO9780511489907.010>
- Fofana, N. K., Latif, F., Sarfraz, S., Bashir, M. F., & Komal, B. (2020). Fear and agony of the pandemic leading to stress and mental illness: An emerging crisis in the novel coronavirus (COVID-19) outbreak. *Psychiatry Research, 291*, Article 113230. <https://doi.org/10.1016/j.psychres.2020.113230>
- Fontil, L., Sladeczek, I. E., Gittens, J., Kubishyn, N., & Habib, K. (2019). From early intervention to elementary school: A survey of transition support practices for children with autism spectrum disorders. *Research in Developmental Disabilities, 88*, 30–41. <https://doi.org/10.1016/j.ridd.2019.02.006>
- Fortuna, L. R., Tolou-Shams, M., Robles-Ramamurthy, B., & Porche, M. V. (2020). Inequity and the disproportionate impact of COVID-19 on communities of color in the United States: The need for a trauma-informed social justice response. *Psychological Trauma: Theory, Research, Practice, and Policy, 12*(5), 443–445. <https://doi.org/10.1037/tra0000889>
- Gilotty, L., Kenworthy, L., Sirian, L., Black, D. O., & Wagner, A. E. (2002). Adaptive skills and executive function in autism spectrum disorders. *Child Neuropsychology, 8*(4), 241–248. <https://doi.org/10.1076/chin.8.4.241.13504>

- Goines, P., & Van de Water, J. (2010). The immune system's role in the biology of autism. *Current Opinion in Neurology*, 23(2), 111–117. <https://doi.org/10.1097/WCO.0b013e3283373514>
- Gunnar, M. R., Herrera, A., & Hostinar, C. E. (2009). Stress and early brain development. In R. E. Tremblay, M. Boivin, & R. D. Peters (Eds.), *Encyclopedia on early childhood development* [online]. <http://www.child-encyclopedia.com/brain/according-experts/stress-and-early-brain-development>
- Hageman, J. R. (2020). The coronavirus disease 2019 (COVID-19). *Pediatric Annals*, 49(3), e99–e100. <https://doi.org/10.3928/19382359-20200219-01>
- Hepburn, S. L., Blakeley-Smith, A., Wolff, B., & Reaven, J. A. (2016). Telehealth delivery of cognitive-behavioral intervention to youth with autism spectrum disorder and anxiety: A pilot study. *Autism*, 20(2), 207–218. <https://doi.org/10.1177/1362361315575164>
- Hill, E. L. (2004). Executive dysfunction in autism. *Trends in Cognitive Sciences*, 8(1), 26–32. <https://doi.org/10.1016/j.tics.2003.11.003>
- Hirko, K. A., Kerver, J. M., Ford, S., Szafranski, C., Beckett, J., Kitchen, C., & Wendling, A. L. (2020). Telehealth in response to the Covid-19 pandemic: Implications for rural health disparities. *Journal of the American Medical Informatics Association*, 27(11), 1816–1818. <https://doi.org/10.1093/jamia/ocaa156>
- Hoogsteen, L., & Woodgate, R. L. (2013). Embracing autism in Canadian rural communities. *Australian Journal of Rural Health*, 21(3), 178–182. <https://doi.org/10.1111/ajr.12030>
- Hughes, C., Leboyer, M., & Bouvard, M. (1997). Executive function in parents of children with autism. *Psychological Medicine*, 27(1), 209–220. <https://doi.org/10.1017/S0033291796004308>
- Hume, K., Waters, V., Sam, A., Steinbrenner, J., Perkins, Y., Dees, B., Tomaszewski, B., Rentschler, L., Szendrey, S., McIntyre, N., White, M., Nowell, S., & Odom, S. (2020). *Supporting individuals with autism through uncertain times*. School of Education and Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill. <https://afirm.fpg.unc.edu/supporting-individuals-autism-through-uncertain-times>
- Iacono, T., Dissanayake, C., Trembath, D., Hudry, K., Erickson, S., & Spong, J. (2016). Family and practitioner perspectives on telehealth for services to young children with autism. In A. J. Maeder, K. Ho, A. Marcelo, & J. Warren (Eds.), *The promise of new technologies in an age of new health challenges* (pp. 63–73). IOS Press. <https://doi.org/10.3233/978-1-61499-712-2-63>
- Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families. *International Journal of Developmental Disabilities*, 65(1), 20–30. <https://doi.org/10.1080/20473869.2017.1347228>
- Individuals with Disabilities Education Improvement Act (IDEA) of 2004, 20 U.S.C. § 1400 *et seq.* (2004).
- Ingersoll, B., & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 337–344. <https://doi.org/10.1016/j.rasd.2010.04.017>
- Ingersoll, B., Wainer, A. L., Berger, N. I., Pickard, K. E., & Bonter, N. (2016). Comparison of a self-directed and therapist-assisted telehealth parent-mediated intervention for children with ASD: A pilot RCT. *Journal of Autism and Developmental Disorders*, 46(7), 2275–2284. <https://doi.org/10.1007/s10803-016-2755-z>
- Irvin, D. W., McBee, M., Boyd, B. A., Hume, K., & Odom, S. L. (2012). Child and family factors associated with the use of services for preschoolers with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 6(1), 565–572. <https://doi.org/10.1016/j.rasd.2011.07.018>
- Isaacs, S. A., Roman, N. V., & Savahl, S. (2019). An exploration of the family resilience needs of a rural community in South Africa: A sequential explanatory mixed methodological study design. *Current Psychology*, 38(6), 1634–1648. <https://doi.org/10.1007/s12144-017-9722-5>
- Jacobson, L. A., Williford, A. P., & Pianta, R. C. (2011). The role of executive function in children's competent adjustment to middle school. *Child Neuropsychology*, 17(3), 255–280. <https://doi.org/10.1080/09297049.2010.535654>
- Keen, D., Couzens, D., Muspratt, S., & Rodger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders*, 4(2), 229–241. <https://doi.org/10.1016/j.rasd.2009.09.009>
- Kennedy, D. P., & Adolphs, R. (2014). Violations of personal space by individuals with autism spectrum disorder. *PLOS ONE*, 9(8), Article e103369. <https://doi.org/10.1371/journal.pone.0103369>
- Kerr, M. E., & Bowen, M. (1988). *Family evaluation*. W. W. Norton & Company.
- Khundrakpam, B. S., Lewis, J. D., Kostopoulos, P., Carbonell, F., & Evans, A. C. (2017). Cortical thickness abnormalities in autism spectrum disorders through late childhood, adolescence, and adulthood: A large-scale MRI study. *Cerebral Cortex*, 27(3), 1721–1731. <https://doi.org/10.1093/cercor/bhx038>
- Kogan, N. (2013). *Cognitive styles in infancy and early childhood (psychology revivals)* (1st ed.). Psychology Press. <https://doi.org/10.4324/9780203795811>
- Lindgren, S., Wacker, D., Suess, A., Schieltz, K., Pelzel, K., Kopelman, T., Lee, J., Romani, P., & Waldron, D. (2016). Telehealth and autism: Treating challenging behavior at lower cost. *Pediatrics*, 137(Supplement 2), S167–S175. <https://doi.org/10.1542/peds.2015-28510>
- Lourenco, S. F., & Tasimi, A. (2020). No participant left behind: Conducting science during COVID-19. *Trends in Cognitive Sciences*, 24(8), 583–584. <https://doi.org/10.1016/j.tics.2020.05.003>
- Maenner, M. J., Arneson, C. L., & Durkin, M. S. (2009). Socioeconomic disparity in the prevalence of autism spectrum disorder in Wisconsin. *Wisconsin Medical Journal*, 108(5), 37–39.
- Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A.,

- Baroud, T., Schwenk, Y., White, T., Rosenberg, C. R., Lee, L., Harrington, R. A., Huston, M., . . . Dietz, P. M. (2020). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveillance Summaries*, 69(4), 1–12. <https://doi.org/10.15585/mmwr.ss6904a1>
- Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37(9), 1795–1802. <https://doi.org/10.1007/s10803-006-0314-8>
- Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116(6), 1480–1486. <https://doi.org/10.1542/peds.2005-0185>
- Matson, J. L., Hattier, M. A., & Belva, B. (2012). Treating adaptive living skills of persons with autism using applied behavior analysis: A review. *Research in Autism Spectrum Disorders*, 6, 271–276. <https://10.1016/j.rasd.2011.05.008>
- McBain, R. K., Kareddy, V., Cantor, J. H., Stein, B. D., & Yu, H. (2020). Systematic review: United States workforce for autism-related child healthcare services. *Journal of the American Academy of Child & Adolescent Psychiatry*, 59(1), 113–139. <https://doi.org/10.1016/j.jaac.2019.04.027>
- McFayden, T. C., Breaux, R., Bertollo, J. R., Cummings, K., & Ollendick, T. H. (2021). COVID-19 remote learning experiences of youth with neurodevelopmental disorders in rural Appalachia. *Journal of Rural Mental Health*, 45(2), 72–85. <https://doi.org/10.1037/rmh0000171>
- McLaughlin, K. A., Sheridan, M. A., & Nelson, C. A. (2013). Adverse childhood experiences and brain development: Neurobiological mechanisms linking the social environment to psychiatric disorders. In K. Koenen, S. Rudenstine, E. Susser, & S. Galea (Eds.), *A life course approach to mental disorders* (pp. 249–258). Oxford University Press. <https://doi.org/10.1093/acprof:oso/9780199657018.003.0023>
- Mehrotra, A., Ray, K., Brockmeyer, D. M., Barnett, M. L., & Bender, J. A. (2020). Rapidly converting to “virtual practices”: Outpatient care in the era of Covid-19. *NEJM Catalyst Innovations in Care Delivery*, 1(2), 1–5. <https://doi.org/10.1056/CAT.20.0091>
- Mello, M. P., Goldman, S. E., Urbano, R. C., & Hodapp, R. M. (2016). Services for children with autism spectrum disorder: Comparing rural and non-rural communities. *Education and Training in Autism and Developmental Disabilities*, 51(4), 355–365. <https://www.jstor.org/stable/26173863>
- Ming, X., Brimacombe, M., Chaaban, J., Zimmerman-Bier, B., & Wagner, G. C. (2008). Autism spectrum disorders: Concurrent clinical disorders. *Journal of Child Neurology*, 23(1), 6–13. <https://doi.org/10.1177/0883073807307102>
- Murphy, M. A., & Ruble, L. A. (2012). A comparative study of rurality and urbanicity on access to and satisfaction with services for children with autism spectrum disorders. *Rural Special Education Quarterly*, 31(3), 3–11. <https://doi.org/10.1177/875687051203100302>
- Neil, L., Olsson, N. C., & Pellicano, E. (2016). The relationship between intolerance of uncertainty, sensory sensitivities, and anxiety in autistic and typically developing children. *Journal of Autism and Developmental Disorders*, 46(6), 1962–1973. <https://doi.org/10.1007/s10803-016-2721-9>
- Nonweiler, J., Rattray, F., Baulcomb, J., Happé, F., & Absoud, M. (2020). Prevalence and associated factors of emotional and behavioural difficulties during COVID-19 pandemic in children with neurodevelopmental disorders. *Children*, 7(9), Article 128. <https://doi.org/10.3390/children7090128>
- Nowell, S., Waters, V., Dees, B., Perkins, Y., Tomaszewski, B., Hume, K., Steinbrenner, J., Sam, A., Szendrey, S., Rentschler, L., & Odom, S. (2020). *Supporting online learning for students with autism*. School of Education and Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill.
- O’Hearn, K., Asato, M., Ordaz, S., & Luna, B. (2008). Neurodevelopment and executive function in autism. *Development and Psychopathology*, 20(4), 1103–1132. <https://doi.org/10.1017/S0954579408000527>
- Parra-Cardona, J. R., Bullock, L. A., Imig, D. R., Villarruel, F. A., & Gold, S. J. (2006). “Trabajando duro todos los días”: Learning from the life experiences of Mexican-origin migrant families. *Family Relations*, 55(3), 361–375. <https://doi.org/10.1111/j.1741-3729.2006.00409.x>
- Pennington, R., Horn, C., & Berrong, A. (2009). An evaluation of the differences between big city and small town special education services for students with low incidence disabilities in Kentucky. *Rural Special Education Quarterly*, 28(4), 3–9. <https://doi.org/10.1177/875687050902800402>
- Pieretti, R. A., Kaul, S. D., Zarchy, R. M., & O’Hanlon, L. M. (2015). Using a multimodal approach to facilitate articulation, phonemic awareness, and literacy in young children. *Communication Disorders Quarterly*, 36(3), 131–141. <https://doi.org/10.1177/1525740114545360>
- Quinn, G. (2009). The United Nations convention on the rights of persons with disabilities: Toward a new international politics of disability. *Texas Journal on Civil Liberties & Civil Rights*, 15, 33.
- Raffaelli, M., & Wiley, A. R. (2013). Challenges and strengths of immigrant Latino families in the rural Midwest. *Journal of Family Issues*, 34(3), 347–372. <https://doi.org/10.1177/0192513X11432422>
- Ramadurai, V., Sharf, B. F., & Sharkey, J. R. (2012). Rural food insecurity in the United States as an overlooked site of struggle in health communication. *Health Communication*, 27(8), 794–805. <https://doi.org/10.1080/10410236.2011.647620>
- Ramírez, A. S., Estrada, E., & Ruiz, A. (2017). Mapping the health information landscape in a rural, culturally diverse region: Implications for interventions to reduce information inequality. *The Journal of Primary Prevention*, 38(4), 345–362. <https://doi.org/10.1007/s10935-017-0466-7>
- Rix, J., Sheehy, K., Fletcher-Campbell, F., Crisp, M., & Harper, A. (2013). Exploring provision for children identified with special educational needs: An international review of policy and practice. *European Journal of Special Needs Education*, 28(4), 375–391. <https://doi.org/10.1080/08856257.2013.812403>
- Rosenthal, M., Wallace, G. L., Lawson, R., Wills, M. C., Dixon, E., Yerys, B. E., & Kenworthy, L. (2013). Impairments in real-world executive function increase from childhood to

- adolescence in autism spectrum disorders. *Neuropsychology*, 27(1), 13–18. <https://doi.org/10.1037/a0031299>
- Schmeer, K. K., & Yoon, A. (2016). Socioeconomic status inequalities in low-grade inflammation during childhood. *Archives of Disease in Childhood*, 101(11), 1043–1047. <https://doi.org/10.1136/archdischild-2016-310837>
- Simacek, J., Elmquist, M., Dimian, A. F., & Reichle, J. (2021). Current trends in telehealth applications to deliver social communication interventions for young children with or at risk for autism spectrum disorder. *Current Developmental Disorders Reports*, 8, 15–23. <https://doi.org/10.1007/s40474-020-00214-w>
- Singh, R. L., Moody, E. J., Rigles, B., & Smith, E. B. (2019). What it takes to raise children with autism in a rural state. *Advances in Neurodevelopmental Disorders*, 3(1), 17–28. <https://doi.org/10.1007/s41252-018-0082-4>
- Skinner, A. C., & Slifkin, R. T. (2007). Rural/urban differences in barriers to and burden of care for children with special health care needs. *The Journal of Rural Health*, 23(2), 150–157. <https://doi.org/10.1111/j.1748-0361.2007.00082.x>
- St. Amant, H. G., Schrager, S. M., Peña-Ricardo, C., Williams, M. E., & Vanderbilt, D. L. (2018). Language barriers impact access to services for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 48(2), 333–340. <https://doi.org/10.1007/s10803-017-3330-y>
- St. John, T., Estes, A. M., Dager, S. R., Kostopoulos, P., Wolff, J. J., Pandey, J., Elison, J. T., Paterson, S. J., Schultz, R. T., Botteron, K., Hazlett, H., & Piven, J. (2016). Emerging executive functioning and motor development in infants at high and low risk for autism spectrum disorder. *Frontiers in Psychology*, 7, Article 1016. <https://doi.org/10.3389/fpsyg.2016.01016>
- Stoppelbein, L., Biasini, F., Pennick, M., & Greening, L. (2016). Predicting internalizing and externalizing symptoms among children diagnosed with an autism spectrum disorder: The role of routines. *Journal of Child and Family Studies*, 25, 251–261. <https://doi.org/10.1007/s10826-015-0218-3>
- Stuart, M., & McGrew, J. H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders*, 3(1), 86–97. <https://doi.org/10.1016/j.rasd.2008.04.006>
- Sullivan, A. L. (2013). School-based autism identification: Prevalence, racial disparities, and systemic correlates. *School Psychology Review*, 42(3), 298–316. <https://doi.org/10.1080/02796015.2013.12087475>
- Sutherland, R., Trembath, D., Hodge, M. A., Rose, V., & Roberts, J. (2019). Telehealth and autism: Are telehealth language assessments reliable and feasible for children with autism? *International Journal of Language & Communication Disorders*, 54(2), 281–291. <https://doi.org/10.1111/1460-6984.12440>
- Tacke, N. F., Bailey, L. S., & Clearfield, M. W. (2015). Socioeconomic status (SES) affects infants' selective exploration. *Infant and Child Development*, 24(6), 571–586. <https://doi.org/10.1002/icd.1900>
- Tarokh, L., Short, M., Crowley, S. J., Fontanellaz-Castiglione, C. E., & Carskadon, M. A. (2019). Sleep and circadian rhythms in adolescence. *Current Sleep Medicine Reports*, 5(4), 181–192. <https://doi.org/10.1007/s40675-019-00155-w>
- Tine, M. (2017). Growing up in Rural vs. Urban poverty: Contextual, academic, and cognitive differences. In G. I. Staicu (Ed.), *Poverty, inequality, and policy* (pp. 9–22). Intech. <https://doi.org/10.5772/intechopen.68581>
- Tonnsen, B. L., Boan, A. D., Bradley, C. C., Charles, J., Cohen, A., & Carpenter, L. A. (2016). Prevalence of autism spectrum disorders among children with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 121(6), 487–500. <https://doi.org/10.1352/1944-7558-121.6.487>
- Trivette, C. M., Dunst, C. J., & Hamby, D. W. (2010). Influences of family-systems intervention practices on parent-child interactions and child development. *Topics in Early Childhood Special Education*, 30(1), 3–19. <https://doi.org/10.1177/0271121410364250>
- Tsami, L., Lerman, D., & Toper Korkmaz, O. (2019). Effectiveness and acceptability of parent training via telehealth among families around the world. *Journal of Applied Behavior Analysis*, 52(4), 1113–1129. <https://doi.org/10.1002/jaba.645>
- Turk, M. A., Landes, S. D., Formica, M. K., & Goss, K. D. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal*, 13(3), Article 100942. <https://doi.org/10.1016/j.dhjo.2020.100942>
- United Kingdom Department for Education. (2020). *Education, health and care needs assessments and plans: Guidance on temporary legislative changes relating to coronavirus (COVID-19)*. <https://www.gov.uk/government/publications/changes-to-the-law-on-education-health-and-care-needs-assessments-and-plans-due-to-coronavirus/education-health-and-care-needs-assessments-and-plans-guidance-on-temporary-legislative-changes-relating-to-coronavirus-covid-19>
- United Nations Educational, Scientific and Cultural Organization. (2002). *Inclusive schools and community support programmes*.
- U.S. Department of Education. (2020a). *Questions and answers on Part C evaluation and assessment timelines*. <https://sites.ed.gov/idea/files/QA-Evaluation-Timeline-Part-C.pdf>
- U.S. Department of Education. (2020b). *Questions and answers on providing services to children with disabilities during the Coronavirus disease 2019 outbreak*. <https://sites.ed.gov/idea/files/qa-covid-19-03-12-2020.pdf>
- Van Eylen, L., Boets, B., Steyaert, J., Evers, K., Wagemans, J., & Noens, I. (2011). Cognitive flexibility in autism spectrum disorder: Explaining the inconsistencies? *Research in Autism Spectrum Disorders*, 5(4), 1390–1401. <https://doi.org/10.1016/j.rasd.2011.01.025>
- Vismara, L. A., McCormick, C., Young, G. S., Nadhan, A., & Monlux, K. (2013). Preliminary findings of a telehealth approach to parent training in autism. *Journal of Autism and Developmental Disorders*, 43(12), 2953–2969. <https://doi.org/10.1007/s10803-013-1841-8>
- Waters, S. F., West, T. V., Karnilowicz, H. R., & Mendes, W. B. (2017). Affect contagion between mothers and infants: Examining valence and touch. *Journal of Experimental Psychology: General*, 146(7), 1043–1051. <https://doi.org/10.1037/xge0000322>

- Wei, X., Wagner, M., Christiano, E. R., Shattuck, P., & Yu, J. W. (2014). Special education services received by students with autism spectrum disorders from preschool through high school. *The Journal of Special Education, 48*(3), 167–179. <https://doi.org/10.1177/0022466913483576>
- White, S. W., Stoppelbein, L., Scott, H., & Spain, D. (2021). It took a pandemic: Perspectives on impact, stress, and telehealth from caregivers of people with autism. *Research in Developmental Disabilities, 113*, Article 103938. <https://doi.org/10.1016/j.ridd.2021.103938>
- Workgroup on Principles and Practices in Natural Environments. (2008). *Agreed upon mission and key principles for providing early intervention services in natural environments*. http://ectacenter.org/~pdfs/topics/families/Finalmissionandprinciples3_11_08.pdf
- Zhou, X. (2020). Managing psychological distress in children and adolescents following the COVID-19 epidemic: A cooperative approach. *Psychological Trauma: Theory, Research, Practice, and Policy, 12*(S1), S76–S78. <https://doi.org/10.1037/tra0000754>