COVID-19 Pandemic and Impact on Patients with Autism Spectrum Disorder

Raman Baweja · Sierra L. Brown · Erin M. Edwards · Michael J. Murray

Accepted: 22 February 2021 / Published online: 10 March 2021
© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2021

Abstract
The COVID-19 infectious disease pandemic has caused significant fear and uncertainty around the world and had significant adverse psychological impact. Children, adolescents and adults with autism spectrum disorder (ASD) are a particularly vulnerable population, impacted by stay-at-home orders, closures at nonessential services, and social distancing standards. This commentary describes various challenges faced by individuals with ASD in the United States including disruptions caused by educational and vocational changes, challenges to home and leisure routines, limited access to behavioral health services and changes in health services delivery due to the pandemic. We highlight the need for ongoing skills development for individuals and development within systems to better respond to needs of the ASD population in future emergencies.

Keywords Autism Spectrum Disorder · Children · Adolescents · Adults · Pandemic

The novel coronavirus (COVID-19) pandemic has caused significant fear and uncertainty as it has negatively impacted almost all aspects of society resulting in near universal hardship and stress. The rapid changes provoked by the virus, and the need to adaptively cope with them can be anticipated to persist for some time. Infectious disease pandemics are often associated with adverse psychological and behavioral responses such as increased anxiety and depression, insomnia, reduced feelings of safety, increased use of alcohol and tobacco, somatic symptoms (such as lack of energy and general malaise), and increased use of medical resources (Brooks et al., 2020; Morganstein et al., 2017). Economic fallout from pandemics can further complicate psychological and behavioral functioning for many individuals who may struggle to meet their family’s basic needs due to unemployment, food insecurity, and/or housing instability (Food Difficulty Getting Enough [FDGE], 2020).

This commentary highlights some of the specific challenges faced by individuals with autism spectrum disorder (ASD) and their families. In the United States (U.S.), for example, individuals with ASD and their families have been affected across several domains, including educational and vocational, home and leisure activities, access to behavioral health services and changes in health services delivery. The full effect of this pandemic—particularly for those with disabilities—has yet to be determined. However, it is clear that individuals with disabilities have already faced significant challenges during this pandemic.

Autism and Increased Vulnerability
The World Health Organization (WHO) defines vulnerability as “the degree to which a population, individual or organization is unable to anticipate, cope with, resist and recover from the impacts of disaster” (World Health Organization [WHO], 2002). Individuals with ASD may be more vulnerable in this pandemic due to the communication, socialization, and executive functioning differences that are inherent in the diagnosis (American Psychiatric Association [APA], 2013) and its common co-occurring conditions (e.g., anxiety disorder, intellectual disability). Across populations, it has been imperative to absorb substantial and rapidly changing public health information on an ongoing basis in order to adapt behavior during the pandemic. Many individuals with ASD experience differences in receptive communication skills and may experience delays in processing information (Wallace et al., 2016), impacting their ability to respond...
to the pandemic effectively and efficiently. Individuals with ASD also may experience expressive communication challenges leading to difficulty communicating pain, symptoms of illness or emotional distress (Hubbard & Trauner, 2007; Rattaz et al., 2013). As a result, many individuals with ASD may find increased reliance on their families, caregivers, or other staff to be able to communicate important pandemic information to them or observe symptoms of potential illness.

While anxiety symptoms have increased in the general population since the pandemic began (Huang & Zhao, 2020), individuals with ASD had disproportionate anxiety symptom frequency and severity pre-pandemic (Van Steensel et al., 2011). Individuals with ASD also may have difficulty with some core components of resilience such as making future predictions, envisioning multiple outcomes to a given situation, adapting and being flexible to abrupt changes (Wallace et al., 2016). Unfortunately, predictability has been severely stressed for most individuals; as that comfort is disrupted, individuals who rely on such predictability and routine as a chief means of sustaining well-being may experience increased struggles. Opportunities for preparation for upcoming new experiences or changes to established activities and/or schedules have been limited due to the pervasiveness and pace of ongoing disruptions. While much is being learned about the novel coronavirus and COVID-19, significant unknowns remain and the longer these unknowns persist the more challenging it becomes to enact a sense of normalcy.

Further complicating adaptive coping, individuals with ASD have high prevalence of co-occurring needs, such as intellectual disability (ID), learning issues, chronic medical concerns like seizure disorders, and behavioral health concerns creating an additional vulnerability (Narzisi, 2020a). Individuals with developmental disabilities are generally more vulnerable to increased risk of mental health conditions than the general public. Preliminary studies have pointed to acute stress reactions and posttraumatic stress symptoms (Liu et al., 2020), recent onset psychotic or mood symptoms with coronavirus exposure (Diaz & Baweja, 2020), and worsening suicidal ideation and suicidal attempts related to fear of COVID-19 (Ammerman et al., 2020) in populations without developmental disabilities, and could be anticipated to be significant challenges for individuals with ASD as well given their higher risk for pre-existing mental health concerns.

In addition to vulnerabilities related to diagnosis and mental health, individuals with ASD may be more likely to share genetic and physiological risk factors for COVID-19. Several studies have documented increased levels of pro-inflammatory cytokines present in individuals with ASD (Saghazadeh et al., 2019). Emerging evidence shows that with at least one phenotype of COVID-19 infections, the body can become upregulated with inflammation through a “cytokine storm,” which can lead to cardiac and pulmonary damage (Lin et al., 2020). A tendency towards a pro-inflammatory state may put individuals with ASD at greater risk of more severe symptoms should they contract the virus (de Sousa Lima et al., 2020). Additionally, studies show individuals with ASD have greater risk for overall poor health compared to the general population (Dunn et al., 2019), sensory impairments and physical disabilities (Kinner et al., 2020), as well as type 2 diabetes (Chen et al., 2016) which has been documented as a specific emerging risk factor for poor recovery from COVID-19 infection (Cariou et al., 2020).

Finally, it is of importance to note that many individuals with ASD identify with various populations documented to experience health disparities, both pre-pandemic and now, during the pandemic. Among transgendered and gender-diverse individuals, there are higher rates of ASD compared to cis-gendered individuals (Warrier et al., 2020), which are populations recognized for experiencing healthcare disparities (Daniel & Butkus, 2015). Similarly African American, Hispanic/Latinx, and other non-white populations, males in particular, have suffered devastating impacts from COVID-19 (Kullar et al., 2020; Macias Gil et al., 2020). While known disparities in medical access and services likely contribute significantly to this disproportion, some research has suggested potential genetic or biological susceptibilities among various ethnic groups as well (Raisi-Estabragh et al., 2020). It could be expected that individuals with ASD within these populations carry even greater risk given the vulnerabilities outlined above, and require prioritized attention during this pandemic.

Impact of COVID on the Autism Community

Mitigation strategies to contend with the threat of COVID-19 were put in place across the globe; in the U.S., many of these strategies (e.g. stay-at-home orders, social distancing) left individuals with disabilities without access to critically needed services and supports resulting in even greater vulnerability. Immediate impacts of this pandemic have been felt first-hand by individuals with ASD, their families, caregivers, and other natural supports as well as the professionals that work with them. Families and caregivers raising children with ASD, especially those with ID or complex needs, know that “it takes a village.” These families utilize multiple services and providers for the educational, vocational and functional needs of their children (Cidav et al., 2013). Adults with ASD may rely on community-based service providers to help them achieve their self-determined community participation goals. Often, these services are best delivered in situ, as evidence has shown that many individuals with ASD struggle with generalization and learn best in
the context in which the skill should be performed (Dot-son et al., 2010). This means that activities of daily living would be taught with support in the home, community skills in the community, and educational and vocational tasks on site. Stay-at-home and shelter-in-place orders, closures of community locations and nonessential health services, and social distancing standards left parents, caretakers and other natural supports attempting to cover the majority of service needs under severely curtailed options (Eshraghi et al., 2020), and professionals struggled to offer their services from a distance. In the U.S., many relied upon services were significantly modified or limited due to the pandemic, impacting educational and vocational activities, available unstructured leisure time opportunities, and access to health services for individuals with ASD.

Education Challenges

In the beginning of the pandemic course, brick-and-mortar schools in the U.S. were abruptly closed to mitigate the spread of infection before many distance learning modalities could be developed. Quickly adapting to distance learning posed a significant challenge for most educators when considering general education curriculum for students without learning disabilities or needs.

This challenge was likely even greater for educators attempting to adapt special education curriculums and related services for children with ASD and complex and/or communication needs. This resulted in a dramatic decline in services provided through special education in the U.S. with little guidance from state or federal departments of education on how to best provide these services. Over the course of the pandemic, many children with ASD have received minimal services such as speech and language therapy, occupational therapy, and physical therapy (Eshraghi et al., 2020). Children who rely on having a routine in school—including the structured environment, familiar schedules and cues, potentially enhanced through supports of 1:1 instruction or a paraprofessional—were now being expected to academically perform in their homes in front of a tablet or laptop. Furthermore, their educational challenges now needed to be supported by their parents or caregivers, who may have been additionally trying to work from home, care for other members of the household, and keep meals and household chores in check. While most likely having great insight into their children’s strengths and needs, parents may not have the required training and experience needed to effectively implement their children’s education plans.

The shift to completing school tasks with parents in their home environments surrounded by temptations of highly preferred activities was likely unfamiliar and challenging for many students. While operating and interacting with a tablet or laptop is probably familiar—and may represent a preferred activity when self-directed such as watching videos on YouTube—to many children, interacting with a teacher and fully attending to virtual instruction would have been much less familiar. For children that use alternative communication, such as gestures or picture exchange, virtual interaction often requires a parent or additional support immediately available to assist with communicating responses. Adapting to these challenges in and of themselves could require considerable time and effort. Then requiring parents and caregivers to additionally learn their child’s educational programming and modifications and adaptations, deliver effective reinforcement strategies, and develop a realistic and sustainable schedule to teach their child can make education delivery a truly herculean task.

Vocational Challenges

Adults with ASD also experienced significant changes during the pandemic with loss of community services (Eshraghi et al., 2020) and potential loss or reduction of employment. In adulthood, individuals with ASD are at greater risk to experience increased social isolation (Howlin et al., 2013), lower community participation (Tint et al., 2017), and decreased participation in social activities. Previous research has shown that adults with ASD across the spectrum face more unemployment and underemployment compared to their neurotypical peers (Roux et al., 2013). Many adults with ASD rely on support staff for transportation, management of work tasks, and effective social engagement in the community (Lindsay, 2017). With services interrupted, jobs furloughed, and community locations temporarily closed, adults with ASD may have been faced with sudden large amounts of unstructured time, few supports, and difficulties adapting to rapid change. Adults with ASD who live in group homes, attend off-site adult day services, or live independently with supports may have moved to be with family members or caretakers as means of reducing risk of contracting COVID-19 (Constantino et al., 2020) While this was important to maximize health precautions and minimize isolation (Giallonardo et al., 2020), it also can contribute to feelings of reduced independence and greater sense of routine disruption. Though no official statistics have been released to date, it can be hypothesized that adults with ASD face significant economic hardships due to the current pandemic.

As countries “re-opened” following the initial wave of the pandemic, the return to community activities, such as school and work, may have continued to pose a challenge for individuals with ASD (Neece et al., 2020). Social environments, though often enjoyed by individuals with ASD, also can be anxiety provoking. Gradual approaches to reintroducing school, work or social locations may be needed for some. Regression with skills that have gone unpracticed for months
may need additional time for retraining to become familiar and comfortable once again. Individuals with ASD—as is true for all members of the community—will need to cope with new restrictive procedures such as required mask wearing and occupancy limits. This may be particularly stressful as they re-engage with what used to be highly comfortable and familiar community activities and settings.

**Home and Leisure Challenges**

Nearly all of us, as a result of limits on work, school, and community access due to needed restrictions of non-essential activities, have experienced some increased unstructured time at home. This has resulted in challenges for many individuals with ASD who can struggle with executive functioning, which includes planning, organization, task initiation and self-monitoring (Wallace et al., 2016). Limitations in these skills make it difficult to alter routines, generate new ideas and independently incorporate them into daily schedules. In addition, many individuals with ASD have restricted or fixed interests. While these interests may not cause difficulties when balanced with a variety of community opportunities, during periods of excess unstructured time and limited scheduled variability, it can be easy to become “stuck” in these highly preferred interests or activities (Lam et al., 2008). These fixations, while comforting, may interfere with needed skills development and adaptations to cope with changing conditions. As schedules begin to normalize, it may be difficult to reallocate time to other important interests and activities. Children or adults with ASD who struggle with maintaining attention to tasks may have relied heavily on family members, caretakers or other natural supports to help them occupy their unstructured time.

**Impact of Service Delivery**

Individuals with ASD demonstrate high rates of service utilization and utilization costs compared to other disabilities (Zerbo et al., 2019). Despite this, there is evidence highlighting significant unmet healthcare needs pre-pandemic: patient-level factors like challenges around appointments and sensory issues; providers-level factors including lack of ASD knowledge and training; and system-level factors such as accessibility of health care facilities, which limit service and referral pathways (Bradshaw et al., 2019). Many people with ASD have experienced disruption in the services they utilized on a regular basis prior to the pandemic due to staff turnover and shortages, mandated community resource closures, and reduced or significantly modified access to needed specialized services (Eshraghi et al., 2020).

**Behavioral Health Services**

Access to behavioral health services has also been greatly impacted during this time. Outpatient and in-home services may have either paused or quickly converted to telehealth. Applied Behavior Analysis (ABA) is an evidence-based treatment for individuals with ASD including those with intellectual disabilities and/or complex communication needs (Roane et al., 2016). However, these services are typically delivered face to face with providers in relatively close proximity to individuals with ASD using shared materials. Converting these services to remote delivery can be challenging as ABA frequently includes observation of behavior that is often beyond the reach of a video camera and requires support of another household member. Although ABA services in some U.S. states were deemed “essential,” agencies lacked on-hand protective personal equipment (PPE) and policy guidelines to ensure safety of providers, individuals with ASD, and their households at the start of pandemic (Kornack et al., 2020). Some who switched to providing telehealth understood it was an atypical form of the service, and may have struggled with prioritizing in-person services amid potential risks (Colombo et al., 2020; Cox et al., 2020). For some children and adults with reliable verbal communication, phone and telehealth services anecdotally seem to have provided some ongoing and continued support.

Outpatient psychiatry visits have been also widely converted into telepsychiatry visits to mitigate the impact of COVID-19. However, providers are not able to monitor patients’ vital signs or complete any needed physical exams to determine safety for potential medication trials and/or monitor for abnormal movements. Some children with ASD as young as 5–6 years old are treated with atypical antipsychotics for significant mood irritability, which requires periodic monitoring of laboratory studies (Volkmar et al., 2014). However, it had not been advisable to go to healthcare facilities for blood work during the peak of pandemic to mitigate exposure risk. There was also some concern about global drug shortages given to the impact of pandemic on patient care and mitigation strategies (Badreldin and Atallah, 2020). During the early part of the pandemic, drug makers reported shortages of sertraline hydrochloride linked to increase demand coupled with supply chain issues (U.S. Food and Drug Administration [USFDA], 2020a). Given these uncertainties, parents have experienced increased worry about availability of needed prescribed medications in their local area. All elements of the supply chain have been vulnerable as workforces may be directly impacted by COVID-19 or resources diverted as part of the pandemic response measures—such as transportation units reallocated to transport other essential goods. It is encouraging that the U.S. Federal Drug Administration (FDA) continues to take steps to monitor the supply chain and has asked
manufacturers to evaluate their entire supply network (U.S. Food and Drug Administration [USFDA], 2020b).

Previous literature indicates adolescents with ASD are four times more likely to access emergency departments (ED) as compared to adolescents without ASD (Liu et al., 2017). Combined externalizing and internalizing psychiatric co-morbidities as well as internalizing conditions alone—such as depression and/or anxiety—are identified risk factors for ED visits among adolescents with ASD (Liu et al., 2019). Children and adults with ASD are at higher risk for suicidal behavior (Mayes et al., 2015); some preliminary evidence has demonstrated increased suicide behavior during the COVID-19 pandemic (Ammerman et al., 2020). Because of significant disruptions in daily routines and interruption of behavioral health services, children, adolescents and adults with ASD may be at higher risk for mental health crises and should be followed closely and assessed frequently for emerging safety concerns.

Placement in specialized psychiatric facilities for ASD and developmental disabilities for safety and stabilization has also been more challenging, as many of these facilities are limiting admission as part of their institutions’ infection control measures (Li, 2020). There is less available capacity in U.S. psychiatric facilities as many have converted multiple bed occupancy rooms to single occupancy rooms or reducing census due to staff shortages. Additionally, implementation of infection prevention guidelines can be particularly challenging in inpatient psychiatric facilities. For example, alcohol-based hand sanitizer cannot be placed in every room, as this can be an ingestion hazard. To prevent exposure of COVID-19, all inpatient psychiatric facilities are carefully screening for COVID risk, which may include low thresholds for testing potential referrals (Li, 2020), further prolonging time to admission. Many day treatments, partial hospitalization and other community programs are also delivering services through telepsychiatry, which are new historic implementations with limited to no evidence for their efficacy (Baweja et al., 2020).

**Telehealth**

Social distancing and other pandemic infection control mandates have resulted in great innovation and quick responsiveness in how services are delivered. Health care, including behavioral health of all levels, adapted services quickly to meet the needs of the people they serve. The increased use of telehealth during this time presented unique opportunities and challenges (Torous & Wykes, 2020). While there are many names for behavioral health services provided on virtual platforms (e.g., telehealth, telemedicine, teletherapy, telepsychiatry), the core common feature is that people in the community are able to access health care professionals via a web-based system rather than an in-person encounter. Telehealth is not a new concept or practice for some behavioral health services and there is strong evidence supporting the efficacy, feasibility, and patient preference of these services (Griffiths et al., 2006; Myers et al., 2008).

There are numerous benefits of telehealth aside from increased convenience. Interruption of in-person services has caused delays in diagnosis for many, which results in delays in treatment access. Diagnostic assessment of autism through telehealth had been minimally researched pre-pandemic (Juárez et al., 2018). However, given the immediate need, many providers are now developing innovative adaptations to be able to conduct assessments via tele-health (Narzisi, 2020b; Sanchez & Constantino, 2020, Sutantio et al 2020; UCLA 2020; Wagner et al. 2020). Though research on the validity of these assessment modifications is still emerging many professionals are working to adapt evidence-based tools to meet the healthcare constraints caused by the pandemic.

Telehealth has become an essential resource for many, as the availability and capacity of providers and health systems has been severely limited for in-person delivery of care during this pandemic. Telehealth provides immediate access to care to individuals who otherwise would experience barriers to this care such as people living in rural communities, patients with transportation challenges, and patients who are homebound (Griffiths et al., 2006). However, telehealth continues to have several limitations including dependence on technology, which can be unreliable, particularly during times of high use as frequently seen over the course of the pandemic. Telehealth may also be difficult to access for patients who may be socioeconomically or techno-geographically disadvantaged (Ramirez et al., 2020).

The literature currently available on the efficacy of telehealth for individuals with ASD is mixed (Hepburn et al., 2016; Knutsen et al., 2016). Telehealth has been well perceived by the youth with ASD and their parents. However, technical problems have been concerns in delivering these services (Hepburn et al., 2016). Despite these barriers, telehealth remains a viable alternative for individuals with ASD when in-person encounters are not possible or feasible. Tele-services have potential for individuals with ASD to provide a variety of services such as individual therapy, family consultation, transfer of skills and skill maintenance, and addressing behavior difficulties and communication needs.

**Preparing for Future**

Evidence from previous disasters has indicated that people with disabilities are disproportionately impacted by emergencies (Campbell et al., 2009). Many of the essential services needed by individuals with ASD have been impacted by the global COVID-19 effects (Neece et al., 2020). Given
that individuals with ASD are especially vulnerable during these times, emergency preparedness is vital to ensure that those at higher risk continue to receive essential behavioral health and support services as we weather potential additional waves of this pandemic or other future health emergencies and/or natural disasters.

In the last two decades, we have faced multiple global health emergencies including SARS, ZIKA, Swine flu and now the novel coronavirus pandemic; it is likely that we will face similar situations in the future (Morens et al., 2020). During the course of the current pandemic, health systems and behavioral health service providers have worked diligently to manage new challenges and provide the best possible care for vulnerable populations. Telehealth has made it easier and more convenient to maintain contact and services with people who need it most. Ongoing mental and behavioral health services via telehealth can assist individuals to process changes in their environment, adapt to a new normal, and plan for reintegration into the community. Going forward, ongoing emergency preparedness efforts might spur even more creative solutions to the challenges of maintaining services and optimizing coping and resilience for future crises. It will be imperative to expand the availability of telehealth and develop clearer guidance on the best use of these platforms for intervention (Torous & Wykes, 2020).

Prior to the pandemic, restrictions on the use of telehealth in behavioral health and psychiatry prevented many practitioners from using these services on a regular basis in the U.S. (Myers et al., 2008). In a very short time, mental health providers had to effectively integrate telehealth into their practice. The maintenance of wide availability of telehealth services appears to be in the best interest of vulnerable members of our communities including individuals with ASD. It is our hope that those that regulate the practice of behavioral health services including U.S. state funding agencies, licensing boards, accreditation bodies, and insurance companies will adopt the availability of telehealth as a new normal, not only during a pandemic, but also when in-person access is limited due to an individual’s environment, conditions or context. This will lead to best practices, establishment of an evidence-base for efficacy, and improved technology.

This pandemic has also highlighted the importance of meaningful collaboration between families, caregivers, behavioral health professionals and other stakeholders who are invested in the overall wellbeing of individuals with ASD especially during times of high need. This includes individuals with ASD themselves, many of whom have participated in collaborations to address specific vulnerabilities in the community (Eidson et al., 2020). Many global, national, and local organizations that recognized and appreciated these needs created valuable resources including a wealth of information for parents, caregivers, and individuals (Autism Speaks, 2020a). Resources that can be easily understood and absorbed by individuals with ASD have been a priority. This may require frequent repetition of core messages and presentation of information in multiple and non-traditional formats including infographics, animations, social media, and social stories. Individuals with ASD participating in creating these resources or providing feedback on them both now and in the future is essential to maximize potential that messaging will meet its intended goal.

Many of these collaborative resources developed have focused on how to cope with the anxiety and uncertainty that the pandemic has caused (Autism Speaks, 2020a). Similarly individuals with autism may continue experiencing symptoms of acute stress or PTSD beyond the duration of the active pandemic (Kildahl et al., 2020). Training programs to assist community first responders in recognizing and de-escalating individuals with autism who may be in distress have been studied and organized in the last decade (Beardon et al., 2018; Love et al., 2020; Railey et al., 2020; Autism Speaks, 2020b). It will be important to continue to educate community service providers and personnel in effective skills and strategies to understand and respond to acute stress reactions in individuals with autism. Attention to assisting children and adults with autism to strengthen effective individual coping skills will continue to be important for the future as well. Coping skills are best taught and practiced when individuals are in a non-anxious, non-crisis state so that they can be more fluidly applied when problems occur. Ongoing attention and creative learning strategies to strengthen resilience and coping skills for individuals with ASD can assist in future unexpected challenges, provide empowerment on a daily basis, and should be strongly considered for treatment or personal development plans.

Providing a safe and supportive environment is crucial. As many parents and caregivers have abruptly taken on the work of multiple providers often while working and maintaining multiple other responsibilities, the important work of “just being a parent” has been stretched thin exposing areas of high need when considering improvement in service design and delivery. Having routines is important to many individuals with ASD; however, education is frequently focused on following a routine rather than skill building for self-determining effective routine and strategy. Introducing greater choice and reinforcement for building or modifying routines and teaching self-management of daily plans can help develop independence and initiation skills (Hume et al., 2009).

This has been a time in which many people have experienced a sudden increase in their unstructured free time as many schools and workplaces are not fully operational. Many individuals with ASD lack the necessary leisure skills to effectively and productively manage free time (Armendariz & Hahs, 2019). Some individuals with ASD may have only limited leisure skills within narrow domains.
(Hochhauser & Engel-Yeger, 2010). Providing direct instruction in teaching diversified independent leisure skills and various options within domains (e.g., physical activity, non-electronic, relaxing, fun) is important and often missing from educational and behavioral health curriculums. This is an area for improvement to both increase preparation for unexpected changes and to increase overall independence.

There may be great value in schools and vocational programs continuing various modes of teaching and participation. Many online and computer-based learning programs exist already; experience and reinforcement with this type of curriculum—in the classroom, in the community, and at home—may improve the generalization of virtual learning and across context learning in students (Khowaja et al., 2020). Vocational programs can consider building and reinforcing home tasks that are related to work skills to minimize regression during times of unemployment and increase employability of adults with ASD. This may also preserve productivity and purpose during times of lost external supports and structure.

Preparing individuals for changes in their environment is essential; many individuals with ASD experience difficulty tolerating uncertainty, change, and novelty (Hodgson et al., 2017). Behavioral health providers have an opportunity to play a critical role in helping individuals anticipate and plan for gradual transitions back into the community as well as planning for potential further community restrictions or other future emergencies. Mental health professionals can be and should be working on these skills in everyday situations—working with children and adults on problem-solving, identifying alternate choices, and predicting outcomes in the context of daily events. Essentially developing the skills to form the proverbial “plan B” in case plans are disrupted or expectations not met. This ongoing attention and effort in non-crisis moments helps to build resiliency and confidence to manage uncertainty when it inevitably arrives.

Conclusion

The recent pandemic has demonstrated that the U.S., as a nation, is far from optimal in emergency preparedness, especially for vulnerable populations like individuals with ASD. COVID-19 has exposed weaknesses in both service provision and skills focus for a population with recognized heightened needs but also great potential. It is essential that local, state, national and transnational preparedness measures take into consideration the unique needs of individuals with ASD. These should support innovation that empowers individuals, their parents, all caregivers, organizations and service providers for working in similar rapidly developing circumstances in the future. Effectively engaging stakeholders in the ASD community—especially individuals with ASD themselves—in ongoing discussions about improving these measures will be critical to the innovation that is sorely needed.

Acknowledgements

Not applicable.

Author Contributions

All authors jointly contributed to conceptualize this manuscript. Dr. Baweja drafted the initial manuscript, reviewed and revised the manuscript. Drs. Brown and Murray and Ms. Edwards critically reviewed and revised the manuscript. All authors read and approved the final manuscript.

Funding

Dr. Murray receives research-funding form the Commonwealth of Pennsylvania Department of Human Services, the National Institute on Disability, Independent Living, and Rehabilitation Research and the National Institute of Health. Drs. Baweja and Brown and Ms. Edwards report no biomedical financial interests or potential conflicts of interest.

References

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

Ammerman, B. A., Burke, T. A., Jacobucci, R., & McClure, K. (2020). Preliminary investigation of the association between COVID-19 and suicidal thoughts and behaviors in the US. Journal of Psychiatric Research. https://doi.org/10.1016/j.jpsychires.2020.12.037

Armendariz, V., & Hahs, A. D. (2019). Teaching leisure activities with social initiations through video prompting. Journal of Behavioral Education, 28(4), 479–492.

Autism Speaks. (2020a). COVID-19 (coronavirus) information and resources. Retrieved December 29, 2020 from https://www.autismspeaks.org/covid-19-information-and-resources.

Autism Speaks. (2020b). Information for First Responders. Retrieved December 29, 2020 from https://www.autismspeaks.org/information-first-responders.

Badreldin, H. A., & Atallah, B. (2020). Global drug shortages due to COVID-19: Impact on patient care and mitigation strategies. Research in Social & Administrative Pharmacy. https://doi.org/10.1016/j.sapharm.2020.05.017

Baweja, R., Verma, S., Pathak, M., & Waxmonsky, J. G. (2020). Development of a child and adolescent tele-partial hospitalization program (tele-PHP) in response to the COVID-19 pandemic. The Primary Care Companion for CNS Disorders. https://doi.org/10.4088/PCC.20m02743

Beardon, L., Chown, N., & Cossburn, K. (2018). First responders and autism. In F. Volkmar (Ed.), Encyclopedia of autism spectrum disorders. Springer. https://doi.org/10.1007/978-1-4614-6435-8_10215_9-1

Bradshaw, P., Pellicano, E., van Driel, M., & Urbanowicz, A. (2019). How can we support the healthcare needs of autistic adults without intellectual disability? Current Developmental Disorders Reports, 6(2), 45–56. https://doi.org/10.1007/s40474-019-00159-9

Brooks, S. K., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenberg, N., et al. (2020). The psychological impact of quarantine and how to reduce it: Rapid review of the evidence. The Lancet, 395, 912–920. https://doi.org/10.1016/S0140-6736(20)30460-8

Campbell, V. A., Gilyard, J. A., Sinclair, L., Sternberg, T., & Kailes, J. I. (2009). Preparing for and responding to pandemic influenza:
Implications for people with disabilities. *American Journal of Public Health, 99* (Suppl 2), S294-300. https://doi.org/10.2105/AJPH.2009.162677

Cariou, B., Hadjadj, S., Wargny, M., Pichelin, M., Al-Salameh, A., Allix, I., et al. (2020). Phenotypic characteristics and prognosis of inpatients with COVID-19 and diabetes: the CORONADO study. *Diabetologia*. https://doi.org/10.1007/s00125-020-05180-x

Chen, M. H., Lan, W. H., Hsu, J. W., Huang, K. L., Su, T. P., Li, C. T., et al. (2016). Risk of developing type 2 diabetes in adolescents and young adults with autism spectrum disorder: A nationwide longitudinal study. *Diabetes Care, 39*(5), 788–793.

Cidav, Z., Lawer, L., Marcus, S. C., & Mandell, D. S. (2013). Age-related variation in health service use and associated expenditures among children with autism. *Journal of Autism and Developmental Disorders, 43*(4), 924–931.

Colombo, R. A., Wallace, M., & Taylor, R. (2020). An essential service decision model for ABA providers during crisis. *Behavior Analysis in Practice, 1*, 306–311. https://doi.org/10.1007/s40617-020-00432-z

Constantino, J. N., Sahin, M., Piven, J., Rodgers, R., & Tschida, J. (2020). The impact of COVID-19 on individuals with intellectual and developmental disabilities: Clinical and scientific priorities. *American Journal of Psychiatry*. https://doi.org/10.1176/appi.ajp.2020.20060780

Cox, D. J., Plavnick, J. B., & Brodhead, M. T. (2020). A proposed process for risk mitigation during the COVID-19 pandemic. *Behavior Analysis in Practice*. https://doi.org/10.1007/s40617-020-00430-1

Daniel, H., & Butkus, R. (2015). Lesbian, gay, bisexual, and transgender health disparities: Executive summary of a policy position paper from the American College of Physicians. *Annals of Internal Medicine, 163*(2), 135–137.

de Sousa Lima, M. E., Barros, L. C. M., & Aragão, G. F. (2020). Could autism spectrum disorders be a risk factor for COVID-19? *Medical Hypotheses*. https://doi.org/10.1016/j.mehy.2020.109899

Diaz, A. D., & Bawea, R. (2020). The role of neurotropism in psychiatric patients with COVID-19. *European Archives of Psychiatry and Clinical Neuroscience*. https://doi.org/10.1007/s00406-020-01197-w

Dotson, W. H., Leaf, J. B., Sheldon, J. B., & Sherman, J. A. (2010). Group teaching of conversational skills to adolescents on the autism spectrum. *Research in Autism Spectrum Disorders, 4*(2), 199–209.

Dunn, K., Rydzewska, E., Macintyre, C., Rintoul, J., & Cooper, S. A. (2019). The prevalence and general health status of people with intellectual disabilities and autism co-occurring together: A total population study. *Journal of Intellectual Disability Research, 63*(4), 277–285.

Eidson, T., Hess, A., Hess, T., & Kelly, A. (2020). Family engagement in the autism treatment and learning health networks. *Pediatrics, 145*(Supplement 1), S30–S34.

Eshraghi, A. A., Li, C., Alessandri, M., Messinger, D. S., Eshraghi, R. S., Mittal, R., & Armstrong, F. D. (2020). COVID-19: Overcoming the challenges faced by individuals with autism and their families. *The Lancet. Psychiatry, 7*(5), 481–483. https://doi.org/10.1016/S2215-0366(20)30197-8

Food, Difficulty Getting Enough. (2020). *Tracking the COVID-19 recession’s effects on food, housing, and employment hardships.* Center on Budget and Policy Priorities.

Giallonardo, V., Sampogna, G., Del Vecchio, V., Luciano, M., Albert, U., Carmassi, C., et al. (2020). The impact of quarantine and physical distancing following COVID-19 on mental health: Study protocol of a multicentric Italian population trial. *Frontiers in Psychiatry, 11*, 533. https://doi.org/10.3389/fpsyg.2020.00553

Griffiths, L., Blignault, I., & Yellowlees, P. (2006). Telemedicine as a means of delivering cognitive-behavioural therapy to rural and remote mental health clients. *Journal of Telemedicine and Telecare, 12*(3), 136–140.

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

Hochhauser, M., & Engel-Yeger, B. (2010). Sensory processing abilities and their relation to participation in leisure activities among children with high-functioning autism spectrum disorder (HFASD). *Research in Autism Spectrum Disorders, 4*(4), 746–754.

Hodgson, A. R., Freeston, M. H., Honey, E., & Rodgers, J. (2017). Facing the unknown: Intolerance of uncertainty in children with autism spectrum disorder. *Journal of applied research in intellectual disabilities, 30*(2), 336–344.

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6), 572–581.

Huang, Y., & Zhao, N. (2020). Generalized anxiety disorder, depressive symptoms and sleep quality during COVID-19 outbreak in China: A web-based cross-sectional survey. *Psychiatry Research*. https://doi.org/10.1016/j.psychres.2020.112954

Hubbard, K., & Trauner, D. A. (2007). Intonation and emotion in autistic spectrum disorders. *Journal of Psycholinguistic Research, 36*(2), 159–173.

Hume, K., Loftin, R., & Lantz, J. (2009). Increasing independence in autism spectrum disorders: A review of three focused interventions. *Journal of Autism and Developmental Disorders, 39*(9), 1329–1338.

Juárez, A. P., Weitlauf, A. S., Nicholson, A., Pasternak, A., Broderick, N., Hine, J., et al. (2018). Early identification of ASD through telemedicine: Potential value for underserved populations. *Journal of Autism and Developmental Disorders, 48*(8), 2601–2610.

Khowaja, K., Salim, S. S., Asemi, A., Ghulamani, S., & Shah, A. (2020). A systematic review of modalities in computer-based interventions (CBIs) for language comprehension and decoding skills of children with autism spectrum disorder (ASD). *Universal Access in the Information Society*. https://doi.org/10.1007/s10209-019-00646-1

Kildahl, A. N., Helverschou, S. B., Bakken, T. L., & Oddli, H. W. (2020). “If we do not look for it, we do not see it”: Clinicians’ experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. https://doi.org/10.1111/jar.12734

Kinneir, D., Rydzewska, E., Dunn, K., Hughes-McCormack, L., Melville, C., Henderson, A., et al. (2020). The relative influence of intellectual disabilities and autism on sensory impairments and physical disability: A whole-country cohort of 5.3 million children and adults. *Journal of Applied Research in Intellectual Disabilities*. https://doi.org/10.1111/jar.12728

Knutsen, J., Wolfe, A., Burke, B. L., Hepburn, S., Lindgren, S., & Coury, D. (2016). A systematic review of telemedicine in autism spectrum disorders. *Review Journal of Autism and Developmental Disorders, 3*(4), 330–344.

Kornack, J., Williams, A. L., Johnson, K. A., & Mendes, E. M. (2020). Reopening the doors to center-based ABA services: Clinical and safety protocols during COVID-19. *Behavior Analysis in Practice*. https://doi.org/10.1007/s40617-020-00462-7

Kullar, R., Marcelin, J. R., Swartz, T. H., Piggott, D. A., Macias Gil, R., Mathew, T. A., & Tan, T. (2020). Racial disparity of coronavirus disease 2019 in African American Communities. *The Journal of Infectious Diseases, 222*(6), 890–893.
Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., State, M., et al. (2014). Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 53*(2), 237–257. https://doi.org/10.1016/j.jaac.2013.10.013

Wagner, L., Corona, L. L., Weitlauf, A. S., Marsh, K. L., Berman, A. F., Broderick, N. A., et al. (2020). Use of the TELE-ASD-PEDS for autism evaluations in response to COVID-19: Preliminary outcomes and clinician acceptability. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04767-y

Wallace, G. L., Kenworthy, L., Pugliese, C. E., Popal, H. S., White, E. I., Brodsky, E., et al. (2016). Real-world executive functions in adults with autism spectrum disorder: Profiles of impairment and associations with adaptive functioning and co-morbid anxiety and depression. *Journal of Autism and Developmental Disorders, 46*(3), 1071–1083.

Warrier, V., Greenberg, D. M., Weir, E., Buckingham, C., Smith, P., Lai, M. C., et al. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nature Communications, 11*(1), 1–12. https://doi.org/10.1038/s41467-020-17794-1

World Health Organization. (2002). *The world health report 2002: Reducing risks, promoting healthy life*. World Health Organization.

Zerbo, O., Qian, Y., Ray, T., Sidney, S., Rich, S., Massolo, M., et al. (2019). Health care service utilization and cost among adults with autism spectrum disorders in a US integrated health care system. *Autism in Adulthood, 1*(1), 27–36.

**Publisher’s Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.