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A White Paper by the IDEALS Institute

## THE INITIAL IMPACT OF COVID-19 ON INDIVIDUALS WITH AUTISM SPECTRUM DISORDER AND THEIR FAMILIES



**Background.** The COVID-19 pandemic has impacted individuals across the world, presenting unprecedented challenges. Individuals with Autism Spectrum Disorder (ASD) and their families are an especially vulnerable population due to the impact of ASD on daily functioning, socialization, and communication. Universal lockdowns caused significant disruptions to the availability of services and the routines of individuals with ASD and their caregivers, presenting unique challenges to this population.

**Objective.** The objective of this paper is to share findings of a systematic review of the emerging literature examining the impact of COVID-19 on individuals with ASD and their families in the areas of healthcare, educational services, and mental health services.

**Methods.** Systematic review procedures were applied to conduct a search of the literature examining the impact, interventions, and recommendations for this population during the COVID-19 pandemic. A cross-disciplinary search of databases specified inclusion and exclusion criteria and a process for selection consensus was employed to ensure comprehensive coverage of literature in the fields of healthcare, education, and mental health services.

**Results.** Results indicate that access to quality healthcare, education, and mental health services have been compromised for those with ASD during the pandemic, including lapses in service that have posed health, learning, and behavioral challenges. Some plausible interventions have been applied to address initial areas of impact during pandemic lockdowns, including telemedicine, teletherapy, teleassessment, and virtual learning. The authors provide corresponding recommendations for supporting individuals with ASD during the reopening phase following the pandemic and beyond.

**Recommendations.** In the area of healthcare, standard telemedicine procedures may require adaptations for these to be an accessible means of healthcare delivery for an individual with ASD, and support for caregivers may be needed as part of any telehealth approach to support an individual with ASD to receive maximum benefit. Teletherapy, teleassessment, and virtual learning in education show promise and, for some, can be viable methods of service delivery. However, when offering instruction from a distance, providers may need to individualize the approach to fit an individual's skills, preferences, and other unique learning profiles. Instructional plans designed for face-to-face learning environments may require adaptations for remote delivery and learners with ASD may require various levels of caregiver support to access remote instruction, even when these adaptations. Decision-making tools and protocols designed for this purpose can be useful in supporting teams of professionals to determine necessary revisions and to select academic and behavioral interventions that best match the needs of the learner with ASD in the home environment. Teletherapy can also be a viable means of providing needed mental health services to individuals with ASD and their families, as they cope with routine changes during and after the pandemic. There is evidence to suggest that the comprehensive mental health needs of individuals with ASD and their families have increased substantially; however, access to mental health services, especially those designed with ASD in mind, are lacking. Collaboration to develop and implement shared resources across mental health professionals, policymakers, researchers, educators, and families is an urgent need that must be prioritized as part of comprehensive pandemic recovery efforts.



The coronavirus (or COVID-19) is an infectious disease characterized by respiratory illness.<sup>1</sup> As of May 2021, there have been 167 million cases of COVID-19 reported in 192 countries, with 3.46 million of these cases resulting in death, worldwide.<sup>2</sup> This pandemic has impacted the lives of people in communities across the world, presenting unprecedented crises in public health, as well as both economic and social disruption.<sup>1</sup> For most, the daily impact of COVID-19 has included personal and/or familial health challenges, business closures, remote work and schooling, economic instability, social isolation due to lockdowns, and a need to comply with social distancing measures, mask-wearing, and sanitization protocols. COVID-19 has presented challenges for many but has created unique and profound challenges for already vulnerable populations, including the elderly, those with disabilities, pre-existing health conditions, and individuals who were already experiencing economic instability.

### Autism Spectrum Disorders

While the effects of COVID-19 extend throughout communities, children with an Autism Spectrum Disorder (ASD), their caregivers, and families are an especially vulnerable population. In the United States, 1 in 54 children are diagnosed with ASD.<sup>3</sup> The developmental disability is characterized by impairments in social communication, social interaction, and restricted or repetitive patterns of behavior. The symptom profile of ASD may pose innumerable difficulties in daily functioning, including but not limited to social issues, communication difficulties, inflexible adherence to daily routines, and learning or intellectual problems. Although these symptoms vary in severity, the conditions may present daily challenges for these individuals and their caregivers. The pandemic has caused significant disruptions to the daily routines of countless children with ASD and their caregivers, and this has presented a unique challenge to this population. Additionally, children with ASD often require services such as special education, speech language therapy, occupational therapy, or approaches associated with Applied Behavioral Analysis (ABA). With lockdowns occurring worldwide, this already vulnerable population was faced with barriers to care in a myriad of areas.

The characteristics associated with ASD may have an impact on the way an individual is able to access healthcare services, educational services, and mental health services. For instance, in healthcare, Malik-Soni et al.<sup>4</sup> identified barriers to healthcare access for individuals with ASD across the lifespan. These barriers include shortage of services, lack of physician knowledge, language and communication barriers, and stigma. When accessing educational services, some students with ASD may require an Individualized Educational Program (IEP) designed to provide them with specially designed instruction, curricular modifications and adaptations, and other supports and services provided by staff trained in addressing the characteristics of ASD in an educational setting. While COVID-19 has caused significant disruptions to many children and families, for those with ASD, the pandemic has further exacerbated issues already affecting this population. Therefore, problems that have been experienced by this population during the pandemic are important to assess to determine the potential impact and identify recommendations for future lines of research inquiry.

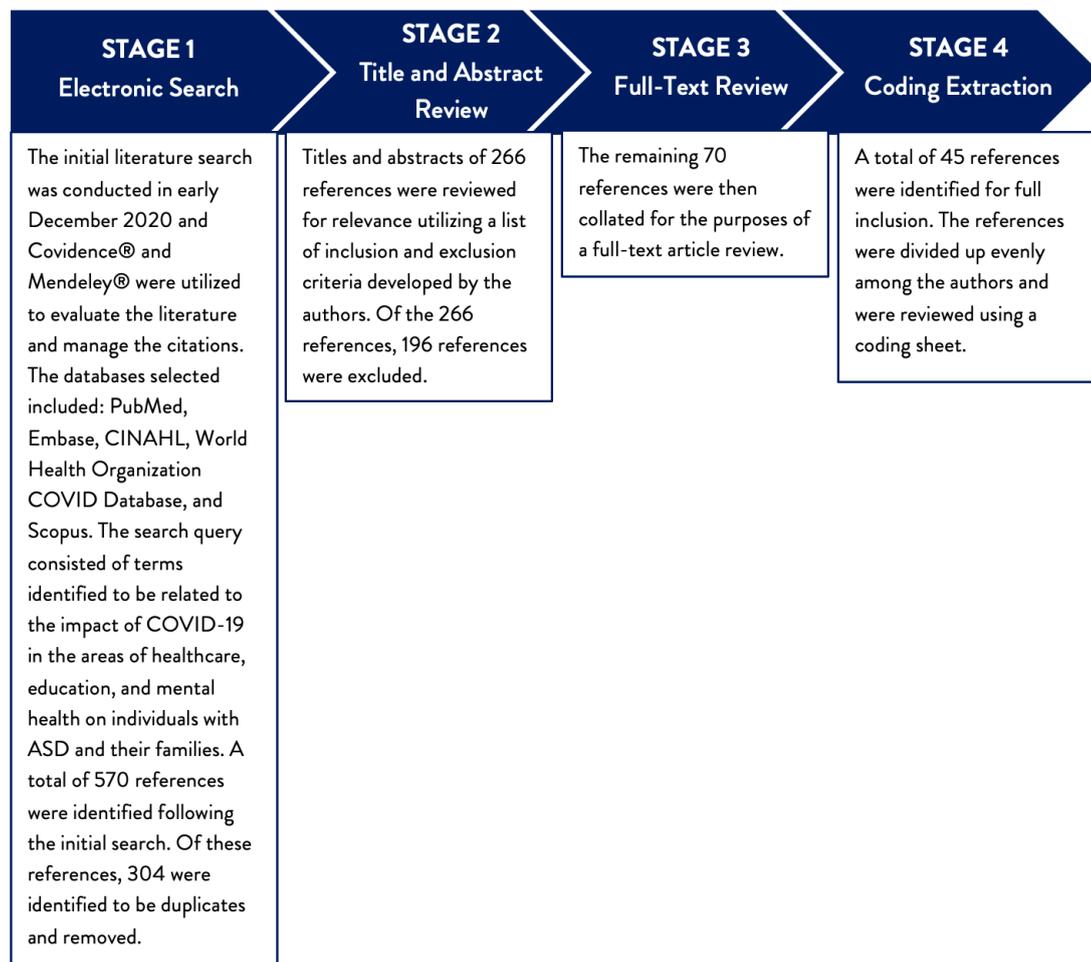
### Purpose of the White Paper

As a result, the purpose of this White Paper was to conduct and present a broad, systematic analysis of literature to synthesize the impact of the population in the areas of medical care, educational services, and mental health services. Given the pressing need for researchers to publish on these issues, the purpose of the review was not to evaluate the methodologies of the existing literature, but to extract information that could be used to further understand how this population has been impacted by the COVID-19 pandemic and draw conclusions from these preliminary results. Additionally, this literature review has been generated to address the emerging and continually evolving circumstances. From the identified literature, interventions and recommendations may be gleaned to further assess the impact of COVID-19 on individuals with ASD and their families.

### Methodology

The systematic procedures applied to conduct this search of the literature on the impacts of COVID-19 on individuals with ASD and their families, as well as interventions and recommendations, are outlined in [Figure 1](#).

Figure 1



## Stage 1

### *Electronic Search*

The initial literature search was conducted in early December 2020 by an informationist, and Covidence® and Mendeley® software were utilized to evaluate the literature and manage the citations. The databases selected included: PubMed, Embase, CINAHL, World Health Organization COVID Database, and Scopus. The databases were identified to ensure comprehensive coverage of the three core focus fields of medical care, education, and mental health, and present the impact of COVID-19 on individuals with ASD and their families within these areas.

The search query consisted of terms identified by the authors and the informationist to be related to the impact of COVID-19 in the areas of healthcare, education, and mental health on individuals with ASD and their families.

A total of 570 references were identified following the initial search. Of these references, 302 were identified to be duplicates and removed. Upon importing the remaining 268 references into Covidence, an additional two references were identified as duplicates and removed.

## Stage 2

### *Title and Abstract Review*

Titles and abstracts of 266 references were reviewed for relevance utilizing a list of inclusion and exclusion criteria developed by the authors. A minimum of two authors reviewed each reference. In the case of disagreements, all three authors engaged in consensus discussions. Of the 266 references, 196 references were excluded based on the aforementioned criteria.

## Stage 3

### *Full-Text Review*

The remaining 70 references were then collated for the purposes of a full-text article review. Disagreements continued to be resolved through consensus discussions amongst all three authors.

## Stage 4

### *Coding Extraction*

A total of 45 references were identified for full inclusion. A coding sheet was developed by the second author. The references were divided up evenly among the authors, and each author reviewed and coded 15 articles.

The articles included in this search have been categorized by healthcare services, educational services, and mental health services as indicated in Table 1. These studies span various methodologies and employ different approaches to analyzing and reporting the collected data. It is important to note that due to the nature of the research area, some studies were conducted rapidly, included a small number of participants, and/or provided preliminary information on data analysis and results. The purpose of this categorization was to provide a synthesis that meets the needs of each professional audience. However, there is an overlap of the topics discussed throughout these publications. For instance, since ABA is an intervention commonly recommended to individuals with ASD based on its base of evidence, many of the articles in this review discussed the disruption of ABA services to children with ASD during the pandemic, the impact of that disruption, and plausible interventions to continue ABA through online methods, such as teletherapy. For the purposes of this review, the authors chose to include articles that primarily address ABA under educational services. In other instances of overlap, results have been categorized based on the key themes or audiences that were addressed in the publication. The section that follows outlines the key areas of impact to individuals with ASD and their families, plausible interventions that have been applied to address these areas of impact, and the corresponding recommendations authors of these publications have made for supporting individuals with ASD during the pandemic and the reopening phase.

[Table 1](#)

## Healthcare Services

### *Impact*

Evidence indicates that individuals with ASD have experienced gaps in their access to healthcare during the pandemic<sup>5,6</sup> and some have been unable to access high-quality telemedicine services.<sup>7</sup> These gaps have occurred due to the universal lockdowns and a lack of many healthcare systems to respond rapidly with telemedicine practices. When receiving healthcare services, the needs of individuals with ASD may present unique challenges that make it difficult for them to comply with the current COVID-19 restrictions and policies. For instance, children with ASD may need a familiar caregiver with them during hospitalization<sup>8</sup> or need increased support to comply with personal protective equipment (PPE) regulations.<sup>9,10</sup> Overall, it is critical that healthcare providers be aware that the disruptions in daily routines have presented great challenges for many individuals with ASD and their families and these interruptions can have an impact on the quality of services provided to these patients.<sup>11,12</sup> At times, disruptions in daily routines during the pandemic have been shown to result in severe behavioral challenges.<sup>5,13,14</sup> Additionally, the physical health of individuals with ASD has been compromised during the pandemic due to a lack of physical activity, which may lead to weight gain, other health concerns such as diabetes and heart disease,<sup>15,16,17</sup> and increased screen time.<sup>16</sup>

### *Recommendations*

The articles in this review provide promising interventions and recommendations for healthcare providers that can be applied to support individuals and families during and following the pandemic. One of the most commonly discussed interventions was the use of high-quality telemedicine practices.<sup>5,6,7,9,10</sup> When delivering telemedicine services, it is important that providers bear in mind that this solution may present complexities for individuals who are nonverbal or minimally verbal.<sup>5</sup> Healthcare systems may find it useful to design safeguards and guidelines that ensure high-quality remote care to individuals with ASD, including the ability to adequately assess patient needs and offer critical support.<sup>11</sup> Regardless of the intervention provided, researchers in the field recommend that an important first step in supporting patients with ASD and their families is to communicate by reaching out to them during a time of social isolation.<sup>6,9,11,18</sup> Once initial communication has occurred, health providers should offer support to caregivers in managing day-to-day life and addressing ongoing health concerns, including physical health and mental health needs.<sup>7,10,17,19</sup> It is also recommended that healthcare providers conduct evaluations to determine levels of need, including risk assessments and physical health exams.<sup>20</sup> Finally, in order to ensure that the unique needs of individuals with ASD are addressed in providing a high quality of care, hospitals may need to consider amending visitor policies based on case-by-case circumstances.<sup>8</sup>

## Educational Services

### *Impact*

The COVID-19 pandemic has had a considerable impact on the education of children with ASD. The greatest concern noted in the literature has been the disruption to educational services, including therapies. For most children with ASD, school closures resulted in a sudden disruption of ABA therapies<sup>18-23</sup> and significant changes in daily routines.<sup>24,25,27,28</sup> When school districts provided online options, many learners with ASD experienced challenges in accessing this instruction due to their complex learning needs.<sup>24-27,30,31</sup> ASD is a disorder primarily characterized by a need for consistency and adherence to routines; therefore, the impact of this disruption to typical daily life is noted in the literature as being one of the single greatest challenges for individuals with ASD. This disruption has caused behavioral difficulties,<sup>28</sup> mental health challenges such as anxiety and depression,<sup>25,32-34</sup> and sleep problems.<sup>12,28</sup> In many systems, disruption in services has also included a halt to evaluations, which leaves families and children requiring early intervention without access to assessment and early intervention services.<sup>36,37</sup> Additionally, stay-at-home orders have increased parents' and caregivers' roles to now include that of teacher and therapist.<sup>27,31,38</sup> There is both evidence and commentary throughout these publications that make clear that caregivers have struggled to adjust to these new roles, and many are in need of support to serve in this role. Furthermore, caregivers may be grappling with difficult decisions as to whether to return to in-person therapies and educational services in attempts to address these impacts, which may, in turn, increase the risk of exposure to COVID-19.<sup>14</sup>

### *Recommendations*

The onset of the COVID-19 pandemic has caused many educational providers and systems to implement virtual learning using a variety of technologies. These approaches include teletherapy<sup>28,31</sup> and tele-assessment.<sup>36,37</sup> However, as previously stated, it is common that learners with ASD may experience challenges in accessing virtual instruction through typical online delivery methods.<sup>27,29</sup> The first stage in determining readiness for any remote instruction, particularly when there has been a lapse in service, is to conduct an assessment of the learner's current skill levels to determine potential regression<sup>29</sup> and then to adjust therapies accordingly.<sup>20</sup> It may be necessary to adjust instructional plans and ongoing curriculum-based assessments to meet the needs of the individual.<sup>20,26,27</sup> Stenhoff et al.,<sup>27</sup> provide an extensive set of recommendations for individualizing online learning plans for learners with ASD, and considerations for coaching caregivers through the process of home-based instruction. In line with Stenhoff et al.'s<sup>27</sup> recommendations for coaching caregivers, Samadi et al.<sup>38</sup> emphasize the need for providing support to caregivers to ensure that the comprehensive needs of the learner and family are adequately met. To properly adapt instructional plans for learners with ASD during the pandemic, practitioners may find it useful to utilize existing decision-making tools and protocols that have been designed expressly for this purpose, such as the model suggested by Rodriguez,<sup>29</sup> which incorporates a treatment-selection matrix; The Acceptance and Commitment Training (ACT) Matrix posed by Tarbox et al.<sup>30</sup>; or use of the Aberrant Behavior Checklist (ABC) discussed by Brondino et al.<sup>13</sup> Overall, decision-making tools can assist educators and therapists in ensuring that children with ASD are receiving an appropriate, comprehensive, and coordinated set of educational services.<sup>19,21</sup> While traditional tele-approaches to instruction may be useful, emerging digital tools such as immersive technologies like virtual reality and head-mounted displays present promising results for learners with ASD.<sup>25</sup> Immersive technologies may be useful for preparing individuals with ASD for a return to school and may reduce the psychological burden of this transition.<sup>25</sup> While the use of virtual instructional and teletherapy may be useful to prevent a complete disruption in service to learners, at best, it comes with challenges for many with ASD based on their complex learning needs. If used, virtual learning and therapeutic methods must be tailored to the needs of the individual and family. However, for most, this mode of instructional delivery is not recommended as a long-term replacement for in-person clinical or educational services. In order to ensure that the unique needs of individuals with ASD are addressed in providing a high quality of care, hospitals may need to consider amending visitor policies based on case-by-case circumstances.<sup>8</sup>

## Mental Health Services

### *Impact*

The emerging literature confirms that individuals with ASD and their families have experienced significant mental health challenges during the COVID-19 pandemic. The impact on mental health has included increased rates of anxiety and depression among individuals with ASD,<sup>25,32-34</sup> limited opportunities for socialization,<sup>40,41</sup> and behavioral problems resulting from psychological distress.<sup>42</sup> During this time of such great psychological challenge, this period has also been marked by a considerable lack of access to mental health providers.<sup>43</sup> Literature in this area indicates that the families of individuals with ASD have also struggled greatly. However, it is important to note that families have identified benefits associated with the pandemic. Neece et al.<sup>44</sup> reported that positives include more time spent with family and improved familial relationships.

Research shows marked increases in parental stress and burnout,<sup>23,33,35,44-46</sup> which can be exacerbated by a lack of necessary resources, such as respite care.<sup>23</sup> Like many families across the world, those parenting children with ASD are also trying to adjust to changes in daily life. However, because of the routine-based nature of individuals with ASD, these families may experience increased struggles in maintaining productive and sustainable family routines during social isolation.<sup>24,35,40,41,44</sup>

### *Recommendations*

The first, and most logical, way to address the emerging needs of individuals and families is to ensure that they have readily available access to mental health services.<sup>45,46</sup> Teletherapy is one viable means of providing access to these services during the pandemic.<sup>33,35,41</sup> Comprehensive mental health services for individuals with ASD should include ongoing mental health support and education to caregivers.<sup>34,44,47,48</sup> For instance, the use of parenting tips or just-in-time support options, such as a parent hotline, may be useful for connecting families with necessary resources.<sup>46</sup> Resources provided to families should focus on helping them to establish a support structure and a routine during lockdown.<sup>35</sup> Despite the current reliance on remote options and supports, the levels of mental health stress need to be carefully monitored in each individual and family. A thoughtful analysis of risk versus benefit is necessary to determine whether maintaining social distancing leaves individuals at risk for harm, particularly if the mental health needs are acute. Hageman<sup>34</sup> indicates that, in some cases, it may be necessary to maintain face-to-face support and to provide trauma-informed care. Given the extensive mental health needs of many individuals and families across communities, researchers insist that we prepare for the post-pandemic mental health needs of this population.<sup>32,40</sup> Building a sense of urgency for this consideration now will help to ensure that systems are prepared to support the resulting psychological needs of children, adults, and caregivers as they return to school, work, and their communities.



The impact of COVID-19 on individuals with ASD and their families has been significant in three key fields. Emerging research indicates that children, adults, and their families have struggled to adapt to change brought on by the pandemic, thus impacting their physical health and access to healthcare. Individuals with ASD have experienced a disruption in critical educational services, which has caused challenges in adapting to new daily routines, limited opportunities for socialization and, in some cases, significant behavioral challenges. The pandemic has also substantially increased the mental health challenges experienced by individuals and families. Overall, impact in these areas is interconnected. Part of the reason for this interconnectivity is due, in large part, to the nature of ASD itself. Children and families often require services across these domains and successful development of skills requires ongoing coordination amongst healthcare, educational, and mental health providers.

Further details are necessary to advance our collective understanding of how these interventions can be applied in the long term and how appropriate resources can be provided to families to support them in the current crisis and in the transition to life that follows. Across these fields, we advocate urgency and immediate action on the part of researchers and providers to share what they know with families, while also simultaneously advancing the research base with conclusive evidence on what works to address critical areas of impact. While additional recommendations are needed, these need to be vetted through rigorous research methods. One of the continuing impacts of this pandemic is that we are learning more about how telehealth and teletherapy can be used to support individuals and families, but we must continue researching these to determine how these methods can best be applied to have the greatest and most sustaining impacts. As part of an evolving research agenda, it is critical that the voices of individuals with ASD and their caregivers take a prominent focus. To date, the voices of these individuals are largely missing from the body of research. Research presenting the experiences of children and adults with ASD and their caregivers, along with promising interventions grounded in research, will advance our understanding of how best to address the needs of this vulnerable population now and for years to come.

## LIMITATIONS

There are challenges associated with conducting a review of the emerging literature in the midst of the pandemic. While there are a series of promising interventions discussed in the results of this review, there are limitations. As the number of empirical studies within this scope continue to grow, the authors were limited to the existing literature available at the time of this review. As previously noted, the sense of urgency created by the pandemic required some studies to be conducted rapidly and provided preliminary information on data analysis and initial results. Furthermore, the scope of this review made it necessary to include the identified 20 empirical studies as well as to include expert commentaries and editorials describing the nature of the pandemic and its impact on individuals with ASD, descriptive and qualitative studies, book chapters, as well as discussion and perspective papers. Overall, the references span an array of various methodologies, employing different approaches to analyzing and reporting data. However, the benefit to presenting preliminary findings is greater than the inherent limitation, as this review is meant to serve as an initial discussion of impact.

Those with ASD have experienced difficulty in accessing healthcare, educational services, and mental health services during the pandemic due to universal lockdowns. For some, accessing services through virtual means (such as telemedicine, teletherapy, or tele-education), has been challenging due to the characteristics associated with ASD. Oftentimes, it is necessary for a provider or system to adapt their practices for virtual delivery, modify a student's original services plan for implementation in the home environment, or provide additional supports to a parent or caregiver so that an individual with ASD can access these services and derive benefit from them. When creating and enacting systemwide policies, it is crucial that the characteristics associated with ASD be carefully considered to ensure that the needs of individuals and their families are met. Retrofitting policy after its generation is ineffective and the unique needs of individuals with ASD are critical to keep in mind from the start. These accessibility issues coupled with the disruption to daily routines during the pandemic have created hardship for individuals with ASD and their families. Emerging literature suggests that the greatest impacts have been disruption to learning, increased rates of anxiety and depression, limited socialization opportunities, and increased behavioral problems due to psychological stress. Distress in children with ASD has contributed to increased parental stress and burnout and difficulty in maintaining productive and sustainable family routines.

While this period has been marked with hardship, there have also been benefits, namely increased connections between individuals with ASD and their caregivers during extended periods of togetherness. Other positive aspects have also emerged, such as a collective willingness to acknowledge the role that technology can play in increasing the continuum of instructional and therapeutic service delivery options available. As we develop new ways to address the impact of the pandemic and its challenges, it is also important that we acknowledge these positive attributes to determine how best to serve those with ASD in the future. Emerging research indicates that those with ASD and their families will have existing needs that extend beyond the phase of acute lockdown and the fields of medicine, education, and social services must be poised to address the longitudinal impacts.

Eventual transition back to *normalcy* provides a time for critical reflection and an opportunity to reconceptualize how these fields can progress. Perhaps we should ask: *What is normal?* The very nature of ASD teaches each of us to examine neurodiversity and to celebrate the many differences that make individuals unique. After the pandemic, how can we make a return to *normal life* even better for individuals with ASD and their families than it was before this crisis? What have we learned about the promising interventions that make life more rewarding and which interventions, when not present, did we learn were more critical than we ever thought before? Many of the challenges discussed in this paper were present for individuals with ASD and their families long before COVID-19. The charge before us is to take what we have learned from this pandemic to improve these interconnected services for individuals with ASD and their families so that they can lead fulfilling lives within their schools and communities.



Members of the IDEALS Institute are conducting ongoing projects and pursuing new initiatives that address these complex issues and are highly interested in developing partnerships with organizations or individuals who wish to collaborate to address these. Readers interested in future partnerships, such as research or other focused initiatives, are encouraged to reach out to [Dr. Andrea Harkins Parrish](#), Corresponding Author and Director of Development and Learning Systems at the IDEALS Institute, at [andrea.parrish@jhu.edu](mailto:andrea.parrish@jhu.edu).

## ABOUT THE [IDEALS INSTITUTE](#)

The Institute for Innovation in Development, Engagement, and Learning Systems (IDEALS) is a research and development hub within the Johns Hopkins University School of Education. The mission of the multidisciplinary team of faculty and staff at the IDEALS Institute is to improve lives by ensuring all people have access to transformative child and adult care, education, health, and social service systems and practices. Our institute staff are guided by the following ideals: (1) every person deserves high-quality care and teaching throughout their entire life, (2) healthy development and learning requires an eco-system model, (3) quality practices start with a competent workforce, and (4) public policy needs to be sustainable and usable. At IDEALS, we strive to be a voice for those who cannot always speak for themselves, to partner with those committed to serving others, and to be a positive disruptor with an entrepreneurial spirit toward entrenched barriers to development, engagement, and learning for any individual, anywhere in the world. Team members at IDEALS are experienced in conducting research, instrumentation, and technology systems, and work collaboratively with school systems while maintaining JHU's standards for research excellence across a variety of large-scale grants, multi-year grants, contracts, and cooperative agreements. The institute has more than 65 full-time faculty and staff with expertise in research; early childhood; educational technology education; special education; workforce development; Quality Rating and Improvement Systems (QRIS); human development and learning; technology development and operation; website development and operation; marketing and communication to create behavioral change and public policy adoption on parts of audiences; strategic partnerships; project management; and business operations.



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