# The Impacts of the COVID-19 Pandemic on Children with Autism Spectrum Disorder (ASD) and their Caregivers

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Children with Autism Spectrum Disorder (ASD) often rely heavily on a strong sense of <u>routine and predictability</u> in order to make sense of the world around them, which can feel confusing and overwhelming. Without this, they can have trouble feeling safe and comfortable in their environment and can feel anxious or depressed or lose their temper.

COVID-19 has had unprecedented impacts on the lives of people all over the world, and has led to increased rates of depression, anxiety, post-traumatic stress as well as other mental health burdens even amongst the <u>general public</u>. As many struggle to come to grasp with all the changes brought about by COVID-19, one group is particularly vulnerable to this sudden upheaval of normality. In the eyes of a child with autism, the drastic social impacts of the pandemic are all the more distressing.

#### BACKGROUND

An estimated <u>1 in 160</u> children suffers from ASD globally, however, this statistic is often considered a drastic underestimate. Individuals with <u>autism</u> have difficulties with "socialemotional reciprocity", nonverbal communication, as well as with creating and maintaining social relationships. Other characteristics children with autism often display include: repetitive behaviours and movements, a need for routine, a tendency to develop fixated/narrow interests and either a heightened or diminished reactivity to external stimuli. The social and emotional characteristics, as well as the associated comorbid conditions, make children with ASD more susceptible to the negative impacts from the COVID-19 pandemic.

## SOCIO-BEHAVIOURAL IMPACTS OF THE PAN-DEMIC

To maintain daily routine and develop their abilities, children with autism often work with a multidisciplinary team of professionals in programs including: behavioural, occupational, and speech therapists; as well as with pediatricians and other healthcare professionals. These multidisciplinary care teams also help children with autism develop their <u>essential</u> <u>skills</u> such as self-regulation or speech ability.

Due to pandemic lockdown measures, many of the institutions that children with autism regularly attend have had to refrain from in-person operations. The breakdown of their care and support network as well as the lack of access to specialist services, can hinder the learning and development



of these children when it comes to essential skills and personal development.

At the same time, the decreased social support and loss of routine can also lead to devastating emotional and behavioural impacts, which is especially poignant given that children with ASD have an <u>increased propensity</u> for mental health symptomatology such as depression, anxiety, and Attention Deficit Hyperactivity Disorder (ADHD).

#### **Impacts on Mental Health**

One of the psychological morbidities associated with autism is a high prevalence of <u>obsessive behaviours</u> as well as obsessive-compulsive disorder (OCD). Children with ASD may become <u>obsessed</u> with reading distressing COVID-19 information, leading to <u>heightened anxiety</u>, as seen in a cross-sectional study conducted in Spain where compared to controls, children with autism displayed more anxiety and obsessive tendencies.

In particular, the COVID-19 pandemic has been notable for its widespread <u>infodemic</u>, with the increased spread of both information and misinformation regarding the disease across a multitude of social media platforms.

Children affected by the psychological comorbidities associated with autism such as ADHD and depression, may also be more psychologically vulnerable when exposed to excessive amounts of distressing information. As a result of these emotional impacts and distractions, children may also



struggle to focus on their coursework and learning, further exacerbating the problem.

#### Impacts on Learning

The psychological impacts and resulting academic consequences for children with autism has been reflected in a number of studies conducted internationally. In a survey of 527 caregivers for children with autism conducted in <u>Italy</u>, 93.9% of participants reported that the COVID-19 pandemic created a period of difficulty for themselves and their children. Specifically, they had challenges in maintaining routine in daily activities, managing free time, and also planning structured activity. As a result of these challenges in maintaining structure and routine of daily life, the children displayed significantly <u>worse behavioural outcomes</u> due to poor adaptation and emotional regulation, sometimes requiring increased specialist support or even emergency interventions.

In another survey of 4,232 patients with autism and caregivers conducted by the <u>UK National Autistic Society</u>, 68% of family members said that the lack of routine resulted in their child having increased anxiety, and 65% of them said that their child could not engage in online work. Additionally, 50% reported that their child's academic performance suffered as a result of the pandemic.

## **IMPACTS ON CAREGIVERS**

Due to the increased needs of children during the pandemic who can no longer attend classes in-person and may struggle with adaptation, caregivers also experience severe impacts. Depending on the severity of symptoms, children with autism often require direct supervision by someone with specific experience or training regarding their needs. Therefore, many caregivers are now spending more time during the working day taking care of their child, especially given that the transition from in-person classes to at-home/online classes can be difficult to adapt to for children with ASD due to the change in routine.

According to the <u>UK National Autistic Society's survey</u>, one in five family members of children with autism has had to reduce working hours due to increased caregiving needs, and 40% of caregivers did not feel confident in their ability to support their child's academic needs. Furthermore, decreased working hours may further increase financial burden beyond the already prevalent financial distress and job uncertainty amongst the general working population as a result of economic impacts of lockdown.

## DIFFICULTIES IN HOSPITAL SETTINGS

Regarding viral transmission and testing, children with autism may have <u>difficulties</u> during hospital visits for COVID-19 testing and health checkups. Specifically, an emergency room is often extremely busy and has an intense atmosphere, which can be overstimulating to children with autism. Children with autism may struggle to remain calm in these high-stress environments, or to understand the concept of social distancing and adhere with mask-wearing. If a child with autism is unable to comply with these infection control measures, this would increase the risk for disease transmission both for themselves and other hospital visitors.

### **MOVING FORWARD**

The unprecedented global impacts of the COVID-19 pandemic, <u>researchers</u> in the field have highlighted the need for pandemic preparedness plans to include considerations for specific vulnerable populations such as individuals with autism, who have additional psychological and behavioural burdens.

Some of the potential solutions being explored by researchers is the potential for further research and development in the field of effective <u>telehealth</u> delivery for children with autism and their caregivers in order to provide continuity of care to children with autism. Given that children with autism may have difficulties in emergency room settings, <u>experts</u> have also signaled that governments and healthcare institutions may also consider specific policies to address this including conducting at-home testing for COVID-19, or training healthcare workers on managing children with autism.

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