

# Caring for Individuals with Autism during a Crisis

In times of crisis, individuals with autism may feel more isolated than ever, requiring increased support from caregivers, family, and friends. This pamphlet can help guide you and your families, but it is important to remember to *include individuals with autism in discussions* about crisis response.

## Preparing for Crises

Preparedness is key in successfully navigating a crisis for individuals with autism. Crises can range from natural disasters, sudden family illness, or the current global pandemic. Although every state, district, and family handles these situations differently, here are some general guidelines to follow.



### Develop an emergency plan

It is important to create a plan of action to prepare for emergency situations. Be sure to conduct a needs assessment to determine what essential resources your family may require. If possible, contact a case manager who can help coordinate transportation services for doctor's appointments, help with online grocery shopping or food delivery, or create alternative living plans. When developing your plan, you can:

- Schedule meetings with your family's speech pathologist, teacher, caregiver, etc. to get their input on emergency planning.
- Identify individuals who could stay with your family member if their caregiver gets sick.
- Create an information sheet with names, pictures, and phone numbers of important contacts, including a network of relatives, friends, or co-workers.
- Check in with local health systems, police departments, first responders to inform them of your plan.

## Follow a daily routine

In times of crisis, it is more important than ever to maintain a regular routine. Keeping your family's schedule consistent can help lessen uncertainty and create structure. It can be beneficial to build off of existing schedules so aspects of the new routine can maintain some degree of familiarity. Tips for developing at-home schedules include creating different activity zones for eating, sleeping, and recreation; incorporating breaks for both you and your family member; and including a visual component to your schedule.

## COVID-19

The novel coronavirus, COVID-19 has impacted millions of people across the globe, and individuals with autism face unique barriers in navigating the pandemic. Individuals living in group homes are at an increased risk of infection due to close living quarters and frequent interactions with healthcare workers, while those living with family or independently may lose access to support staff. Day programs and work opportunities for individuals with autism have also halted in an effort to promote physical distancing, and these disruptions in routine may be especially detrimental to people with autism.



## Losing physical contact with a caregiver

Many support services are being interrupted due to COVID-19 quarantines and physical distancing recommendations, while caregivers for individuals with autism are already difficult to maintain due to low wages. Support services, including regular communication with aides, speech pathologists, therapists, teachers, etc. should remain accessible virtually whenever possible. Virtually, support staff can assist the autistic individual with school work, help prompt them to follow their schedule, and engage in leisurely activities together. Individuals should also utilize telehealth services to stay on schedule with doctor's appointments.

## Maintaining social support through alternative methods

To allow for continued interaction and socialization during the crisis, individuals with autism can engage in virtual support groups or social hours with family, friends, and peers. Individuals can meet online through platforms like Zoom to discuss their feelings, current events, or to just hang out. Social distance walks, or going on walks while maintaining a 6-foot distance, can be incredibly beneficial to help with feelings of isolation. Also try watching a movie or playing a game while video chatting with a friend.

## Treatment discrimination in hospitals

When seeking care for COVID-19, individuals with autism could face treatment discrimination in hospitals. Each state in the US has a Crisis Standard of Care Plan which discusses how medical care may change in the event of equipment and resource shortages. When health care systems reach capacity and doctors must resort to choosing which patients to care for, individuals with disabilities may be put at the back of the line. Unfortunately, these guidelines assume that individuals with disabilities have a poor quality of life. Alabama's plan says that people with severe intellectual disabilities "are unlikely candidates for ventilator support". This may put individuals with autism at high risk for complications or death from COVID-19 due to a lack of or delay in treatment.

However, the US Department of Health and Human Services issued a bulletin in late March which emphasizes that **discriminating against individuals with disabilities remains prohibited even in times of crisis**. It is essential to know your rights, and advocate for yourself or your loved one in emergency situations.

## Resources

- [COVID-19 guidelines for people with disabilities](#)- US Centers for Disease Control and Prevention (CDC)
- [Fighting discrimination in COVID-19 treatment](#)- Autism Self Advocacy Network (ASAN)
- [Coronavirus Aid, Relief, and Economic Security \(CARES\) Act](#)- Summary of how this affects the autism community (via Autism Society)
- [Q&A on providing services to children with disabilities during the COVID-19 outbreak](#)- US Department of Education