



How Americans with disabilities can cope with the COVID-19 crisis

The COVID-19 pandemic poses a severe risk to the health and well-being of individuals with disabilities. Here are some tips on how to protect and advocate for yourself during this unprecedented crisis.

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COVID-19 is upending the lives of every American. Many public health officials remain cautious, anticipating the need to continue prevention efforts for an extended time. For people with disabilities, the impact can be severe, increasing barriers to accessing critical public health information, healthcare and support services. The coronavirus brings new challenges as well such as difficulty engaging in preventative measures such as physical distancing and frequent hand-washing. Although many people with disabilities are healthy, some have secondary conditions that increase their risk for contracting COVID-19. All of these factors can contribute to stress and anxiety.

Tips to help navigate the complexities of COVID-19

Beyond the precautions recommended for all individuals such as hand-washing and physical distancing, individuals with disabilities can take extra steps to protect their health and well-being.

Take extra steps to protect your health

Wash your mobility equipment down, such as push rims on wheelchairs, walkers, crutches. Adjust how you carry out some daily activities. For example, if you have limited hand function, avoid using your mouth to take your gloves off. Find a different mechanism to remove gloves, such as using an assistive device. If you are blind or have low vision, you may touch more surfaces during navigation than others. If possible, wear gloves when going out in public.

If you depend on multiple caregivers to help with daily tasks, try to limit the number to help practice physical distancing.

Think about your communications needs

If you are deaf or hard of hearing, it may be challenging to know what doctors and nurses are communicating through their personal protective equipment such as masks. They may also talk to you from behind a window or curtain, making it harder for you to understand them. Ask health staff to convey information in writing. Plan to have alternative modes of communication with you. For example, bring a paper and pen or a small whiteboard and marker or a digital notebook.

Develop a strategy for personal care

If you rely on personal care attendants to assist with activities of daily living, easy access to caregivers may be more challenging during the pandemic. The Center for Disability Rights provides a helpful resource (<http://cdrnys.org/blog/programs-services/action-steps-for-attendant-service-users-in-response-to-coronavirus-disease-2019-covid-19/>) specific to personal care attendants. The Coronavirus Aid, Relief, and Economic Security Act (CARES) Act allows state Medicaid programs to pay for direct support professionals to assist disabled individuals in the hospital.

Plan for possible medical care

If you experience health issues specific to your disability, they may need to be managed differently during the pandemic. You may face difficult decisions about whether to delay treatment, possibly suffering more pain or a more extended healing period, or risk infection by entering a medical facility. Many hospitals across the country are operating on lockdown procedures, not permitting family members or friends to remain with you. Consult with your health care providers ahead of time, so they can assess whether going to the hospital is the appropriate course of action given the risks involved.

Take stock of essential medical supplies or medications

It may be harder to access necessary medical supplies or medicines due to shortages of resources, insurance company policies, and shipment delays. Assess what supplies and medications you have, how long they will last and plan ahead for reorders and refills. In some cases, you may advocate for a 90-day refill instead of monthly. Be prepared for longer shipping times, given the national increase in online orders and deliveries.

Anticipate disruptions to food delivery and other services

If you are blind or need assistance with essential errands, factor in limited transportation opportunities at this time. Conveniences that you used before the pandemic, such as home grocery delivery, are sometimes limited due to increased demands, scarce supplies, or backorders. Plan ahead and ask family, friends and neighbors for help obtaining groceries or sign up for subscription food delivery services.

Take extra precautions against infection

If you are at high risk for complications due to COVID-19, explain to family, friends and neighbors that you are following further safeguards. Do not feel guilty about staying healthy and safe. Advocate for yourself and educate others about your disability. Ask them to respect your decisions.

Review your finances

The pandemic has disrupted the economy and employment, contributing to stress and worry over job security and finances. Managing a disability can add to those concerns. Review your finances and identify available options. For example, the CARES Act stipulates that social security or social security disability insurance (SSDI) recipients are eligible to receive a stimulus check. The National Disability Institute offers a financial resilience center (<https://www.nationaldisabilityinstitute.org/financial-resilience-center/>) to help people with disabilities and their families deal with the current pandemic financially.

Advocating for yourself during COVID-19

Nondiscrimination laws are not waivable during times of crisis. You have a right to advocate for yourself during this pandemic.

Care rationing

Several national disability groups are advocating against care rationing policies that deny or limit COVID-19 care for people with disabilities. Care rationing may be an increasing threat as hospital systems and as supplies fail to meet the growing demands caused by the rapid spread of COVID-19. Reach out to your state-run Protection & Advocacy system (P&As) to seek further advice. Find your local P&A here. (<https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>)

Hospital visitation

Most hospital policies include language that allows for exceptions to visitation restrictions for people with disabilities. While recognizing the need to stop the spread of COVID-19 as the rationale for newly restrictive visitation policies, you can request an exception as a reasonable accommodation.

Accessibility of information

The rapid pace of new information presents access barriers when these materials do not follow accessibility standards for those who require alternate formats by screen reader, captioning, or in American Sign Language. Disability organizations ensure that this critical information is accessible. If you are having trouble accessing information in your community, demand that those who release information make it accessible.

Accessibility of telework platforms

Many organizations and workplaces are using various popular technologies for telework. Each one has different strengths and weaknesses in terms of accessibility features and compatibility. If you previously used these services, it can be frustrating to experience lags and slow response times due to the recent rapid increase of users. If your employer or affiliated organization is providing information or using a tool that is not accessible to you, demand that they make it so. Depending on the nature of your issue, you may rely on your local P&A or state center for independent living to help you advocate for yourself.

Disability-specific COVID-19 resources

- Access Living: COVID-19 Resources for the Disability Community (<https://www.accessliving.org/our-services/covid-19-resources-for-the-disability-community/>)
- Administration for Community Living COVID-19 Resource Page (<https://acl.gov/COVID-19>)
- CDC COVID-19 Resource: Groups at Higher Risk for Severe Illness (PDF, 491KB) (<https://www.cdc.gov/coronavirus/2019-ncov/downloads/community-mitigation-strategy.pdf>)

Plain language information on COVID-19

- Contra Costa Health Services: COVID-19 Information by and for People with Disabilities (<https://cchealth.org/coronavirus/pdf/COVID19-Info-for-People-with-Disabilities.pdf>)

If you require the use of personal care attendants

- Center for Disability Rights: Action Steps for Attendant Service Users in Response to Coronavirus Disease 2019 (COVID-19) (<http://cdrnys.org/blog/programs-services/action-steps-for-attendant-service-users-in-response-to-coronavirus-disease-2019-covid-19/>)

Information about COVID-19 in American Sign Language

- CSD: Information for the Deaf Community about COVID-19/Coronavirus (<https://www.csd.org/coronavirus/>)
- Health Signs Center COVID-19 Resource Page (<https://www.healthsignscenter.org/covid-19>)
- National Association for the Deaf: Communicating with Medical Personnel During Coronavirus (<https://www.nad.org/2020/03/28/communicating-with-medical-personnel-during-coronavirus/>)

If you rely on a guide dog or service dog

- American Foundation for the Blind: Guide Dogs, Pets, and the Coronavirus (<https://www.afb.org/blog/entry/guide-dogs-coronavirus>)

Financial information

- National Disability Institute Financial Resilience Center (<https://www.nationaldisabilityinstitute.org/financial-resilience-center/>)

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The authors have intentionally chosen to use identity-first language of "disabled people" interchangeably with person-first language of "individuals with disabilities". This reflects shifts in language use, led by the members of the disability community who prefer to refer to themselves as disabled. Section 5.4 of the American Psychological Association Publication Manual (2019) states that identity-first language can be used interchangeably with person-first language.

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