
Advocacy Strategies for Ensuring Access to Services and Healthcare for Survivors with Disabilities During COVID-19 and Beyond

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Strategies for Directly Supporting Survivors with Disabilities During COVID-19

A word about me and Dissociative Identity Disorder (DID)



Olga Trujillo sitting next to a bookshelf

Challenging our Coping Strategies

- There are strategies we employ each day to help us move through the world.
- Creating routine
- Limiting stimulation

Challenging our Coping Strategies (2)

- Managing tasks and schedules – not multitasking
- Creating predictability – knowing what to expect
- Changing Conditions that create challenges

Consequences of Change

- Stressful and disruptive
- Creates chaos
- Challenges our ability to think and relax
- Creates fear and worry

Consequences of Change (2)

- Kicks up anxiety and panic
- Leaves us feeling exhausted, unfocused, manic, caught in a loop of irritability, distrust and tension
- Makes it hard to get up and through our day
- Dissociative

What You Can Do

- Help and support regaining routine
- Be patient as we settle into routine
- Help us as we figure out how to comply with new requirements
 - Social distancing
 - Wearing masks

What You Can Do (2)

- Help us plan and create predictability at a time of great uncertainty
 - Personal care
 - Health care
 - Plans for quarantine if someone gets sick

What You Can Do (3)

- Financial
- Work
- Getting food etc.

What You Can Do (4)

- Remember we are super capable, functioning people
- We might do it differently – but we are still here
- Help and support with that in mind

What You Can Do (5)

- Support us in deciphering between what we can and cannot control
- Support us in our planning over what we can control
- Remind us that we don't have to be perfect
- Remember we will not be perfect

What You Can Do (6)

- Learn about grounding techniques
- Help us stay grounded in times of high stress, fear and anxiety

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ADVOCACY TOOLS FOR ADVOCATES AND PEOPLE WITH DISABILITIES DURING COVID-19

The COVID-19 Information Disparity

- It is critical that people with disabilities, supporters, advocates be provided with the information and resources they need to advocate for healthcare rights during this pandemic
- People with disabilities (“high risk populations,” “the most vulnerable,” people in congregate settings + nursing homes) disproportionately likely to be infected and die from COVID-19
- COVID-19 patients with disabilities are being denied medically necessary services and supports and cut off from support networks

COVID-19 Information Disparity (2)

- Nonetheless:
 - Limited information on COVID-19 that is cognitively and physically accessible to people with disabilities
 - State and local advocates often lack critical information, tools, and resources that may be utilized to defend their clients and constituents

Plain-Language Resources for Understanding COVID-19 (1)

- People with intellectual and developmental disabilities (I/DD) and other cognitive disabilities **must** understand what COVID-19 is, how it is transmitted, how to protect against it, to protect themselves
- ASAN has produced a [plain language video](#) on COVID-19



Plain-Language Resources for Understanding COVID-19 (2)

- Green Mountain Self Advocates (GMSA) and ASAN together produced a comprehensive [guide to the coronavirus pandemic](#) for self advocates
- The guide covers a diverse variety of topics, including what the coronavirus is and how to protect yourself from it, in simple language

Resources for Understanding COVID-19 for People with Disabilities

- A number of disability rights organizations have released instructive guides for the people they serve or their caregivers on COVID-19
 - [Q&A on COVID-19 and Down Syndrome](#)
 - [Wheelchair and Assistive Technology Precautions for COVID-19](#)
 - [Spina Bifida Association's COVID-19 guide](#)
- A list of guides can be found on AADMD's ["Resources" page](#)

Advocating for the Rights of People with Disabilities during COVID-19 (1)

- Remember: Your legal rights and those of your clients are not waived just because of COVID-19
 - Hospitals, public and private, are subject to Title II or Title III of the Americans with Disabilities Act (ADA)
 - Title II: Prohibits discrimination in state and local government run hospitals + clinics
 - Title III: Hospitals operated by corporations, private owners that are open to the public
 - Section 504 of the Rehabilitation Act: Hospitals and clinics run by the federal government



Advocating for the Legal Rights of People with Disabilities during COVID-19 (2)

- The ADA and Section 504 prohibit discrimination on the basis of disability in the provision of healthcare services
- Prominent disability rights attorneys have [argued](#) successfully that this prohibits hospital or state triage policies that discriminate on the basis of disability
- HHS has put out a [bulletin](#) on the civil rights of people with disabilities during the COVID-19 pandemic

Advocating for the Legal Rights of People with Disabilities during COVID-19 (3)

- The ADA and Sec. 504 also mandate that people with disabilities must be provided with effective communication
- Title III requires that priority be given to “person’s preferred method”
- You **can and should** argue this means you must be provided with sign-language interpreters, AAC, communication aides in hospitals

Advocacy Resources and Tools on COVID-19 and Legal Rights

- The Administration for Community Living (ACL) has released a [list of resources](#) people with disabilities and healthcare advocates can utilize to define and defend their rights
- The American Psychological Association's "[How disabled Americans can cope with the COVID-19 crisis](#)" page
- DREDF has released "[Know Your Rights to Medical Care: COVID-19](#)" one-pagers

Reasonable Accommodations and Supporters in Hospitals

- People with disabilities have the right to the reasonable accommodations they need to receive the same quality of care as people without disabilities
- Nonetheless, personal care assistants and supporters have reportedly been denied access to their COVID-19 positive clients in hospitals
- The following best practices (“advocacy steps”) and resources will assist you in obtaining these necessary services



Advocacy Step 1: Convey Information on Needs in Medical Settings

- Sometimes the disabled person merely requires a clear-cut way of stating that their supporters and/or reasonable accommodations are medically necessary services
- GMSA's [Self Advocate's Guide to the Coronavirus](#) contains a [plain language Medical Information Form](#) which a PWD can fill out
- Stony Brook University created a form that people with disabilities can fill out that describes their support needs in hospitals, [customized by state](#)
- The Illinois Council on Developmental Disabilities' [My Health Passport](#)

Advocacy Step 2: Requesting A Change in Hospital Policy

- If a request for reasonable accommodations does not work, people with disabilities and their advocates may need to request and justify a change in hospital policy
- GMSA's [Self Advocate's Guide to the Coronavirus](#) contains a template letter that people with disabilities can submit to hospital staff or directors to request a policy change
- It may be useful to show them the opinions of prominent provider organizations on the subject,
 - AADMD's [policy brief](#) on the rationale for revising hospital "No Visitors" policies for COVID-19 patients

Advocacy Step 3: Collaborate with Disability Rights Organizations

- ASAN and many other organizations on CCD have released letters to [governors](#) and [hospital administrators](#) detailing the legal and public policy rationale for allowing reasonable modifications to hospital policies
- Reach out to these organizations to request advice and use their policy briefs to make legal arguments that access to reasonable accommodations is mandatory under federal law
- Reach out to [Protection and Advocacy \(P&A\)](#) and [Legal Aid](#) organizations in your state

Access to Government Benefits During the COVID-19 Pandemic

- Many people with disabilities and their caregivers and supporters have been concerned that they will be unable to access government funded LTSS during the COVID-19 pandemic, or unable to receive their stimulus checks due to their receipt of Social Security
- GMSA's plain language resource has advice on both what to do [concerning LTSS](#), the [stimulus checks](#), and how to get [unemployment benefits](#) if you have recently become unemployed
- When advocating on this issue: The Center for Public Representation (CPR)'s COVID-19 page contains information on legislation, public policy, opposition to waivers of Medicaid-funded services, and ways to get involved

Always Remember: During the Worst
of Times People with Disabilities Have
Rights, and They're Worth Fighting
For

Questions?

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