

Accompanying Your Loved one with an Intellectual or Developmental Disability (IDD) at the Hospital During the COVID-19 Crisis



For many families, their loved ones with I/DD need assistance to communicate their needs in healthcare situations. Some need help to feel comfortable in medical environments. During the COVID-19 pandemic most hospitals do not permit companions inside hospitals with patients. This resource provides important information that supports families in this situation.

On April 3, 2020, several advocacy organizations, including The Arc U.S., issued a document titled, Applying the U.S. HHS's Guidance for States and Health Care Providers On Avoiding Disability-Based Discrimination In Treatment Rationing. Based on the March 28, 2020, U.S. Department of Health and Human Services BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19) (<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>), document, it says:

The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

OCR remains in close coordination with federal partners to help ensure that the Nation's response effectively addresses the needs of at-risk populations. To this end and as resources allow, government officials, **health care providers**, and covered entities **should not overlook their obligations under federal civil rights laws to help ensure** all segments of the community are served by:

- **Providing effective communication with individuals** who are deaf, hard of hearing, blind, have low vision, or **have speech disabilities through the use of qualified interpreters, picture boards, and other means**
- Providing meaningful access to programs and information to individuals with **limited English proficiency through the use of qualified interpreters and through other means**
- **Making emergency messaging available in plain language and in languages prevalent in the affected area(s) and in multiple formats**, such as audio, large print, and captioning, and ensuring that websites providing emergency-related information are accessible
- **Addressing the needs of individuals with disabilities**, including individuals with mobility impairments, individuals who use assistive devices, auxiliary aids, or durable medical equipment, individuals with **impaired sensory, manual, and speaking skills**, and individuals with immunosuppressed conditions including HIV/AIDS in emergency planning

Comments to help explain the language in the Bulletin:

- Providing effective communication to individuals with disabilities who are patients or family members of patients is critical to ensuring compliance with federal law. **Without effective communication, the patient's autonomy and ability to participate in their care is taken away** and doctors risk substituting misplaced assumptions and biases about the individual with a disability in place of verifiable information and medical history.
- **Providing effective communication to patients is critical and must not be overlooked during this pandemic.** Without providing effective communication, it is impossible to **avoid discrimination against patients with disabilities and/or their family members.**
- **If the individual requires an accommodation that involves the presence of a family member, personal care assistant, communicator, or similar disability service provider, knowledgeable about the management of their care and/or able to assist them with communicating their needs, to assist them during their hospitalization, this should be allowed provided that proper precautions can reasonably be taken to contain the spread of infection.**
- Central in providing care to all individuals with disabilities, **medical and human services providers must ensure the full participation of the individual and/or a family member, guardian, or care coordinator in the decision-making process, consistent with normative practice.** This is the fundamental right of any individual receiving medical or human service care. The exercise of this right must be reasserted, especially during this public health emergency, which is fluid with uncertainty. This right to participate in the decisions related to one's own care must represent the solid ground that people can stand on.

This all comes together to mean that reasonable modifications, accommodations, or additional services due to disability must be made when needed for a person with a disability to have equal opportunity to access to and benefit from treatment.

If you find yourself at a hospital and denied the ability to participate in your loved one's care, contact Disability Rights Tennessee (800/342-1660) or you can also reach out to The Arc's Director of Legal Advocacy, Shira Wakschlag (wakschlag@thearc.org).

This resource was created by The Arc Tennessee. For more information contact Loria Hubbard, Director of Programs at, lhubbard@thearctn.org or 615/248-5878 X28.

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