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**April 9, 2020**

**TO: Hospital and Medical Personnel**

**Allowing Family Caregivers and Direct Support Professionals to Accompany People with Intellectual/Developmental Disabilities into a Hospital or Acute Care Setting**

During this time of unprecedented crisis, medically fragile populations are at increased risk for contracting an illness that can require time spent in a hospital or an acute care setting. In this situation, there are two issues that are of utmost importance.

1. We must ensure that people with intellectual/developmental disabilities (I/DD) are allowed to have their parent/family caregiver or direct support professional (DSP) with them while in a hospital or acute care setting.
2. People with I/DD must have access to medical equipment.

On April 3, 2020 several advocacy organizations, including The Arc of the United States, issued a document titled *Applying the US HHS's Guidance for States and Health Care Providers On Avoiding Disability-Based Discrimination In Treatment Rationing*. Based on the March 28, 2020, US 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.”

*(Continued)*

To this end and as resources allow, government officials, healthcare 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 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."

We ask that you refer to [Section 4111 of the federal CARES Act \(S. 3548\)](#). It authorizes I/DD direct support professionals to accompany clients on acute care hospital visits.

The Arc of North Carolina is committed to advocating for the people we serve and their families. We feel that these rights must be upheld to ensure the safety and treatment of people with I/DD.

Sincerely,

John Nash  
Executive Director, The Arc of North Carolina