Joint Position Statement on the Right to Equal Access to Medical Treatment

In the context of the COVID-19 crisis, the undersigned organizations agree and strongly endorse the message that the presence of intellectual and developmental disabilities, including those with the most significant disabilities, should not be an indicator for withholding or limiting access to medical care. We recognize that this population is particularly vulnerable to limited access to healthcare and experiences increased risk for isolation and lack of timely, accessible information regarding healthcare. In recent days, we have grown increasingly concerned with the information provided regarding the healthcare treatment guidelines published related to the COVID-19 outbreak (Cha, 2020; Mounk, 2020). These guidelines pave the way for increased discrimination toward individuals with disabilities and older individuals who have contracted COVID-19.

We assert that individuals with intellectual and developmental disabilities, including those with significant disabilities, have the following human and civil rights:

- Access to high-quality, appropriate medical treatment
- Access to timely and accurate information in accessible formats (e.g., plain text, visuals, plain language)
- Access to supports and support persons to address the individual’s unique support needs related to social/emotional, communication, physical, and healthcare aspects.
- Access to supported decision making (see below resource on describing supported decision making) and representation during any emergency guardianship or conservatorship proceedings

In addition to the above rights, people with intellectual and developmental disabilities, including those with the most significant support needs, have the right to practice self-determination and live with maximum autonomy according to their unique abilities. More than ever, there is a critical need to provide individuals with intellectual and developmental disabilities access to support persons of their choice and individualized services, including creative accommodations, as they access healthcare. We encourage healthcare providers to be mindful about promoting physical distancing without limiting opportunities for people with intellectual and developmental disabilities to benefit from social support networks.

We advise against actions concerning medical treatment that perpetuate ageism and ableism. There is a long history of unethical practices, including eugenics and institutionalization, which has led to the dehumanization, disenfranchisement, and devaluation of the lives of individuals with disabilities. These practices have occurred in particular around access to resources and information. It is our responsibility to ensure we do not return to these unethical practices and ensure the humanity of all individuals is maintained.

Respectfully,

(signed organizations)
Resources on Plain Language Information and Supported Decision-Making

Plain Language Information on COVID-19 (in Spanish with pictures (text only version) and English with pictures (text only version))

What is Self-Advocacy?

Using Plain Language

Supported Decision Making

Thinking Ahead (planning for care) resource

National Resource Center on Supported Decision-Making

Supported Decision-Making FAQs

References:
