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,

TASH
Spina Bifida Association
Autistic Self Advocacy Network
United Cerebral Palsy National
Georgia Advocacy Office
American Association of People with Disabilities
United States International Council on Disabilities
Disability Awareness
The Arc of the United States
Ohio TASH
Missouri TASH
Ohio Safeguards, Inc
Good Life Networks
Total Living Concept, Kent, Washington
Institute on Disabilities, Temple University
Marbridge Foundation
abicommunity.org
Cal-TASH
IGNITE Collective, Inc.
Autism Society of America
Disability Rights Vermont, Inc.
Famly and Advocate
New Directions for Maine Families
Autism Society Of Southern Illinois
Illinois Council on Developmental Disabilities
The Learning Community
Support Development Associates
Illinois Parents of Adults with Developmental Disabilities Unite
Vision for Equality, Inc.
Institute on Disability and Human Development, University of Illinois at Chicago
Arizona TASH
West Philadelphia Parent Support Group
Shared Support Maryland, Inc.
PA Families Need Nurses Now
Center for Public Representation
Illinois TASH Chapter
Disability Rights International
The Fund for Community Reparations for Autistic People of Color's Interdependence, Survival, and Empowerment
Thomas' Supports, Inc.
KFI
Bridges of Indiana
The Alliance for Citizen Directed Supports
The Collaborative for Citizen Directed Supports-New Jersey
Values Into Action
Autistic Women & Nonbinary Network
Down Syndrome Connection of the Bay Area
Down Syndrome Connection of the Bay Area
Physicians for a National Health Program
The College of New Jersey
The Arc Wisconsin
Wisconsin Board for People with Developmental Disabilities
The Arc of New Mexico
The Arc Georgia
HIGH IMPACT Mission-based Consulting & Training
Center for Outcome Analysis
Pennhurst Memorial & Preservation Alliance
Maryland Developmental Disabilities Council
Virginia Board for People with Disabilities
Lester and Rosalie Anixter Center
The Arc of Ohio
Syntiro
Rhode Island Developmental Disabilities Council
Equip for Equality
Volunteers of America Mid States
University of Central Florida
The Arc New York
National Disability Rights Network
KY-TASH
Iowa Developmental Disabilities Council
Kansas Council on Developmental Disabilities
Self-Directed Advocacy Network of Maryland, Inc.
National Council on Independent Living
Pennhurst Memorial and Preservation Alliance
New Jersey Council on Developmental Disabilities
The Arc Maryland, Inc.
The Arc of Delaware
The Arc in Hawaii
Sibling Leadership Network
The Arc of Illinois
Governor's Council on Disabilities and Special Education
Disability Rights Pennsylvania
Family Voices NJ
SPAN
NJ Family Voices
Garden Center Services
Disability Law Center of Alaska
Idaho Council in Developmental Disabilities
Washington State Developmental Disabilities Council
Lutheran Family Services of Virginia
The Arc of Illinois
Ga Parent Mentor Partnership
Maryland Center for Developmental Disabilities
Speaking for Ourselves
Green Mountain Self-Advocates
AUCD
Autism National Committee (AutCom)
Lesley University
Self-Advocates Becoming Empowered (SABE)
Diversified Enterprises, DBA Tift Co. Bd. of Health
The Community of Exceptional Artists
Indiana Governor’s Council for People with Disabilities
Brain Injury Association of Maryland
Disability Rights Maryland
NAMI Maryland
The Freedom Center
The Arc, Jefferson, Clear Creek & Gilpin Counties
TASH New England
Self Advocates United as 1, Inc.
Pennhurst Memorial and Preservation Alliance
California State Council on Developmental Disabilities
Missouri TASH
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:
