



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

May 8, 2020

Dear Governor,

The undersigned members of the Consortium for Citizens with Disabilities (CCD) and allies write to ask you to ensure that hospital and other healthcare provider visitor policies include reasonable modifications for people with disabilities who need the physical presence of a support person in order to ensure equal access to health care. Although safety concerns are paramount, numerous states, including New York, have already clarified visitor policies to ensure that individuals with disabilities have access to necessary in-person supports while hospitalized. These supports will help save lives by ensuring equal access to healthcare, enhancing the safety of individuals with disabilities seeking hospital or clinic-based care, and increasing the effectiveness and efficiency of health care staff.

The current COVID-19 crisis has resulted in dramatic changes to hospital and healthcare office policies and protocols. To help curb the spread of COVID-19, hospitals and healthcare offices have dramatically restricted the presence of visitors. These policies pose serious challenges to individuals with disabilities who rely on in-person supports both in and out of the hospital, including but not limited to:

- Deaf and Deafblind patients, especially those who cannot benefit from video relay interpretation
- Patients with mobility impairments
- Patients who need in-person communication supports
- Patients with psychosocial, intellectual, developmental, or cognitive disabilities who rely on in-person supports for orientation, anxiety management, and assistance with making decisions

The Americans with Disabilities Act (ADA) and Rehabilitation Act (Rehab Act) protect patients with disabilities. As the Department of Health and Human Services' Office of Civil Rights has clarified,¹ these laws remain in effect during the current crisis. Hospitals and doctor's offices must continue to make reasonable accommodations and modifications to policies where necessary to ensure that people with disabilities enjoy an equal benefit as that offered to others.² In addition, the CARES Act permits Medicaid

¹ Department of Health and Human Services (HHS) Office for *Civil Rights, Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease (COVID-19)*, 1-3 (Mar. 28, 2020) https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt_0asYiXi91XW4rnAKW8kxcog.

² Americans with Disabilities Act, 42 U.S.C. §12132 (prohibition against discrimination in Title II of the ADA); 42 U.S.C. §12182 (Title III); 28 C.F.R. § 35.130 (regulations implementing Title II of the ADA); 28 C.F.R. 28 C.F.R. §36.201 (regulations implementing Title III of the ADA).

to pay for home and community-based supports and services, such as a personal care attendant, during an acute hospital stay.³

Hospitals and health clinics have already recognized that, in limited circumstances, it is both possible and necessary to allow patients to be accompanied by a support person who follows appropriate safety protocols. For example, hospitals typically permit minors to be accompanied by a parent, permit individuals in labor to be accompanied by a supporter, and permit a visitor to accompany a patient at the end of life.⁴

In light of the accommodations health providers are already making for classes of patients such as minors, people in labor, and people at the end of life, making an additional limited exception to the visitor policy for individuals with disabilities would be a reasonable modification.

In fact, permitting people with disabilities to be accompanied by supporters would greatly improve the safety of people with disabilities. Patients who cannot effectively communicate with doctors may not receive the healthcare they need. Patients who are confused, disoriented, or panicked may find themselves unable to benefit from healthcare services and may not be able to follow counter-infection protocols without the in-person support of a trusted person. Patients who rely on the assistance of a personal care attendant (PCA) or family member for activities of daily living would be safer receiving these potentially intimate services from someone who has already been in close contact with them rather than from a hospital nurse or technician, who may have been exposed to COVID-19.

In recognition of the ADA, Rehab Act, and the practical benefits of making reasonable accommodations to visitor policies, other states and localities have already issued policies clarifying that people with disabilities can bring supporters:

- On April 10, 2020, New York State released guidance titled “Health Advisory:COVID-19 Updated Guidance for Hospital Operators Regarding Visitation,” clarifying that hospitals must permit a support person to accompany a patient “for whom a support person has been determined to be essential to the care of the patient (medically necessary) including patients with intellectual and/or developmental disabilities and patients with cognitive impairments including dementia.”⁵
- On April 11, 2020, Oregon released revised guidance clarifying that hospitals may permit visitation by “essential individuals” including “health care interpreters” and “[g]uardians or

³ Coronavirus Aid, Relief, and Economic Security Act (“CARES Act”), Pub. L. 116-136 (2020), Title IV, Sec. 4411.

⁴ See, e.g., GBMC Healthcare, “Visitor Policy Changes,” available at <https://www.gbmc.org/policy> (last accessed April 20, 2020) (permitting visitors for end-of-life care, pediatric patients, patients in the labor and delivery unit, and patients undergoing emergency surgery, among other exceptions); George Washington University Hospital, “Health Alert,” available at <https://www.gwhospital.com/health-alert> (last accessed April 20, 2020) (restricting visitors to end-of-life care, labor and delivery, and guardians of pediatric patients).

⁵ New York Dep’t of Health, “Health Advisory:COVID-19 Updated Guidance for Hospital Operators Regarding Visitation,” available at https://coronavirus.health.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_041020-002.pdf (last accessed April 20, 2020).

caregivers of patients with altered mental status or intellectual disabilities if in-person visitation is necessary to [f]acilitate treatment” or “[e]nsure the safety of the patient or facility staff.”⁶

- On April 10, 2020, Illinois issued guidance on the application of disability rights laws to hospital policies, including a statement that persons with disabilities are entitled to reasonable accommodations such as “interpreter services or the presence of an assistant, aide, or family member, provided that essential precautions can be taken to contain the spread of infection.”⁷
- The American Academy of Developmental Medicine and Dentistry has issued a policy statement urging hospitals to permit patients with intellectual and developmental disabilities to be accompanied by a support person.⁸

Although each of these policies has strengths and weaknesses, they demonstrate the feasibility and importance of ensuring that people with disabilities receive the supports they need while hospitalized. We urge you to follow the lead of these institutions by adopting a policy that:

- 1) mandates, and does not merely permit, that supporters be allowed to accompany a person with a disability, to the maximum extent possible;
- 2) is inclusive of all people with disabilities for whom a support person is necessary, rather than limiting visitors to only one category of people with disabilities;
- 3) applies to all areas of the hospital where other visitor policy exceptions (such as exceptions for parents of minors) permit visitors to go; and
- 4) includes a detailed discussion of steps taken to prevent the spread of coronavirus, such as requiring supporters to wear masks or face shields, restricting supporters to the room where the patient is located, screening supporters for signs of illness, and mandating careful hand hygiene. To the extent possible, supporters of people with disabilities should be provided with PPE at least to the same extent as supporters of other patients, such as minors or people in labor.

⁶ Oregon Health Authority, “REVISED COVID-19 Guidance for Entry into Acute Health Care Facilities: April 11, 2020,” available at <https://sharedsystems.dhsosha.state.or.us/DHSForms/Served/1e2282.pdf> (last accessed April 20, 2020).

⁷ Illinois Dep’t of Public Health, Illinois Dep’t of Human Svcs., Illinois Dep’t of Human Rights, & Illinois Office of the Governor, “Guidance Relating to Non-Discrimination in Medical Treatment for Novel Coronavirus 2019 (COVID-19)” (April 10, 2020), available at <https://coronavirus.illinois.gov/sfc/servlet.shepherd/document/download/069t000000AioFZAA3?operationContext=SI> (last accessed April 20, 2020).

⁸ American Academy of Developmental Medicine and Dentistry, Committee on Public Policy and Advocacy, “Hospitalized Patients & Designated Support Staff Policy Statement: Providing hospitalized patients with Intellectual and Developmental Disabilities (IDD) with Designated Support Staff During the COVID19 Pandemic: Rationale for Revised Visitor’s Policy” (April 2020), available at <https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5e9e1cbefc832d0a6866fed4/1587420352080/Visitation-PolicyStatement.pdf>.

We appreciate your attention to this matter. For more information or for further questions, please do not hesitate to contact Sam Crane, scrane@autisticadvocacy.org or Jennifer Mathis, jenniferm@bazelon.org.

Sincerely,

National Organizations

American Academy of Developmental Medicine and Dentistry
American Association of People with Disabilities
American Board of Developmental Medicine
American Council of the Blind
American Network of Community Options & Resources (ANCOR)
American Occupational Therapy Association
American Physical Therapy Association
The Arc of the United States
Association of Programs for Rural Independent Living
Association of University Centers on Disabilities (AUCD)
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Center for Public Representation
Christopher & Dana Reeve Foundation
Coalition for Disability Health Equity
CommunicationFIRST
Council of State Administrators of Vocational Rehabilitation
Disability Rights Education & Defense Fund (DREDF)
Diverse Disability Media
Easterseals
Fund for Community Reparations for Autistic People of Color's Interdependence, Survival, and Empowerment
Epilepsy Foundation
Justice in Aging
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Center for Parent Leadership, Advocacy, & Community Empowerment (National PLACE)
National Council of State Agencies for the Blind
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Down Syndrome Society
Partnership for Inclusive Disaster Strategies
RespectAbility

United States International Council on Disabilities
World Institute on Disability
WITH Foundation

State and Local Organizations

ADAPT Montana
ADAPT of Texas
Alabama Council on Developmental Disabilities
ALL Self Advocacy Group (North Dakota)
Aloha Independent Living Hawaii
The Advocacy Institute
The Arc Maryland
The Arc Michigan
The Arc Minnesota
The Arc of Anchorage
The Arc of Arizona
The Arc of California
The Arc of Colorado
The Arc of Delaware
The Arc of Illinois
The Arc of Massachusetts
The Arc of Maui County
The Arc of Nebraska
The Arc of New Mexico
The Arc of North Carolina
The Arc of Oregon
The Arc Rhode Island Family Advocacy Network
The Arc of South Carolina
The Arc of Virginia
The Arc of Washington State
The Arc of Washington State
The Arc Wisconsin
California Down Syndrome Advocacy Coalition
California State Council on Developmental Disabilities
California State Independent Living Council
Chesapeake Down Syndrome Parent Group (Baltimore, MD)
The Coelho Center for Disability Law, Policy and Innovation
Colorado Cross-Disability Coalition

Colorado Developmental Disabilities Council
Commonwealth Council on Developmental Disabilities Kentucky
Connecticut Council on Developmental Disabilities
DC Special Kids
Democratic Disability Caucus of Florida
Designer Genes of North Dakota, Inc.
Disability Rights Tennessee
Down Syndrome Association of Connecticut
Down Syndrome Association of Greater Charlotte
Down Syndrome Association of Greater Cincinnati
Down Syndrome Association of Middle TN (DSAMT)
Down Syndrome Awareness Group of East Tennessee
Down Syndrome Connection of the Bay Area
Down Syndrome Guild of Greater Kansas City
Down Syndrome Indiana
El Paso Desert ADAPT
Family Voices of CA
Full Life Hawaii
Fuller Lives (HI)
Grupo D.I.O. Dignidad, Igualdad, Oportunidad (El Paso, TX)
Gulf Coast ADAPT
Hawaii Family Caregiver Coalition
Hawaii Self-Advocacy Advisory Council
Hawaii State Council on Developmental Disabilities
Hawaii State Self-Advocacy Advisory Council
Hawaii Youth Services Network
Heart to Heart Parent Consulting
Idaho Council on Developmental Disabilities
Keiki Education Living Independent Institute (HI)
Kenfield|Shreve Consulting
Massachusetts Developmental Disabilities Council
Massachusetts Down Syndrome Congress
Missouri Association of Counties Developmental Disabilities Services
Missouri Governor's Council on Disability
Missouri Developmental Disabilities Council (MODDC)
Nebraska Consortium for Citizens with Disabilities (NCCD)
Nebraska Council on Developmental Disabilities
NH Council on Developmental Disabilities
North Dakota State Council on Developmental Disabilities
Northwest Iowa Down Syndrome Society
Personal Attendant Coalition of Texas
San Antonio ADAPT
Service Center for Independent Life

South Dakota Council on Developmental Disabilities
Tennessee Council on Developmental Disabilities
The California Foundation for Independent Living Centers
Tri-County Independent Living
Utah Developmental Disabilities Council
Virginia Board for People with Disabilities
Washington State Developmental Disabilities Council
Wisconsin Board for People with Developmental Disabilities