



April 2, 2020

Honorable Douglas James Burgum, Governor, State of North Dakota
Ms. Mylynn Tufts, State Health Officer, North Dakota Department of Health
Mr. Christopher D. Jones, Executive Director, North Dakota Department of Human Services

Re: Securing the Civil Rights and Applying Best Practices in the Provision of Health and Human Services to Individuals with Disabilities During the COVID-19 Public Health Emergency

We, the member organizations of the North Dakota Disabilities Advocacy Consortium (NDDAC), a statewide association of organizations who advocate for public policies that support people with disabilities across the lifespan, write **to extend our gratitude for the leadership you are providing to the state at this critical time and to offer our assistance in proposing, for your consideration and adoption, a series of recommendations to guide medical and human services providers in securing the civil rights and providing the most appropriate services to individuals with disabilities, who deserve and require appropriate consideration for their unique needs.**

Assessing Our Current Need for Clear Guidance

The state of North Dakota is currently facing an unprecedented challenge in monitoring and protecting the health and welfare of all its residents, without standing, during this current public health emergency, including the appropriate consideration and care for all individuals with disabilities across the lifespan. The state's many public and private health and human service agencies, organizations, and providers are being asked to prepare for and respond to emerging needs based on the most current best-practices guidelines issued by recognized public and professional authorities, including the North Dakota Department of Health, the North Dakota Department of Human Services, and the various state agencies responsible for serving the needs of individuals with disabilities.

We submit this petition mindful of the state's efforts to secure quality services to individuals with disabilities, which have been evolving over time. Yet, we are also cognizant of disturbing instances emerging among certain states to employ draconian measures related to the potential rationing of health services based on disability status. The use of information about a person's disability in limiting or rationing their services, supplies, or equipment poses great peril to our society's values of fundamental human rights. Such measures reveal a callous disregard for and bias against individuals with disabilities that cannot be condoned and must be safeguarded from occurring within our state. A March 28, 2020, directive from the U.S. Department of Health and Human Services, Office of Civil Rights (<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>) has reasserted the unbending civil rights that must be accorded to individuals with disabilities, especially in light of the current public health emergency, as enacted within Section 1557 of the Affordable Care Act, Section 504 of the Rehabilitation

Act, and the Americans with Disabilities Act. These efforts to promote and protect the human rights of individuals with disabilities has extended into related legal and policy developments, including the Olmstead Decision, Medicaid Home and Community Based Services (HCBS) waiver programs, the HCBS Rule, among others. The equal value of all persons exists without regard to their status as respect to disabilities (<https://dredf.org/the-illegality-of-medical-rationing-on-the-basis-of-disability/>). These legally secured rights stand as an unbending testament of our nation's and state's commitment to recognize and protect the integrity of every human being, regardless of standing, even during—and especially during—a public health emergency, such as we are experiencing.

We are grateful to you for any time and attention you have offered to us during these early days, as we, as a state, have begun to assess and understand the scope and magnitude of the situation that lies before us. **We extend to you our full commitment to partner with you in providing best-practice guidelines that will aid our state's medical and human services providers.** Our service providers need and are entitled to receive the best guidance we can provide them during this difficult time. Our service providers' responsibilities are great, and we must support them. The guidelines we provide to our medical and human services providers must clearly communicate the paramount need to elevate and secure the human and civil rights of equality, self-determination, and true belonging in our community.

We respectfully request that the recommendations provided herein be considered, adopted, and disseminated to the state's many health and human services providers, to those public agencies that similarly service the needs of individuals with disabilities, and to the wider public. During this public health emergency, we cannot afford to lessen our concern for any individual. We cannot leave anyone behind. We must stand as one community, where every member is recognized, honored, and protected.

Safeguarding Processes that Secure Each Person's Civil Rights and Participation

We request that the state, through the uniform actions of its various agencies, provide clear and decisive guidance to reaffirm the civil rights of all individuals, including individuals with disabilities, and to eliminate any practices that might implicitly influence or bias what should otherwise be fair, appropriate medical and human service decisions. The state's guidance should assist medical and human service professionals, who may encounter difficult decision-points during times of stress, in discerning options and making decisions that are consistent with established person-centered principles and practices. Whether addressing emergency response, public health practices, or restructuring rules and regulations, we must balance what is essential *to* the individual with what is essential *for* the individual.

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.

The disability community is a broad, inclusive community of individuals, covering a broad range of unique life experiences and who range from infants to older adults, who are well positioned to provide assistance to the state and its various agencies regarding the provision of appropriate care. We, the member organizations of NDDAC, offer our services and insights to assist the state in securing the integrity of this process, during this challenging period.

If the state of the COVID-19 emergency in ND demands the establishment of emergency triage treatment protocol which assesses an individual's ability to survive and/or benefit from treatment, we urge you to convene an emergency task force to develop the protocol and include members from the North Dakota Disability Advocacy Consortium to provide technical assistance on supporting individuals with disabilities across the lifespan during this time.

Recommendations for Adoption and Implementation

To this end, we urge strong consideration and implementation of the following recommendations, applicable to individuals of all ages, during the COVID-19 outbreak:

Process Considerations-

- Hospitals and clinics can accommodate patients with disabilities by ensuring that COVID-19 treatment policies, such as those limiting hospital admittance, explicitly allow for the reasonable modifications and exceptions needed by people with various disabilities and of all ages.
- Many medical models consider someone's diagnosis that constitutes a disability as making them unhealthy. It should be recognized that other developmental and/or psycho-social models, see a person's diagnosis as being a valued part of who they are. Consider a broader scope of understanding in developing any protocols for treatment triage.
- In developing and implementing protocols, focus on intentional strategies to avoid judgements about quality of life. Without this attention to one's own values, biases, and perspectives, it will be easy to violate the rights of individuals based on disability, income, race, gender identity, age, and more.
- Case Management entities should be focused on creating emergency plans with consumers, in the event of either the individual with a disability and/or the caregiver becomes ill. Upon admittance to a hospital social work staff need to assess whether a plan is in place and work with individuals and family members to create one if one has not been completed.
- Avoiding hospitalization for individuals with disabilities is the most optimal outcome. Ensuring that supplies, including Personal Protection Equipment, and protocols are in place for their caregivers should be considered as essential.

Assurances-

- We want to ensure that individuals with disabilities living in home and community based residential settings as well as institutional settings have assurances that they will not lose their "homes" because of any type of medical crisis. Every effort should be made to ensure an individual's ability to return to their "home" after a hospitalization. State and provider policies should support this effort.

- Any changes that will affect an individual’s ability to remain in their “home”, should be subject to a team review, including the individual, individual’s spouse, individual’s parent, guardian, caregiver, and/or other family member.
- Any procedures developed should focus on using preventive and positive behavioral supports for individuals who are displaying undesired behaviors.
 - Recognize that all behavior is communication and work to understand why the behavior is happening. Choose to understand before implementing extreme measures that psychotropic controls and/or restraint.
 - Support your communication with the individual through picture symbols, clearer and broken information, sign language, or through a person who has established a relationship with the individual.
 - Note signs of agitation and back off from an intervention prior to having the individual escalate into a full-blown incident.
 - Use child life specialists and adult behavioral health professionals to support individuals with disabilities.

Visitation-

- We are asking that individuals’ need for advocacy and communication are a consideration in creating visitation policies in their home and community based residential settings, institutional settings, and if needing to be hospitalized. This is especially true for children and older adults who are at risk and vulnerable with special health care needs and/or complex conditions.
 - We recommend flexible policies on making decisions who may accompany an individual with disability during a hospitalization or restrictions in a facility. This allows for the facility to make decisions that are in the best interest of the individual.
 - Consider the delicate balance between keeping people physically safe and healthy and their social-emotional status due to isolation.
 - If a “no visitor” rule is being strictly enforced, create procedure that identifies individuals who need more focused patient advocacy, social work, and/or ombudsman attention. Use these tools to assure that spouses/caregivers/parents/guardians/family members have a single point of contact for two-way communication purposes, including virtual communication with the individual hospitalized.

- We recommend that the restriction be reviewed periodically - at least every two weeks to ensure that it remains both necessary and is the least restrictive means for ensuring health and safety.

Communication and Accessibility-

- In all instances, allow and ensure that effective communication tools are provided through qualified interpreters, picture boards, and other augmentative means for individuals who are deaf, hard of hearing, blind, visually impaired or who have an intellectual disability and/or have a behavioral health disorder that is supported with alternate communication tools.
- Develop emergency messaging that is available in plain language and multiple formats, such as audio, larger print, closed captioning, and visuals/pictures. Assure that any websites providing emergency-related information are compliant for accessibility purposes.

Discharge and After-Care

- Ensure that upon discharge from a hospitalization, that an individual is able to leave with the equipment, supplies, medications, and/or durable medical equipment that they were admitted with, including personally owned ventilators.

The NDDAC extends its support to you for your leadership during this public health emergency. We respectfully request your consideration to adopt and implement these recommendations in support of the many North Dakotans with disabilities across the lifespan who will benefit from and find comfort in these measures. We offer our best efforts in providing additional counsel on any aspects of this request or of other challenges that the state may encounter as we wade through these turbulent waters. We stand ready to assist you.

Sincerely,

Julie Horntvedt, Chairperson
North Dakota Disabilities Advocacy Consortium

Member Organizations:

Advocates Leading their Lives
Designer Genes of ND, Inc.
Family Voices of North Dakota
Mental Health Advocacy Network
Mental Health America of North Dakota
Minot Housing Authority
ND Assistive
North Dakota Association of the Blind
North Dakota Association of Community Providers
North Dakota Association for Persons in Supported Employment

North Dakota Consumer Family Network
North Dakota Federation of Families for Children’s Mental Health
North Dakota Protection and Advocacy Project
North Dakota State Council on Developmental Disabilities
The Arc of North Dakota