

Connecticut Cross Disability Lifespan Alliance

March 25, 2020

The Honorable Governor Ned Lamont
State Capitol
210 Capitol Avenue
Hartford, CT 06106

Re: People with Disabilities During COVID-19 Pandemic & CT's Call To Action

Dear Governor Lamont:

One in four adults in the US has a disability. Globally, well over 1 billion people have disabilities. Children and adults with disabilities and older adults are 2-4 times more likely to be injured or die in a disaster due to a lack of planning, accessibility, and accommodation. As of 2015, 390,600 Connecticut residents had one or more disabilities. Most people with disabilities are not inherently at a greater risk for contracting COVID-19, despite misperception that all people with disabilities have acute medical problems. However, Connecticut residents with disabilities and chronic health conditions are experiencing escalating fear and anxiety, on top of any physical effects of viral illness. We ask for your continued leadership to communicate and ensure that Connecticut will protect the rights and access of people with disabilities.

The attached ***Connecticut Call To Action***, signed by ----disability organizations and advocates, outlines the critical areas that need to be addressed for people with disabilities in Connecticut. People with disabilities require the same resources and assistance that everyone does – adequate information and instructions, social and medical services, and protection from infection by those who have contracted the virus. However, some peoples with disabilities may have needs that warrant specific steps by the public and private sectors that may not be necessary for others. Below we set out some particular areas where these steps are necessary but do not appear to be addressed by current strategies. We urge the federal, state and local governments to address expressly each of the areas described below in their planning and response.

- **Prevent and prohibit medical “rationing” based on disability:** The prospect of shortages of medical staff and equipment for treating those made severely ill by COVID-19 has triggered discussion of “rationing” medical care. While the coronavirus crisis poses serious challenges to our social and health care systems, state and federal laws including the ADA, Section 504, Section 1557 of the ACA, prohibit any “rationing” measures by public or private entities which discriminate on the basis of disability. Denying care to disabled individuals who are likely to benefit from care is unlawful.

- **Urge state agencies to issue a directive to health plans and insurers, hospitals, and other medical providers to maintain their legal obligations:** During the coronavirus crisis, The state should take action through DPH to assure people with disabilities are not denied equal care by hospitals based purely on their disability status.

Guidance should include the following basic principles: 1.) The presence of a disability, including a significant disability, is not a permissible basis for denying people access to care or giving them a lower priority for care; 2.) The ADA and Section 504 prohibit treatment allocation decisions from being made based on the perception that people with a disability has a lower prospect of survival. While the possibility of a person's survival may receive some consideration in allocation decisions, that consideration must be based on the prospect of surviving the condition for which the treatment is designed—in this case, COVID-19—and not other disabilities. In addition, it must be based on a clear indication from the person's individual circumstances that the person is unlikely to survive or to benefit from treatment.; 3.) The fact that a person with a disability may require reasonable accommodations during treatment, or more intensive treatment, is not a permissible basis for denying care or allocating the person a lower priority for care; 4.) All medical decisions about providing care must be based on current objective medical evidence, and not based on generalized assumptions about a person's disability. Treatment decision may not be made based on misguided assumptions that people with disabilities experience a lower quality of life.

- **Ensure Access to Home-and Community-Based Services and Related Services:** Individuals with various disabilities who rely on personal care assistants face a dilemma during the COVID-19 crisis. No person with a disability should have to choose between catching a potentially deadly new virus and receiving the assistance needed to perform critical activities of daily living such as toileting, eating, dressing, and managing medications. No personal care assistant, whether paid or unpaid, should be required to perform their duties without proper protective equipment to ensure both their own well-being as well as the continued well-being of their own families and other clients with disabilities, or face the ethical dilemma of rendering necessary duties while beginning to feel sick.

The following measures are needed to preserve the well-being of people with disabilities while they shelter in place: 1.) Fund and establish backup personal care assistant (PCA) registries, for both public and private pay PCAs, and establish streamlined on-call emergency back-up alternatives to ensure PCA services when scheduled PCAs are unavailable; 2.) Provide and efficiently distribute protective gear for paid and unpaid PCAs, including family, friends, and volunteers who are providing personal attendant services; 3.) Include disability-specific providers and needs within guidance on categories of "essential business" and "essential personnel," such as public and private personal care attendants, public transit and paratransit, privately contracted Non-Emergency Medical Transportation (NEMT) providers, durable medical equipment providers/repairers, and veterinarians.

- **Ensure Legal Services and Prompt Affirmative Responses to the Potential Violations of Rights of people with disabilities in Connecticut:** Urge Connecticut to bolster financial and human resources in Connecticut’s legal service organizations to ensure that they have the capacity to provide timely representation for individuals who face unlawful medical “rationing” based on disability, any unnecessary and involuntary institutionalization, and other forms of discrimination in COVID-19 treatment and testing.

We further ask that you ensure that Connecticut and its agencies respond immediately and effectively to any reports or complaints indicating that the rights of people with disabilities are being violated. While this must include prioritization and streamlining of administrative complaint procedures at the DHCS Office of Civil Rights and other agencies, we call on the Governor and the heads of relevant agencies to respond affirmatively and forcefully to any formal or informal report.

Please make Connecticut a leader in protecting the civil rights of people with disabilities. We would welcome the opportunity to work with your administration on ensuring that people with disabilities in our state receive equal and effective healthcare during the COVID-19 crisis under the priorities detailed above.

Sincerely,

Connecticut Cross-Disability Lifespan Alliance Steering Committee

Melissa Marshall, Coordinator, Connecticut Cross-Disability Lifespan Alliance
Daria Smith, CT State Independent Living Council
Walter Glomb, CT Council on Developmental Disabilities
Kathy Flaherty, CT Legal Rights project and Keep the Promise Coalition
Michelle Duprey, City of New Haven, Department of Services for Persons with Disabilities
Gretchen Knauff, advocate
Chris Blake, advocate
Josie Torres, People First
Keith Mullinar, advocate
Mary-Ann Langton, advocate

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Commissioner Amy Porter, Aging and Disability Services
Commissioner Jordan Scheff, Department of Developmental Services
Commissioner Miriam Delphin-Rittmon, Department of Mental Health and Addiction Services
Commissioner Deidre Gifford, Department of Social Services
Commissioner Renée Coleman-Mitchell, Department of Public Health
Commissioner Joseph Giulietti, Department of Transportation
Commissioner Rollin Cook, Department of Correction