

Testimony before the Joint Assembly Committees of
Aging and Senior Services and Military and Veterans Affairs
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Thank you, Chairwoman Vainieri Huttle, Chairwoman Tucker, and members of the committee for your invitation to speak here today about the COVID-19 public health emergency and long-term care in New Jersey. I speak today on behalf of individuals with disabilities and am appreciative that the Committees included their voices in this conversation.

Disability Rights NJ is the federally funded, designated protection and advocacy system for people with disabilities in the State of New Jersey. Under our federal enabling statutes, we provide legal representation, advocacy, education and training, and information and referral to people with disabilities, their families, and the professionals who serve them. Created in 1975 by Congress in response to a series of investigative reports which exposed abuse and neglect at a New York state institution for individuals with developmental disabilities, a core function of protection and advocacy agencies including Disability Rights NJ is to have a regular, ongoing presence in facilities where individuals receive services, and to investigate incidents of abuse and neglect. Our jurisdiction includes nursing homes.

Disability Rights NJ's COVID-19 advocacy has been all-encompassing since mid-March; more information can be found at our COVID-19 website, which is at the top of my remarks. Today, I would like to highlight three areas of our recent work that I believe may be helpful to your

committees and the broader discussion of ensuring the health and safety of residents of institutions during public health emergencies.

1. Access to residents and facilities by Disability Rights NJ and the Long-Term Care Ombudsman must be ensured during a crisis.

An essential function of Disability Rights NJ is to be present in any setting where an individual with a disability may receive services. We are eyes and ears, collecting, verifying and analyzing information in order to ensure that human, civil and legal rights are upheld.

We knew from the outset of this public health emergency, especially when visitation at the state's institutions closed down, that we had to find a way to be present, to continue our monitoring function, to reinforce through our presence the responsibility of State and other actors.

From the start, Disability Rights NJ was in regular, weekly conversations with the Department of Human Services, Division of Developmental Disabilities regarding developmental centers, and the Department of Health, Division of Behavioral Health, regarding state psychiatric hospitals. Each week, these Divisions provided us with updates on residents and patients as well as staff who were COVID-positive, in the hospital, and tragically, who had died. State officials explained in detail the availability and use of PPE, cohorting strategies, tele-services and programming that was continuing, and later, the roll out of universal testing and results at each DC and hospital.

Early on, Disability Rights NJ stressed the importance of the public release of information regarding positive results and deaths, and we were encouraged when that information became public. Both DDD and the Department of Health also independently report to us certain deaths, so we are able to corroborate the public numbers with our private reports.

In April, we began actively monitoring at the psychiatric hospitals, first using telephone calls with patients, and later moving onto tablets. In May, we rolled out a similar virtual process in the DCs. In both cases, residents and patients are provided an opportunity to speak directly to their federal designated advocacy agency. Throughout, our contacts in the DHS and DOH have been forthcoming, transparent, and always available. Because of this, we have effectively fulfilled the role given to us under federal law in DCs and state psychiatric hospitals.

To allow this level of monitoring in nursing homes, Disability Rights NJ supports the recommendation of the Manatt report for strong cross-agency alignment and communication, including the designation of a senior-level position to be responsible for overseeing and coordinating activities across the long-term care system.

2. Emergency restrictions on visitation in healthcare facilities, including hospitals and nursing homes, must include exceptions for individuals with disabilities and designated support persons, consistent with federal civil rights laws.

From our first virtual Town Hall on April 2, Disability Rights NJ heard from individuals with disabilities and families that one of their greatest fears was that an individual with an intellectual or cognitive disability, or cognitive impairment including dementia, communication barriers or behavioral concerns would be alone in the ER or hospital, without an essential support person. Consistent with the ADA, Section 504 of the Rehabilitation Act, and Section 1557 of the ACA, we advocated for an exception to the strict restriction on visitors in hospitals for individuals with disabilities, and we believe that the amended policy issued by the Commissioner of Health on May 12, 2020, is one of the best in the country, a model for other states.

Last week, Connecticut resolved an Office of Civil Rights complaint regarding its restrictive visitation policy, adopting a policy substantially similar New Jersey's. In briefing advocates on

the resolution, the federal OCR made clear that the principles underlying hospital policies apply equally to nursing homes. Today, Disability Rights NJ will be sending a letter to the Department of Health asking that its May 12 policy regarding support persons for individuals with disabilities be extended to nursing homes consistent with civil rights laws.

I would add that visitation with family and loved ones is a basic human need, a human right, and that we are hearing more and more from our clients and their families that some level of visitation needs to be restored in nursing homes as well as group homes, DCs, and state hospitals. While we need to remain cognizant of very real health and safety concerns, Disability Rights NJ urges state agencies to adopt guidelines as quickly and safely as possible to restore these basic human rights.

3. New Jersey needs to revisit its PASRR process, and provide greater access to quality, affordable home and community-based services to individuals with disabilities in nursing homes, consistent with the Olmstead mandate.

Prior to the onset of the COVID-19 emergency, we began a project to identify individuals with documented serious mental illness, intellectual or developmental disabilities, and traumatic brain injury living in nursing homes as a first step in our efforts to advocate for nursing home to HCBS transition for these individuals. COVID-19 interrupted our efforts. Nevertheless, we have reason to believe that these individuals may be inappropriately placed in nursing homes, contrary to the federal PASRR law, which requires that the state screen individuals prior to nursing home placement, in part, to determine the most appropriate, least restrictive setting where the individual's needs can be met.

Tragically, this is not a hypothetical problem. In April, we began an abuse and neglect investigation into the Andover nursing homes in northern New Jersey. That investigation is ongoing, but as we suspected, it appears that over 300 Andover I and II residents were

individuals with documented disabilities, and at least 50 of the residents who died from COVID-19 were individuals with disabilities.

Disability Rights NJ supports the Manatt recommendation that the Governor create a Task Force to focus, in part, on increasing quality, affordable home and community-based services to allow people with disabilities to live in their own homes with the services and supports they need to live lives of inclusion.

Thank you again for allowing me to testify here today, and I would be happy to answer any questions you may have.