

Testimony before the Assembly Human Services Committee
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Thank you Chairwoman Downey and members of the committee for inviting me to speak here today about how the COVID-19 public health emergency affected individuals with disabilities, especially those residing in developmental centers, group homes and other community-based residential placements, and to give some thoughts to future planning.

Disability Rights New Jersey 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.

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 four areas of our recent work that I believe may be helpful to your committee and the broader discussion of ensuring the health and safety of individuals with developmental disabilities who reside in developmental centers, group homes or other

community-based placements during public health emergencies. I will also touch briefly on individuals with disabilities in nursing homes during the COVID-19 crisis.

- 1. It is essential during a health emergency that Disability Rights NJ, the designated protection and advocacy system under federal law, have meaningful access to residents of developmental centers, group homes, or any setting where an individual with an intellectual or developmental disability is receiving services.**

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.

Since March, Disability Rights NJ has been in regular, weekly conversations with the Department of Human Services, Division of Developmental Disabilities regarding developmental centers, group homes, and individuals receiving services in their own homes. Each week, DDD provided us with updates on DC residents 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 later, the roll out of universal testing and results at each DC.

Throughout these weekly meetings, Disability Rights NJ also discussed the safety and needs of individuals in group homes, individuals residing in their own homes, and their families. DDD provided us information about the availability and distribution of PPE for use in community-

settings, access (or the lack thereof) to testing for individuals in the community and staff, and information on the waiver of certain DDD Medicaid rules, for example parents serving as DSPs for their children, during this emergency. Along with our DD partners – the Council on Development Disabilities, the Boggs Center at Rutgers University, and the DD Ombudsman – we were able to share this information quickly through virtual Town Halls, and we were deeply appreciative to Assistant Commissioner Seifried when he participated in a Town Hall on a Saturday in April.

Disability Rights NJ also knew that it was critical that we have opportunities to monitor the developmental centers during this period, to make ourselves available to the residents who wanted to speak with their federally designated advocates. To that end, we have worked with DDD to establish workable virtual protocols at each developmental center which we began implementing in late-May. In the near future, we intend to once again have a physical presence, consistent with safety protocols, at the developmental centers.

As we all know, DDD services in New Jersey whether in DCs or home and community-based settings are inextricably linked to Medicaid, and so it was also important that Disability Rights NJ have frequent access to the state Medicaid agency, and there too state officials have been similarly transparent, available, and forthcoming. This communication was key in assuring that Medicaid recipient rights were protected and that important information about the many Medicaid changes due to COVID were quickly conveyed and explained to advocates.

During a healthcare crisis, the essential role that Disability Rights NJ plays in assuring accountability, freedom from abuse and neglect, and a focus on the rights of individuals with disabilities is an invaluable piece of emergency planning. I would note here that our access to individuals with disabilities is akin to and consistent with the role of the long-term care ombudsman as discussed by CMS in Frequently Asked Questions on nursing home visitation issues yesterday.

2. It is essential during a healthcare emergency that the State have healthcare facility visitation policies that protect the civil rights of individuals with disabilities, and allow for compassionate care situations.

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.

Yesterday, we asked the Department of Health to extend that policy to nursing homes, to consider a designated support person essential to resident care for individuals with disabilities due to intellectual or cognitive disabilities, including dementia. Earlier in June, 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.

Disability Rights NJ also believes that visitation with family and loved ones is a basic human need, a human right. Over the past weeks, we heard from our clients and their families that some level of visitation needed to be restored in developmental centers, group homes, and nursing homes. We appreciated the visitation protocols for visitors issued by the Department of Health and DDD which allowed for outdoor visits to begin again this past Sunday. We ask that these policies be re-visited now given the new nursing home visitation FAQs issued by CMS

yesterday, and in particular, we ask that the state adopt policies consistent with the broader interpretation of compassionate care situations outlined in those FAQs.

3. It is essential during a health emergency that the State's Allocation of Critical Care Resources policy does not discriminate on its face or in its application against individuals with disabilities.

Early into the COVID-19 emergency, there was a significant, growing concern about the availability of critical care resources such as ventilators as more and more individuals fell ill. For individuals with developmental disabilities, this concern was particularly heightened: people were worried about medical rationing that would de-value their lives solely on the basis of their disability compared to non-disabled individuals. Disability Rights NJ advocated for a policy that was consistent with the Americans with Disabilities Act, which prohibits discrimination against individuals with disabilities in the allocation of scarce medical resources.

While we appreciated that the State developed a plan to address the allocation of resources which does not categorically exclude individuals with disabilities, we remain concerned that the current policy does, in fact, have an unintended disparate impact on individuals with disabilities. The plan relies on the Sequential Organ Failure Score (SOFA) for the basis of its determination of short-term survival, which negatively impacts individuals who have disabilities. For example, an individual who is a chronic ventilator user starts with a higher SOFA score as a baseline condition. Similarly, a disability that causes a shorter life expectancy renders that person less likely to be allocated scarce resources than a non-disabled person, and therefore, may be inconsistent with disability rights laws.

We are also concerned that the current plan provides minimal opportunity for an appeal of the decision. The lack of a meaningful appeal process exacerbates the disparate impact as an individual who has been given a score solely based upon their disability has no opportunity to

show that the decision is based upon assumptions related to the disability rather than on actual medical circumstances. Any decision regarding the denial of a medical resource must provide the individual with an opportunity to appeal.

Should there ever come a time when medical resources are scarce and decisions must be made as to their allocation, individuals with disabilities must be given the same consideration for receiving these resources as non-disabled individuals, and must be given an opportunity for a meaningful appeal. For this reason, we ask now that the State revisit its April 11th Allocation of Critical Care Resources policy, and in doing so, consult with a broad range of individuals with disabilities and advocacy groups, including Disability Rights NJ.

4. New Jersey should 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 and the Manatt report.

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. While COVID-19 interrupted our efforts, we nevertheless 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. If nothing else, this COVID-19 emergency showed that individuals with disabilities living in institutions, including DCs and nursing homes, were at much higher risk of infection, and tragically, death than individuals living in the community.

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