

Testimony before the Joint Hearing of the Senate Health, Human Services and Senior Citizens  
Committee and the Assembly Aging and Senior Services Committee  
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Thank you Chairman Vitale, Chairwoman Vainieri Huttle and members of the committees for the opportunity to testify here today on behalf of individuals with disabilities who reside in New Jersey's long-term care facilities. At the outset, I want to thank the committees and the sponsors of these bills for your diligent work crafting a legislative remedy responsive to the tragedy that unfolded in our nursing homes over the last six months.

Disability Rights NJ strongly supports all of the legislation under consideration today. We believe it reflects the recommendations made by many advocates for nursing home residents during the COVID-19 pandemic, including us and the long-term care Ombudsman, as well as recommendations set forth in the Manatt report.

Since the pandemic began in March, Disability Rights NJ has held a unique position in the state advocating for individuals with disabilities wherever they live, across the spectrum of services they may receive. As the state's designated protection and advocacy agency under federal law, 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. During a healthcare crisis, Disability Rights NJ plays an essential role in assuring accountability, freedom from abuse and neglect, and a focus on the rights of individuals, an invaluable piece of emergency planning.

Akin to the long-term care Ombudsman's authority under the federal Older Americans Act, our authority comes from federal law, which requires every state to establish a protection and advocacy agency for people with disabilities. These statutes give Disability Rights NJ unique access to residents and patients of institutions, including Developmental Centers, the state psychiatric hospitals, and nursing homes. Whereas the prime focus of the long-term care Ombudsman is to advocate for older adults, we advocate for individuals with disabilities in those settings, including children and adults with developmental or intellectual disabilities, serious mental illness, traumatic brain injury, and physical disabilities.

One of our focuses this year, before the COVID-19 pandemic, was to get an accurate accounting of the number of individuals with disabilities, particularly developmental or intellectual disabilities and serious mental illness, living in nursing homes. That information is not easily obtainable, because no one single State agency is responsible for information about nursing home residents. Instead, that information is scattered among various State agencies (i.e., the Division of Developmental Disabilities, the Division of Medical Assistance and Health Services, the Division of Aging Services, the Department of Health). But we have good reason to believe that number is significant: for example, our preliminary investigation of Andover I and II suggests that more than 350 residents were individuals with disabilities, and that of those who sadly passed away early in the pandemic, upwards of 50 were individuals with disabilities. For this reason, it is essential that any legislation that seeks to improve New Jersey's long-term care system include the needs and perspective of individuals with disabilities.

With that background, I would like to highlight two areas of particular importance to Disability Rights NJ:

- 1. Disability Rights NJ strongly supports the establishment of a Task Force on Long-Term Care Quality and Safety.**

Several bills under consideration establish long-term care advisories. S2787/A4481 establishes a New Jersey Task Force on Long-Term Care Quality and Safety. While we support this bill, we respectfully request that in addition to the New Jersey long-term care ombudsman, Disability Rights NJ also be named an ex officio member as the state's designated protection and advocacy agency for individuals with disabilities of all ages, living in nursing homes. In addition, we ask that the current configuration of the task force be more strongly balanced toward residents and their family members. We also applaud the focus on expanding home and community-based services in this bill.

Disability Rights NJ strongly supports S2759/A4478 which establishes additional requirements for sanctions and penalties on long-term care facilities and S2790/A4476 which establishes a long-term care emergency operations center, but we respectfully request that to the extent these bills also establish advisories, that Disability Rights NJ be included in the legislation to ensure that the voices of individuals with disabilities who reside in long-term care facilities are fully heard.

**2. Disability Rights NJ fully supports legislative measures to consolidate and strengthen the response through a central long-term care emergency operations center that would coordinate all activities and communications for nursing homes including real-time input regarding testing, staffing, PPE, and operational issues.**

As stated above, Disability Rights NJ has monitoring authority with respect to Developmental Centers and the state psychiatric hospitals. Since mid-March, we have been meeting weekly with the Division of Developmental Disabilities and the Department of Health, Division of Behavioral Health. Throughout this crisis, we have worked with these state partners to have access to real-time information about the number of COVID cases among residents, patients and staff; testing, including the role-out of universal testing in late April; PPE availability and use; treatment and activity strategies, including telemedicine; visitation strategies; and tragically, deaths. Beginning in late April, with the essential cooperation of our state partners, we began virtual monitoring, allowing residents and patients to meet with our advocates and

attorneys on a weekly basis, ensuring that they had the ability to report abuse, neglect, and just talk to us about their isolation, fears, needs, and the conditions in the institutions. To the extent they needed legal representation, virtual monitoring provided an opportunity to connect with those legal services we provide.

S2790/A4476 establishes a Long-Term Care Emergency Operation Center in the Department of Health to ensure real-time coordination of information and response during a health care emergency such as COVID-19. This is an essential role in state government, and one that would facilitate our monitoring and investigatory responsibility in long-term care facilities during a health crisis. We also support this bill's requirement to develop a data dashboard, which must be robust, transparent, and public.

In the interest of time, Disability Rights NJ will submit written testimony on each of the bills under consideration today, but we want to emphasize our support of measures taken across this legislative package: greater accountability and oversight of long-term care facilities, including ownership; increased public dollars tied to quality measures and enhanced rates and benefits for direct-care staff; partnership with managed care organizations in an effort to improve quality; and the potential for meaningful staffing ratio legislation.

Finally, Disability Rights NJ thanks our state partners, especially those in the Department of Health, Division of Developmental Disabilities, and Division of Medical Assistance and Health Services. We have worked with them closely throughout this COVID-19 pandemic – sometimes at 7pm on a Saturday night. The dedication and genuine care they have shown to New Jersey's most vulnerable residents fills my heart with gratitude and gives me hope in this difficult time.