New Jersey

State Report – June 2023

Division of Developmental Disabilities

The Division of Developmental Disabilities (DDD) serves eligible New Jersey adults, age 21 and older, with intellectual and developmental disabilities (I/DD). Services are primarily provided through fee-for-service reimbursement to provider agencies and include day and residential programs and family support in the community. DDD serves more than 24,000 individuals with I/DD in its two waiver programs, the Supports Program, and the Community Care Program. The Direct Support Professional (DSP) shortage continues to worsen, and there still exists a lengthy waiting list for services.

State Intermediate Care Facilities a.k.a. Developmental Centers

In addition to the state's two waiver programs, NJ operates five (5) Intermediate Care Facilities for Individuals with Intellectual Disabilities(ICFs/IID), termed Developmental Centers (DCs). These residential/habilitation centers offer and deliver the most comprehensive continuous (24/7) care and treatment in the state and are subject to certification by CMS (Centers for Medicare and Medicaid). Funding is provided through state and federal dollars and individuals' contribution to care. With the closure of the North Jersey and Woodbridge DCs in July 2014 and January 2015, respectively, there are no state-run ICFs in the northern part of the state. Currently, about 1,100 individuals reside in NJ's five remaining DCs. NJ has closed three DCs, including two since 2014. The worsening DSP shortage has impacted recruitment and retention of DSPs in DCs; informal communiques indicate that DDD is trying to address this issue.

NJ has One "Private" Intermediate Care Facility

Spectrum for Living operates group homes, a medical group home, and supervised apartments as well as a 60-bed ICF which opened in 1983. This is the only privately-operated ICF/IID in the state. Spectrum for Living also operates adult day programs and provides case management and respite services to people in the community.

NJ State Budget for Fiscal Year 2024

The following excerpts (*in italics*) are directly quoted from NJ's Fiscal Year 2024 budget. The link to the proposed budget in its entirety is BIB.pdf (nj.gov)

Disability Supports and Services

The Murphy Administration's vision for equity and inclusion drives efforts to elevate the lives of individuals with disabilities, improve access to services, and strengthen the workforce serving persons with disabilities. Over the last year, the Department of Human Services (DHS) continued to serve over 24,500 individuals with developmental disabilities.

This budget proposes \$36 million to increase the rates paid to services providers for residents with developmental disabilities.

It also adds \$31.3 million for wage increases to direct support professionals and \$10.4 million to address wage compression among supervisors, continuing the Governor's record investments in his first term to ensure that workers enter and remain in this important profession.

DHS will also lead a one-year, \$86.75 million effort to shore up the workforce that upholds the system of home- and community-based services on which New Jersey's residents with disabilities and others needing long-term care depend. The initiative will include a package of recruitment and retention payments, student loan redemption and related programs, subsidized training, and assistance for the translation of training materials into a variety of languages.

Gov. Murphy's proposed budget represents the sixth consecutive year that extra monies have been sought for the sole purpose of increasing DSPs' wages but in HCBS settings only, not in ICF/IID settings. NJ VOR members Sam Friedman (past president) and Joanne St. Amand (president) have testified before both houses of the NJ Legislature and met with state senate budget committee member's legislative staff to seek redress for this inequity.

NJ State Ombudsman Annual Report for 2022

Paul S. Aronsohn is NJ's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families. The link to the entire report is 2022-Annual-Report.pdf (nj.gov). Below are some key excerpts (in italics) from the report:

Workforce Shortage in Perspective To provide direct care staff, many State-licensed provider agencies receive a lot of Medicaid funding through the NJ Division of Developmental Disabilities. In fact, some home health agencies are paid more than \$55 per hour per client. Some residential provider agencies are paid more than \$43 per hour per resident. Yet, these agencies generally pay their direct care staff only \$16-20 per hour — a wage comparable to the starting salary in many supermarkets and retail stores. Hence, in New Jersey, the estimated Direct Support Professional turnover rate is at least 44% and the vacancy rate is at least 20%.

Autism in Perspective New Jersey's autism prevalence is 1 in 34 children – one of the highest rates in the world. More specifically, an estimated 220,000 New Jerseyans have autism, including 60,000 children, according to Autism New Jersey. And it is estimated 1 in 3 children with autism engage in self-injurious behavior, meaning an estimated 20,000 New Jersey children have likely banged their own head against a wall, punched themselves in the face, bitten themselves or engaged in some other self-injurious aggression – often as a pattern of ongoing behavior.

Complex Medical Needs in Perspective Over the past 4.3 years, individuals with intellectual or developmental disabilities have been admitted to New Jersey nursing homes on at least 2,268 occasions - about 1,587 (70%) of these occasions have involved long-term stays; - about 1,255 (55%) have involved people under the age of 63 years. And there are currently more than 1,000 New Jerseyans living in the State's 6 Intermediate Care Facilities, including the 5 Developmental Centers.

This crucial observation, from the 2021 NJ State Ombudsman's Annual Report, continues to be substantively unaddressed: *Moreover, despite all the talk about "de-institutionalization" over the years – including efforts to close down the Developmental Centers – the State has (inadvertently) fostered a "reinstitutionalization"* by effectively forcing many people with complex medical needs – children as well as adults – into hospitals and nursing homes.

Data provided by NJ DDD on the Preadmission Screening and Review (PASRR) Level II, completed in 2023 by DDD, for number of admissions to nursing homes, was 69 in January, 52 in February, 64 in March, and 60 in April, for a total of 245.

Section 14c Certificate Program

Section 14(c) of the Fair Labor Standards Act (FLSA) certifies programs that are highly regulated and overseen by the Wage & Hour Division of the U.S. Dept. of Labor and that benefit a very specific cohort of individuals on the I/DD spectrum -- those developing skills and/or who desire to work and/or enjoy or benefit from interacting with peers, but who may not be likely candidates for competitive employment. These individuals benefit from working in a supervised environment with job coaches who also understand their challenges and are prepared to address them. NJ currently has about 31 such facilities with about 1,300+ participants. The reference for this data is the US Department of Labor per 14(c) Certificate Holders | U.S. Department of Labor (dol.gov)

NJ Disability Action Committee (DAC)

The NJ DAC arose during the COVID-19 pandemic as it became clear that people with disabilities and their loved ones were disproportionately bearing the consequences of the emergency. DAC comprises a cross-section of New Jerseyans representing a broad range of disabilities, including self-advocates, family/guardian/caregiver advocates, and support professionals. According to the NJ Department of Human Services, there are an estimated 1.7 million residents with disabilities in New Jersey. VOR member Sam Friedman, appointed to DAC early on, continuingly advocates for VOR's priorities (particularly for choice and, relatedly, deconstructing the persistent myth of "institutional bias"), and spearheaded a letter from DAC to several NJ legislators who sponsored or co-sponsored a bill that would require the closure of most of NJ's remaining state-operated ICFs/IDD, urging them to table the bill (A.1289/S.1082) and cease efforts to close the ICFs; and suggesting meeting with DAC members to discuss alternative ways of supporting individuals with I/DD.

Conclusion

- In this year's budget, Gov. Murphy proposes \$36 million to increase the rates paid to services providers for residents with developmental disabilities, \$31.3 million for wage increases to direct support professionals and \$10.4 million to address wage compression among supervisors, DHS will also lead a one-year, \$86.75 million effort to shore up the workforce that upholds the system of home- and community-based services.
- The Ombudsman's Annual Report points out the shortfalls in the NJ DDD system, including workforce shortages; abuse and neglect in state-licensed residences; severe lack of assessments, treatments, supports, and services for those with severe challenging behaviors; and many New Jerseyans with complex medical needs -- children as well as adults -- continuing to live in nursing homes.
- Developmental Centers (ICFs/IID) continue to provide high-quality care for those needing ICF-level of services. Admissions appear to be rare, mostly through court order, and after all other residential settings have failed.

Respectfully Submitted,

Joanne St. Amand, Sibling and Co-Guardian for Rosemary Sam Friedman, Sibling and Co-Guardian for Jackie