

New Jersey

State Report 2021 - 2022

NJ VOR members Sam Friedman, Joanne St. Amand, Susan Anderson, and Janet Ressa participated in the second virtual Legislative Initiative. We held Zoom meeting with 3 of 12 Representatives and are arranging virtual appointments with the remaining over the next few weeks. (Appendix I).

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.

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 (ICFs/IID) known as developmental centers. 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 the individuals' contribution to care. With the closure of the North Jersey and Woodbridge Developmental Centers in July 2014 and January 2015, respectively, there are no public ICFs in the northern part of the state. Currently there are approximately 1,100 individuals residing in NJ Developmental Centers. It is common knowledge that the census will continue to decline with the state's policy of no admissions and the population aging. In addition, the NJ Council on Developmental Disabilities (NJCDD) and the NJ Association of Community Providers (NJACP) have publicly testified that the state should close the remaining five developmental centers and use their budgets to increase Direct Support Professionals' (DSPs') salaries. NJ has closed three centers, including two since 2014, however the DSP wage situation continues to worsen, there still exists a lengthy waiting list for services, and NJ has a moratorium on admissions to its five state-operated developmental centers

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 persons in the community.

NJ State Budget for Fiscal Year 2023

The following excerpts are directly quoted from NJ's Fiscal Year 2023 budget. The link to the proposed budget in its entirety is [BIB.pdf \(nj.gov\)](#)

Capital Investments

This year, the Administration proposes another substantial investment of \$114.6 million to ensure that State facilities are safe and functioning. This investment will fund critical projects at State facilities such as psychiatric hospitals, correctional institutions, and developmental centers which will ensure protection for the most vulnerable, those under our supervision, and the employees responsible for their treatment and care. These projects will address infrastructure and life safety concerns, fire protection and security enhancements, and roof replacements.

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 continued to serve over 24,000 individuals with developmental disabilities, provided \$347 million in additional pandemic-related relief funding to providers, and supported the safe reopening of in-person day and employment programs for individuals with intellectual and developmental disabilities. The Governor's budget includes \$31.3 million more for Direct Support Professionals and \$10.4 million to address wage compression among supervisors, continuing the Governor's record investments in the first term to ensure that workers enter and remain in this important profession. This year the Governor also signed legislation (P.L.2021, c.421) to establish the Direct Support Professional Career Development Program. The budget also includes \$8.2 million for a rate increase to support individuals with complex needs receiving care out of state, and nearly \$9 million for one-time renovations at Hunterdon Developmental Center. To further support individuals with disabilities in their home, the FY2023 budget includes increased funding for the Personal Assistance Services Program (PASP). In FY2023, the Governor will also launch a new, virtual Disability Information Hub, informed by individuals with disabilities, to help individuals with disabilities better plan for their future by providing up-to-date, consumer-friendly, accessible information about disability services in a central location. The Department of Human Services will also utilize \$5 million of SFRF to raise broader awareness among the public about the Department's services and supports through a targeted advertising campaign.

NJ State Ombudsman Annual Report for 2021

Paul S. Aronsohn is the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families. The following excerpts are directly quoted from his 2021 Annual Report. The link to the entire report is [Microsoft Word - 2021 Annual Report -- Final Draft \(nj.gov\)](#)

Complex Medical Needs

Last year, we continued to hear concerns from people with complex medical needs and their families on topics important to them – from the scarcity of day programs to the unreliability of transportation options to the unpredictability of managed care organizations. Mostly, we heard about the desperate need for staff, housing, and medical care.

· *Staff: For people with complex medical needs to live safely and fully in the community, they often need Private Duty Nurses (PDN). As discussed in the “Staffing” section below, however, PDN are in dangerously short supply. This workforce shortage is due, in part, to the fact that the Medicaid salary rate for PDN in New Jersey – about \$28 per hour -- has not increased in more than a decade. Moreover, the NJ Department of Human Services (DHS) does not have a program to meet the needs of adults who have both complex medical needs and severe challenging behavior. Families, like one featured below, who need to hire both PDN and “individual supports” are effectively forced to choose one or the other, because DHS’s Community Care Program - which includes individual supports - does not include nursing.*

· *Housing: Without access to PDN, many people with complex medical needs cannot live in their own home or even a family home. They need some type of congregate residential setting. However, there are not enough “medical” group homes or other privately-run congregate residences that have the capacity to provide nursing/medical support; nor is the State allowing (with few exceptions) new admissions to the Developmental Centers it runs. This often leaves many adults and their families with two bad, dangerous choices: live at home without proper supports or live in a congregate care setting, including a nursing home, without proper supports.*

· *Medical Care: Accessing quality healthcare is a serious challenge for many, if not most, people with disabilities. Many physicians/psychiatrists/dentists do not accept Medicaid. Many are not willing or trained to treat people with intellectual or developmental disabilities. And some of the top specialists are in New York and Pennsylvania and are therefore not necessarily covered by New Jersey’s managed care organizations.*

*The disconnect here is serious. Despite all the talk about “home and community based” services and supports, many people with complex medical needs and their families do not have access to the tools to make living in the community a safe, sustainable reality. 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 “re-institutionalization”** by effectively forcing many people with complex medical needs – children as well as adults – into hospitals and nursing homes.*

DSP Wages

The 2021 Ombudsman’s Annual Report also discusses DSP wages. Directly from his report is the following:

We expect professionals – DSPs, SDEs, PDNs and others, including Behavior Analysts – to provide first-rate care and support to people with significant medical, physical and/or behavioral needs; yet we often pay them at sub-standard rates and often give them minimal training. In so doing, we are effectively setting the system up for failure. Moreover, the disconnect is even more disturbing when consideration is given to the significant amount of money paid to many provider agencies to support just one individual – again, up to \$1,275.84 per day for home health agencies and up to \$999.36 per day for residential provider agencies

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 benefit a very specific cohort of

individuals on the I/DD spectrum -- those developing skills and desire to work and interact with peers, yet 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 32 such facilities with about 1,400 participants.

Developmental Centers' Family and Friends Associations

Although the Family and Friends Associations of NJ Developmental Centers have not held in-person meetings for more than two years due to Covid, leadership for the family organizations have had virtual meetings and written letters to several State officials, State legislators and Division of Developmental Disabilities leadership. Sam Friedman's 30+ years' experience at the NYC Department of Health helped him understand early on the extreme importance of testing and identifying those who were positive but had no symptoms, so as to properly isolate and quarantine staff and residents. Sam spearheaded a campaign and formed a "NJ Developmental Centers Families' COVID-19 Alliance" with the Family Associations' leadership from Hunterdon, New Lisbon, Woodbine, and Green Brook Developmental Centers. This ad hoc Alliance fought to keep the Developmental Centers at the top of the state's priority list for testing, supplies and services. The Alliance's actions included:

- letter to Governor Murphy, NJ Health Commissioner Persichilli, and then NJDHS Commissioner Johnson, with a detailed rationale for demanding action on behalf of residents
- online meeting with Assemblywoman JoAnn Downey, then Human Services Committee Chair
- phone conference with State Sen. Tom Kean
- several online meetings with Paul Aronsohn, Ombudsman for Individuals with ID and their Families and Christine Bakter, Associate Director
- two TV interviews with NJ Spotlight News
- Initiation of online meetings with NJ DDD Assistant Commissioner Jonathan Seifried

The Alliance's advocacy led to Sam being appointed to the NJ COVID-19 Disability Action Committee (DAC), on which he represents Developmental Center residents and their families. This was a step forward because it is rare and difficult for those who speak for Developmental Center residents to have a voice on bodies that are heard at the State level.

The NJ Department of Health, Division of Developmental Disabilities, continually publishes the status of Covid at the five developmental centers (Appendix II), every two weeks.

Disability Action Committee

This Committee was assembled during the COVID-19 pandemic when it became clear that people with disabilities and their loved ones were going to bear the consequences of this crisis disproportionately. In response the Disability Action Committee was formed from a diverse group of individuals from across the state of NJ that are a part of the Disability Community. The committee includes self-advocates, family/caregiver advocates, and support professionals. According to the New Jersey Department of Human Services, there are an estimated 1.7 million residents with disabilities in New Jersey. Once assembled, the DAC immediately went to work conducting research and creating reports to advocate for our community's needs. VOR's past president Sam Friedman was appointed to the Committee, and

instrumental in having language included regarding the “Context for Supporting Those in Long Term Care Facilities Recommendation.”

Individuals with Developmental Disabilities locked down in NJ Nursing Home

Sadly, the state has been placing individuals with ID/DD into nursing homes because adequate services are not available for these individuals in the community, and the state refuses to admit them into the Developmental Centers. Covid has hit this group very hard. Many of the deaths in Nursing Homes were among people with intellectual disabilities.

A particularly tragic instance of nursing home abuse and neglect, the Woodland Behavioral Health and Nursing Center, in Andover, NJ -- one of NJ’s largest long-term care facilities, and subject of intense scrutiny after 17 bodies were found in a makeshift morgue during the height of the pandemic, and a scathing federal report detailing such poor non-compliance at the facility that patients’ lives were believed to be in serious jeopardy – certainly involves residents with ID/DD, although facts about their fate are difficult to come by.

Gwen Orlowski, executive director for Disability Rights New Jersey (DRNJ), stated in February 2022 that Woodland confines nearly 200 residents diagnosed with traumatic brain injuries, mental illness, developmental disabilities, or recovering from strokes on a locked floor.

NJ is about to wrest control of the facility, whose license is suspended, from its owner; CMS is expected to cut off funding in mid-June 2022. Re-location of most if not all residents is stated to be now among the highest priorities. But a DRNJ legal director Michael Brower was quoted in early June 2022 news coverage as bemoaning insufficient group home or other community housing, but making no mention of the existence or role of state-run ICFs (i.e., Developmental Centers) for those qualified.

Links: [Nearly 200 people are locked down, living in ‘inhumane’ conditions at N.J. nursing home, advocate says - nj.com](#)

[A nursing home where 83 residents died of Covid is still in business under a new name \(nbcnews.com\)](#)

<https://www.njspotlightnews.org/2022/06/woodland-behavioral-and-nursing-center-andover-subacute-and-rehabilitation-center-covid-19-makeshift-morgue-suspended-license-restructuring-receiver-dementia-mental-illness/>

Conclusion

Highlights from this report include:

- The Governor has included money in this year’s budget for DSPs and renovations at Hunterdon Developmental Center.
- The Ombudsman’s Annual Report provides thorough observations of disastrous shortfalls of housing and services, and recommends how to make some improvements in the DD system.

- A tragedy brought front and center by the pandemic is that NJ has been placing individuals with ID/DD into nursing homes. One of these facilities has been in the news because of deplorable conditions, and the state is in the process of moving its residents to other residential housing, and likely closing the facility. Unfortunately, these options apparently will not include any of NJ's five Developmental Centers.
- Developmental Centers (ICF/IID) continue to provide a high-quality care for those needing ICF level of services. Admissions appear to be only through court order, after all else has failed. The Family and Friends' Associations formed an Alliance at the beginning of the pandemic to help assure that the needs of the Developmental Centers are at the top of the state's priority list.

Respectfully Submitted,

Joanne St. Amand

Sam Friedman

June 2022

Appendix I

NJ Congressional Members. Developmental Centers reside in District 2 (**Woodbine and Vineland**),
District 3 (**New Lisbon**) and District 7 (**Hunterdon and Green Brook**).

New Jersey (red type = VOR initiative - meetings completed)

District	Name	Party	Office Room	Phone	Committee Assignment
1st	Norcross, Donald	D	2437 RHOB	(202) 225-6501	<ul style="list-style-type: none"> • Armed Services • Education and Labor
2nd	Van Drew, Jefferson	D	331 CHOB	(202) 225-6572	<ul style="list-style-type: none"> • Agriculture • Natural Resources
3rd	Kim, Andy	D	1516 LHOB	(202) 225-4765	<ul style="list-style-type: none"> • Armed Services • Small Business
4th	Smith, Chris	R	2373 RHOB	(202) 225-3765	<ul style="list-style-type: none"> • Foreign Affairs
5th	Gottheimer, Josh	D	213 CHOB	(202) 225-4465	<ul style="list-style-type: none"> • Financial Services
6th	Pallone Jr., Frank	D	2107 RHOB	(202) 225-4671	<ul style="list-style-type: none"> • Energy and Commerce
7th	Malinowski, Tom	D	426 CHOB	(202) 225-5361	<ul style="list-style-type: none"> • Foreign Affairs • Transportation and Infrastructure
8th	Sires, Albio	D	2268 RHOB	(202) 225-7919	<ul style="list-style-type: none"> • Budget • Foreign Affairs • Transportation and Infrastructure
9th	Pascrell Jr., Bill	D	2409 RHOB	(202) 225-5751	<ul style="list-style-type: none"> • Ways and Means
10th	Payne Jr., Donald	D	103 CHOB	(202) 225-3436	<ul style="list-style-type: none"> • Homeland Security • Transportation and Infrastructure

New Jersey (red type = VOR initiative - meetings completed)

District	Name	Party	Office Room	Phone	Committee Assignment
11th	Sherrill, Mikie	D	1208 LHOB	(202) 225-5034	<ul style="list-style-type: none">• Armed Services• Science, Space, and Technology
12th	Watson Coleman, Bonnie	D	2442 RHOB	(202) 225-5801	<ul style="list-style-type: none">• Appropriations• Homeland Security

Appendix II



NJ Department of Human Services
Division of Developmental Disabilities

Coronavirus Disease 2019 (COVID-19) Dashboard As of 5/29/22

Developmental Center Total (Population: 1,094; ~4,300 Staff)		
	Residents	Staff
Total Current Positives	20	43
Total Recovered Positives*	789	2211
Total Passings where COVID-19 is listed as Cause of Death of Death Certificate	42	4

<i>Green Brook Regional Center: Census (Somerset)</i> Census: 66		
	Residents	Staff
Current Positives	1	0
Recovered Positives*	31	150
Total Passings where COVID-19 is listed as Cause of Death of Death Certificate	5	0
<i>Hunterdon Developmental Center (Hunterdon)</i> Census: 398		
	Residents	Staff
Current Positives	12	17
Recovered Positives*	259	701
Total Passings where COVID-19 is listed as Cause of Death of Death Certificate	7	0
<i>New Lisbon Developmental Center (Burlington)</i> Census: 248		
	Residents	Staff
Current Positives	6	13
Recovered Positives*	216	432
Total Passings where COVID-19 is listed as Cause of Death of Death Certificate	10	3

<i>Vineland Developmental Center (Cumberland)</i> Census: 166		
	Residents	Staff
Current Positives	1	8
Recovered Positives*	106	450
Total Passings where COVID-19 is listed as Cause of Death of Death Certificate	9	1
<i>Woodbine Developmental Center (Cape May)</i> Census: 216		
	Residents	Staff
Current Positives	0	5
Recovered Positives*	177	478
Total Passings where COVID-19 is listed as Cause of Death of Death Certificate	11	0

Results reflect universal testing which began 4/2020.

DC residents who pass away are listed as COVID-19 related if it is listed on their death certificate as cause of death.

*Recovered Positives – Resident who met the CDC standard to discontinue isolation (<https://www.cdc.gov/coronavirus/2019-ncov/hcp/disposition-in-home-patients.html>). Staff who met the CDC standard to return to work (<https://www.cdc.gov/coronavirus/2019-ncov/hcp/return-to-work.html>).

*DHS compiles community totals using data from incidents that are reported by provider agencies and by the families of individuals who reside in