

# New Jersey

## State Report 2019

NJ will be represented at the VOR Annual Conference in Washington, D.C. by several dedicated advocates. They will visit the offices of NJ's U.S Senators Booker and Menendez, and all twelve Congressional offices (Appendix I) to discuss legislation and policies that affect individuals with intellectual and developmental disabilities. Currently, NJ has a moratorium on admissions to their 5 state-operated developmental centers (Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)). This report discusses the Department of Human Services FY2020 budget and some issues for the last year.

### **State Budget – Department of Human Services (DHS)**

The Governor's Budget recommends a total of \$18.834 billion for the DHS in FY 2020, a decrease of \$13.7 million (0.1 percent) from the \$18.847 billion in FY 2019 adjusted appropriations.

The DHS includes five major divisions with gross annual budgets over \$100 million, and 4 smaller ones whose budgets will remain relatively the same for 2020. The Division of Developmental Disabilities (DDD) is one of the major divisions in DHS. Governor Murphy said he is committed to providing resources for services and supports to assist adults with intellectual and developmental disabilities to live as independently as possible.

All budget information is taken from "DHS Analysis of the Budget for FY 2019 – 2020". Link to this document is below:

[https://www.njleg.state.nj.us/legislativepub/budget\\_2020/DHS\\_analysis\\_2020.pdf](https://www.njleg.state.nj.us/legislativepub/budget_2020/DHS_analysis_2020.pdf)

The Governor's FY2019-2020 budget recommendation includes \$22.5M in new funding for DHS's - the Division of Developmental Disabilities (DDD), including an additional \$15.5M in State funding to continue New Jersey's emphasis on home and community-based services and co-occurring mental illness (dual diagnosis). The budget also includes \$7M for a comprehensive response to address the current gaps in the behavioral health system for those with co-occurring disabilities and mental health needs. This response includes a statewide analysis of in-patient stabilization services and additional short-term crisis stabilization beds. The Governor's budget also continues the additional funding for Direct Service Providers added by the Legislature in FY2018 and FY2019.

The three largest changes are: 1) the reduction of \$248.7 million in federal matching funds for the Affordable Care Act Medicaid expansion population on account of a lower federal cost sharing percentage, whose loss the Executive offsets largely by increasing All Other Funds revenues; 2) a \$121.3 million increase in federal funds for the Community Care Program; and 3) \$92.3 million in State funding reductions attributable to a federal one-year moratorium on the

Affordable Care Act Health Insurance Providers Fee (the associated \$166.4 million reduction in federal funds appropriations is matched by an equal loss of federal revenue).

### **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 division also operates the State's five residential developmental centers for individuals with developmental disabilities. Gross funding for the five State developmental centers is recommended to decrease by \$2.7 million (1.0 percent), to \$277.2 million with federal funds accounting for the entire decline. The continued initiative to move individuals from the developmental centers into the community, along with a moratorium on new admissions, drives the funding decrease. The average daily population for all centers is projected to fall by 61 (4.7 percent) to 1,235.

### **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 (ICF/IID) known as developmental centers. These residential/habilitation centers offer and deliver the most comprehensive continuous (24/7) care and treatment 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 the Woodbridge Developmental Centers in July 2014 and January 2015, there are no public ICF's in the northern part of the state. Currently there are approximately 1,200 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 5 developmental centers and use their budget to increase the Direct Support Professionals (DSPs) salaries. However, NJ has closed 3 centers, two since January 2015 and the DSP wage situation continues to get worse and there still exists a lengthy waiting list for services.

### **NJ has 1 "Private" Intermediate Care Facility**

Spectrum for Living operates group homes, a medical group home, 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.

## **Stephen Komninos Law adds oversight in the Community**

Signed into law on October 6, 2017 and became effective this year on May 1, 2018. Named after Mr. Stephen Komninos, and individual who resided in a New Jersey group home.

Two unannounced site visits annually by a DHS representative to all community residential programs (group homes and supervised apartments) to evaluate if individuals residing in these settings are at risk of, or being subjected to, abuse, neglect or exploitation by a caregiver<sup>1</sup>

Notification in-person or by phone within two hours must be made to an individual's guardian of all major, moderate and minor physical injuries as defined by DHS regulation. If there is no guardian, a family member who requests notification may be notified, unless the individual prohibits the family member from receiving this information

## **Community Care Waiver renamed Community Care Program: A Call for Informal Comments**

The New Jersey Department of Human Services, Division of Developmental Disabilities (Division) intends to propose amendments to the Community Care Waiver Waiting List Procedures at N.J.A.C. 10:46C. These will include technical amendments to reflect the renaming of the Community Care Waiver as the Community Care Program, when this waiver was incorporated into New Jersey's Comprehensive Medicaid Waiver in 2017. The amendments will also reflect that the Department of Children and Families now provides services to eligible individuals under the age of 21 years. In addition, amendments will clarify that the Division serves individuals who meet the level of care for an Intermediate Care Facility for Individuals with Intellectual Disabilities through the Community Care Program, and serves individuals who do not meet that level of care through the Supports Program, which is also part of the Comprehensive Medicaid Waiver. Additional technical amendments will also be proposed. Interested parties were asked to submit informal comments on an advance notice within thirty (30) days of its publication (was due May 25, 2019) on the Department of Human Services' website.

*Personal Note:* Of concern is the underlined statement above about "clarifying amendments" because the state has closed admissions to the developmental centers and indicates it will address those needing ICF/IID services through their Community Care Program. Those individuals who need or choose ICF/IID level of care cannot be equally cared for through the Community Care Program. The Community Care Waiver, the essence of the renamed Community Care Program is fundamentally different than the ICF/IID level of care. One does not equate with the other. If you provide CCW level of care instead of the ICF/IDD level of care you are providing a much less comprehensive level of care. The developmental centers (ICF/IIDs) are the most comprehensive program offered by CMS. A person in need of an "active treatment plan" can only be adequately served in an ICF/IID. Other types of residences and congregate care facilities may model some of their services after an ICF/IID, but none are mandated by federal law to provide neither the same oversight nor the hallmark "active treatment plan." A description of Active Treatment from the CMS website is provided in Appendix II

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showing the definition and comprehensiveness of the “active treatment plan.” Appendix III is a copy of submitted informal comments to DHS in response to their notice of proposed amendments.

### **Bellwether Behavioral Health barred from operating in NJ**

State of NJ has barred Bellwether Behavioral Health from running group homes in NJ. Bellwether operates 62 homes for approximately 400 NJ residents. The number of incidents at Bellwether homes investigated by the state over the last year – 71 - was more than three times higher than for any other agency, according to state records. The state-appointed monitor, who spent months visiting Bellwether homes and talking with residents, families, staff and management, found numerous examples of resident-on-resident violence, medication mistakes, filth and other licensing deficiencies. At least two Bellwether residents have died and two others were grievously injured over the past two years, according to lawsuits filed against Bellwether.

Robin Dobrowski, 56, diagnosed with an intellectual disability has lived in group homes operated by five different agencies including Bellwether, since leaving Vineland Developmental Center seven years ago. None have been satisfactory, said Linda Czyzewski, Dobrowski's legal guardian.

Link to recent article:

<https://www.northjersey.com/story/news/2019/05/25/nj-bars-bellwether-behavioral-health-running-group-homes/1220958001/?fbclid=IwAR1QvpH7bUXtgGS1OzpbJJKTf2e0zpohQwVeGORh61fluVFrRo4eXctNIpg>

### **Conclusions**

The state of NJ continues to decrease the budget to their Developmental Centers and has a moratorium on admissions. The state and their federally funded disability related “businesses” and agencies continue to push for the transfer of developmental center residents into group home placements. Those living in the centers are pressured to leave despite numerous examples that many of the group homes are ill equipped to properly care for the most vulnerable nor keep them safe. Developmental Centers continue to provide the highest quality care, and the overwhelming majority of families and guardians of developmental center residents continue to oppose group home placements.

# 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

District	Name	Party	Office Room	Phone
1st	<a href="#">Norcross, Donald</a>	D	2437 RHOB	(202) 225-6501
2nd	<a href="#">Van Drew, Jefferson</a>	D	331 CHOB	(202) 225-6572
3rd	<a href="#">Kim, Andy</a>	D	1516 LHOB	(202) 225-4765
4th	<a href="#">Smith, Chris</a>	R	2373 RHOB	(202) 225-3765
5th	<a href="#">Gottheimer, Josh</a>	D	213 CHOB	(202) 225-4465
6th	<a href="#">Pallone Jr., Frank</a>	D	2107 RHOB	(202) 225-4671
7th	<a href="#">Malinowski, Tom</a>	D	426 CHOB	(202) 225-5361
8th	<a href="#">Sires, Albio</a>	D	2268 RHOB	(202) 225-7919
9th	<a href="#">Pascrell Jr., Bill</a>	D	2409 RHOB	(202) 225-5751
10th	<a href="#">Payne Jr., Donald</a>	D	103 CHOB	(202) 225-3436
11th	<a href="#">Sherrill, Mikie</a>	D	1208 LHOB	(202) 225-5034
12th	<a href="#">Watson Coleman, Bonnie</a>	D	2442 RHOB	(202) 225-5801

# Appendix II

## Active Treatment (42 CFR 483.440(a))

Refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. Active treatment does not include services to maintain generally independent clients who are able to function with little supervision or in the absence of a continuous active treatment program.

### Components of Active Treatment:

A. Comprehensive Functional Assessment (42 CFR 483.440(c)(3)). The individual's interdisciplinary team must produce accurate, comprehensive functional assessment data, within 30 days after admission, that identify all of the individual's:

- Specific developmental strengths, including individual preferences;
- Specific functional and adaptive social skills the individual needs to acquire;
- Presenting disabilities and when possible their causes; and
- Need for services without regard to their availability.

B. Individual Program Plan (IPP) (42 CFR 483.440(c)). The interdisciplinary team must prepare an IPP which includes opportunities for individual choice and self-management and identifies: the discrete, measurable, criteria-based objectives the individual is to achieve; and the specific individualized program of specialized and generic strategies, supports and techniques to be employed. The IPP must be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible and the prevention or deceleration of regression or loss of current optimal functional status.

C. Program Implementation (42 CFR 483.440(d)). Each individual must receive a continuous active treatment program consisting of needed interventions and services in sufficient intensity and frequency to support the achievement of IPP objectives.

D. Program Documentation (42 CFR 483.440(e)). Accurate, systematic, behaviorally stated data about the individual's performance toward meeting the criteria stated in IPP objectives serves as the basis for necessary change and revision to the program.

E. Program Monitoring and Change (42 CFR 483.440(f)). At least annually, the comprehensive functional assessment of each individual is reviewed by the interdisciplinary team for its relevancy and updated, as needed. The IPP is revised as appropriate.

# Appendix III

Informal Comments submitted regarding proposed amendments to the Community Care Waiver Waiting List Procedures at N.J.A.C. 10:46C.

Contact Information:

Joanne St. Amand, President

**Association for Individuals with Intellectual Disabilities, and  
Green Brook Regional Center Family and Friends Association**

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[jrst.amand@verizon.net](mailto:jrst.amand@verizon.net)

Carol L. Jones, Administrative Practice Officer  
Division of Developmental Disabilities  
P.O. Box 726  
Trenton, New Jersey 08625-0726

via email to: [DDD-CO.LAPO@dhs.state.nj.us](mailto:DDD-CO.LAPO@dhs.state.nj.us)

RE: Propose amendments to the Community Care Waiver Waiting List Procedures at N.J.A.C. 10:46C.

I am the sister and legal guardian of Rosemary, age 64, who has been living at Green Brook Regional Center (GBRC) since March 2014. Rosemary lived at Woodbridge Developmental Center for 39 years and was forced to leave because of its closure in January 2015. I am also the president of the Green Brook Regional Center Family and Friends Association, and the Association for Individuals with Intellectual Disabilities.

Although I have and will always advocate for high quality care for all individuals with Intellectual and Developmental Disabilities (I/DD) no matter where they choose to live, I am a strong supporter of our state's developmental centers which are licensed by the Centers for Medicare and Medicaid Services (CMS) as an Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities (ICF/IID).

I am concerned with your statement:

“In addition, amendments will clarify that the Division serves individuals who meet the level of care for an Intermediate Care Facility for Individuals with Intellectual Disabilities through the Community Care Program,”

Those individuals who need or choose ICF/IID level of care cannot be equally cared for through the Community Care Program. The Community Care Waiver, the essence of the renamed

Community Care Program is fundamentally different than the ICF/IID level of care. One does not equate with the other. If you provide CCW level of care instead of the ICF/IDD level of care you are providing a much less comprehensive level of care. The developmental centers (ICF/IIDs) are the most comprehensive program offered by CMS. A person in need of an “active treatment plan” can only be adequately served in an ICF/IID. Other types of residences and congregate care facilities may model some of their services after an ICF/IID, but none are mandated by federal law to provide neither the same oversight nor the hallmark “active treatment plan.” I refer you to the link below showing the definition and comprehensiveness of the “active treatment plan.”:

[https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/ICFMR\\_Glossary.pdf](https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/ICFMR_Glossary.pdf)

In addition, the federal CMS rules on admissions to ICF/IID says states must provide access to ICF/IID services to the individuals who request these placements through their guardians. I quote from the Medicaid.gov site:

<https://www.medicaid.gov/medicaid/ltss/institutional/icfid/index.html>

### ***Eligibility for ICF/ID Benefit***

*ICF/ID is available only for individuals in need of, and receiving, active treatment (AT) services. AT refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. AT does not include services to maintain generally independent clients who are able to function with little supervision and who do not require a continuous program of habilitation services. States may not limit access to ICF/ID service, or make it subject to waiting lists, as they may for Home and Community Based Services (HCBS). Therefore, in some cases ICF/ID services may be more immediately available than other long-term care options. Many individuals who require this level of service have already established disability status and Medicaid eligibility.*

ICF/IID level of care by definition and in function, can only be provided by a CMS licensed ICF/IID and not the NJ Community Care Program. I request the Proposed Readoption with Amendments: N.J.A.C 10:46C reflect this difference. It is misleading and dishonest to suggest that the CCW / Community Care Program can or will provide the same level of care as an ICF/IDD.

Thank you for this opportunity to provide informal comments on this extremely important issue.

Sincerely,  
Joanne St. Amand