

ACCESSING HOUSING AND RESIDENTIAL SERVICES FOR INDIVIDUALS WITH AUTISM AND DEVELOPMENTAL DISABILITIES

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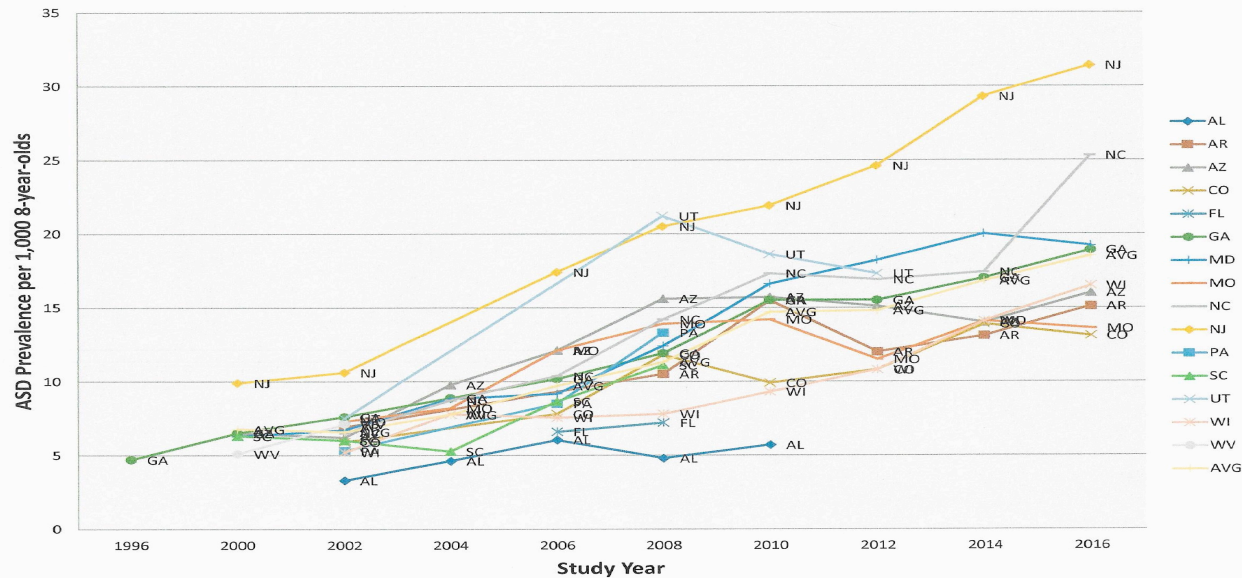
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ADDM ASD Prevalence: 1996 -2016



Autism Prevalence Rate

According to the Centers for Disease Control and Prevention (CDC) the national rate of children identified with Autism Spectrum Disorder is 1 in 54 children. This statistic is based on their evaluation of health and educational records of 8-year-old children in 2016 in 11 states, including New Jersey. New Jersey has the highest rate of autism in the nation: 1 in 32 children, or 3.1 % of 8 year-old children. New Jersey's prevalence continues to exceed and outpace other states.

(AutismNJ.org)

URGENT NEED

- **More than 80,000 adults waiting for housing needed in the next year.**
- **Waiting lists can be as long as 15 years.**
- **Nearly one million living with caregivers age 65 or older.**
- **Fear and anxiety surrounding
“What will happen when I’m gone?”**

WHICH SYSTEM?

Children (under 21 covered by IDEA) vs. Adults (over 21 within the Division of Developmental Disabilities - DDD). Funding streams and eligibility criteria differ.

What is funding needed for?

- **Housing itself – construction costs.**
- **Cost of rent (e.g., housing vouchers, monthly SSI payments.)**
- **Budget for services and supports such as direct support professionals in both licensed (e.g., group home, supervised apartment) and unlicensed settings (e.g., rental properties with self-directed employees providing support.)**

FUNDING SOURCES FOR RESIDENTIAL SERVICES FOR CHILDREN (under 21 years)

- **School District (e.g., out of state campus programs).**
- **Children's System of Care (CSOC)/PerformCare**
 - DDD used to serve children as well as adults. As of January 1, 2013, DDD transferred most developmentally disabled children (under 21) that had been served by DDD to the Department of Children and Families (DCF).
 - CSOC now serves children (under 21) with developmental disabilities. CSOC also serves children with mental, emotional, and behavioral health needs as well as youth with substance abuse challenges.
- **Health Insurance** — Acute, stabilization, generally short term (e.g., Kennedy Krieger Institute at Johns Hopkins).

SCHOOL DISTRICT FUNDING OF RESIDENTIAL PLACEMENTS

- **IDEA requires that local school districts provide students residing within their districts with a Free Appropriate Public Education (“FAPE”).**
- **Pursuant to the FAPE provision of the IDEA school districts are required to provide disabled children with special education and related services that meet their *individualized needs*.**
- **These services *may include residential placements* which must be provided at no cost to the child’s parent or guardian. 20 U.S.C. §1401(9)(A); 34 C.F.R. §300.17(a); N.J.A.C 6A14-1.1(d)(1)**
- **Note: FAPE is a federal entitlement and a school district cannot require a family to pursue state funding or health insurance.**

SEMINAL THIRD CIRCUIT CASE ON RESIDENTIAL PLACEMENT BY SCHOOL DISTRICT

*Kruelle v. New Castle County School
District*, 642 F. 2d 687 (3d Cir. 1981)

In *Kruelle*, the school district argued that the proposed residential placement was “too restrictive” and services sought were “more in the nature of parenting than education.” The Court rejected the school district’s argument and held that the lower court properly placed responsibility on the school district for residential placement in order to provide FAPE for the student noting that “*consistency of programming and environment is critical to student’s ability to learn.*”

ADULT SERVICES-DIVISION OF DEVELOPMENTAL DISABILITIES (DDD)

- The Community Care Program (CCP), formerly the Community Care Waiver (CCW), is a Medicaid program used to fund DDD in home services and residential placements. The CCP is part of the Comprehensive Care Waiver.
- An individual **MUST** be enrolled in Medicaid in order to be placed in the CCP.
- For community based programs (not Developmental Centers, nursing homes) waiver funding source is federal matching program through Home and Community Based Services (HCBS).

RESIDENTIAL SERVICES CONTINUED...

Waiting List - There is currently a long waiting list for the CCP. In order to be placed on the waiting list.

- The person's parents must both be aged 55 or over
- In certain circumstances where a person is at risk of “imminent harm or homelessness” they may be able to **bypass the list** and be placed directly in the CCP or granted an emergency residential placement.
- Community Care Program waiting list – not priority or general.

KEY QUESTIONS

What can you use your HCBS funds for?

or

Where are you *allowed* to live if you are developmentally disabled or have autism?



LET'S PAUSE FOR TERMINOLOGY

- ASD – Autism Spectrum Disorder
- I/D/D – Intellectual/Developmental Disability
- CSOC/PERFORMCARE – Children's System of Care
- IDEA – Individuals with Disabilities Education Act
- DDD – Division of Developmental Disabilities
- CCP – Community Care Program
- SP – Supports Program
- HCBS - Home and Community Based Services

States lay out their plans for services and housing options funded by HCBS in Statewide Transition Plans (STP).

WHAT IS AN STP?

- STP stands for Statewide Transition Plan.
- As part of the federal Affordable Care Act, each state is required to create an STP that must be filed with the Centers for Medicare & Medicaid Services (CMS).
- This is a necessary requirement in order for the state to receive Medicaid funding for adult services. States were initially directed to come into full compliance with these Medicaid rules by March 17, 2019 however implementation has been delayed until March 17, 2022.
- **Critical questions – what types of settings are “in compliance?” What do the feds allow? What does New Jersey allow?**

ADVOCACY FOR CHOICE

“Housing policies on all levels – federal, state and local – should aim to remove barriers and unleash new options and capacity. To this end, we call for a system that incentivizes and supports a full continuum of residential options.” *National Council on Severe Autism – NCSA.org*

“Just as housing and supports options for seniors have diversified and expanded over the past fifty years, individuals with autism and other I/DD’s should also be able to access a variety of choices to meet their broad spectrum of support needs and diverse lifestyle preferences.” *APlaceInTheWorld.org*

“I would like to live on a farm with my friends.” *Adult with autism testifying at New Jersey Public Comment Session on STP.*

FEDERAL SETTINGS RULE - OUTCOME ORIENTED

The definition is designed to be **outcome-oriented and experiential**. This means a determination about whether or not a setting meets these characteristics is based upon the needs of the people receiving services there, as reflected in their person-centered plans. **It is not based upon the physical location of the setting, the size of the setting, or a prescribed duration or number of community-based activities.**

- No setting size, physical characteristics, person or density limit.
- However, Federal Rule allows states to be more restrictive.

“PRESUMED NOT ELIGIBLE” – FEDERAL CONCEPT

The settings are presumed to have the qualities of an institution and must go through a “heightened scrutiny” review.

- any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,
- any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or
- any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.

(NOTE – DEFINITION OF “EFFECT OF ISOLATING” = KEY QUESTION AND SOURCE OF CONFUSION)

NJ's STP – Problems with Original STP:

- 4-6 bed limit for group homes;
- 25% density limit for public or private housing complexes;
- Outright ban on campuses, intentional communities and farmsteads; and
- Requirement that individuals spend 75% of each day in the community and away from their program's main center – eventually changed to “majority of the day” participating in community based activities after outcry from the community.
- **MOST RESTRICTIVE STP OF ANY STATE.**
Advocacy in opposition to restrictions and in support of choice grows and is ultimately successful in New Jersey.

NJ's STP – History and Advocacy

- January 26, 2015 – NJ released STP for public comment – **Outreach to the community very poor** – most people are not made aware of the significance of the STP – how it will affect people with developmental disabilities
- February 19, 2015 – **Say NO to NJ's Statewide Transition Plan – Say Yes to Choice!** Facebook Page created to organize advocates.
- February 26, 2015 – Deadline for comments. As a result of advocacy DDD receives over 1000 comments with concerns about the most stringent parts of the plan – density limits on housing – mandates on time spent in community
- March 18, 2015 - 30-day extension granted by CMS for DHS/DDD to fully incorporate comments into plan
- April 18, 2015 - Plan submitted by DHS/DDD to CMS – Grandfathers in current programs but still problematic for new programs – Advocacy continues
- July 1, 2016 – DDD released Addendum to the Statewide Transition Plan (STP). The Division also posted a pre-recorded webinar to provide an overview of the Statewide Transition Plan. DHS conducted three open comment sessions in August of 2016.
- December 8, 2016 - Amended (current) version of STP publicly released and submitted to CMS for approval.

12/8/16 – AMENDED VERSION OF STP SUBMITTED TO CMS. ADVOCACY WORKS!

- “Density Review Process” replaced with a more inclusive “Community Integration Review” that will take into account factors other than just numbers of residents when deciding if a setting is in compliance with Medicaid’s Home and Community Based Settings Rule.
- Additionally, the stipulation that Developers/Providers will not be able to apply for state density review (now “community integration review”) until a setting is operational and occupied was removed in order to allow projects to be reviewed during the planning phase, encouraging much needed new development.
- Currently New Jersey is open to an array of choices and has been approving a variety of models.

FEDERAL CLARIFICATIONS

- At federal level, discussion regarding unintended consequences under the HCBS final rule resulted in issuance of new guidance on March 22, 2019
- Settings described in previous guidance are no longer presumed institutional nor isolating and will no longer be forced to go through heightened scrutiny if the state determines the setting is compliant with the HCBS Final Rule.
- “I want to emphasize that the HCBS settings rule does not prohibit individuals from receiving Medicaid HCBS in congregate settings, farmsteads, gated communities and disability specific settings.” *Seema Verma, CMS Administrator, June 27, 2018*

Benjamin's Hope – Holland, Michigan



A 2018 N.J. Superior Court decision upheld Fair Share Housing Center's formula regarding the obligation of municipalities to create affordable housing. This decision may require the creation of over 150,000 affordable housing units statewide, which includes housing for the developmentally disabled.

(In the Matter of the Municipality of Princeton; In the Matter of West Windsor Twp., Docket Numbers MER-L1560/1561-15)

Now is the time to improve and create!

RESOURCES

- **Follow “NJ Citizens for Choice in DD Housing and Services” on Facebook**
- **Join Coalition For Community Choice:**
<http://coalitionforcommunitychoice.org>
- **Join Together for Choice:**
<http://Togetherforchoice.org>
- **Join National Council on Severe Autism**
<http://ncsautim.org>

Visit <http://circlehaven.org>



QUESTIONS???

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