

A Snapshot of Developmental Disabilities Services in New Jersey: *Demographics & Service Trends*

A Policy Brief by The Boggs Center on Developmental Disabilities

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Introduction:

As New Jersey's federally designated University Center for Excellence in Developmental Disabilities Education, Research, and Service, The Boggs Center has a mandate to provide information to individuals with disabilities, their families, those who provide supports and services, and policymakers. This document presents a profile of demographics and service trends among New Jersey's citizens with developmental disabilities. The data presented provides information about adults with developmental disabilities receiving services through the State's Department of Human Services, Division of Developmental Disabilities, including diagnosis, living arrangements, and fiscal effort devoted to services. This data was collected through national research projects and reflects trends in supports and services reported for fiscal year 2015 (FY15), the most recent year for which this information is available. Where possible, more recent information from the Division was used.

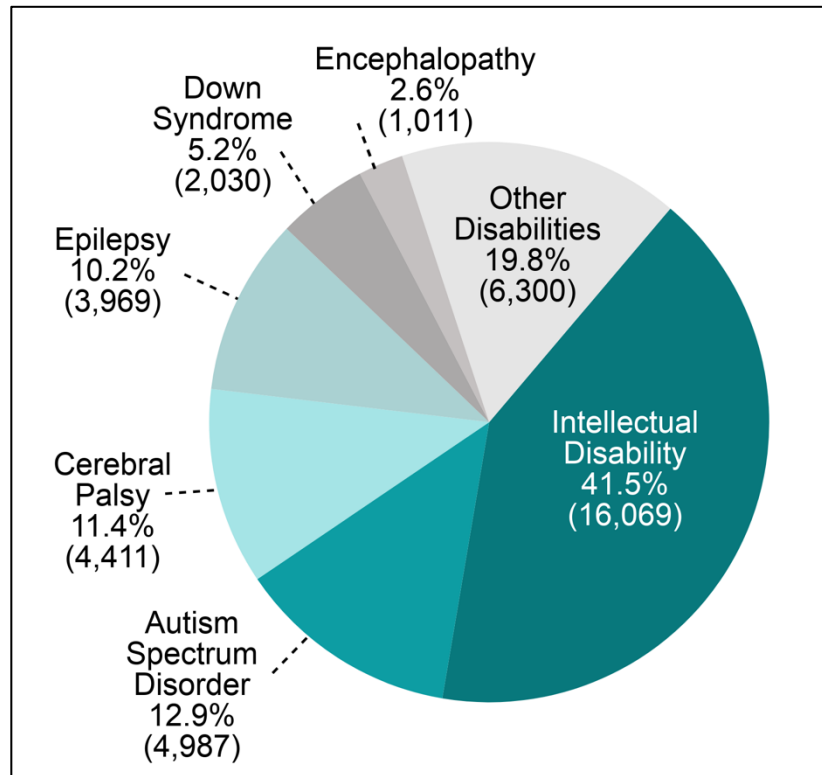
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Who is Served by the New Jersey Division of Developmental Disabilities?

Individuals Served In-State through the Division of Developmental Disabilities by Diagnosis (FY15)*

Figure 1



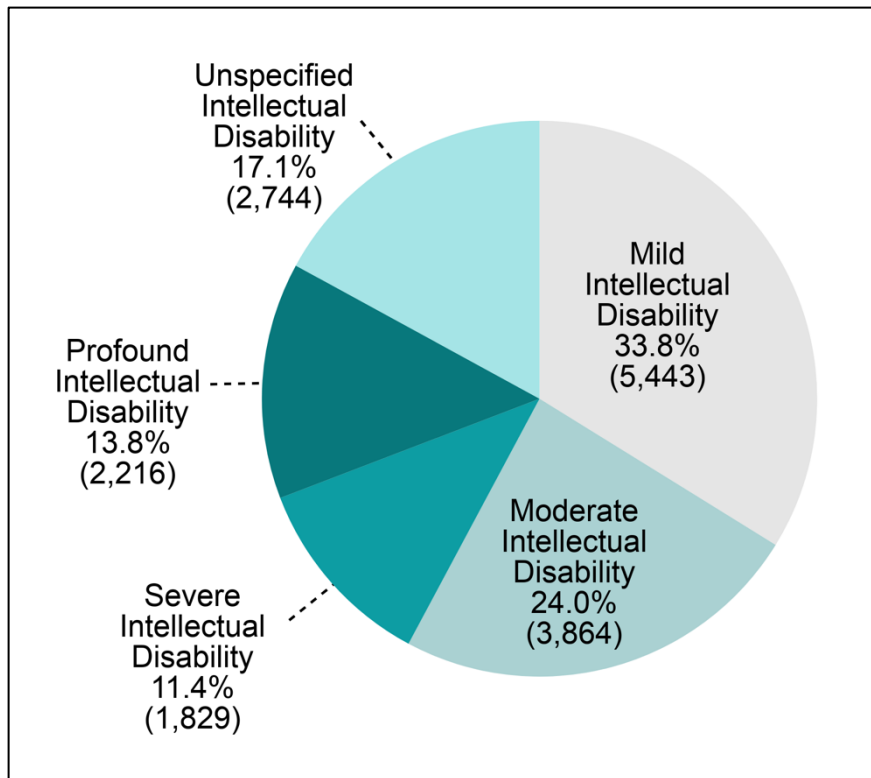
The chart above displays the range of conditions experienced by adults with developmental disabilities (DD) served through New Jersey's Department of Human Services, Division of Developmental Disabilities between July 1, 2014 and June 30, 2015. This data is reflective of individuals who may have more than one disability; therefore, the total number of individuals is higher than the number served by the Division in FY15 (25,371).

- The largest portion of those receiving services in FY15 were diagnosed with intellectual disability (**41.5%**)
- A smaller percentage of those receiving services were diagnosed with:
 - autism spectrum disorder (**12.9%**),
 - cerebral palsy (**11.4%**),
 - epilepsy (**10.2%**),
 - Down syndrome (**5.2%**),
 - encephalopathy (**2.6%**).
- The remaining portion of those receiving services (**19.8%**) represented 105 different conditions

****Data is reflective of individuals who may have more than one diagnosis***

Intellectual Disability Among Those Served In-State by Severity (FY15)*

Figure 2



- The largest portion of those served by the Division of Developmental Disabilities diagnosed with an intellectual disability had mild intellectual disability (**33.8%**)
- Nearly one-quarter (**24.0%**) were diagnosed with moderate intellectual disability
- A smaller percentage of individuals with intellectual disability were diagnosed with:
 - severe intellectual disability (**11.4%**)
 - profound intellectual disability (**13.8%**)
 - unspecified intellectual disability (**17.1%**)

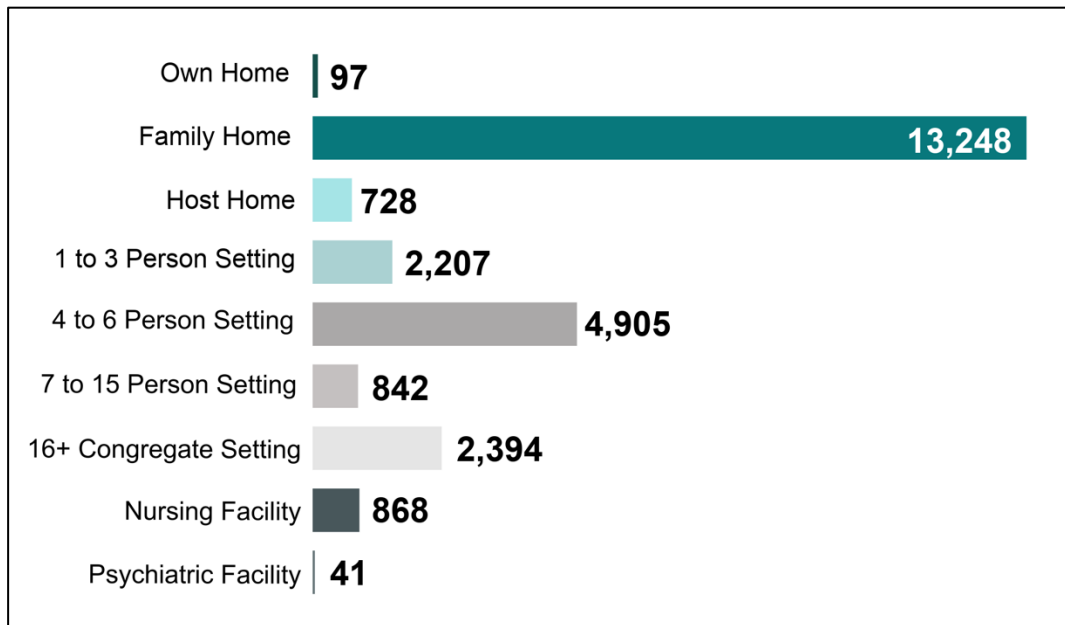
The information described in this section was compiled from the New Jersey Department of Human Services, Division of Developmental Disabilities Fiscal Year 2015 Data Report: http://www.nj.gov/humanservices/ddd/documents/division_census_data_report_.pdf

****Individuals reflected in this data may have additional developmental disabilities beyond intellectual disability***

Where Do People with Developmental Disabilities in New Jersey Live?

Residence Size and Type of Those Receiving Services Through the Division of Developmental Disabilities (FY15)

Figure 3



- The majority of people receiving services in New Jersey lived within their family home (**52.3%**)
- The largest portion of those living outside of the family home lived in a group home of 4 to 6 people (**19.7% of people receiving services**)
- Far fewer people lived in smaller, 1 to 3 person individualized settings (**8.7%**)
- Less than one percent (**0.4%**) lived in their own home
- In FY15, New Jersey was listed among the top 5 states in terms of institutional census
 - The number of people served in New Jersey's Developmental Centers has decreased since the time of data collection (**1,336** as of May 2018)

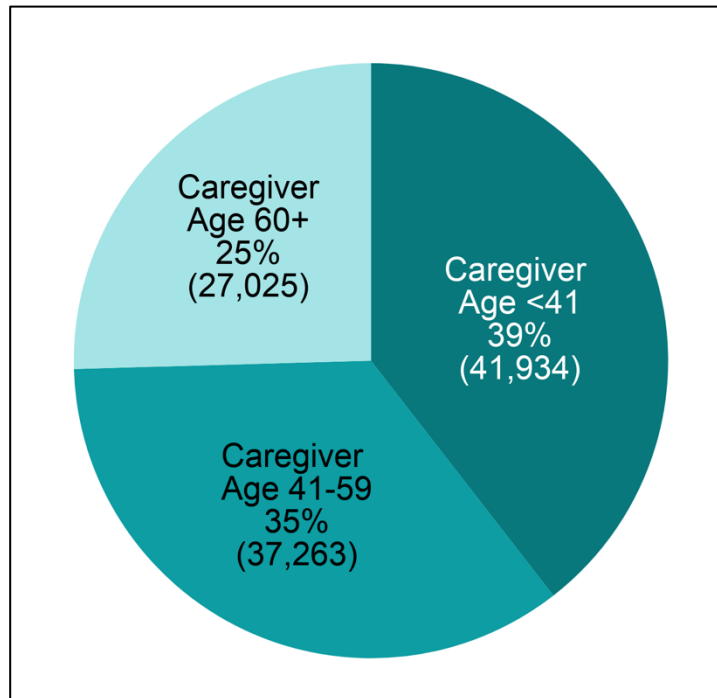
This information was obtained through the *National Residential Information Systems Project (RISP)*, a longitudinal study of long-term supports and services for people with intellectual and developmental disabilities conducted by the University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. The most recent *Residential Information Systems Project Annual Report: Status and Trends Through 2015* and state profiles can be found on the RISP website:

<https://risp.umn.edu/>

The updated institutional census information for New Jersey was provided by the Division of Developmental Disabilities.

Estimated Number of Individuals with Developmental Disabilities Living with Family Caregivers in New Jersey by Caregiver Age (FY15)*

Figure 4



* Braddock et al. 2016, based on Fujiura 2008, 2012

The chart above displays the estimated number of individuals with DD living with family caregivers in New Jersey by caregiver age. This estimate is based on the prevalence of developmental disabilities in the state, and accounts for both those who are and are not known to the system.

Family members frequently serve as the main supporters of children and adults with DD.

- An estimated **35%** of people with DD were living with family caregivers age 41-59 in FY15. Caregivers in this age group may experience the added responsibilities of caring for an aging parent while also attempting to balance demands for care with other responsibilities, including: employment, healthcare, and maintaining family and social relationships
- One quarter (**25%**) of people with DD in New Jersey were estimated to be living with caregivers over age 60. There are many challenges in supporting aging caregivers:
 - they tend to be socially isolated,
 - may not be connected with service systems, and
 - might not have planned for who will care for their loved one with a disability when they are no longer able to do so

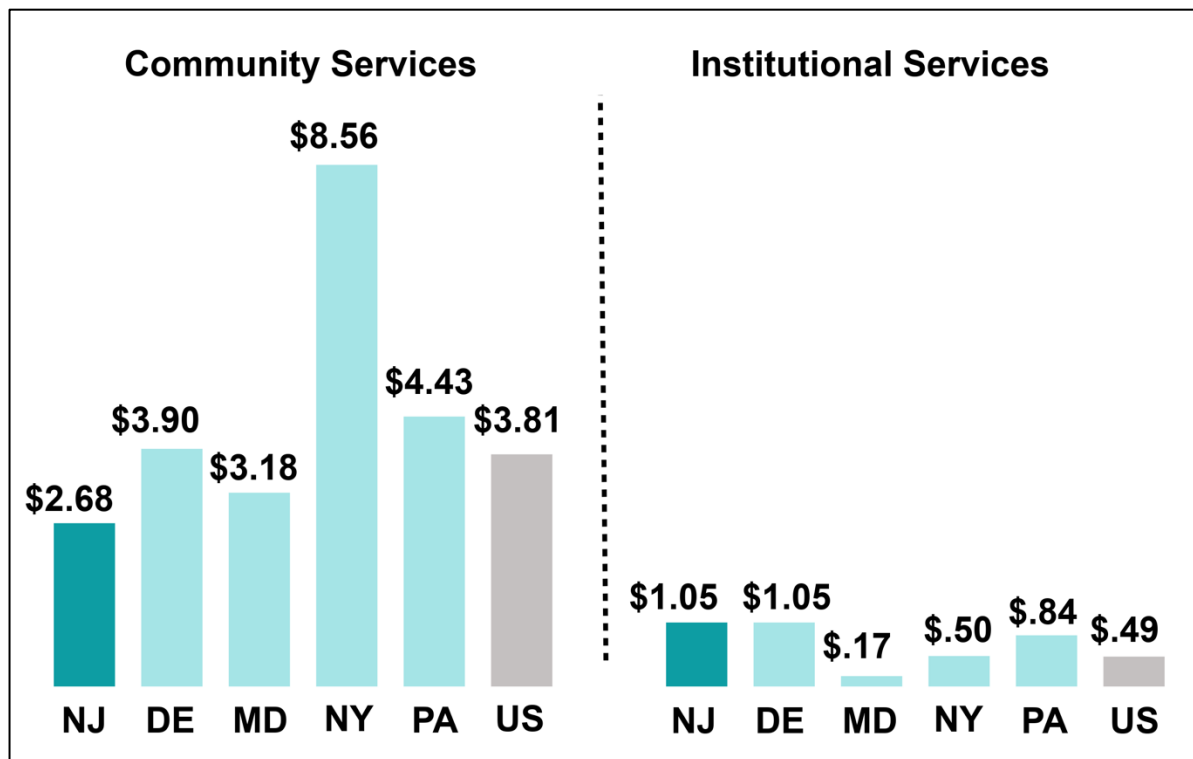
The information in this graph was obtained through *The State of the States in Intellectual and Developmental Disabilities*, a national longitudinal study of financial and programmatic trends in DD services conducted by the University of Colorado, Department of Psychiatry and

Coleman Institute for Cognitive Disabilities in collaboration with the University of Chicago, Department of Disability and Human Development. State profiles and a create-a-chart feature are available on The State of the States in Developmental Disabilities website: <http://stateofthestates.org/>

How does New Jersey Spend for Developmental Disabilities Services?

Fiscal Effort for Community and Institutional Services (FY15)

Figure 5



- In FY15, New Jersey ranked **4th** in fiscal effort dedicated to institutional settings, and **39th** in spending for services provided in the community
- New Jersey spent less than neighboring states (**\$2.68**) for services in the community and more (**\$1.05**) for services provided in institutional (16+ person) settings

This information was obtained through the create-a-chart feature of *The State of the States in Intellectual and Developmental Disabilities Project* website: <http://stateofthestates.org/index.php/create-idd-chart>

***Fiscal effort is measured in terms of spending for DD services per \$1,000 of statewide aggregate personal income.**

References:

Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2017). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2015*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

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