

# **NJ Adults with Cognitive Disabilities: Some Need Guardianships, Most Don't**

by Thomas F. Coleman

As in all states, guardianship laws in New Jersey are intended to protect adults who have mental or developmental disabilities so serious that they lack the capacity to govern themselves or manage their affairs. Guardianships for such adults may be ordered only if less restrictive alternatives are not viable. Such alternatives could include trusts, powers of attorney, or supported decision-making.

New Jersey is home to some 7.3 million adults. According to data from the federal Centers for Disease Control, about 10% of these adults (730,000) have a cognitive disability. There are only 36,000 open adult guardianship cases in New Jersey. That means that about 694,000 adults with cognitive disabilities in the state are living their lives independently or with support systems that do not involve judicial supervision through a guardianship.

A guardianship petition can be filed against any adult with a mental or developmental disability. About 2,900 petitions are [filed annually](#) in New Jersey. The court must then distinguish between those who need a guardianship and those who do not. Each case must be decided on its own merits. A mere diagnosis of a disability is not sufficient to warrant a guardianship. There must be a showing, by clear and convincing evidence, that the individual lacks capacity to make major life decisions and that less restrictive alternatives are not viable.

Some adults with autism may need a guardianship but most do not. A New Jersey Autism Study found that 2.9% of 8-year-olds in the state were on the autism spectrum. If that percent applies to adults, there are 211,700 autistic adults in New Jersey. Only 39% of people in the autism study had an intellectual disability. Some 61% did not. Generalizing this percentage to the larger autistic adult population would result in 129,137 autistic adults without intellectual disabilities.

The Centers for Disease Control found that of 20,000 autistic children whose records were reviewed, some 26.7% had profound autism. If that percent were applied to the 211,700 autistic adults in New Jersey, only 55,523 would have profound autism. While most adults with that diagnosis may require a guardianship, the reverse may be true for adults whose autism is not profound.

The law declares that self-determination is a fundamental right. It also states that adults, regardless of disability status, are presumed to be competent. The factual reality of competency demonstrated by the data described above coincides with this legal presumption. Most adults with cognitive disabilities, including those with autism, do not need a guardianship. Judges who decide cases, and legislators who pass laws, should keep this in mind. So should organizations that assist people with developmental disabilities and their families. Existing legal protections for people with disabilities should be respected, not weakened to make guardianships more expedient. ◇◇◇

Thomas F. Coleman is the legal director of [Spectrum Institute](#), a nonprofit organization advocating for justice and equal rights for adults with mental and developmental disabilities who become involved with guardianship or conservatorship proceedings. Contact: [tomcoleman@spectruminstitute.org](mailto:tomcoleman@spectruminstitute.org)

[2020-21 New Jersey Adult Family Survey Web Report](#)

[2020-21 New Jersey Family/Guardian Survey Web Report](#)

[2020-21 New Jersey In-Person Survey \(IPS\) State Report](#)

[https://idd.nationalcoreindicators.org/survey-reports-insights/report-library/?exposed\\_search&exposed\\_taxonomy\\_state%5B0%5D=61](https://idd.nationalcoreindicators.org/survey-reports-insights/report-library/?exposed_search&exposed_taxonomy_state%5B0%5D=61)

## New Jersey Overuses Guardianships for Adults with Developmental Disabilities

(as compared to the national average of other states)

Table 29. Level of Guardianship

State v NCI-IDD	None	Limited Guardianship	Full Guardian	Has Guardian, but Unable to Distinguish Level	Don't Know	N
NJ	31%	9%	52%	3%	4%	405
Weighted NCI-IDD Average	53%	10%	27%	8%	2%	19,826

Table 9. Family Member Has Legal Court Appointed Guardian or Conservator

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
NJ	0%	7%	88%	4%	208
Weighted NCI-IDD Average	29%	13%	52%	6%	2919

Table 8. Family Member Has Legal Court Appointed Guardian or Conservator

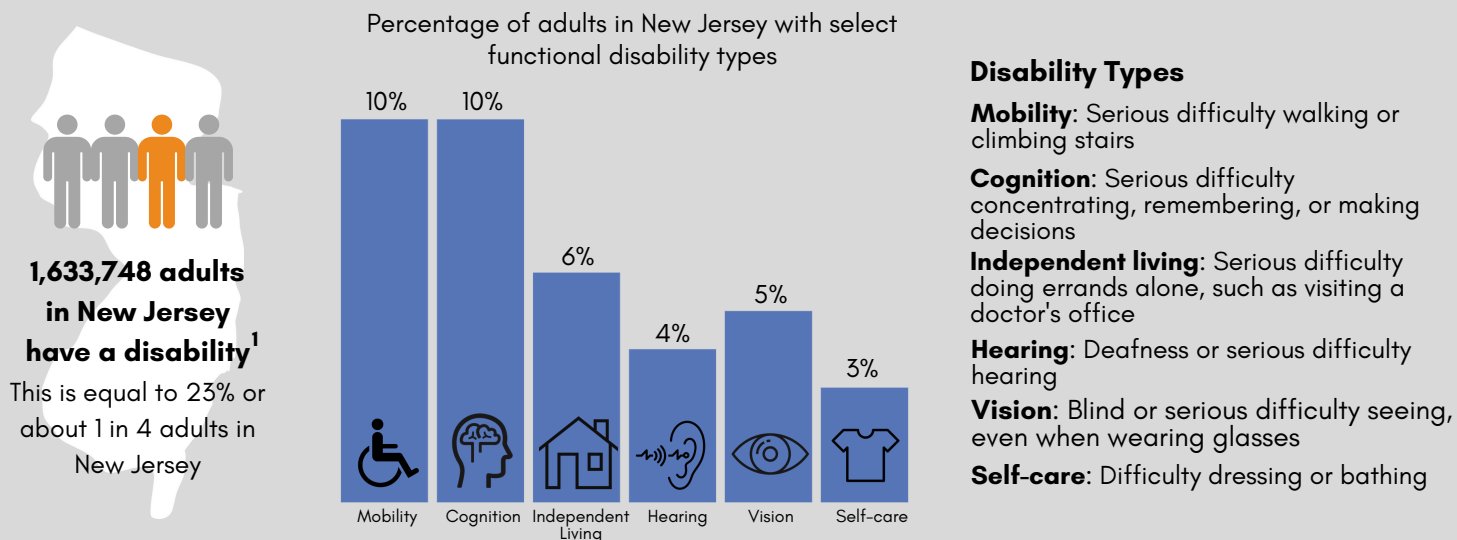
All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
NJ	2%	7%	88%	2%	282
Weighted NCI-IDD Average	28%	11%	57%	4%	4610

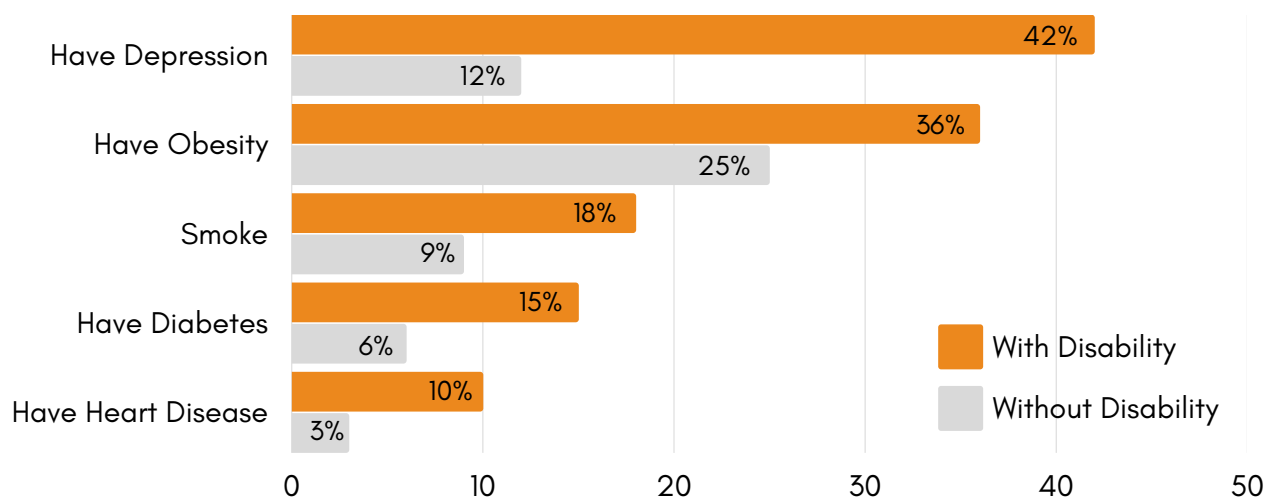
**Data Sheet Produced by Spectrum Institute**  
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Everyone can play a role in supporting more inclusive state programs, communities, and health care to help people with, or at risk for, disabilities be well and active in their communities. Join CDC and its partners as we work together to improve the health of people with disabilities.



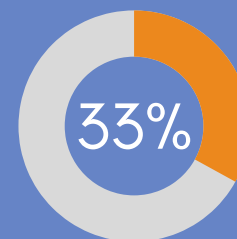
Adults with disabilities in **New Jersey** experience health disparities and are more likely to...<sup>1</sup>



Visit [dhds.cdc.gov](https://dhds.cdc.gov) for more disability and health data across the United States.

**DISABILITY HEALTHCARE COSTS IN NEW JERSEY<sup>2</sup>**

- About **\$24.8 BILLION** per year, or up to **33%** of the state's healthcare spending
- About **\$21,415** per person with a disability



Learn how CDC and state programs support people with disabilities at [www.cdc.gov/ncbddd/disabilityandhealth/programs.html](https://www.cdc.gov/ncbddd/disabilityandhealth/programs.html).

NOTE: DATA ARE ROUNDED TO THE NEAREST WHOLE FIGURE. FOR MORE PRECISE PREVALENCE DATA, PLEASE VISIT [DHDS.CDC.GOV](https://dhds.cdc.gov).

1. DATA SOURCE: 2021 BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS).  
 2. DISABILITY HEALTHCARE COSTS ARE PRESENTED IN 2017 DOLLARS AS REPORTED IN KHAVJOU, ET AL. STATE-LEVEL HEALTH CARE EXPENDITURES ASSOCIATED WITH DISABILITY. 2021. PUBLIC HEALTH REP.



# A Snapshot of Autism Spectrum Disorder in New Jersey

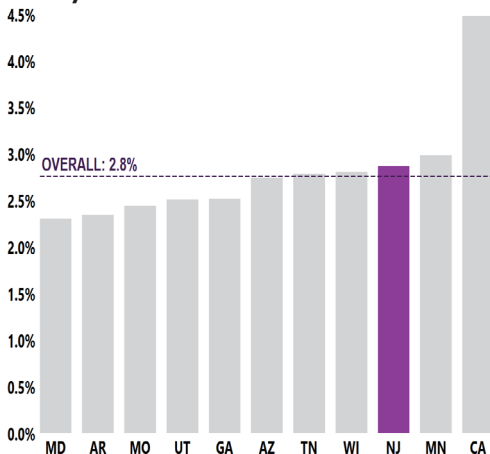
Findings from the New Jersey Autism Study (NJAS) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

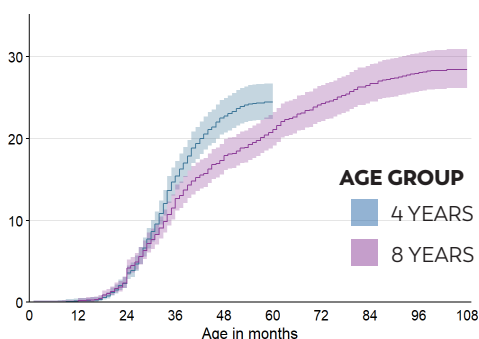
## 1 in 35

Or **2.9%** of 8-year-old children in New Jersey were identified with ASD by in 2020.



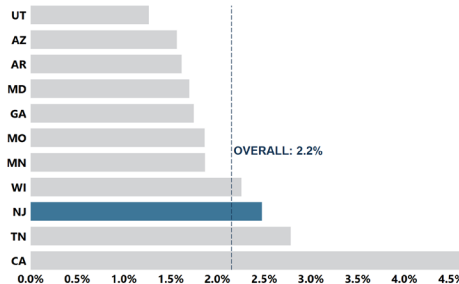
This is higher than the average identified with ASD (2.8%) across US communities where the ADDM Network tracked ASD among school-age children.

**Children aged 4 years** were 1.3 times as likely to receive an ASD diagnosis by 48 months of age compared to **children aged 8 years in NJAS.**



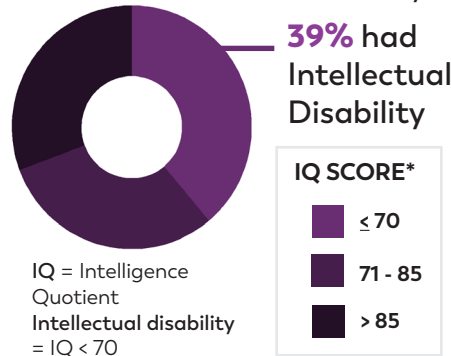
## 1 in 40

Or **2.5%** of 4-year-old children were identified with ASD by NJAS.



## IQ data available for 63%

Of children identified with ASD by NJAS

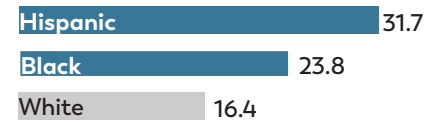


## 58% of 8-year-old children

were identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



**Among NJAS 4-year-olds**, Hispanic children were 1.9 times as likely to be identified with ASD and Black children were 1.4 times as likely to be identified with ASD compared to White children.

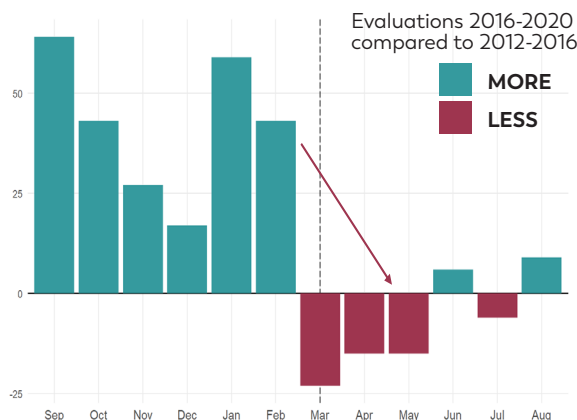


Values indicate prevalence per 1000.

**Among 8 year olds**, Hispanic, and Black children were 1.7 times as likely to be identified with ASD as White children.



Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between white and A/PI children in NJAS.



**The COVID-19 pandemic disrupted many aspects of life, including the ability to evaluate children for autism.** Before the pandemic, 4-year-old children had higher ASD identification than 8-year-old children had when they were aged 4 years. In the first few months of the pandemic, **4-year-old children were less likely to have an evaluation than 8-year-old children had when they were the same age.**

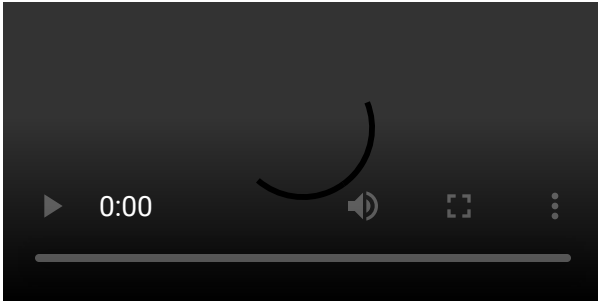
# What Is Profound Autism?

[childmind.org/article/what-is-profound-autism](https://childmind.org/article/what-is-profound-autism)

A proposed category for kids on the severely impaired end of the autism spectrum

Writer: [Caroline Miller](#)

Clinical Experts: [Cynthia Martin, PsyD](#) , [Catherine Lord, PhD](#)



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10 min



Autism affects children in dramatically different ways. On one end of the autism spectrum are college- and career-bound children with distinctive talents and abilities. On the other end are kids who are intellectually disabled, nonverbal, and unable to function without intensive, lifelong support.

Last week the CDC [released a study](#) measuring the prevalence of those on the severely impaired end of the spectrum. Over the last two years, a proposal has been gaining traction for giving them a separate category *ordiagnosis*

from those who are higher functioning: profound autism.

The CDC study, based on a survey of records of more than 20,000 8-year-old children on the autism spectrum, found that 26.7 percent would meet the criteria for profound autism.

## What is profound autism?

Profound autism is defined as having an IQ of less than 50 or being nonverbal or minimally verbal. Kids with profound autism need help with tasks of daily living, such as dressing, bathing, and preparing meals. They are also likely to have medical issues like epilepsy and behaviors like self-injury and aggression that interfere with safety and well-being. They require round-the-clock support, throughout their lives, to be safe.

The CDC study follows [a 2021 report by a Lancet Commission](#) on the Future of Care and Research in Autism that endorsed the need for a new classification of profound autism.

“The main purpose was to call attention to the fact that these kids and adults exist, and that they do need different services,” said [Catherine Lord, PhD](#), the co-chair of the Lancet Commission. “And that we can predict who they will be, not at age 2 but by age 8 or 9, and we need to plan for them.”