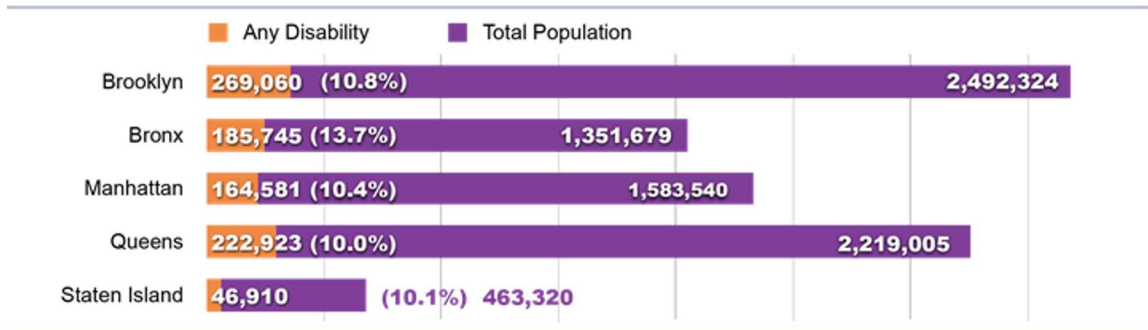


Prevalence data for people with Intellectual and Developmental Disabilities

- An estimated 7.37 million people in the U.S. had some form of intellectual or developmental disability (I/DD) in 2016.¹
- Almost one million individuals with disabilities reside in NYC (11.1% of population).²



- The Centers for Disease Control and Prevention (CDC) reported that the estimated prevalence rate for autism among individuals in the U.S. is 1 in 59 children (1 in 38 Boys and 1 in 152 girls).³
- A CDC and the Health Resources and Services Administration (HRSA) study found that 17% of children aged 3–17 years had a developmental disability, and importantly, that this percentage increased over the two time periods compared, 2009–2011 and 2015–2017; increases were also seen for specific developmental disabilities in the same age group.” (data from the National Health Interview Survey (NHIS), included parent-reported data from 88,530 children aged 3–17 years).
 - The study showed some groups of children were more likely to have been diagnosed with a developmental disability than others, such as:
 - Boys compared to girls;
 - Non-Hispanic white and non-Hispanic black children compared to Hispanic children or non-Hispanic children of other races;
 - Children living in rural areas compared to children living in urban areas; and
 - Children with public health insurance compared to uninsured children and children with private insurance.

¹ Golub, D. & Berns, P. Disability data digest 2018. Accessed at:

<http://www.inarf.org/uploads/2/5/1/7/25171275/august-2018-disability-data-digest-medisked.pdf>

² Center for Independence of the Disabled, NY. Disability matters: unequal treatment and the status of people with disabilities in New York City and New York State. Accessed at: <http://researchondisability.org/docs/default-document-library/disability-matters.pdf?sfvrsn=2> and Accessible NYC : an annual report on the state of people with disabilities living in NYC 2018 Edition. Accessed at:

<https://www1.nyc.gov/assets/mopd/downloads/pdf/accessiblenyc-2018.pdf>

³ Center for Disease Control and Prevention. Data and statistics on autism spectrum disorder. Accessed at: <https://www.cdc.gov/ncbddd/autism/data.html>

- The percentage of children aged 3–17 years diagnosed with a developmental disability increased—from 16.2% in 2009–2011 to 17.8% in 2015–2017.
 - Specifically, diagnoses increased for attention-deficit/hyperactivity disorder (8.5% to 9.5%), autism spectrum disorder (1.1% to 2.5%), and intellectual disabilities (0.9% to 1.2%).

** “The reasons for these increases were not examined in the current study, but previous research has found improved awareness, screening, diagnosis, and service accessibility may contribute to the increases seen.”⁴*

Disparities in Diagnosis and Access to Services for ASD

- Early identification of developmental delays among young children is an important first step in providing the opportunity for children to receive early intervention services to increase functional skills.⁵
- Research suggests that low-income children with ASD might be under-identified and less likely to be receiving ASD-related services than middle- and high-income children with ASD.⁶
- Research also shows racial and ethnic minority families receive services at a later age, and often a different mix of services than their white counterparts.
 - White children are about 19% more likely than black children and 65% more likely than Hispanic children to be diagnosed with autism.⁷
 - Research also shows significantly lower odds of service use among racial and ethnic minorities (resulting from economic factors, service sector factors, and a lack of cultural competency in service delivery).⁸
 - There is no biological reason for autism prevalence to differ across racial and ethnic groups. Research suggests the difference in rates of prevalence are due to a lack of access to diagnostic services.⁹

⁴ CDC – Increase in developmental disabilities among children in the United States. Accessed at: <https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities.html>

⁵ CDC - Screening for Developmental Delays Among Young Children — National Survey of Children's Health, United States, 2007. Accessed at: <https://www.cdc.gov/mmwr/preview/mmwrhtml/su6302a5.htm>

⁶ Boat, T. F., & Wu, J. T. (Eds.). (2015). Prevalence of autism spectrum disorder. In *Mental disorders and disabilities among low-income children* (pp. 241–266). Washington, DC: The National Academies Press.

⁷ Furfaro, H. (2017). Race, class, contribute to disparities in autism diagnoses. Spectrum News. Accessed at: <https://www.spectrumnews.org/news/race-class-contribute-disparities-autism-diagnoses/>

⁸ Dorsett, A., (2015). The intersection of poverty and autism spectrum disorder: a study of institutional and individual disparities in healthcare for autism. Accessed at: https://repository.wlu.edu/bitstream/handle/11021/32376/RG38_Dorsett_Poverty_2015.pdf?sequence=1&isAllowed=y

⁹ Furfaro, H. (2017). Race, class, contribute to disparities in autism diagnoses. Spectrum News. Accessed at: <https://www.spectrumnews.org/news/race-class-contribute-disparities-autism-diagnoses/>

- Another study found that by 24 months of age, black children were almost five times less likely than white children to receive early intervention services, and that a lack of receipt of services appeared more consistently among black children who qualified based on developmental delay alone compared to children with a diagnosed condition.
- Research suggests that non-white children are disproportionately underrepresented in early intervention services and less likely than white children to be diagnosed with developmental delays.¹⁰
- Research highlights the need to ensure developmental screening in low-income, racially diverse urban populations, where the risk of delay is greater and access to services can be more difficult.

Disability and Health

- 38.2 percent of adults with a disability are obese while 26.2 percent of adults without a disability are obese.
- 28.2 percent of adults with a disability smoke while 13.4 percent of adults without a disability smoke.
- 11.5 percent of adults with a disability have heart disease while 3.8 percent of adults without a disability have heart disease.
- 16.3 percent of adults with a disability have diabetes while 7.2 percent of adults without a disability have diabetes.¹¹
- Adults with intellectual and developmental disabilities and diabetes were 2.6 times more likely to be hospitalized than adults without a disability and diabetes.¹²
- Individuals with I/DD are four to five times more likely to have a chronic disease and preventable mortality.¹³ They also struggle with risk factors associated with chronic conditions including poor nutrition, obesity, and sedentary lifestyles.¹⁴

Lack of access to specialized care – (I/DD population)

- When compared with the general population, individuals with I/DD experience poorer health outcomes and inadequate access to healthcare services.¹⁵

¹⁰ Yudin, M. (2014). Early screening is vital to children and their families. Accessed at: <https://blog.ed.gov/2014/04/early-screening-is-vital-to-children-and-their-families/>

¹¹ CDC. Disability and Health. Accessed at: <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

¹² Balogh, R.S., Lake, J.K., Lin, E., Wilton, A. Lunsby, Y. (2015). Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: a population-based study. *Disability Med* 32(2): 235-42. Accessed at <https://www.ncbi.nlm.nih.gov/pubmed/25185567>

¹³ Havercamp, Scandlin & Roth, 2004 & Horowitz, Kerker, Owens & Zigler, 2000

¹⁴ Rimmer, J.H., Chen, M.D., Hsieh, K. (2011). A conceptual model for identifying, preventing, and managing secondary conditions in people with disabilities. *Physical Therapy*. 91(21): 1728-39. Accessed at <https://www.ncbi.nlm.nih.gov/pubmed/22003160>.

¹⁵ Hayden, Kim & DePaepe, 2005 & Krahn, Hammond & Turner, 2006

- Researchers at The Ohio State University Wexner Medical Center’s Nisonger Center conducted a telephone survey of 42,876 adults and 10,122 proxy interviews for children and found that, when comparing age groups, children and older adults with developmental disabilities experienced the greatest disparities in unmet healthcare needs.
 - Key Findings:
 - Among children zero to 18 years of age with developmental disabilities, 14% reported problems receiving needed care, compared to 2% of children without developmental disabilities.
 - Children with developmental disabilities were over three times as likely to have one or more unmet health need as children without developmental disabilities
 - Among adults age 65 years and older, 50% of those with developmental disabilities reported one or more unmet healthcare needs, compared to 17% of those without such disabilities.
 - Adults with developmental disabilities also experienced the greatest unmet dental, vision, and prescription needs. Additionally, adults with developmental disabilities were more than twice as likely to have difficulties accessing specialty care as adults without developmental disabilities.¹⁶
 - Older adults with developmental disabilities were more than seven times as likely to report problems obtaining needed care compared to older adults without developmental disabilities.
- Although more at risk for chronic diseases, individuals with I/DD experience less access to appropriate health care services, and prevention services are rarely implemented with this population.¹⁷
- There are very few providers who specialize in providing comprehensive medical, dental and behavioral healthcare services to individuals with I/DD. Most provider systems do not possess the requisite training and expertise to adequately meet the needs of this population. In addition, conventional care models are generally unsuited to the promotion of the integration and coordination needed to provide efficient and effective care.¹⁸

¹⁶ Four ways mco’s can reduce health disparities in patients with disabilities: Accessed at: <https://www.managedhealthcareexecutive.com/managed-healthcare-executive/news/four-ways-mcos-can-reduce-health-disparities-patients-disabilities/page/0/2>

¹⁷ Anderson, L.L., Humphries, K., McDermott, S., Marks, B., Sisirak, J. & Larson, S. (2013). The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*. 51(5): 385-98. Accessed at: <https://www.ncbi.nlm.nih.gov/pubmed/24303825>.

¹⁸ Ervin, D.A., Hennen, B., Merrick, J., & Morad, M. (2014). Healthcare for persons with intellectual and developmental disability in the community. Accessed at: <https://www.frontiersin.org/articles/10.3389/fpubh.2014.00083/full>.

- According to one survey, almost 60% of the 57 providers surveyed felt that they provide unequal quality of care to patients with I/DD due to a lack of training, time constraints, and communication barriers.¹⁹

*** All data below from:

Braddock, D.L, Hemp, R.E., Tanis, E.S., Wu, J. & Haffer, L. (2017). The state of the states in intellectual and developmental disabilities: 2017. Washington, DC: The American Association on Intellectual and Developmental Disabilities.

Federal, State, and Local Medicaid Spending

- In the U.S. the number of individuals with I/DD residing in settings for six or fewer increased exponentially from approximately 20,000 people in FY 1977 to 559,172 in FY 2015 and public spending for I/DD services grew from \$15.89 billion in 1977 to \$65.21 billion in 2015.
- Total I/DD spending in FY 2015 was \$65.21 Billion
 - HCBS Waiver (70%)
 - Public & Private ICFs/ID (22%)
 - State Plan Medicaid (8%)
- 88% of FY 2015 financial resources in the U.S. was allocated for community residential services for 15 or fewer persons (611,294 individuals), which included:
 - Supported living for 337,264 people
 - Day programs and community supports such as supported employment for 109,954 individuals, and
 - Family support for 523,501 families

New York Statistics

- In FY 2015 there were 72,086 individuals with I/DD living in out-of-home residential settings in New York.
 - 69% (49,618) in 1-6 person settings
 - 25% (18,024) in 7-15 person settings
 - 6% (4,444) in 16+ person settings
- Total public spending for individuals with I/DD in NY (FY 15) was 10.23 Billion
 - Medicaid HCBS (49%)
 - Medicaid ICF/ID (16%)
 - Related Medicaid (8%)
 - State Funds (20%)
 - Other Federal Funds (7%)

¹⁹ Stief, H.D., & Clark, M. (2013). A survey of patients, families, and providers about care of patients with intellectual disabilities. Accessed at: <https://aadmd.org/articles/survey-patients-families-and-providers-about-care-patients-intellectual-disabilities>

- HCBS Waiver participants in NY (FY 15) - 73,815 (cost per participant \$68,200)
- Individual and Family Support Participants and Cost in NY (FY 15)
 - Supported Living participants in NY – 31,101 (cost - \$559.8 million)
 - Family Support participants in NY – 55,194 (cost – 488.3 million)
 - Supported Employment participants in NY – 9,457 (cost – 53.8 million)
- Annual Cost of Care by Residential Setting in NY: FY 2015
 - 16+ State Operated Institution - \$421,185
 - Public ICF/ID (<16) - \$250,330
 - 16+ Private ICF/ID – \$319,415
 - Private ICF/ID (<16) - \$170,058
 - Supported Living - \$17,998
- Estimated Number of Individuals with I/DD by Age Group Living with Family Caregivers in NY: FY 15
 - Caregiver Age < 41 – 77,764 (39%)
 - Caregiver Age 41-49 – 69,067 (35%)
 - Caregiver Age 60+ - 50,054 (25%)
- Estimated Number of I/DD Caregiving Families and Families Supported by I/DD Agencies in NY (FY 15) – 196,880 (28% supported by State I/DD Agencies)

Demographic Shift

- The need for long-term services and supports for the I/DD population is increasing.
- The number of Americans aged 65 years and older will reach 55 million in 2020 and 98 million by 2060.
- In FY 2015, approximately 3.6 million of the 5.1 million people with I/DD in the U.S. received residential care and supports from family caregivers.
 - 871,420 individuals with I/DD were residing with caregivers aged 60 years or more in the U.S.
 - Family caregivers are aging beyond their caregiving capabilities.

Key Challenges Ahead for Supporting the I/DD population as noted by the State of the States in Intellectual and I/DD:

- “Enhance the near-poverty level wages and benefits of direct support staff in community services programs, to improve quality and reduce staff turnover,
- Develop additional Medicaid-funded, person-centered, community residential services, supported living and family support programs to reduce wait lists,
- Develop and implement dramatically more health promotion and disease prevention programs in residential and community services settings,
- Reduce the 75%-80% unemployment rates for people with I/DD
- Accelerate the development and utilization of assistive and cognitive technologies for people with I/DD to support independent living, productivity, and health and safety”