# How Many Autistic Children (0-21 years) Live in the District of Columbia (DC)?



DC AUTISM COLLABORATIVE

Autism or <u>autism spectrum disorder (ASD)</u> is a neurodevelopmental disorder that may be associated with social, communication, and behavioral challenges. Autistic individuals may communicate, interact, behave, and learn in ways that are different from people without autism.

## WHY IS IT IMPORTANT TO KNOW HOW MANY AUTISTIC CHILDREN LIVE IN DC?



This information is used to determine policy, resource allocation, and other decisions, such as which programs and services may be most needed. If children are not accurately counted, children may not get their fair share of money to fund needed services.



Data also shows patterns over time and needs or inequities based on factors, such as race, sex, and Ward. This information can then be used to address any concerning trends.



Knowing more about the prevalence of autism in DC (and information gaps) can inform advocacy efforts to ensure that autistic children in DC get the recognition and resources they need.

### AUTISM IN NUMBERS:

National prevalence of autism: It is estimated that **1 in 36** children (2.8%) in the US have autism<sup>1</sup> but prevalence varies widely across communities

#### Two separate data sources suggest the following information about children with autism in DC:

separate



Approximately 70%<sup>4</sup> of children in DC are insured through Medicaid.

**1.5%** of those children **(~1 in 65)** had a medical diagnosis of ASD in fiscal year (FY) 22<sup>2</sup>

<sup>1</sup> Source: https://www.cdc.gov/ncbddd/autism/data.html

<sup>2</sup> Data provided by DC DHCF includes DC Medicaid beneficiaries under age 21 enrolled in FY 2022 with a diagnosis of ASD on 2+ claims in the past year (1,604/104,402 individuals)



Public Schools in DC Education Data (includes both DC Public Schools and DC Public Charter Schools, covering approximately 85% of all DC children):

**1.7%** of children (~1 in 58) had an Individualized Education Program (IEP) under the classification of autism in school year 2021-2022<sup>3</sup>



- <sup>3</sup> Data provided by OSSE based on children with Individualized Education Program classification code of autism (2022\_Q77D -1613 of 94,532)
- <sup>4</sup> Source: <u>American Community Survey (ACS) data</u> https://data.census.gov/table?q=population%20by%20age&g= 040XX00US11

#### WHAT THIS MEANS:

There are a lot of children with autism in DC who will need services, though we do not yet know the true prevalence.

While looking at health and education data separately helps us learn more about autism in DC, we do not know how well these data capture children with autism in part given that we do not know how much overlap there is in these datasets. These datasets will also miss some children (e.g., those in private school or who do not have a medical diagnosis/educational classification). Details vary between datasets and we have not yet explored differences based on race, ethnicity, sex, or Ward. We need more accurate data to clearly know how many children need supports and therefore how much money should be allocated to this issue.

There are differences between DC and national data that make it hard to compare, but these estimates show **there may be fewer children in DC identified as having autism than would be expected,** indicating that we may be under-diagnosing/under-identifying autistic children in DC. This is worrisome because missed diagnoses may mean missed intervention services, resources, and supports.

#### NEXT STEPS:

Establish a data tracking system that could link health and education data and give us a better picture of how common autism is in DC. Programs exist in other states (e.g., CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network<sup>5</sup>, PA Autism Census<sup>6</sup>), but no such program exists in DC.

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prevalence can help to address the needs of autistic children and their families in the District, and aligns with recommendations made in the 2021 paper: <u>Current Landscape of</u> <u>Behavioral Health Services for</u> <u>Children with Autism Spectrum</u> <u>Disorders Insured by Medicaid in</u> <u>Washington, DC</u><sup>7</sup>. For example, it can guide our understanding of which children we are missing so that we can improve identification systems and inform the amount of funding and resources that should be dedicated towards services.

Better understanding autism





We look forward to working with families and other partners to continue improving our understanding of autism prevalence in DC and improving the system of care for autistic children and their families.

For questions or to learn more about the DC Autism Collaborative and autism resources in DC, contact <u>dcac@childrensnational.org</u> or go to <u>www.childrensnational.org/dc-ac</u>.

- <sup>5</sup> Source: CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network https://www.cdc.gov/ncbddd/autism/addm.html
- <sup>6</sup> Source: PA Autism Census https://paautism.org/pennsylvania-autism-census/

<sup>7</sup> https://www.childrensnational.org/ in-the-community/child-health-advocacy-inst itute/community-mental-health/publications