



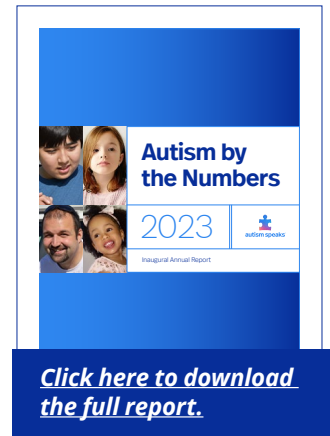
# Autism by the Numbers

## EXECUTIVE SUMMARY

2023 ANNUAL REPORT

The autistic community experiences disparities in multiple areas, including education, healthcare and employment. Current autism data and the way it is presented does not provide an accurate sense of the lived experience of people with autism spectrum disorder (ASD) in the U.S. For the first time, *Autism by the Numbers* offers accessible, state-level information that will enable autistic individuals and their families to make meaningful life decisions.

Autism by the Numbers, created by *Autism Speaks* in collaboration with the *National Autism Data Center at Drexel University*, has the potential to transform the way we understand and meet the needs of autistic individuals and their families. This central, authoritative hub of reliable data about people with autism will allow insight into the strengths and weaknesses of systems that exist to improve health, education, employment and advocacy. The Autism by the Numbers *Annual Report* and *Dashboard* can also be used to support the creation of precision public health programs specific to the diverse needs of the autistic community.



[Click here to download the full report.](#)

**Nationally, we have made progress toward increasing the well-being of the autistic community, but unmet needs remain across the life span of autistic individuals.**

## CHILDHOOD EARLY INTERVENTION & DIAGNOSIS

Autism by the Numbers data show that **1 in 35 children aged 3-17 in the U.S. are diagnosed with ASD**. These numbers are closely aligned with the **CDC prevalence rate of 1 in 36 children aged 8**.

**On average, Autism by the Numbers data show that autistic children receive intervention services and support prior to being diagnosed.**

- This demonstrates that screening processes have been somewhat effective.
- However, there is a need for better screening tools that allow us to identify and support underdiagnosed groups.
- Girls and people with more complex autism symptoms are often diagnosed later, with the **average age of diagnosis for girls at 5.6 years**.

**Prior research has proven that intervention services are crucial, and earlier is better to make a meaningful impact.**

- Research shows that autism can be reliably diagnosed by age 2, though the **average age of diagnosis is age 5**.
- Early diagnosis and intervention can have a positive lifelong impact on people with autism. Studies show that interventions started before age 4 may improve cognition, language, daily living skills and social skills.
- Earlier diagnosis makes it easier to map out a path for the future, including planning for special education services and other public programs.

**1 in 35 children**  
aged 3-17 are  
diagnosed with ASD

Average age of intervention  
and diagnosis in the U.S.

**4.7** average age of  
intervention

**5.0** average age of  
diagnosis

**5.6** average age of  
diagnosis **for girls**

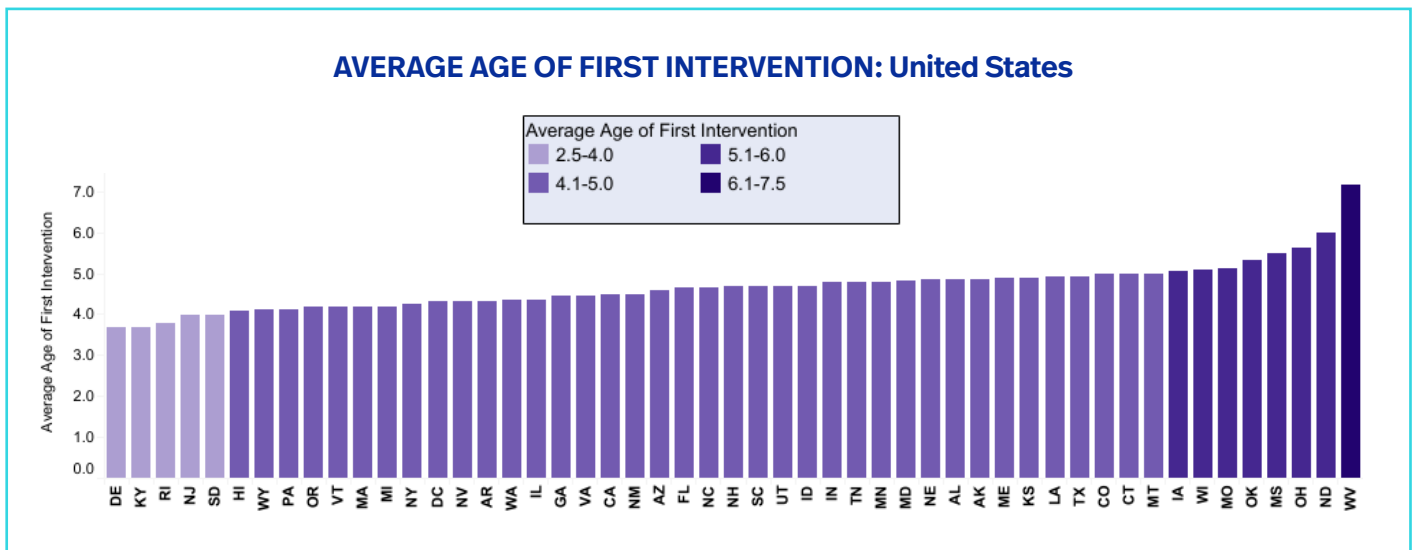
# Autism by the Numbers EXECUTIVE SUMMARY

Autism by the Numbers data also show variation between states in access to diagnosis and early intervention.

- Average age of first intervention ranges from 3.7 to 7.2 years of age across states.
- Average age of diagnosis ranges from 3.6 years to 7.6 years across states.
- Delaware and Kentucky have the youngest age of first intervention, at 3.7 years in each state.
- Oklahoma (5.3 years), Mississippi (5.5 years), Ohio (5.6 years), North Dakota (6.0 years) and West Virginia (7.2 years) show an average age of intervention above the national average, indicating a possible need to improve screening processes or access to intervention services.

average age of first intervention ranges from **3.7 to 7.2** years of age across states

More in-depth research is needed to understand why some states are able to effectively screen for ASD and provide early intervention services, while others experience significant delays in care.



Autism by the Numbers has the power to bring vital data to light that can be used for advocacy and policy changes to improve screening and cut down on delays to services.

- State-specific data could allow states to better allocate resources and explore ways to improve screening and increase access to services and supports.
- The data can also benefit families, improving awareness of and access to services and support programs in their state.

## Free Screening Tool for ASD

If your child is experiencing developmental delays and may need an autism evaluation, the [Autism Speaks M-CHAT screening tool](#) is a good place to start.



## Free Virtual Training for Caregivers

If your child is waiting for services, you can help them build communication, engagement, positive behavior and daily living skills through the virtual [WHO Caregiver Skills Training](#) (eCST) program – at no cost.



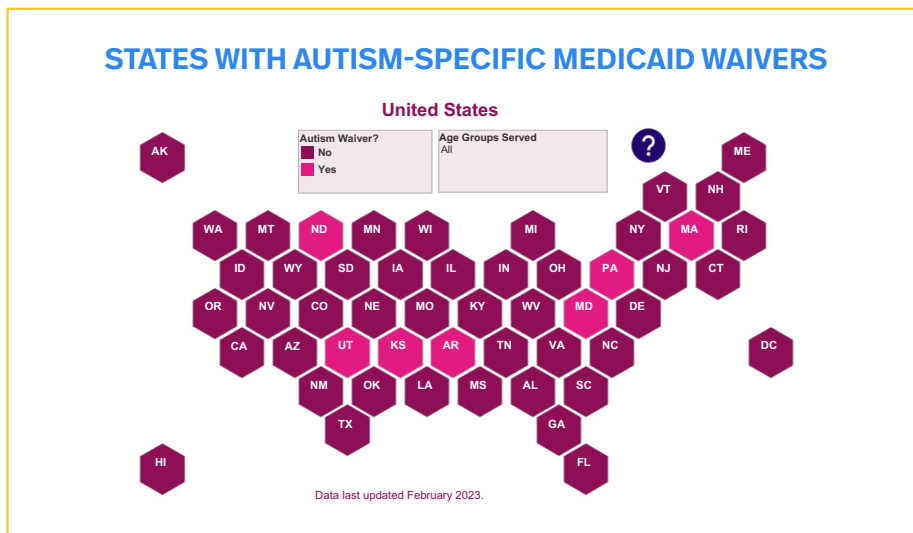
## HEALTHCARE COSTS

Children with autism have a higher rate of mental and physical health concerns that may require more healthcare services, such as provider visits and medications – and therefore, higher expenses.

The downside of not having accurate or reliable data about the autistic community is that it prevents Medicaid and other insurers from providing ample resources. Autism by the Numbers can help draw a more complete picture of the amount and kinds of coverage needed to properly care for autistic individuals. Additional healthcare needs experienced by autistic children underscore the importance of ensuring they have reliable healthcare coverage.

### Nationally, most autistic children have some kind of coverage through Medicaid, one of the main insurance providers.

- Some states offer Medicaid waivers for all people with intellectual or developmental disabilities, while others have special waivers specifically for autism.
- While autism waivers exist, there can be delays and other barriers preventing easy access to them.



### Autism by the Numbers data explores the costs of common services related to autism:

- While healthcare costs are generally higher for autistic children, care is usually paid for by public or private insurance.
- We do not have an accurate sense of the out-of-pocket healthcare costs of autistic individuals and their families, but the data indicate that these costs vary greatly by state.

Service category	Average median cost	Highest Charge
Adaptive behavior	\$82.25	\$780.60
Developmental screening	\$165.95	\$933.81
Emergency Department	\$1,397.22	\$9,588.91
Physical therapy	\$74.99	\$512.36
Psychiatry	\$253.40	\$2,544.90
Speech/Language	\$174.80	\$1,692.68
Therapeutic behavioral	\$175.44	\$1,006.76

## TRANSITIONING OUT OF HIGH SCHOOL

Many people with autism receive services through their school systems but lose access to those services and vital supports upon leaving high school. Without continuity of services, it can be more difficult for autistic adults to obtain employment, continue their education or live independently, which could potentially impact their future.

### Autism by the Numbers data shows the outcomes for autistic students who receive special education services.

- Nationally, 10% of students in special education programs receive special education services for autism. Not all autistic students qualify for special education, so there may be students who lack necessary support in school.
- **73.6% of autistic students receiving special education graduate with a high school diploma** and another 19.3% finish with certificates.
- **8.1% drop out of high school**, though we don't know why.

### Vocational Rehabilitation (VR) training and services provide an effective pathway to preparing autistic adolescents and teens for employment.

- Autistic students receive VR services at a lower rate than students with other disabilities, and transition-age autistic adults have lower rates of employment than those with other disabilities.
- On average, **50% of autistic youth and young adults receive VR services**. This ranges from 10% in New Jersey to 77% in Oklahoma.
- Among those who received VR services in high school, **60% had a job when they left school**. This range was from a low of 32% in Washington, D.C. to a high of 76% in Nebraska.

### There is still work to be done to increase the number of autistic students who graduate high school and go on to find employment.

We need research to further explore these questions:

- What are the longitudinal employment trends for autistic individuals?
- Why is the dropout rate so high, and how can we better support autistic students to have a positive experience in school?
- How many autistic young adults did not receive VR training, and why? How can we improve this number?
- How can we better serve students in pursuing education or employment after high school?

The challenges autistic people experience while transitioning out of school and into adult life are an important area of focus for Autism Speaks. As the Autism by the Numbers Dashboard evolves, it will include more attention to and information about this life step.

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of autistic high school students receiving special education graduate with a diploma.

**19.3%**

finish high school with certificates.

**8.1%**

drop out of high school.

**50%** of autistic youth and young adults

receive VR services.

of those who qualify for and receive VR training,

**over 40%** of young adults with autism do not find employment after high school.



For autistic individuals looking for employment, Autism Speaks [Workplace Inclusion Now](#) can help. The program was created for:

**Job seekers with autism • Employers searching for talent • Communities looking to prioritize inclusion and diversity**

WIN helps connect autistic people with employers and further the goal of creating a more diverse and inclusive workforce.



## ADULTS AND AGING WITH AUTISM

There is a pressing need to put systems in place to care for the approximately 5.4 million adults with autism in the U.S. While there is limited research and information on aging in autism, expanding our knowledge around this topic is of vital importance.

### Currently, knowledge of aging in autism suggests that:

- The population of autistic adults in the U.S. is growing.
- Autistic adults need specific support programs and appropriate care.
- Adults with autism continue to have greater medical needs and lifetime healthcare costs.
- We lack a full understanding of the needs of autistic adults and how to care for them.
- There are currently no official practice guidelines or standards of care for treating autistic adults.

Additional research, conducted in close partnership with autistic individuals, can eventually lead to the creation of practice guidelines that will advance healthcare for autistic adults.

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*No official clinical practice guidelines, standards of care or position statements from American medical organizations focus on the care of autistic adults.*



## THE FUTURE

Annual updates to the Autism by the Numbers Dashboard will continue to track and expand data on the most pressing areas of concern for autistic people and their families, including but not limited to mental and physical health and food security across the lifespan.

Autistic people interact with multiple systems. Linking, or connecting, data sources can help us to better understand the day-to-day experiences of the autistic community. For example, linking survey data with administrative claims data can provide us with a fuller picture of the needs of autistic people across systems. In the future, we plan to conduct data linkages and provide important indicators back to the community.

**Because the Autism by the Numbers platform pulls information from many different sources of data into one central location, we have the ability to mobilize reliable and actionable information to make a positive impact in the lives of the autistic community.**

***Explore the Autism by the Numbers [Dashboard](#) and [Annual Report](#)***