A Snapshot of Autism Spectrum Disorder in Utah

Findings from the Utah Autism and Developmental Disabilities Monitoring (UT-ADDM) Project help us 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. Read on to learn more about ASD in Utah and how this important information can be useful to you.

About 1 in 58 or 1.7% of 8-year-old children were identified with ASD by UT-ADDM in 2012. This percentage is higher than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

Boys were more likely to be identified with ASD than girls. White children were more likely to be identified with ASD than Hispanic children.

Among children identified with ASD who had IQ scores available, less than a quarter also had intellectual disability.

* No significant differences between white and black children or black and Hispanic children

* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by UT-ADDM. Intellectual disability defined as IQ score ≤ 70.

About 81% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 38% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 4 years and 2 months.

1 IN 58

Boys were more likely to be identified with ASD than girls. White children were more likely to be identified with ASD than Hispanic children.

4.3x MORE LIKELY among boys vs girls

1.3x MORE LIKELY among white vs Hispanic children

Average or above average intellectual ability

Borderline range

Intellectual disability

58%

22%

20%

* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by UT-ADDM. Intellectual disability defined as IQ score ≤ 70.
Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- Hispanic children are less likely to be identified with ASD than white children. This may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to other groups in Utah.
- Despite the developmental concerns noted in many of the children’s records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

UT-ADDM’s latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Utah might consider different ways to

1. Lower the age of first evaluation by community providers.
2. Increase awareness of ASD among Hispanic families, and identify and address barriers in order to decrease the age at which Hispanic children are evaluated and diagnosed.

How and where was this information collected?

This information is based on the analysis of data collected from the health and special education records of children who were 8 years old and living in one of three counties (Salt Lake, Davis, Tooele) in Utah in 2012. Overall, the tracking area included 24,945 eight-year-olds (73% white, 2% black, 19% Hispanic, 5% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else did UT-ADDM do besides tracking ASD among 8-year-olds?

UT-ADDM collaborated with the Utah Department of Health and investigators from the University of Utah to track the number and characteristics of 8-year-olds and 4-year-olds children with ASD and/or intellectual disability. UT-ADDM, as an extension of the Utah Registry of Autism and Developmental Disorders (URADD), provided community outreach through participation in community events, awareness activities, and professional education meetings.

“At the Utah Autism Coalition, we are very grateful for the work of UT-ADDM. Very little practical work can be done before someone measures the size of a problem. The efforts of the UT-ADDM were crucial in helping us convince our state legislature to take reasoned action.”

-Jon Owen
President of the Utah Autism Coalition

Get Resources and Connect Families to Services and Support in Utah

Autism Council of Utah
www.autismcouncilofutah.org

Baby Watch Early Intervention Services
801-273-2998
www.utahbabywatch.org

Learn the Signs. Act Early
health.utah.gov/utahactearly/

Utah Parent Center
801-272-1051
www.utahparentcenter.org

Utah State Office of Education
801-538-7587
www.schools.utah.gov/sars

Connect with UT-ADDM
Deborah Bilder, MD
University of Utah
801-585-9107
Deborah.Bilder@hsc.utah.edu