

Autism in Utah and Around the World: Prevalence and Challenges

What is Autism?

Autism Spectrum Disorder (ASD) is defined as a neurodevelopmental disorder characterized by the American Psychiatric Association (2013) as:

- Persistent deficits in social communication and social interactions across multiple contexts
- Restrictive, repetitive patterns of behavior, interests or activities
- Onset in the developmental period
- Significant limitations in social, academic or occupational function

The prevalence of ASD in Utah is estimated to be approximately 1.7 percent of the population or 1 in 58 eight-year olds. In the U.S. as a whole, the estimate is approximately 1.5 percent, or 1 in 68 eight-year olds. The reason for Utah having a larger prevalence may be explained by high level of collaboration across health, education and academic sectors in Utah. Utah surveillance systems obtain data on children with autism

diagnosis from both health and education systems – not common in other states (Centers for Disease Control & Prevention, 2016).

In both Utah and the U.S. prevalence is approximately four times greater for boys than for girls. Non-Hispanic white children have a higher prevalence than non-Hispanic black children, and both groups have higher prevalence of ASD than Hispanic children of any race (Centers for Disease Control & Prevention, 2016).

Prevalence

In a review of academic research articles published from 1966 through 2008, Dr. Eric Fombonne (2009) estimated the prevalence and incidence of Autism Spectrum Disorder (ASD). Prevalence refers to the proportion of individuals in a population who experience the condition, while incidence refers to the number of new cases that occur in a population over a period of time. A question Dr. Fombonne was seeking to answer was: Is there an epidemic of autism? His review concluded that ASD is much more common than previously believed. Reasons for larger prevalence estimates are most likely

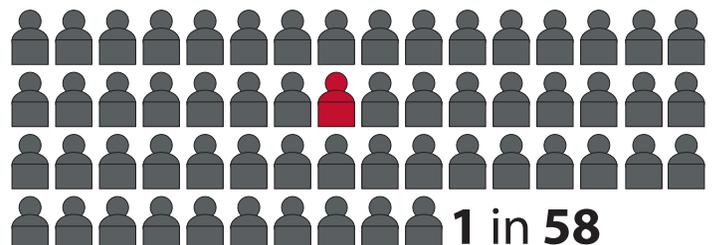
How many children were identified with ASD?

United States



About 1 in 68 or 1.5 percent of 8-year-olds in the U.S. were identified with ASD by the ADDM network (CDC, 2016).

Utah



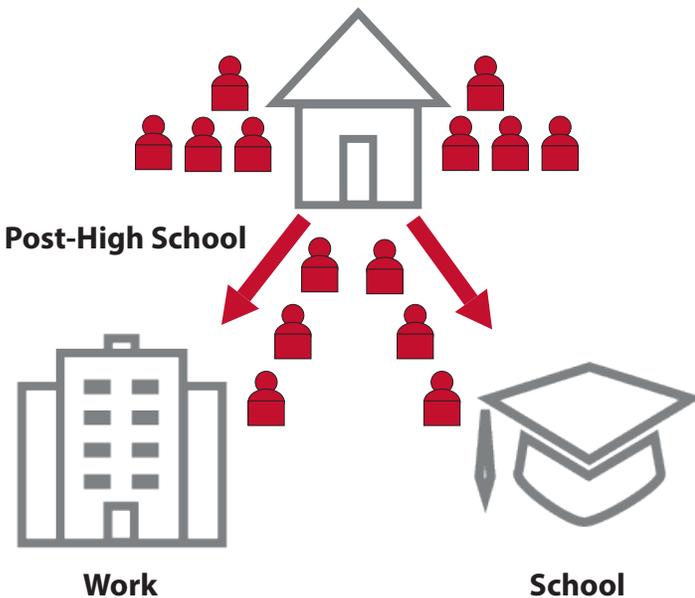
About 1 in 58 or 1.7 percent of 8-year-olds in Utah were identified with ASD by the UT-ADDM in 2012 (Bakian, 2012).

due to broadening of the concept of autism, expansion of diagnostic criteria, greater availability of services and improved awareness among the general public and professionals. The review concluded there was a lack of evidence for a growing incidence of ASD due to a dearth of tightly controlled studies at the time.

Lifelong Condition

Autism is a lifelong condition and co-occurs with an intellectual disability in about 25 percent of individuals with ASD. School-age youth with ASD may receive special education or other accommodations to address learning challenges and prepare them for employment and independent living. Special education supports end at age 22 and studies show the unemployment rate among young adults with autism is high. A large national survey (NLTS-2) found that more than 50 percent of young adults with ASD had no participation in employment or education within two years of leaving school (Shattuck, *et. al.*, 2012).

Outcomes for young adults with ASD



More than 50 percent of young adults with ASD had *no participation* in employment or education, according to a national follow-up study of young adults who received special education services (Shattuck, *et.al.*, 2012).

Lifetime Costs

Adults with ASD have a high dependence on public supports such as Medicaid and Social Security Disability benefits (SSI and SSDI). Lifetime costs of supporting an individual with autism spectrum disorder (ASD) and an intellectual disability in the U.S. during his or her lifespan is estimated at \$2.4 million. The largest cost components for adults were residential care or supportive living accommodations and individual productivity loss. Medical costs were much higher for adults than for children (Buescher, *et. al.*, 2014).

References

American Psychiatric Association. (2013). Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5).

Bakian, Amanda. (2016) Utah Registry for Autism & Developmental Disabilities, The University of Utah Department of Psychiatry.

Buescher, A., Cidav, Z., Knapp, M., Mandell, D. (2014). Costs of Autism Spectrum Disorders in the United Kingdom and the United States. *JAMA Pediatrics*, 168(8):721-728.

Centers for Disease Control & Prevention. (2016). Prevalence and Characteristics of Autism Spectrum Disorder among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network (ADDM), 11 Sites, U.S., 2012. Atlanta, GA: CDC, Surveillance Summaries, 65:3.

Fombonne, E. (2009) Epidemiology of Pervasive Developmental Disorders, *Pediatric Research*, 65: 591-598.

Shattuck, P. N., Carter Narendorf, S., Cooper, B., Sterzing, P.R., Wagner, M., Lounds Taylor, J. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129:1042-1049.