

Investment in research saves lives and money



facts about:

Autism Spectrum Disorder (ASD)

*"If you think research is expensive, try disease."
- Mary Lasker 1901-1994*

Today:

- ASD affects as many as one in every 68 children in the U.S.*
- Approximately 10% of individuals with ASD also have other genetic and chromosomal disorders.*
- ASD is commonly associated with co-morbidities such as seizures, gastrointestinal disorders, sleep disturbances, attention deficit and hyperactivity disorder and anxiety.*
- Men are nearly five times more likely to have ASD than women.*

* CENTERS FOR DISEASE CONTROL AND PREVENTION <WWW.CDC.GOV>
 Δ JACOB, A. ET. AL. PLOS ONE, 2015. 10(10): E0139896.
 ● AUTISMSPEAKS.ORG
 ‡ LEIGH, J. P. AND JUAN DU. J AUTISM DEV DISORD, 2015. 45: 4135-4139
 ◆ BUESCHER, AV. ET. AL. JAMA PEDIATR, 2014. 168(8):721-728.
 + LEIGH, JP, ET. AL. PLOS ONE, 2016, 11(3)

The Cost:

- The total U.S. economic burden of ASD was estimated to be \$268 billion in 2015. The burden is projected to nearly double to \$461 billion by 2025.‡
- On average, ASD costs families \$60,000 annually.*
- A recent analysis found that the California Department of Developmental Services spent an average of \$26,500 per year for each adult living with ASD.†

perspective:



NAME: Tim Naeder
 AGE: 29
 DIAGNOSIS: Autism Spectrum Disorder

Tim Naeder's mother first noticed his repetitive behaviors and loss of speech when he was just 2½ years old. After consulting with the family pediatrician, Tim was diagnosed with autism. Tim received in-home services focused on helping him reach developmental milestones, followed by special education services starting with a pre-kindergarten program for children with developmental disabilities. Tim's mom became a tireless advocate for him to access the services and support he needed throughout his years in school. This included participating in a transition program preparing him to enter the world of adult services and employment. However, after Tim turned 21 he was no longer eligible to receive any of the services that had been so beneficial throughout his childhood, creating many barriers to his continued development and success.

His older sister, Lindsay, is the director of the Autism Response Team at Autism Speaks, which helps to provide educational resources and support to families impacted by ASD. Lindsay is intimately aware of the challenges faced by the ASD community, and communicates daily with families across the country in need of support. "Autism is a life-long condition, and over time an individual and their family's need for support changes," says Lindsay. "It's important to understand and advocate for what services and supports are available."

Tim loves to be outdoors, watch movies and travel. However, he still faces ongoing challenges and requires daily support. As a result of an unavoidable move over state lines, Tim lost access to those direct supports, and he and his family have had to work to rebuild his network of service providers. "We need to bring research and deliver best practices to families affected by autism," says Lindsay. Research from the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and Agency for Healthcare Research and Quality (AHRQ) have led to a better understanding of what causes autism and how to best support individuals with ASD, but more needs to be done. "The services that are currently available are not enough," she adds. "There needs to be a priority on applied research that empowers people with autism and their families to improve quality of life."

IMPROVING LIVES
 SAVING MONEY

HOW RESEARCH IMPROVES LIVES:

- An estimated 20-33% of children in the U.S. with ASD have epilepsy, compared to 1-2% percent of the general population. Research also suggests that diseases of the nervous system, such as epilepsy, account for 9% of premature deaths in ASD. In addition to helping caregivers recognize the signs of epilepsy in individuals living with ASD, researchers have developed operational classifications of seizure types to design better clinical trials and treatment strategies.^^
- Researchers have started to examine whether behaviors typically associated with autism may actually be a response to underlying, comorbid medical conditions. Noting that gastrointestinal issues may prompt behaviors to alleviate pain and discomfort, scientists are now prescribing treatments that address these medical issues directly, improving the quality of life of those living with ASD.†

HOW RESEARCH SAVES MONEY:

- According to social scientists, children with ASD who received early-intervention special education and therapy require less support later in life. While more expensive to administer than standard public education, the intervention protocol pays for itself in just eight years by reducing subsequent services. Some studies estimate for every \$1 invested in early interventions for children with ASD, \$8 will be saved in support services costs in the future.♦^^
- The National Standards Project provides a resource for caregivers, practitioners and organizations to make informed decisions about evidence-based treatments and interventions in ASD. This tool can highlight best practices to reduce time and money spent on ineffective or untested treatments.°

^ MANDELL, D. AUTISM, 2018
 ● AUTISMSPEAKS.ORG
 ‡ FISHER, R.S. ET. AL. EPILEPSIA, 2017. 58(4): 522-530
 + CHILDMIND.ORG
 ◆ AUTISM SPEAKS <WWW.AUTISMSPEAKS.ORG>
 ^^ KLIN, A. ET. AL. YALE J BIOL MED, 2015. 88(1):73-79.
 ° NATIONALAUTISMCENTER.ORG

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Hope for the Future:

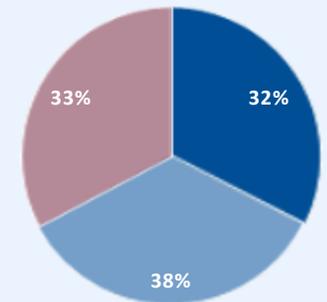
- Scientists are always seeking more accurate ways to measure outcomes associated with clinical trials that provide useful, detailed and reproducible data. This can be especially challenging for conditions like ASD, which do not have a diagnostic biomarker (i.e., blood test). Janssen Research & Development is testing a new system, Janssen Autism Knowledge Engine (JAKE), which seeks to monitor clinical outcomes in individuals with ASD. JAKE could be a powerful tool for future clinical trials, providing quantifiable and standardized data to assess potential medical interventions.*
- Breakthroughs in genetic analysis have allowed Autism Speaks and Google to partner in developing a genomic database, MSSNG, which currently contains whole genome sequences of more than 7,000 individuals from families involved in the Autism Genetic Research Exchange. This database allows researchers to take a completely new approach at understanding, diagnosing, and treating ASD.^
- The BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) seeks to revolutionize our current understanding of the brain. Researchers plan to map mechanisms and structure within the brain to identify the causes of conditions like ASD. This new knowledge is crucial for the development of new treatments, preventative measures, and even cures.†

* CLICALTRIALS.GOV <CLICALTRIALS.GOV>
 † NATIONAL INSTITUTES OF HEALTH <BRAININITIATIVE.NIH.GOV>
 ^ AUTISM SPEAKS <WWW.MSS.NG>

National Poll: Americans split on whether health care services are based on best available research.

Do you believe the health care services you receive are based on the best and most recent research available?

■ Yes ■ No ■ Not sure

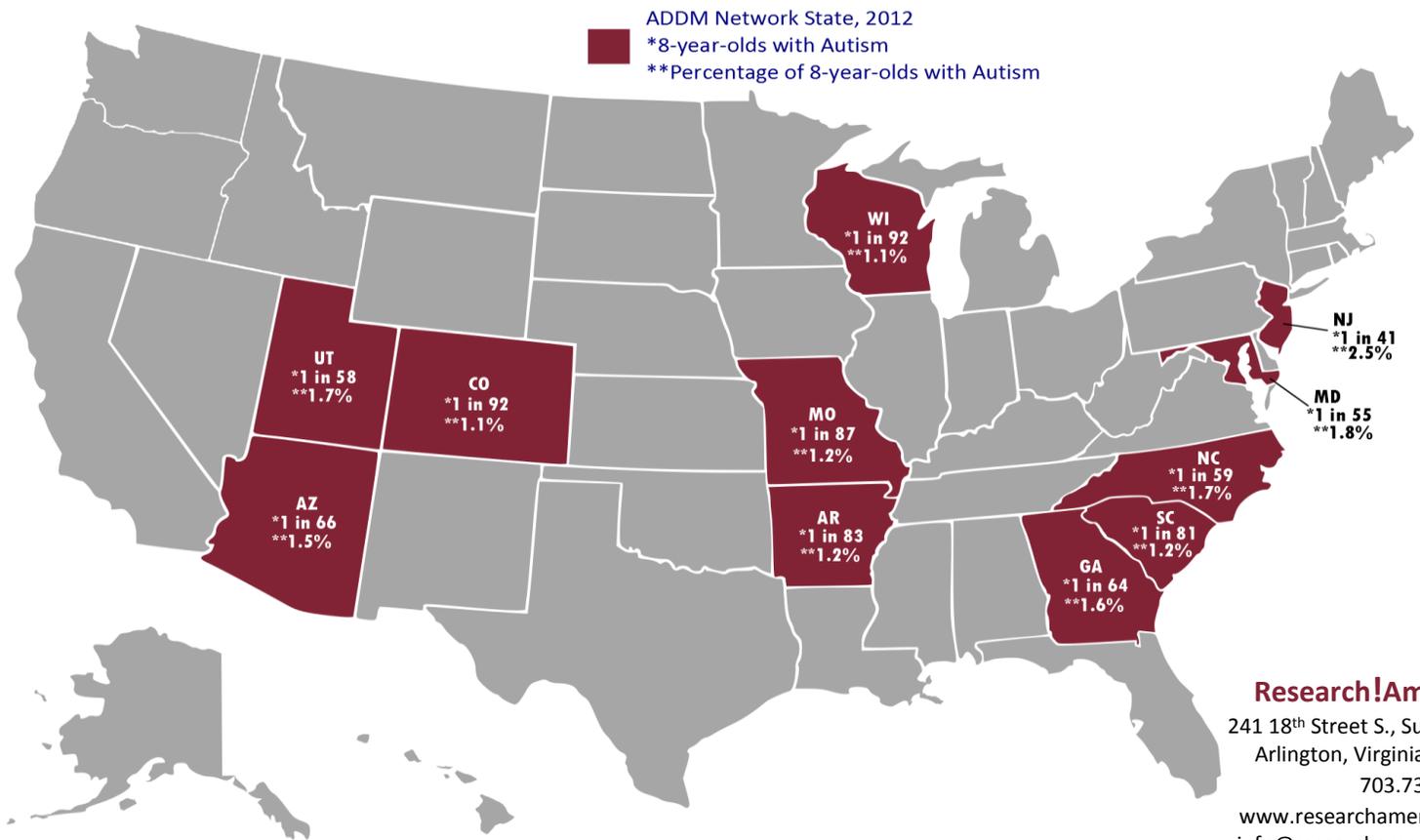


A RESEARCH!AMERICA POLL OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN JANUARY 2018.

The Bottom Line:

Despite affecting an estimated one in every 68 children in the U.S., ASD has no identified cause, no clinical diagnostic test and no cure. Current interventions are limited to behavior modifying medications, therapy and special education. Additional funding is desperately needed to support promising new avenues of discovery and the development of effective clinical interventions.

State Autism Prevalence in 2012



Research!America

241 18th Street S., Suite 501
 Arlington, Virginia 22202
 703.739.2577
www.researchamerica.org
info@researchamerica.org