



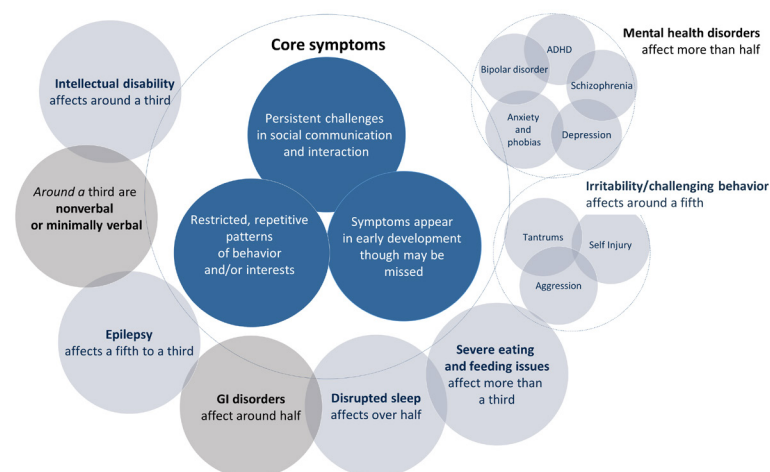
HEALTHCARE & INSURANCE

HISTORICAL SUCCESSES, BREAKTHROUGHS AND WHERE WE ARE TODAY

AUTISMSPEAKS.ORG

The healthcare needs of people with autism are complex.

Autism spectrum disorder (ASD) refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication. In many cases, an autism diagnosis is accompanied by sensory sensitivities and co-occurring medical conditions.



Children with autism have disproportionately poorer health outcomes than their disabled and non-disabled peers.

Children with ASD have nearly four times higher odds of having unmet health care needs compared to children without disabilities, whereas children with other disabilities have nearly two times higher odds of having unmet healthcare needs compared to children without disabilities.¹

Federal legislation has begun to address this health disparity. The **Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population Act (HEADs UP Act) of 2019** recognized individuals with intellectual or developmental disabilities (I/DD) as a medically underserved population. This designation makes available needed primary care and specialist services, incentivizing new research and more favorable reimbursement rates for providers who treat people with I/DD.

Access, affordability and quality of healthcare services are crucial factors influencing health outcomes for people with autism.

Medically necessary care for autism includes, but is not limited to, therapies such as occupational therapy, speech therapy and applied behavior analysis (ABA). While early intervention can improve outcomes later in life, the out of pocket expenses for medically necessary care is prohibitive for most families.

¹ Karpur, A. Lello, A. Frazier, T. Dixon P. Shih, A. (2018). Health Disparities among Children with Autism Spectrum Disorders: Analysis of the National Survey of Children's Health 2016. *Journal of Autism and Developmental Disorders*, Volume 49, Issue 4, pp 1652-1664. <https://www.autismspeaks.org/sites/default/files/JADD-D-18-00881.pdf>



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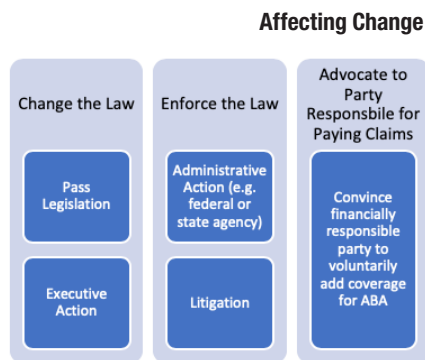
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Health insurance coverage is a primary barrier to accessing medically necessary autism care.

Advocacy efforts to include medically necessary care for autism under different health benefit plans are crucial to improving timely intervention. ABA therapy receives particular focus in these advocacy efforts because, unlike many other treatments and therapies, ABA is generally denied unless a law requires its coverage.

Healthcare Benefit Plans

A single approach cannot affect change in all types of healthcare benefit plans. In general, we can advocate to change the law, advocate to enforce the law or advocate to the party responsible for paying health benefit claims.



This authority lies with the entities that make the laws regulating the plan type (e.g. state and federal government) and entities that are responsible for paying the claims (e.g. insurance companies and employers).

Fully Insured Plans are either employer-sponsored or provided directly from insurance company. The insurance company is financially responsible for claims payments. These plans are **regulated by state law**. Autism insurance reform has taken place in 49 states through a combination of legislative mandates, administrative action and litigation.

Self-Funded Plans are employer-sponsored, and the employer is financially responsible for claims payments. They are **regulated by federal law**, such as the Employee Retirement Income Security Act of 1974 (ERISA) which establishes minimum standards for health, retirement and other welfare plans that are voluntarily established by an employer. Autism coverage can be added through litigation or convincing an employer to voluntarily add coverage.

Medicaid is a government-funded health benefit program that receives joint financial contributions from federal and state governments for claims payments. It is **regulated by federal and state law**. The Early Periodic Screening, Diagnostic and Treatment (EPSDT) benefit of Medicaid requires that all enrolled beneficiaries age 0-21 years old receive coverage for all medically necessary services to treat a condition. Autism coverage has been ensured under Medicaid through litigation and administrative action as well as advocacy for the appropriation of state funds to cover required benefits. Since 2014, most states have implemented coverage for ABA by amending their state Medicaid plan or adopting state regulations.

“Gaps and caps” in coverage for autism still exist. Age, dollar and hour caps in coverage for autism persist in some state mandates. Qualified health plans i.e., individual or small group plans issued after March 23, 2010, have also been carved out from some state autism coverage mandates.

RESOURCES

For more information and healthcare benefit tool kits, visit AutismSpeaks.org

Autism Speaks continues to work to close the gaps and expand coverage in all health benefit plans in order to improve timely intervention to medically necessary treatments for individuals impacted by autism.