

Autism In Texas

A 2019 Legislative Update



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Advocacy Priorities

- Autism Speaks is enhancing lives today and accelerating a spectrum of solutions for tomorrow. The Autism Speaks Advocacy Team works across the country to achieve this mission focusing on the following priorities:

Increase global understanding and acceptance of autism by

- Educating legislators and regulators on autism spectrum disorder to ensure policymaking benefits individuals across the spectrum.

Be a catalyst for life-enhancing research breakthroughs by

- Increasing funding for autism research at federal agencies, including the National Institutes of Health and the Department of Education.
- Reauthorizing the Autism CARES Act.

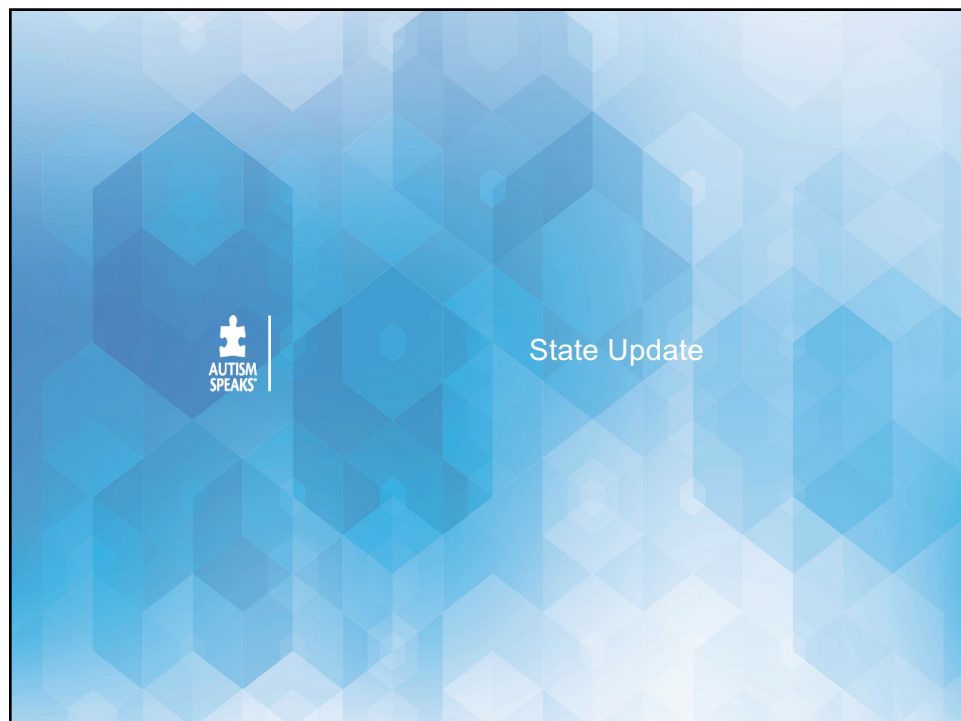
Increase early-childhood screening & timely intervention by

- Ensuring that individuals with autism have access to the healthcare they need, irrespective of payer (Medicaid, private insurance, etc.).

Improve outcomes for transition-age youth across the spectrum by

- Increasing access to housing and community-based services (HCBS) for individuals and increasing HCBS capacity to provide meaningful services for people with autism and their families.
- Improving the quality and accessibility of employment-focused training systems for individuals with autism as well as advocating for increased employment opportunities.
- Increasing equitable access to high-quality postsecondary education opportunities for students with autism.
- Expanding support for resources and practices that keep our community safe, including Kevin and Avonte's Law.
- Making ABLE accounts widely available.
- Ensuring staff across settings have appropriate training, particularly related to challenging behaviors, safety, sensory needs, and augmentative and alternative communication.





Medicaid Coverage for Children with Autism

- In July, 2014, the Centers for Medicare and Medicaid (CMS) provided clarification that Medicaid should cover “medically necessary” care for autism
- This coverage is required under the Early Periodic Screening, Diagnosis and Treatment (EPSDT) section of the federal Medicaid statute
- EPSDT applies to individuals under the age of 21

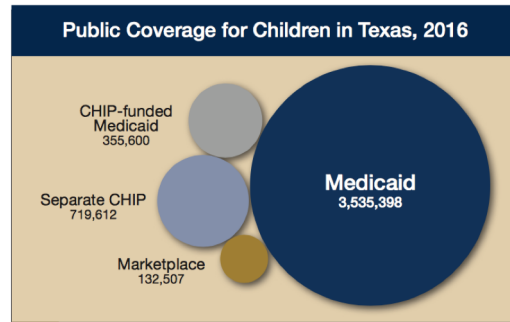


- Starting in 2014, Autism Speaks and other Texas stakeholders began meeting with
 - Governor's Office
 - HHSC leadership
 - Various legislators
- Model state plan amendment language and fiscal impact data were provided in the meetings



HHSC Includes as Budget Item

- HHSC included coverage as exceptional item 45 in their legislative appropriations request for the 2020/2021 budget year



https://ccf.georgetown.edu/wp-content/uploads/2017/09/fed_advocacy_chip_texas.pdf

AUTISM SPEAKS

Current Status

- Senate Finance
- House Appropriations Subcommittee on Article II
- Testimony at Public Hearings



AUTISM SPEAKS

We Need You!

- 80,000 Medicaid-enrolled kids in Texas are diagnosed with ASD
- More than 40 states have implemented coverage
- Join our Facebook Group!



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Other Critical Issues

- ECI budget has been slashed while there is continued growth in demand for services. (Exceptional Item #5 in the Budget)
- HCBS State Transition Plan
- Special Education Corrective Plan being implemented by TEA

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Autism in Texas

An estimated **104,614 children** with autism reside in the state of Texas.



HOME & COMMUNITY-BASED SERVICES

115,913

individuals with developmental disabilities are waiting for Home and Community-Based Services

20,156

caregivers of individuals with developmental disabilities received 'family support' such as respite

387%

growth in total support services would be required to meet the current need

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EMPLOYMENT

65%

of people with autism who received Texas Vocational Rehabilitation (VR) services are employed

2%

of total VR participants had autism

667

people with autism used VR services

32%

of VR participants with autism were high school students

13%


of people with intellectual or developmental disabilities participated in integrated employment services

\$8.46

less per hour is paid to workers with autism on average compared to their non-disabled peers


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Federal Update: Autism CARES Act

- The Challenge:**
- Signed into law on August 8, 2014, the **Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES Act)** is the foundation for federal efforts around autism. The Autism CARES Act authorizes federal funding for autism research, services, training and monitoring. Unless Congress acts, portions of the law will sunset on September 30, 2019.
- The Opportunity:**
- In its 2016-2017 Strategic Plan, the Interagency Autism Coordinating Committee recommended doubling the government and private autism research budget by 2020. In the words of the committee, doubling the research budget "would represent an aggressive, yet realistic jump start to support research that can significantly move the field forward." Reauthorizing the Autism CARES Act is a necessary step to ensure that new and improved treatments and interventions and evidence-based services are developed and the needs of youth, young adults, and older adults on the spectrum are met.


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Federal Update: Autism CARES Act

- The Autism CARES Act reauthorized activities related to autism research, services, and support, including but not limited to
- Epidemiological studies and research on autism and other developmental disabilities;
- Autism-related educational services, early detection, and intervention;
- Support for regional centers of excellence in autism for research and training;
- Use of research centers or networks for providing training in respite care and for research to determine practices for interventions to improve the health and well-being of individuals with autism;
- The addition of language that includes adults as well as children as the focus of funded activities; and
- A report to Congress on federal activities related to youth and young adults with autism and the challenges they face regarding the transition from school-based to adult service systems. This report was published in October 2017 and identified gaps and recommendations for further consideration in federal research, programs, and services that support youth with autism.



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Federal Efforts | Autism CARES

S.427 and H.R.1058

Today

Combating
Autism Act
2006



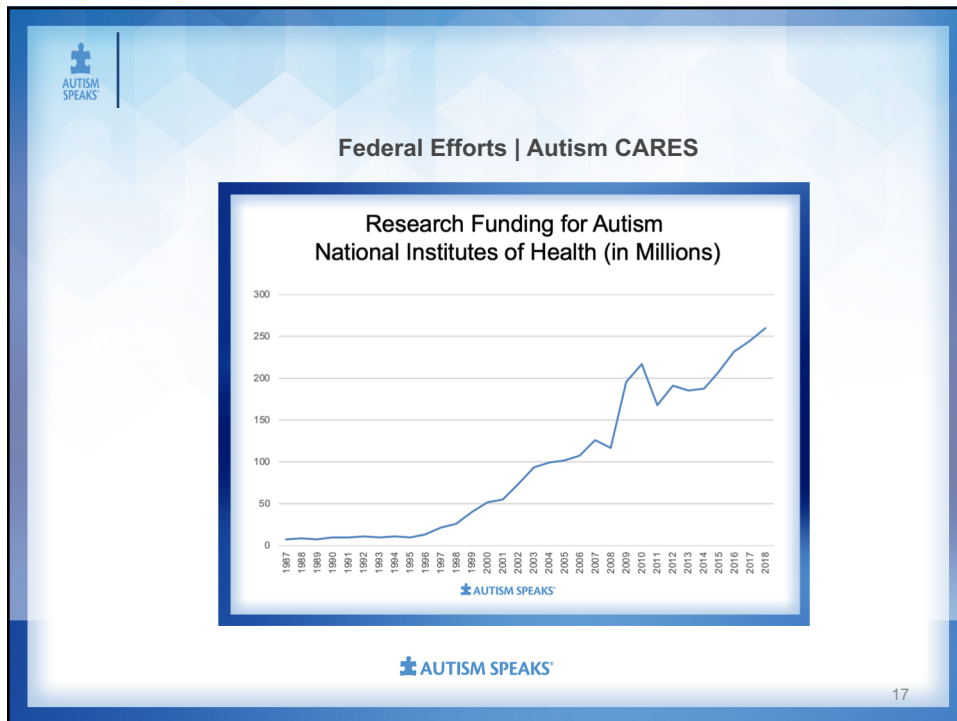
Combating Autism
Reauthorization Act
2011



Autism CARES Act
2014



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Federal Update: Autism CARES Act

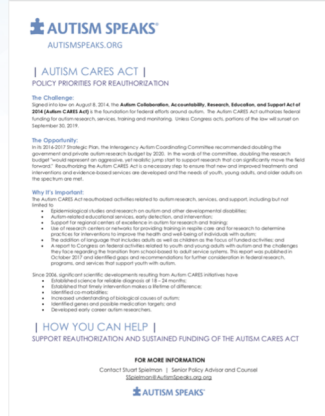
- **Since 2006, significant scientific developments resulting from Autism CARES initiatives have**
 - Established science for reliable diagnosis at 18 – 24 months;
 - Established that timely intervention makes a lifetime of difference;
 - Identified co-morbidities;
 - Increased understanding of biological causes of autism;
 - Identified genes and possible medication targets; and
 - Developed early career autism researchers.

AUTISM SPEAKS

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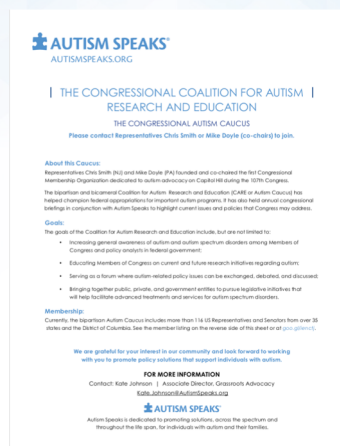
- Unless Congress acts, portions of the law will sunset on

- **Ask for members this month:
Please support the Autism
CARES Act.**



- Ask for ALL members of Congress this month:

- Please join the Congressional Coalition for Autism Research and Education.





Federal Update: Budget

- **President Trump will release portions of his FY 2020 budget the week of March 11.**
- The White House Office of Management and Budget (OMB) will issue the main budget volume containing the president's budget message, top priorities and summary tables during the week of March 11. The remaining materials will be released the week of March 18, including: the appendix, which contains detailed line-item information for each agency; "major savings and reforms" volume, which details proposed cuts to mandatory and discretionary programs; and the analytical perspectives document, which contains information on a variety of topics ranging from the long-term budget outlook to funding priorities that cut across several agencies like research and development.
- We will continue to keep you all informed on this process and how it will impact our efforts.



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Federal Update | The Congressional Coalition for Autism Research and Education

- **About this Caucus:**
- Representatives Chris Smith (NJ) and Mike Doyle (PA) founded and co-chaired the first Congressional Membership Organization dedicated to autism advocacy on Capitol Hill during the 107th Congress.
- The bipartisan and bicameral Coalition for Autism Research and Education (CARE or Autism Caucus) has helped champion federal appropriations for important autism programs. It has also held annual congressional briefings in conjunction with Autism Speaks to highlight current issues and policies that Congress may address.
- *"THE CONGRESSIONAL AUTISM CAUCUS"*
- **Goals:**
- The goals of the Coalition for Autism Research and Education include, but are not limited to:
- Increasing general awareness of autism and autism spectrum disorders among Members of Congress and policy analysts in federal government;
- Educating Members of Congress on current and future research initiatives regarding autism;
- Serving as a forum where autism-related policy issues can be exchanged, debated, and discussed;
- Bringing together public, private, and government entities to pursue legislative initiatives that will help facilitate advanced treatments and services for autism spectrum disorders.


Membership:

Currently, the bipartisan Autism Caucus includes more than 116 US Representatives and Senators from over 35 states and the District of Columbia.

How can a member join? They can contact Representatives Chris Smith or Mike Doyle (co-chairs) to join.




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Planning out your in-person visit

- First: Check your Congressional calendar to see when your Member of Congress (MOC) will be in the district:
- HOUSE - <https://www.house.gov/legislative-activity>
- SENATE - https://www.senate.gov/legislative/2019_schedule.htm



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Best Practices for Scheduling an In-Person Meeting



Sending a Meeting Request

- After you've looked up the schedule, send their office an email to request a meeting.



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Before your meeting...

Establish 3 Key-Identifying Factors

- Choose 3 things about yourself that you want your MOC to remember about you
 - Full Name
 - I'm a constituent (I live in _____)
 - Establish credibility

Practice Your Personal Story

- Practice, practice, practice!
- Elevator Speech:
 - 10 second, 30 second, 1 minute and 5 minute versions.
- Practice anecdotes that relate in context to the policy initiatives.

Legislative Ask

- Keep asks simple
 - Examples: Please join the autism caucus and please support Autism CARES reauthorization.
- If they ask you something you do not know, ALWAYS remember the safest phrase: "I'm not sure, but I can connect you with the policy team at Autism Speaks who can better assist you."



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Final thoughts...



- **You are an expert on YOUR story...**
- ...and that's the only thing you need to be an expert on! They want to hear why these topics are important to you and why autism is important to you.
- The safest phrase if they ask you a question and you don't know the answer is, "I don't know, but I'd be happy to connect you with an Autism Speaks expert who will be able to better assist you."
- If you are nervous or want any more advice, feel free to send me an email and we can chat before your meeting!



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Thank you!

What Can Advocates Do?

- Continue to develop relationships with your state and federal legislators.. Yes, you!
- Register to receive advocacy alerts at www.autismvotes.org
- Consider becoming an Autism Speaks Advocacy Ambassador
- Questions? E-mail me at judith.ursitti@autismspeaks.org or find me on Facebook at <https://www.facebook.com/judith.ursitti>



judith.ursitti@autismspeaks.org
Twitter @JudithUrsittiAS
<https://www.facebook.com/autismvotes/>

Autism Speaks Autism Response Team
(888) 288-4762
familyservices@autismspeaks.org

Autism Cares Grants