

An Important Message from Autism Speaks

Racism and discrimination have no place in our society.

Deeply ingrained in the Autism Speaks mission is a commitment to creating a more equitable world for those we serve. The autism community is diverse and broad, including all races, ethnicities, abilities, socioeconomic groups, belief systems and identities.

We stand with our volunteers, our colleagues, our partners and every member of our community in speaking out against racism and speaking up for a world that is more inclusive and empathetic – where all people are respected, protected and valued.



autism speaks[®]

**Supporting the Connecticut Autism Community
During COVID-19 Through Advocacy**

July 23, 2020



our mission

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.



Mission Objectives

Through partnerships and collaboration,
we are committed to:

- Increasing global understanding & acceptance of people with autism
- Being a catalyst for life-enhancing research breakthroughs
- Increasing early childhood screening & timely interventions
- Improving the transition to adulthood
- Ensuring access to reliable information & services throughout the life span



We've reimagedined the Walk – join us!

Find out how at autismspeakswalk.org



Connecticut *Walk on Wheels*

Rentschler Field

East Hartford, CT

Sunday, August 16, 2020



Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information provided in this email is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. Autism Speaks has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism.

Challenges the Autism Community is Facing

- Abrupt discontinuation of educational services
- Closure of day programming
- Closure of clinics
- Shift to telehealth
- Mental health supports
- Lack of connection to community opportunities and supports
- Severe disruption of community employment
- Discontinuation of respite relief for families
- Disruption of much-needed routines
- Loss of income for families
- Challenging behaviors
- Access to healthcare with appropriate supports
- Uncertainty about in-person versus virtual learning



Autism Response Team (ART)

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How to contact ART

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Your call will be routed to the team member for your region. We also have a dedicated Spanish language toll-free number,

1-888-AUTISM2 (1-888-288-4762)

En Español: 1-888-772-9050

help@autismspeaks.org

Who can call?

We are happy to talk with people with autism, parents, grandparents, friends, teachers, social workers, and everyone in between.

Even if you have no connection to autism but have a question, please feel free to reach out. We assist people of all ages, including children, teens, and adults with autism.

We're Here to
Help Chat with Us

Agenda

Welcome
Sarah Hawkes,
Manager Field
Development
Connecticut

Federal Advocacy
Update
David Sitcovsky
Senior Director,
Policy & Federal
Government
Affairs

State Advocacy
Update
Judith Ursitti,
Director State
Government
Affairs

Community
Outreach
Colleen Shinn
Director,
Community
Outreach



Federal Advocacy Response

Federal COVID Legislation – What’s passed?

MARCH 6: COVID 1 – Coronavirus Preparedness and Response Supplemental Appropriations

\$8.3 billion in emergency funding

MARCH 18: COVID 2 – Families First Coronavirus Response Act

Included *many* provisions affecting our community.

Of particular note – it provided emergency paid sick and family leave

MARCH 27: COVID 3 – Coronavirus Aid, Relief and Economic Security (CARES) Act

\$2 trillion in funding for a number of provisions affecting our community.

Of particular note – economic impact payments to most Americans; increased unemployment benefits; assistance for small businesses and employers; billions of dollars for schools; and extends the Money Follows the Person Program

APRIL 24: COVID 3.5 – Paycheck Protection Program and Health Care Enhancement Act

Interim bill to replenish small business assistance program and address other issues

Federal COVID Legislation – What’s next?

COVID 4 – Ongoing Negotiations

On May 15th, the House passed the Heroes Act - \$3 trillion relief package. The Senate had not indicated that it will take up this bill.

Priorities that were included in the Heroes Act

- Substantial increase in funding for home and community-based services (HCBS)
- \$100 billion for education (in addition to \$1 trillion in general assistance for state and local governments)
- Dependents over 17 retroactively eligible for economic impact payments
- Eligibility for additional \$1,200 payments

Senate Majority Leader McConnell is unveiling the Senate’s starting point for COVID 4 this week with the goal of passing a bipartisan deal before the recess begins on **August 8th**.

The path from here is unclear. . .

Our advocacy priorities during the COVID crisis

- Additional funding for home and community-based services (HCBS)
- Additional funding to meet the educational needs of students with autism
- Protecting the [rights of students under the Individuals with Disabilities Education Act](#) (IDEA) and other laws
- Expanded access to telehealth services for health care needs
- Eligibility for \$500 economic impact payments for dependents over age 17
- According caregivers of adults with disabilities the [same emergency paid sick and family medical leave](#) policies accorded caregivers of children
- [Preventing discrimination](#) in treatment decisions and care allocation based on disability

Congressmen Chris Smith (R-NJ) and Mike Doyle (D-PA), co-chairs of the Congressional Autism Caucus, have sent letters to congressional leadership advocating for many of these priorities.



State Advocacy Response

Life before COVID 19



Autism in Connecticut



An estimated **11,420 children** with autism reside in the state of Connecticut.

About **500,000 youth** with autism nationwide will enter adulthood over the next decade and most will continue to need some type of services or supports.

Many young adults with autism face a "**service cliff**" on the last day of high school, when special education ends and access to needed supports and services drops off dramatically.

More than one-third of young adults with autism do not transition into either employment or continued education after high school although

Employment for individuals with autism in Connecticut

7% of total Voc Rehab participants were individuals with autism

161 people with autism used VR services

70% of VR participants with autism were high school students

51% of people with intellectual or developmental disabilities did not participate in integrated employment services



HEALTHCARE

HOME AND
COMMUNITY
BASED SERVICES

SPECIAL
EDUCATION/EARLY
INTERVENTION

HEALTHCARE and Home and Community Based Services

Under Connecticut's Medicaid Plans (aka Husky Plans) we worked with legislators and regulators to make sure [1135](#) and [Appendix K](#) waivers were secured that would:

- Modify provider enrollment process
- Modify pre-authorization requirements
- Modify appeals process
- Allow for use of alternative settings
- Allow self-directed workers to be paid during member hospitalization associated with COVID-19 for up to 30 days
- Provide meals on wheels as a service for individuals in their own home
- Legal guardians to provide certain waiver services and be compensated for such care.
- Retainer payments for all residential and day programs to ensure continuous operations
- Supports to be provided in a group, telephonically, or via electronic face to face system

Telehealth Services

- States have broad flexibility to cover telehealth through Medicaid including the methods of communication (such as telephonic, video technology commonly available on smart phones and other devices) to use.
- Telehealth is important not just for people who are unable to go to the doctor, but also for when it is not advisable to go in person. No federal approval is needed for state Medicaid programs to reimburse providers for telehealth services in the same manner or at the same rate that states pay for face-to-face services.
- Governor Lamont issued an [Executive Order](#) that included coverage of telehealth. Several other executive orders further clarified this requirement.
- The Connecticut legislature is currently considering [a bill](#) during their special session that would extend the telehealth changes through June 30, 2021.

Telehealth Services

- Behavioral health, including applied behavior analysis
- Speech, occupational and physical therapy
- Psychological and psychiatric care



Special Education



Via E-Mail

Governor Ned Lamont
Commissioner Miguel Cardona
Commissioner Josh Gelske

Re: Educational Priorities for the Connecticut Autism Community During COVID-19

Dear Governor Lamont, Commissioner Cardona and Commissioner Gelske:

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families through advocacy and support, increasing understanding and acceptance of people with autism spectrum disorder, and advancing research into causes and better interventions for autism spectrum disorder and related conditions. We support measures that ensure that people with autism have access to the services and supports across the lifespan needed to lead fulfilling, meaningful lives.

It's important to note:

- In 2010 the U.S. CDC (Centers for Disease Control and Prevention) determined that approximately 1 in 54 children is diagnosed with an autism spectrum disorder (ASD).
- 20% of children with ASD have an intellectual disability (intelligence quotient (IQ) <70), 20% are in the borderline range (IQ 70-85), and 44% have IQ scores in the average to above average range (i.e., IQ >85).
- Autism affects all ethnic and socioeconomic groups.
- An estimated one-third of people with autism are nonverbal.
- Nearly 28 percent of 3-year-olds with ASD have self-injurious behaviors.

I write to respectfully request your consideration of the following concerns, noting that funding could be tapped from the Governor's Emergency Education Relief (GEER) Fund and Elementary and Secondary Emergency Relief Fund under Sec. 1800(c)(1) and (E) and Sec. 1800(d) of the CARES Act, as may be needed:

- The acquisition and dissemination of hardware, software, communication devices, and other assistive technology to promote inclusive distance learning.
- The requirement that the option of resuming in-person services is provided to students with autism as soon as is safely possible after Connecticut's school closure period, including over the summer months. The full range of individualized special education services should be provided, including but not limited to the following:
 - Academic instruction;
 - Behavioral supports;
 - Related supports, which may include transportation, occupational therapy, speech language pathology, physical therapy, applied behavior analysis, augmentative and alternative communication, postsecondary transition services and any other related service indicated on each student's current individualized education program.
- Transition service eligibility be extended to allow accommodations for missed services when students:
 - age out of early intervention into special education at age 3 and
 - age out of special education.
- Encouragement to school districts to undertake the following steps during the current period of school closure:
 - Regular communication to parents of special education students, including ongoing updates as well as notification of and scheduling of remote services.
 - Not requesting IEP amendments simply due to the remote learning environment, but accepting virtual IEP meeting requests, as may be needed or helpful to the IEP team including the student and their family members.

Your consideration and leadership in this matter is deeply appreciated. Please do not hesitate to contact me at judith.unitt@state.ct.gov or at (203) 763-4034 if you need additional information.

Sincerely,



Judith Unitt
Director - State Government Affairs

Chief of Staff Paul Mounds
Majority Leader Matt Riter
Speaker Joe Brewster
President Pro Tempore Martin Loney

Majority Leader Bob Duff
Senator Ian Faurot
Representative Thomas Kurkies



Special Education/Early Intervention

The state of Connecticut is receiving funds from the COVID-3 (CARES) stimulus package through the Education Stabilization Fund:

K-12	\$ 104.4 million
Post-secondary	\$ 131.7 million
Governor's Discretionary	\$ 26.8 million

- Hardware, software, communication devices, and other assistive technology
- Appropriate transition from early intervention to special education
- Services not received during the time of school closures and remote learning, **including in-person services** provided as soon as is safe and feasible (i.e. this summer)
- Appropriate transition out of special education to adulthood

Information about Connecticut's response to date can be found [here](#) including developments related to early intervention and transition out of special education.

Connect with us!

Sign up for advocacy alerts and emails and find your elected officials at www.autismspeaks.org/advocacy

Follow our advocacy profiles



| [Autism Speaks Advocacy](#)



| [@AutismVotes](#)



| [@AutismVotes](#)



Join our regular Connecticut Advocacy

Zoom Meetings!

E-mail me at judith.ursitti@autismspeaks.org



Community Outreach

COVID-19 Information and Resources

These are particularly challenging times for the autism community:

- Disrupted routines, changes in access to services and the uncertainty is taxing for people with autism and their families.
- Parents and caregivers are taking on roles of teacher, service provider and therapists.
- Adults with autism are cut off from services face loss of jobs.
- Autism Speaks is making resources and support available to help our community weather this storm. We are in this together.



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Information and Resources

- [Virtual Learning and Summer Activities](#)
- [Autism Speaks COVID19 Resources](#)
- [How to handle clinical care during social distancing and school/program closures](#)
- [What should the autism community know about the coronavirus outbreak?](#)
- Visit our [Facebook](#) and [Instagram](#) channels, where we will regularly share the ideas we're hearing from throughout the community. For local information, join an [Autism Speaks Facebook Group](#) in your area.

Information and Resources



[What Is Autism?](#)

[Help & Information](#)

[Our Work](#)

[Get Involved](#)

[Que es el autismo?](#)

[Donate](#) >

Information by Topic

Autism Speaks is committed to providing the autism community with resources to meet each person and family's unique needs throughout every stage of life. To help with your search for support, we have organized our resources, information, expert advice and personal stories by category.

[Financial Planning](#) | [Safety](#) | [School](#) | [Technology](#)

[Health and Wellness](#) | [Behavioral Challenges](#) | [Medical Resources](#) | [Transition to Adulthood](#)

[Adults](#) | [Family Support](#) | [Community Life](#) | [Miscellaneous](#)



Thank You