



autism speaks®

**Supporting New York Families
During COVID-19 Through Advocacy**

April 24, 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.

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.



Take 5,400 steps (alone or as a team) to help
increase understanding and acceptance of the 1 in 54
U.S. children with autism.

Opening Ceremony at 1:00pm ET
Steps Send-off at ~1:15pm ET
RSVP to the Facebook Live Event

Challenges the Autism Community is Facing

- Abrupt discontinuation of educational services
- Closure of day programming
- Closure of clinics
- Shift to telehealth
- Mental health supports for parents
- 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





Contact our Autism Response Team

The Autism Response Team (ART) is an information line for the autism community. Our team members are specially trained to provide personalized information and resources to people with autism and their families.

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



Agenda

Welcome

- Nicole Thornton,
Senior Director Field
Development New
York Metro

Federal Advocacy Update

- David Sitcovsky,
Senior Director
Policy and Federal
Government Affairs

State Advocacy Update

- Judith Ursitti,
Director State
Government Affairs
- Mark Ustin and
Vanessa Bongiorno,
Farrell Fritz PC

Community Outreach

- Ginny Green,
Director Community
Outreach



Federal Advocacy Response

Federal COVID Legislation – What's already passed

MARCH 6: Coronavirus Preparedness and Response Supplemental Appropriations

Provides \$8.3 billion in emergency funding for federal agencies to respond to the coronavirus outbreak (COVID 1)

MARCH 18: Families First Coronavirus Response Act (COVID 2)

- Provides emergency paid sick and family leave
 - DOL has provided Q&A regarding these provisions of the law
- Tax credits
- Free COVID-19 testing (where available)
- Expands food assistance and unemployment benefits
- Increases Medicaid funding

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

Provides \$2 trillion in funding for provisions, including:

- Economic impact payments to most Americans
- Increased unemployment benefits
- Hundreds of billions of dollars to address the public health response
- Assistance for small businesses and other employers to retain employees and keep their businesses operating
- Billions of dollars for schools
- [Extends the Money Follows the Person program through November](#)

Implementation of the COVID bills - A few issues of note

- Economic Impact Payments and SSI
- Distribution of education dollars
- IDEA Waiver Report
- Emergency Paid and Family Leave

Federal COVID Legislation – Current State of Play

Paycheck Protection Program and Health Care Enhancement Act (COVID 3.5)

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

- Limited scope to address Paycheck Protection Program and funding for hospitals and testing.
- Passed in House and Senate. Will be signed by the president today.

COVID 4/5

Additional Relief and Stimulus

- Timeline still TBD – House and Senate not back in session until May 4th, at earliest.
- What will be contained in these bills: ???
 - Examples of potential items:
 - \$ for the public health response
 - Additional economic relief for individuals and small businesses
 - \$ for state and local governments
 - \$ for education
 - Additional nutritional assistance
 - Housing assistance
 - USPS finances
 - Infrastructure investment

Our advocacy priorities during the COVID crisis

- Additional funding for home and community-based services (HCBS)
- Expanded access to telehealth services for health care needs
- 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
- 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 Smith and Doyle sent a letter to congressional leadership last week expressing some of our concerns and requests for additional support for people with autism.



State Advocacy Response

Albany Update

- Status of Legislative Session
- Budget Info





HEALTHCARE

New York was approved for an 1135 emergency waiver by CMS, the federal Medicaid agency. This allows for a great deal of flexibility related to authorizations/benefits in Medicaid plans include the ability to:

- Temporarily suspend Medicaid fee-for-service prior authorization requirements.
- Extend pre-existing authorizations
- Suspend Pre-Admission Screening and Annual Resident Review
- Enroll providers from other states
- Provide services in alternative settings

Additional information can be found [here](#).

HEALTHCARE - Telehealth Services

State Agencies Issue [Guidance](#) on March 17, 2020 to ensure that there are no regulatory barriers to telehealth visits

- DFS
- DOH
- OMH
- OASAS
- OPWDD



HOME AND COMMUNITY BASED SERVICES

The Centers for Medicare and Medicaid Services (CMS) is providing emergency flexibilities for Home and Community Based Waiver Services through Appendix K.

New York's [Appendix K application](#) was approved by CMS on April 7, 2020

For the 90,000 New Yorkers who receive services through OPWDD, some of these flexibilities include:

- Delivery of services at an alternate or out-of-state site
- Temporary waiver of staff training and qualifications
- Extension of the timeframes for completion of Level of Care (LOC) assessments and Plan of Care review
- Modifications to person-centered service planning
- Options for retainer day payments for Community Habilitation, Day Habilitation and Prevocational Service providers
- Increase Residential Habilitation services reimbursement to address increase in day-time staffing needs and Increase fees for Respite and Community Habilitation services to address additional equipment and staff training needs

Hospitals are required to permit a patient support person at the patient bedside for:

- Patients in labor and delivery;
- Pediatric patients;
- Patients for whom a support person has been determined to be essential to the care of the patient (medically necessary) including patients with intellectual and/or developmental disabilities and patients with cognitive impairments including dementia.

More details [here](#).

Provision of waiver services during the school day continues to be on ongoing issue.

Special Education/Early Intervention

SED released a memo outlining [Provision of Services to Students with Disabilities During Statewide School Closures Due to Novel Coronavirus \(COVID-19\)](#) on March 27th

Students with disabilities must be provided a free appropriate public education (FAPE) consistent with the need to protect their health and safety, as well as the health and safety of the individuals who provide them with their education, specialized instruction, and related services. NYSED will allow school districts as much flexibility as federal and State laws and regulations allow in determining how FAPE is to be provided during the Coronavirus outbreak, and we will continue to seek further guidance regarding additional flexibility during this pandemic.

Special Education/Early Intervention

The state of New York will be receiving funds from the COVID-3 stimulus package from the Education Stabilization Fund.

K-12	\$1,012.8 billion
Post-secondary	\$ 797.6 million
Governor's Discretionary	\$ 168.1 million

It is critical that advocacy occur so that New York students with autism receive appropriate supports and services, including but not limited to:

- Acquisition and dissemination of 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
- Appropriate transition out of special education to adulthood

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](#)





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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Utilize our Videos

How to handle school closures and services for your child with autism

March 13, 2020



Arianna Esposito, BCBA
Director, Lifespan Services and Supports

We're Here to
Help Chat with Us

Information and Resources

- [Dealing with School Closures](#)
- [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.
- NEW April 9 - Autism Certification Center (ACC) and Autism Speaks are teaming up to make 30+ hours of [online video learning resources](#) available at no cost for the autism community.





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