Supporting the New Jersey Autism Community During COVID-19 Through Advocacy

May 15, 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
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 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

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**How to contact ART**

Call our toll-free number or send us an email—we're available between 9am and 5pm in all time zones. Live chat is also available between 9am and 5pm ET.

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
Kristen Apen
Executive Director
New Jersey

Federal Advocacy Update
David Sitcovsky
Senior Director
Policy and Federal Government Affairs

State Advocacy Update
Judith Ursitti
Director State Government Affairs

Community Outreach
Ginny Green
Director
Community Outreach
Federal Advocacy Response
Federal COVID Legislation – What’s Passed

MARCH 6: COVID 1
Coronavirus Preparedness and Response Supplemental Appropriations
Provides $8.3 billion in emergency funding for federal agencies to respond to the coronavirus outbreak

MARCH 18: COVID 2
Families First Coronavirus Response Act
• 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: COVID 3
Coronavirus Aid, Relief and Economic Security (CARES) Act
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
Federal COVID Legislation – What’s Passed

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:

• Limited scope to address Paycheck Protection Program and funding for hospitals and testing.
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.
What’s next?

- COVID 4 – negotiations ongoing

- On Tuesday, House Democrats introduced The Heroes Act – a $3 trillion relief package.

- Priorities that are included in The Heroes Act:
  - Substantial increase in funding for 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. Eligible for additional $1,200 payments in Heroes Act.
  - Clarifies eligibility for emergency paid sick and family leave for caregivers of adults with disabilities
  - $10 million for DD Act activities

- House scheduled to vote on Friday. From there, path is unclear...
State Advocacy Response
Impact Statement

Autism Speaks is enhancing lives today and accelerating a spectrum of solutions for tomorrow.

HEALTHCARE

HOME AND COMMUNITY BASED SERVICES

SPECIAL EDUCATION/EARLY INTERVENTION
HEALTHCARE

New Jersey was approved for an 1135 emergency waiver on March 23, 2020 by CMS, the federal Medicaid agency. This allows for greater flexibility which will:

- Temporarily suspend Medicaid fee-for-service prior authorization requirements.
- Extend pre-existing authorizations for which a beneficiary has previously received prior authorization through the end of the public health emergency
- Suspend Pre-Admission Screening and Annual Resident Review (PASRR) Level I and Level II Assessments for 30 days
- Modify State Fair Hearing Requests and Appeal Timelines
- Modify Provider Enrollment
- Allow Provision of Services in Alternative Settings

Additional information can be found here.
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.
Telehealth Services

Governor Murphy Announces Departmental Actions to Expand Access to Telehealth and Tele-Mental Health Services in Response to COVID-19

Governor Phil Murphy announced departmental actions from the Department of Human Services, Department of Banking and Insurance, Department of Treasury, Department of Health, Department of Children and Family Services and the New Jersey Division of Consumer Affairs to ensure New Jerseyans have access to telehealth and tele-mental health services to the greatest extent possible during the COVID-19 outbreak. Additional details can be found here.
Services the autism community could potentially access via telehealth include but are not limited to:

• Behavioral health treatments, including applied behavior analysis
• Therapeutic services, including speech therapy, occupational therapy and physical therapy
• Psychological and psychiatric care
HEALTHCARE

• The New Jersey Department of Health also announced new guidance requiring hospitals to allow a designated support person to accompany an individual with a disability during a hospitalization despite other restrictions on visitors at this time.

• The designated support person may be a family member, personal care assistant or another disability service provider and is subject to screening by the hospital and required to be asymptomatic for COVID-19.
HOME AND COMMUNITY BASED SERVICES
The Department of Human Services has:

• Closed day programs where individuals participated in daily congregate activities to reduce risk;
• Provided bridge payments to day program providers;
• Enhanced payments to group home providers to allow them to bring in additional staff given the added time residents are at home;
• Modified rules to quickly allow families and providers to hire workers to support their loved ones;
• Restricted visitors to group homes to reduce risk;
• Delivered PPE to group homes and supervised apartments, as well as family homes where aides come into the home;
• Released guidance on requirements surrounding hygiene, cleaning and disinfecting, and critical supplies for group home providers.
• implemented a temporary $3 per hour wage increase for direct support professionals who care for adult individuals with intellectual and developmental disabilities living in group homes and supervised apartments for three months

Additional details can be found [here](#) and [here](#)
Special Education/Early Intervention

According to the New Jersey Department of Education:

*This is a temporary situation, and districts must offer special education services to the most appropriate extent possible while students are away from their schools/programs. IEP teams may need to consider compensatory services when students return to school and IEPs may need to be adjusted accordingly. The IEP team should determine the amount of compensatory related services students with IEPs may require, on a case-by-case basis, when school resumes.*


Additional information can be found [here](https://www.autismspeaks.org/ryan-center/coronavirus-outbreak).
**Special Education/Early Intervention**

The state of New Jersey is receiving funds from the COVID-3 stimulus package through the Education Stabilization Fund.

- K-12: $303.2 million
- Post-secondary: $275.7 million
- Governor’s Discretionary: $68.9 million

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

- 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
Impact Statement

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Connect with us!

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

Follow our advocacy profiles

Facebook | Autism Speaks Advocacy
Twitter | @AutismVotes
Instagram | @AutismVotes
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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

• **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.**
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Information and Resources

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