

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.



**Supporting the North Carolina Autism Community
During COVID-19 Through Advocacy**

June 17, 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
- 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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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
Lauren Kidder

Executive Director
Field Development
Carolinas

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

State Advocacy Update

Patrick Ballantine
Ballantine Company
Judith Ursitti
Director State
Government Affairs

Community Outreach
Janet Williams
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 May 15th, the House of Representatives passed 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
- The Senate has not indicated that it will take up this bill. Path from here is unclear...



State Advocacy Response

UPDATE FROM RALEIGH

[House Bill 671](#) is under consideration in the North Carolina Senate. It is critically important to ensure that North Carolina families can access ABA provided or supervised by a BCBA. Please make sure your state senator is working to ensure passage of this bill by the senate before they adjourn. You can find out who your state senator is [here](#).





HEALTHCARE

North Carolina was approved for an 1135 emergency waiver on [March 23, 2020](#) by CMS, the federal Medicaid agency. This allows for greater flexibility which will:

- Modify provider enrollment procedures
 - Provision of Services in Alternative Settings
 - 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
 - Temporarily suspend Medicaid fee-for-service prior authorization requirements.
- Section 1135(b)(1)(C) allows for a waiver or modification of pre-approval requirements, including prior authorization processes required under the State Plan for particular benefits.

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. Information on NC Medicaid's inclusion of telehealth can be found [here](#).



Telehealth Services

**Telehealth Links from the North Carolina
Department of Insurance**

[Aetna \(Telehealth\)](#)

[Blue Cross Blue Shield \(Telehealth\)](#)

[CIGNA \(Telehealth\)](#)

[Also CIGNA \(Telehealth\)](#)

[United Health \(Telehealth\)](#)

[FirstCarolinaCare \(Telehealth\)](#)



Telehealth Services

Services the autism community could potentially access via telehealth include but are not limited to:

- Behavioral health treatments
- Therapeutic services, including speech therapy, occupational therapy and physical therapy
- Psychological and psychiatric care

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

HOME AND COMMUNITY BASED SERVICES (Innovations Waiver)

North Carolina's Appendix K was Approved on April 6, 2020 and again on May 27, 2020

- Temporarily increase the cost limits for entry into the waiver
- Allow for an increase in service hours from what is in the person-centered plan without prior authorization for this time period.
- Respite may be provided when family is out of state due to evacuation/displacement until they return home.
- Temporarily expand settings where services may be provided
- Temporarily provide services in out of state settings
- Temporarily permit payment for services rendered by family caregivers or legally responsible individuals
- Temporarily modify provider qualifications
- Temporarily modify processes for level of care evaluations or re-evaluations
- Temporarily allow for payment for services for the purpose of supporting waiver participants in an acute care hospital or short-term institutional stay
- Temporarily include retainer payments to address emergency related issues
- Add Home Delivered Meals as an additional service.

Special Education

North Carolina State Board of Education Issued this [Guidance](#) on May 8, 2020
Regarding Remote Learning for Children with Disabilities:

Schools must provide FAPE “consistent with the need to protect the health and safety of students with disabilities and those individuals providing education, specialized instruction, and related services to these students”. [OSEP Supplemental Fact Sheet- March 21, 2020] “However, federal disability law provides flexibility in determining how to meet the needs of students with disabilities. The determination of how FAPE is to be provided may need to be different in this time of unprecedented national emergency”.

“Whether and to what extent compensatory services may be needed when the school resumes normal operations” will be determined on an individual basis by the student’s IEP Team.

Special Education/Early Intervention

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

K-12	\$ 378.4 million
Post-secondary	\$ 357.6 million
Governor's Discretionary	\$ 95.6 million

We have met with the Governor's office and specifically expressed that It is critical that North Carolina 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, **including in-person services** provided as soon as is safe and feasible (i.e. this summer)
- Appropriate transition out of special education to adulthood

Connect with us!

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www.autismspeaks.org/advocacy

Follow our advocacy profiles



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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

- [Summer Camp Information](#)
- [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