Supporting Illinois Families During COVID-19 Through Advocacy and Supports

April 21, 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
Agenda

Welcome
• Amy Helgeson, Executive Director Illinois

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

State Advocacy Update
• Judith Ursitti, Director State Government Affairs
• Mike Grady, President, Strategic Advocacy, Inc.

Community Outreach
• Colleen Shinn
  Director Community Outreach Midwest and South Central
Challenges the Autism Community is Facing

- Abrupt discontinuation of educational services
- Closure of day programming
- Closure of clinics
- Shift to telehealth
- Lack of connection to community opportunities and supports
- Community employment disruption
- Discontinuation of respite relief for families
- Disruption of much-needed routines
- Loss of income for families
- Challenging behaviors
- Access to healthcare with appropriate supports
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

MARCH 18: 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: 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
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

COVID 3.5
Interim bill to replenish small business assistance program and address other issues:
• Limited scope to address Paycheck Protection Program and potentially funding for hospitals, testing, and possibly state/local governments
• Negotiations ongoing, but possible it will pass this week

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.
Updates from Springfield

• Status of Legislature
• Budget and Potential Graduated Income Tax
• Direct Service Providers
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
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HEALTHCARE

Illinois Medicaid

Illinois 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:

- Waive certain provider screening requirements
- Allow out-of-state providers with equivalent licensing in another state
- Permit out-of-state providers to provide care to emergency state’s Medicaid enrollee
- Allow service provision in alternative settings, including unlicensed facilities
- Suspend prior authorizations
- Require providers to extend pre-existing prior authorizations

Additional information can be found here.
Illinois 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. Illinois submitted their Appendix K application to CMS on March 27, 2020 and is pending approval.

- Children and Young Adults with Developmental Disabilities-Support Waiver
- Children and Young Adults with Developmental Disabilities-Residential Waiver
- Adults with Developmental Disabilities Waiver

  - temporarily increase individual eligibility cost limits
  - modify service, scope, or coverage requirements
  - exceed service limitations
  - add services to the waiver
  - provide services in out-of-state settings, and/or
  - permit payment for services rendered by family caregivers or legally responsible individuals
Healthcare - Telehealth Services Under Medicaid

- 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.

- Illinois Medicaid issued a provider notice on March 20th requiring provision of telehealth services during the pandemic.
Illinois Governor JB Pritzker executed an order to expand access to telehealth services under state-regulated private health insurance plans.

All health insurers regulated by the Department of Insurance are required to cover telehealth services and reimburse providers at the same rate as in-person visits and are prohibited from imposing any cost-sharing for in-network providers.
Special Education/Early Intervention

The Illinois Department of Education has posted information on their website regarding the delivery of special education.

The state of Illinois will be receiving funds from the COVID-3 stimulus package earmarked for education. It is critical that advocacy occur so that Illinois students with autism receive appropriate supports and services, including but not limited to:

- 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
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.
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.
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
Impact Statement

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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
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

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
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
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
Thank You