Supporting the Pennsylvania Autism Community During COVID-19 Through Advocacy

May 14, 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
Impact Statement

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

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- HEALTHCARE
- HOME AND COMMUNITY BASED SERVICES
- SPECIAL EDUCATION/EARLY INTERVENTION
**HEALTHCARE**

Pennsylvania was approved for an 1135 emergency waiver on March 27, 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
- 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

On March 6, 2020, Governor Wolf issued an emergency disaster declaration in response to the presence of the COVID-19 (coronavirus) in Pennsylvania.

Pursuant to this disaster declaration, the Office of Medical Assistance Programs (OMAP) issued guidance to advise providers that telemedicine may be used to provide services to Medicaid fee-for-service beneficiaries and Physical HealthChoices members.

Subsequent guidance was provided by Office of Mental Health and Substance Abuse Services (OMHSAS) for behavioral health.
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Telehealth Services

On March 10th, 2020 the Pennsylvania Insurance Department released a Bulletin notice regarding COVID-19 insurance coverage. In the notice, the Insurance Department discusses telehealth delivery of services. It states:

*Telehealth Delivery of Services. Given that COVID-19 is a communicable disease, some insureds may prefer to use telehealth services instead of in-person health care services. Health insurers are encouraged to review their respective participating telehealth service provider arrangements, provide coverage of costs related to telehealth services and to be prepared to meet any increased demand for that means of delivery.*
Telehealth Services

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
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. Pennsylvania has been approved through several Appendix K applications to:

- Temporarily modify process for level of care evaluations/re-evaluations
- Extend reassessment/reevaluation dates
- Permit virtual person-centered-planning/evaluation meetings
- Modify service scope of coverage
- Exceed service limits/add services
- Expand settings where services may be provided
- Modify provider requirements
HOME AND COMMUNITY BASED SERVICES – Details

Coronavirus Disease 2019 (COVID-19):
Operational Guidance and Recommendations for Providers of Intellectual Disability and Autism Services

PA.0147 Appendix K (PDF, 122.67 KB)
PA.0235 Appendix K (PDF, 95.33 KB)
PA.0235 Appendix K - Amended (PDF, 134.49 KB)
PA.0324 Appendix K - Amended
PA.0354 Appendix K (PDF, 149.39 KB)
PA.0386 Appendix K (PDF, 95.01 KB)
PA.0386 Appendix K - Amended (PDF, 134.48 KB)
PA.0593 Appendix K (PDF, 160.92 KB)
PA.1486 Appendix K (PDF, 107.36 KB)
Special Education/Early Intervention

The Pennsylvania Department of Education advises schools and EI programs to make every effort to provide some type of continuity of education for all students in the most appropriate and accessible ways possible. In so doing, schools and EI programs also need to ensure consideration for the provision of FAPE for students with disabilities and appropriate accommodations for English learners that are reasonable and appropriate based on student need and current circumstances.

In addition, districts and schools must ensure that, to the greatest extent possible, each student with a disability can be provided the special education and related services identified in the student’s Individualized Education Program (IEP) or Section 504 plan. Once school resumes, a child's IEP team (or appropriate personnel under Section 504) must make an individualized determination whether and to what extent compensatory services may be needed, consistent with applicable requirements, including to make up for any skills that may have been lost during the closure within a reasonable timeframe. https://www.education.pa.gov/Schools/safeschools/emergencyplanning/COVID-19/Pages/AnswersToFAQs.aspx#specialeducation
Special Education/Early Intervention

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

- K-12: $541.4 million
- Post-secondary: $417.6 million
- Governor’s Discretionary: $101.1 million

It is critical that advocacy occur so that Pennsylvania 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
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.
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
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