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 Oregon Autism Community During COVID-19 Through Advocacy

June 10, 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

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
Agenda

Welcome
Lori Kiehle
Manager Field Development

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

State Advocacy Update
Judith Ursitti
Director State Government Affairs

Community Outreach
Marianne Sullivan
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
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

Oregon was approved for an 1135 emergency waiver on March 25, 2020 and again on May 8, 2020 by CMS, the federal Medicaid agency. This allows for greater flexibility related to:

• Temporarily suspend Medicaid fee-for-service prior authorization requirements
• Extend existing authorizations 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
• Extend State Fair Hearing requests and appeal timelines
• Provisionally enroll out-of-state providers who are already enrolled in Medicaid or Medicare
• Provide services in alternative settings
• Suspend public notice and tribal consultation requirements to expedite State Plan Amendment submissions

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.
- Oregon Health Plan coverage telemedicine/telehealth service information for physical and behavioral health providers can be found [here](#).
Telehealth Services

For the duration of the COVID-19 outbreak, or until otherwise directed by the directors of the Department of Consumer and Business Services and the Oregon Health Authority, the state of Oregon expects health plans of all types to provide increased access to health care services through telehealth delivery platforms and to encourage patients to use telehealth delivery options to limit the amount of in-person health care they seek.

Oregon Health Authority and Department of Consumer and Business Services will continue to develop more specific guidance for CCOs and commercial health insurance plans and the agencies will identify whether additional barriers to telehealth delivery exist for specific populations or services and will work to eliminate those barriers. If you have a recommendation, please email us at OrCOVID19.JIC@dhsoha.state.or.us.

This includes commercial health plans regulated by DCBS and Medicaid health plans regulated by OHA. Click here for full details.
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:
State Medicaid agencies may submit the Appendix K to request temporary adjustments to the conditions of their 1915(c) Home and Community Based Services waivers.

Oregon’s approved Appendix K Applications for the Children's HCBS Waiver, Adults' HCBS Waiver, Medically Involved Children's Waiver, Medically Fragile Model, Behavioral Model Waiver can be found [here](#), [here](#) and [here](#).

Some modifications approved include:

- Temporary modify process for level of care evaluations and reevaluations
- Extend reassessment and reevaluation due dates
- Permit virtual evaluation, assessment and person-centered planning meetings
- Temporarily expand settings where services can be provided
- Temporarily modify provider qualifications
- Temporarily increase provider rates
- Temporarily provide retainer payments to providers

Additional information can be found [here](#) on the Oregon Health Authority Medicaid Policy website.
Special Education/Early Intervention

Free Appropriate Public Education (FAPE) must be provided for students who receive special education and related services during distance learning. Districts, during this time, will begin to implement students’ IEPs, to the maximum extent possible, and make appropriate modifications in consultation with a student’s IEP team, if necessary. It is important to note that during the extended closure, IEP services could look different than in a school setting during normal circumstances.

Frequently Asked Questions About the Novel Coronavirus (COVID-19) For Parents and Families of a Child who Experiences Disability can be found here.
Special Education/Early Intervention

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

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<thead>
<tr>
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<th>Amount</th>
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<tr>
<td>K-12</td>
<td>$140.8 million</td>
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<tr>
<td>Post-secondary</td>
<td>$139.8 million</td>
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<tr>
<td>Governor’s Discretionary</td>
<td>$33.4 million</td>
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It is critical that advocacy occur so that Oregon 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**
Oregon Efforts Specific to Discrimination Against Those with Disabilities

The Oregon disability community has been asking the State to issue clear and specific guidance protecting the rights of Oregonians with disabilities and older adults against discrimination.

According to Paul Terdal, Founder, “Autism Insurance for Oregon”

- Intellectually disabled patients with COVID-19 have been pressured into signing Do Not Resuscitate / Do Not Intubate orders that they do not understand, based on the Physician’s belief in their “low quality of life.”
- Other individuals with disabilities have been denied access to caregivers, even when necessary to support communication needs essential to provide informed consent and participate in care, in violation of the Americans with Disabilities Act.

Governor Brown and the Oregon Health Authority have been asked to work with the disability community to ensure that Oregon’s guidance to health care providers clearly prohibits such discriminatory conduct. For additional information or to become involved, please contact Paul at paul@autisminsuranceor.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
Community Outreach
COVID-19 Information and Resources

We

The Autism Response Team responds emails and phone calls

Autism Cares Grants specifically to help families with financial needs

COVID-19 pages

• We have general resources, resources for families, healthcare providers, educators, and people with autism.
• Resources are updated weekly and posted on social channels as well as our website

www.autismspeaks.org/covid-19-information-and-resources
48 Autism Speaks tool kits for children, adults, families & healthcare professionals

*100 Day Kit in 17 languages*
Resource GUIDE

Community Events
Did You Know?

We have an Autism Response Team

If you need resources or have questions about autism, call 888-288-4762 or email familyservices@autismspeaks.org
Thank You