The Federal Response to COVID-19: ADDRESSING THE NEEDS OF THE AUTISM AND DISABILITY COMMUNITIES APRIL 28, 2021 • 2:00 PM - 4:00 PM **VIRTUAL EVENT**





The Mental Health Impacts of the Pandemic on the Autism/Disability Community and NIH/NIMH Efforts

Joshua A. Gordon, M.D., Ph.D. Director, NIMH Chair, Interagency Autism Coordinating Committee (IACC)

The Federal Response to COVID-19: Addressing the Needs of the Autism and Disability Communities April 28, 2021



Twitter: @NIMHDirector



COVID-19 Has Affected Many Aspects of Life





Individuals on the Autism Spectrum Have Unique Vulnerabilities to Impacts of COVID-19

- Higher levels of pre-existing co-occurring physical and mental health conditions
- Increased difficulty with adapting to and being flexible with abrupt changes and other traits can impact resilience
- Increased vulnerability to social isolation and economic hardship
- Individuals with intellectual and developmental disabilities (IDD) have a higher likelihood of contracting and dying from COVID-19, especially when living in congregate settings





SPARK Survey: Impact of COVID-19 Pandemic on Families/Caregivers

Survey respondents: 8,000 families with dependents on the autism spectrum; March 2020

School 84%

Percent of families reporting settings for services or therapies that have been disrupted Professional Clinic 52% Home (Administered by visiting staff) 26% Home (Administered by a parent or caregiver) 15% Daycare 7% Residential programs 6%





SPARK Survey: Impact of COVID-19 Pandemic on Autistic Adults

Survey respondents: 636 adults on the autism spectrum; March-April 2020

LEVELS OF PSYCHOLOGICAL DISTRESS





Autism Speaks Study: Food and Housing Insecurity During the COVID-19 Pandemic

Households of people with autism struggled with meeting basic needs like food and housing.





7 link&utm_campaign=espeaks

Autism Speaks Study: Food and Housing Insecurity During the COVID-19 Pandemic

Households of people with autism are experiencing significant food insecurity, especially minority households, compared with households with no disability

HOUSEHOLD FOOD INSECURITY RATES BEFORE AND AFTER COVID-19

*Children with no disability 20% 27	′.1% **	(after)				
*Children with autism	41%		57%	**(afte	er)	
HOUSEHOLD FOOD INSECURITY R **No disability 27.1%	ATES,	FALL 20	20			
Person with autism, white	43.89	6				
Pe	rson wit	h autism, Bl	ack non-His	spanic	65.7 %	l
			Person	with au	ıtism, Hispo	anic 74

Survey respondents: 1,369 individuals and families with dependents on the autism spectrum; November-December 2020





.5%

Promoting Resilience and Long-term Recovery from the COVID-19 Pandemic

- Meet immediate needs
- Promote health and provide access to care for COVID-19 illness
- Increase access to vaccination for vulnerable populations
- Practice healthy coping habits and make mental health supports accessible
- Avoid social isolation and find ways to help others
- Maintain hope for the future and sense of control





SPARK Surveys: What's Working During the Pandemic?

Autistic adults report:



Telehealth



Check-ins with therapists via email and phone



Journaling



Maintaining a schedule and sticking to it



Walks and exercise



Keeping in touch with family and friends via phone and video chat



March-April 2020

Families report: Social stories



Breaks for rest and relaxation



Telehealth appointments



Pursuing hobbies



Cooking for family



Enjoying time with family in person and virtually

10 https://sparkforautism.org/discover_article/covid-19-and-its-impact-on-autistic-adults/; https://sparkforautism.org/discover article/covid-19-impact-asd/



Potential Positive Impacts of the Changes Brought on by the COVID-19 Pandemic

- Innovations in service delivery such as increased use of telehealth
- Increased parent/caregiver involvement in delivery of interventions



- Increased remote education and employment opportunities
- Increased use of virtual platforms for socializing & community interactions
- Some report reduced social demands and social stress

Ameis SH, Lai MC, Mulsant BH, Szatmari P. Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. Mol Autism. 2020 Jul 22;11(1):61. doi: 10.1186/s13229-020-00365-y. PMID: 32698850; PMCID: PMC7374665.



lab

IACC/OARC Online COVID-19 Resources for the Autism Community



https://www.coronavirus.gov.

https://iacc.hhs.gov/resources/coronavirus/



NIMH Online COVID-19 Resources



https://www.nimh.nih.gov/health/education-awareness/shareable-resources-oncoping-with-covid-19.shtml



NIH Online COVID-19 Resources



https://covid19.nih.gov/



COVID-19 Vaccination and People on the Autism Spectrum

Karen Remley, MD, MBA, MPH, FAAP Director, National Center on Birth Defects and Developmental Disabilities

The Federal Response to COVID-19: Addressing the Needs of the Autism and Disability Communities National Institute of Mental Health 28 April 2021





cdc.gov/coronavirus

Updates on vaccine recommendations and timeline



Currently authorized vaccines

- Pfizer-BioNTech
- Moderna





Johnson & Johnson/Janssen

Viral vector vaccine Requires one dose

- All three vaccines were tested in tens of thousands of adults from diverse backgrounds, including older adults and communities of color.
- All of the available vaccines have been proven effective at preventing serious illness, hospitalization, and death from COVID-19.
- It is unknown how long protection from vaccines might last.

https://www.pfizer.com/news/press-release/press-release-detail/pfizer-and-biontech-conclude-phase-3-study-covid-19-vaccine https://investors.modernatx.com/news-releases/news-release-details/modernas-covid-19-vaccine-candidate-meets-its-primary-efficacy

Health equity for people with disabilities

To help the United States succeed against COVID-19, federal, state, local, and tribal partners and community-serving organizations are working together to ensure all public health actions address health disparities for all populations.

Populations of focus:

- Racial and ethnic minority populations
- People living in rural or frontier areas
- People experiencing homelessness
- Essential and frontline workers
- People with disabilities
- People with substance use disorders
- People who are justice-involved

Intersection of disabilities and special healthcare needs



COVID-19 Vaccination Accessibility

- CDC is working with partners across the country on implementation of vaccination plans for their respective areas.
- CDC playbook was developed to provide important information for jurisdictions to consider when vaccinating people with disabilities.
- Vaccinating older adults and people with disabilities (for jurisdictions): <u>https://www.cdc.gov/vaccines/covid-19/clinical-considerations/older-adults-and-disability/access.html</u>
- Vaccinating older adults and people with disabilities (for vaccination sites): https://www.cdc.gov/vaccines/covid-19/clinical-considerations/older-adults-and-disability.html

Available Accessible COVID-19 Resources

- Resources about COVID-19 for people with limited English and that are easyto-read or in <u>American Sign Language</u>
- CDC Foundation supported the GA Institute of Technology (GA Tech) to translate COVID-19 <u>resources</u> into accessible formats
- Ongoing development of repository of accessible COVID-19 vaccine information



Photo source: CDC YouTube site

White House Virtual Forum: *Breaking Down Barriers for People Who* Have Challenges Accessing COVID-19 Vaccination (April 21, 2021)



Supporting People with Autism Spectrum Disorder and Related Disabilities

- Partner organizations disseminating disability-related vaccine guidance and accessible documents
 - Autism Science Foundation
 - Autistic Self Advocacy Network
 - Autism Speaks
 - Autism Society
 - Other organizations such as AAP, AAHD, AAPD, AUCD, NACDD, NASEM and more
- <u>Disability Toolkit</u> with COVID-19 vaccine equity and prevention guidance
- <u>Promising Practices</u>: Reaching Populations with Limited Access to Vaccines
- <u>Prioritizing and Scheduling</u> People with Disabilities and Caregivers for Vaccination



Photo source: iStock

Study to Explore Early Development

- CDC longitudinal study of children aged 3-9 with autism spectrum disorder, other developmental disabilities, and in the general population who participated at ages 2-5
- COVID-19 impacts including
 - Education and use of remote learning;
 use of services and telemedicine; testil
 and mitigation strategies; and changes
 routines and well-being.
 - Changes in household structure, finances, employment and health insurance; and COVID-19 infection
 - Pre-COVID-19 and post-COVID-19 assessment of behavior problems



Study to Explore Early Development (SEED): Phases 1, 2, and 3

Considerations for pediatric populations and children with disabilities and special healthcare needs



Vaccine clinical development: children

	BIONTECH Pfizer	moderna		OXFORD AstraZeneca
Platform/ Design	mRNA: encodes stabilized spike; lipid NP	mRNA: encodes 2P- stabilized spike; lipid NP	Replication incompetent Ad26; stabilized spike	Replication incompetent ChAdOx1 chimp Ad; wild type spike
Dose/Schedule Adults	IM 2 doses X 30 μg 21 days apart	IM 2 doses 100 μg 28 days apart	IM 1 dose at 5 x 10 ¹⁰ vp (also testing 2 doses (0, 56 days))	IM 2 doses at 5 × 10 ¹⁰ vp (0, 28 days)
Current Status	Emergency Use Authorization (EUA) ages 16 and up	EUA ages 18 and up	EUA ages 18 and up	Phase 3 adults
Adolescents	Fully enrolled	Fully enrolled	Start 4-6wks after results from adult trials	TBD
Younger Children	Studies have begun	Studies have begun	TBD	TBD

Adapted from source: Emily Erbelding, M.D., M.P.H. Director, Division of Microbiology and Infectious Diseases, NIAID

Routine vaccines widely available to pediatric populations

- Children receive routine vaccinations according to the recommended schedule.
- The Vaccines for Children (VFC) program provides vaccines at no cost to children who might not otherwise be vaccinated because of inability to pay.
- Approximately half of U.S. children are eligible for VFC and ~86% of U.S. pediatricians provide care in a VFC-enrolled practice.





https://www.cdc.gov/vaccines/parents/schedules/index.html

Whitney CG, Zhou F, Singleton J, Schuchat A. Benefits from immunization during the Vaccines for Children program era—United States, 1994-2013. MMWR Morb Mortal Wkly Rep 2014;63:352–5. O'Leary ST, Allison MA, Vogt T, et al. Pediatricians' experiences with and perceptions of the Vaccines for Children program. Pediatrics 2020;145:1204–7. https://www.cdc.gov/vaccines/parents/schedules/index.html

Considerations for ensuring equity to vaccine access for children with disabilities or other healthcare needs

- It is important that people with disabilities get the COVID-19 vaccine.
- Some children may have more interaction with trusted healthcare or service specialists than with general pediatricians.
 - Pediatric hospital systems
 - Pediatric specialists and/or disability-specific practices and clinics
 - Occupational, physical, or speech specialists
- Vaccinating children with disabilities and special healthcare needs, their caregivers, family members (e.g., parents and siblings), and service providers as soon as they can to reduce risk of negative outcomes from COVID-19.
- Vaccination sites and providers and vaccination messaging should be accessible to all populations with disabilities.

https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/disabilities.html





For more information, contact CDC 1-800-CDC-INFO (232-4636) TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



Office of Special Education Programs COVID Technical Assistance

LARRY WEXLER DIRECTOR, RESEARCH TO PRACTICE LARRY.WEXLER@ED.GOV



<u>HTTPS://IRIS.PEABODY.VANDERBILT.</u> EDU/MODULE/C19/CHALLENGE/# CONTENT

Resources from Across the Department



Department Coordination



- Formed ED Technical Assistance Coordination Team (OESE, OSEP, IES)
- Collecting and Disseminating Resources
 - Collected Continuity of Learning Resources
 - Created COVID-19 resource pages
 - Cross-posting and sharing resources
 - Hosting webinars with grantees



Updating ed.gov and POC websites



 Coordinating with Partner Organizations (NAESPA, CCSSO, NASDSE)





OSEP COVID-19 Resources

OSEP Continuity of Learning During COVID-19 Homepage

This webpage offers information, tools, and resources to help educators, families, and related service providers meet the educational, behavioral, and emotional needs of children and youth with disabilities through remote and virtual learning.

Continuity of Learning During COVID-19 Resource Database

K-12 Resources

National Center on Systemic Improvement (NCSI): COVID-19 Resources for Supporting Students with Disabilities

https://ncsi.wested.org/

Early Childhood Resources

Early Childhood Technical Assistance Center (ECTA): COVID-19 Early Childhood Resources and Information Webpage

https://ectacenter.org/topics/disaster /coronavirus.asp

<u>Webinar Series</u>: <u>Continuity of Learning During</u> <u>COVID-19</u>

- Highlighting Resources for Teachers and Parents to Enhance the Continuity of Learning During COVID-19 for Children with Disabilities
 - Highlights products from OSEP-funded investments to support teachers, providers, and parents to provide services and supports to children with disabilities through distance instruction.
- Highlighting Strategies and Practices in Providing Related Services to Enhance the Continuity of Learning During COVID-19 for Children with Disabilities
 - Focuses on the provision of related services to address the ongoing needs children with disabilities through remote and distance methods.
- Highlighting Resources and Practices to Support Back to School and Continuity of Learning During COVID-19 for Children with Disabilities
 - Highlights exemplar resources and practices for teachers, leaders, and other providers to support students with disabilities from Preschool—Grade 12 in in-person, remote, and hybrid instructional formats.
Brief Series: Evidence-Based and Promising Practices to Support Continuity of Learning for Students With Disabilities



https://osepideasthatwork. org/sites/default/files/SWD Learning-Families-508.pdf https://osepideasthatwork. org/sites/default/files/SWD Learning-Teachers-508.pdf

https://osepideasthatwork. org/sites/default/files/SWD Learning-Providers-508.pdf

IRIS CENTER

PARENT RESOURCE FOR DISTANCE EDUCATION

FIVE CENTER COLLABORATION PBIS LEAD TO LITERACY SPDG NCIL MI INTEGRATED SYSTEM OF SUPPORT

GUIDE: RETURNING TO SCHOOL DURING AND AFTER A CRISIS

HTTPS://WWW.YOUTUBE.COM/WATCH?V=JUXPGNJ2CFY

Returning to School During and After Crisis

https://www.pbis.org/current/returning-to-school-during-and-

State & District





School & Classroom





Guides & Briefs

- <u>School Guide</u>
- <u>Creating Teaching</u> <u>Matrix for Distance</u> <u>Learning</u>
- Adapting CICO for Distance Learning

Example Webinars & Videos

- Effective Environments
- High Leverage
 Instructional Practices
 Action Plan Templates
- <u>Staff PD Day Agenda</u>
 <u>Template</u>
- <u>Creating Effective</u>
 <u>Classroom</u>
 Environment
 - Te me leite

Guides & Briefs

- Supporting Families
 with PBIS at Home
- <u>Supporting Students</u> with Disabilities at <u>School and Home</u>

Example Webinars & Videos

Coming soon

Action Plan Templates

• <u>Supporting PBIS at</u> <u>Home Template</u>

Guides & Briefs

• <u>State Guide</u>

CHOOL DURIN

- District Guide
- <u>Attendance in</u> <u>Remote Learning</u>

Example Webinars & Videos

- <u>Meeting Social &</u> <u>Emotional Needs for</u>
- Action Plan Templates
- District & State Action
 Plan

TIES AND NCEO

HELPING YOUR CHILD WITH COMMUNICATION AT HOME

HTTPS://VIMEO.COM/451891910/3BE2BFE213

NCPMI

WEARING MASKS

HTTPS://CHALLENGINGBEHAVIOR.CBCS.USF.EDU/DOCS/WEARING-MASKS STORY.PDF

NATIONAL DEAF CENTER

INTRODUCING DEAF SUCCESS IN FALL 2020

HTTPS://WWW.NATIONALDEAFCENTER.ORG/FALL2020GUIDES

Questions?

Autism & COVID-19

Updates from the U.S. Department of Labor's Office of Disability Employment Policy

Jennifer Sheehy Deputy Assistant Secretary

April 28, 2021



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What Do We Do?

- Develop and influence policies that increase the number and quality of
 - employment opportunities for
 - people with disabilities



Office of Disability Employment Policy

Current Priorities

- Ensure a disability-inclusive COVID response and recovery
 - "Recover Into Inclusion"
- Promote racial and social equity in disability policy and programs
- Support workers with <u>mental health</u> conditions and promote mental health-friendly workplace policies and practices
- Expand opportunities for training and employment in <u>clean/green</u> energy and other high-growth industries
- Help <u>youth with disabilities</u> prepare for and succeed in employment in the post-pandemic era



Ensuring an Inclusive Response & Recovery

- Assisting workers with disabilities who have lost jobs
- Ensuring workers with disabilities have access to needed accommodations and supports
 - Including those experiencing Long COVID
- Helping employers and workers understand the intersection between safety and health guidelines and the ADA
- Promoting best practices for workplace mental health
- Educating about accessible telework



An Inclusive Recovery: Tools to Assist from JAN



AskJAN.org

- Wide range of resources on pandemic-related topics:
 - -Stress and mental health conditions, such as:
 - -Requesting accommodations
 - -Masks in the workplace
 - -Telework
 - -Long COVID
- One-on-one assistance with individual situations



Response & Recovery: "Long COVID"

- Between 10 and 30% experience ongoing symptoms
- May be covered by ADA and other laws (and thus entitled to accommodations)
- JAN can help!



AskJAN.org



An Inclusive Recovery: Tools to Assist from EARN



AskEARN.org



COVID-19 and Job Applicants and Employees with Disabilities: Emerging Practices to Employ and Protect Workers



Adopting an Integrated Telework Policy for Employees With and Without Disabilities



Mental Health Toolkit







Driving Change 🛨 Creating Opportunity

Autism-Specific Resources

- JAN (AskJAN.org)
 - -Common accommodations
 - -Interviewing tips
- EARN (AskEARN.org)
 - -Neurodiversity in the Workplace
- Autism@Work Roundtable (DisabilityIn.org)



Questions?

Jennifer Sheehy Deputy Assistant Secretary Office of Disability Employment Policy Sheehy.Jennifer.C@dol.gov





Thanks

IACC Website: https://iacc.hhs.gov/ VideoCast: https://wideocast.nih.gov/



