

## **Autism Society of Greater Akron Policy Statement on COVID Vaccine**

The [Autism Society of Greater Akron](#) (ASGA) conducted a survey of parents, direct support professionals and self-advocates across the State of Ohio about their beliefs, support, or concerns about the COVID-19 vaccine as part of its Autism Summit. While the survey was sent via the Autism Society of Ohio's network and results should not be over-generalized, the following themes emerged that we wish to urge policy makers to consider:

### **1. Address healthcare disparities and better equip medical personnel to care for individuals with intellectual and developmental disabilities when they are ill.**

People with **intellectual and developmental disabilities** are three times more likely to die from COVID-19. Our state and national leaders must continue to address health care disparities for this vulnerable population. Survey respondents were not confident that if a person with an intellectual/developmental disability became ill, they would receive adequate healthcare. In addition, racial inequities were identified as magnifying the problem.

### **2. Prioritize caregivers who live in private homes and individuals with severe I/DD.**

ASGA believes the U.S. Centers for Disease Control and the State of Ohio should recognize the need to prioritize vaccinations for caregivers of people with intellectual and developmental disabilities outside of congregate settings, i.e., parents/guardians.

We also urge prioritizing individuals with severe intellectual and developmental disabilities – without underlying medical conditions – who would have difficulty managing their illness, and hospital staff would have difficulty supporting. Highly involved individuals would also require 24/7 support from their personal caregiver, putting their caregiver at risk and logistically compounding matters.

### **3. Open schools to provide an in-person learning option for individuals who need it.**

Students with autism spectrum disorder and other developmental disabilities can have a difficult time navigating online learning. Many survey respondents expressed the need for children to have access to the vaccine so their children can safely return to school. We urge schools to re-open, with or without availability of the vaccine, for those who need in-person learning.

ASGA also recognized the [Autism Society of America's](#) national leadership on the COVID vaccine and [statement](#) urging people with autism and other intellectual/developmental disabilities "to be vaccinated as distribution becomes possible" with the COVID-19 vaccine.

*The **Autism Society of Greater Akron** (ASGA) is part of a nationwide network of affiliates that are part of the Autism Society of America, the nation's largest and oldest grassroots autism organization. ASGA serves Summit, Stark, Wayne, Portage and Medina counties (OH) and works locally to achieve its mission --to improve the lives of all affected by autism. The [Autism Society of Ohio](#) is a coalition of the local Ohio Autism Society affiliates and focuses on statewide advocacy, awareness and services in areas not covered by a local affiliate.*

## ABOUT THE SPEAKERS

### **Lisa Wiggins, Ph.D., Developmental Psychologist**

Centers for Disease Control and Prevention

Dr. Wiggins is a Behavioral Scientist with the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC). She is currently deployed as the disabilities unit lead within the CDC Vaccine Task Force. In that role, Dr. Wiggins works with advocates, partners, and jurisdictions to ensure equal COVID-19 vaccination access for people with disabilities. Dr. Wiggins has a Ph.D. in developmental psychology, M.A. in developmental psychology, and M.S. in applied clinical psychology. She has 20 years of experience with developmental assessment and has authored of over 100 publications and presentations. She researches and lectures on a variety of topics, including the surveillance, epidemiology, and early detection of young children with autism spectrum disorder.

### **Donald Dumford, M.D., Infectious Disease Specialist**

Cleveland Clinic Akron General

Dr. Dumford is a lifelong Northeast Ohio resident. He grew up in Strongsville. He then attended the University of Dayton for undergraduate studies and the Boonshoft School of Medicine at Wright State University for medical school. He returned to Northeast Ohio to continue his training at Case Western Reserve University/University Hospitals-Cleveland Medical Center where he completed his internal medicine residency and infectious disease fellowship. During this time he also participated in the VA Quality Scholars training program and received his Master's in Public Health from Case Western Reserve University. He has been on the Cleveland Clinic Akron General medical staff in the Division of Infectious Disease since 2012 and for the past year has served as the Medical Director of Infection Prevention. Outside of work he also serves on the associate board for the Ohio and Erie Canalway Coalition. He lives in Bath with his wife Rachel and daughter Cecilia. When not at work or at home, you can find him on a trail in the national park or one of our local MetroParks.

### **Scott Pangonis, M.D., MS, FAAP - Associate Director, Infection Control**

Pediatric Infectious Disease Physician

Akron Children's Hospital

Dr. Pangonis is a pediatric infectious disease physician and associate director of Infection Control at Akron Children's Hospital, where he's been practicing since 2020. A graduate of the University of South Florida Morsani College of Medicine, he completed his pediatric residency at the University of Nevada School of Medicine. He went on to complete a pediatric infectious diseases fellowship at Cincinnati Children's Medical Center. Dr. Pangonis has a special interest in pediatric infectious diseases and infections in the immune-compromised patient. He is certified in pediatrics by the American Board of Pediatrics, and is a fellow of the American Academy of Pediatrics. He's also a member of the Infectious Disease Society of America, the Pediatric Infectious Disease Society and several other professional organizations. In his spare time, he enjoys playing chase with his 4 year old son.

## **Thomas Quade, Health Commissioner**

Geauga County Public Health

Tom is the County Health Commissioner for Geauga County, Ohio. Prior to that, he served as the Health Commissioner for Marion County, Ohio for more than five years, the Deputy Health Commissioner in Summit County, Ohio for three years, and a decade of public health service beginning in 2000 and culminating in his appointment as the Interim Director of Health for the City of Akron, Ohio health department.

Mr. Quade's commitment to public health is underscored by decades of volunteer state and national leadership. He is a Past President of both the Ohio Public Health Association (OPHA) and the American Public Health Association (APHA). He served on the Kresge Foundation's Emerging Leaders in Public Health advisory committee, on the national Public Health Accreditation Board's accreditation committee, and on the selection panel for the De Beaumont Foundation's "40 under 40 in Public Health". He is a Board Member on the National Board of Public Health Examiners. He has served as the keynote speaker for state public health conferences across the country on health equity and the need for novel community partners.

He is a member of the Special Olympics International Center for Inclusive Health's Advisory Committee. He served as the chairperson for the national workgroup on health and disability for the National Association of County and City Health Officials. He is the current President of the Summit County Board of Developmental Disabilities.

He has had numerous columns published in "The Nation's Health" and he co-authored the chapter "The Structure and Function of the Public Health System in the United States" in the 16<sup>th</sup> edition of "Public Health and Preventive Medicine". Mr. Quade has received a number of professional recognitions over the course of his career, including recognition from the Ohio General Assembly for national leadership in the field of public health in 2015 and the John D. Porterfield Distinguished Service Award in 2019.

## **John Trunk, Superintendent**

Summit County Board of Developmental Disabilities

John began his employment with the Summit County Developmental Disabilities Board (Summit DD) in December 2013. He brings nearly forty years of administrative experience in the field of developmental disabilities. Prior to Summit DD, John served as the Superintendent for the Lucas County Developmental Disabilities Board for twelve years where some of his responsibilities included program development, fiscal management of up to \$90 million dollar budget, successful passage of five levies, strategic planning and execution and human resource management. John has also held the Superintendent position for the Williams County Board for eight years and was Residential Director of Richland County Developmental Disabilities Board from 1988-1991.

His career working with people with developmental disabilities began in 1980 in Chicago where he was born and raised. His early experience included direct care responsibility in both day program and residential settings.

John believes in respect of others and their opinions, open communication, maintaining the highest professional ethics and supporting the competencies of others. He is the spokesperson for the organization with a thorough knowledge of the disabilities field and firm decision making.

John holds a Bachelor of Science in Psychology from Illinois State University and a Master's of Science in Rehabilitation Administration from DePaul University. He has been married for almost 40 years. He has four adult children and eight (soon to be nine) grandchildren.

# COVID VACCINE SURVEY RESULTS

The Autism Society of Greater Akron conducted the COVID vaccine survey as part of its Autism Summit, our event focused on policy issues important to individuals with autism spectrum disorder, their families, and those who support them. Thank you to everyone who responded and provided thoughtful comments. This survey was distributed through the Autism Society of Ohio network and therefore its results may not be generalizable.

## IN COLLABORATION WITH:

**Autism Society of Greater Cincinnati, Greater Cleveland, Central Ohio, Mahoning Valley, Northwest Ohio**

## WHO TOOK THE SURVEY?

**583**

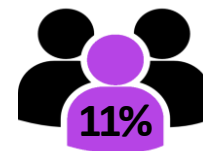
Participants



Self-Advocates



Parents / Guardians



Direct Support Professionals

## THE DECISION TO VACCINATE OR NOT



**YES**

**UNSURE**



**NO**

### ALL SURVEY PARTICIPANTS

74%	8%	18%
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### DIRECT SUPPORT PROFESSIONALS

72%	8%	20%
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### PARENT / GUARDIANS

(Vaccine For Self)

74%	8%	18%
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### PARENT / GUARDIANS

(Vaccine For Child(ren) with Autism/DD)

68%	12%	20%
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### SELF-ADVOCATES

76%	12%	12%
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## SURVEY COMMENTS SUMMARIZED

- If adults with developmental disabilities and their Direct Support Professionals can be prioritized, it does not make sense that parents of children who do not live in group homes are not prioritized." *Parent*
- "Working with a population that often will not tolerate PPE, vaccine is needed to keep everyone safe." *Direct Support Professional*
- "Not me – they need to find another person to use as a test subject." *Self-Advocate*
- "I think healthcare equity will be based more on race than disability. Black and Latinos with a disability are unlikely to get adequate medical care." *Parent*
- "Individuals who have severe developmental and intellectual disabilities – who would have great difficulty managing being ill and hospitals would have difficulty treating them – should be a priority. Racial inequities compound this problem." *Parent*
- "Children need access to the vaccine, as we have to get them back to school!" *Parent*
- "As a caregiver, I am worried if I get sick or die, who will care for my children." *Parent*
- "The vaccine will help people feel safer about getting back into the community." *Self-Advocate*
- I'm afraid not having the vaccine will affect my son's work status." *Parent*

## REASONS TO GET THE VACCINE



It's Safe/  
Effective



I'll Get  
Sick



Family Will  
Get Sick



All of  
These

ALL Participants	64%	55%	58%	48%
Direct Sup Prof	66%	48%	60%	48%
Parent/Guardian	64%	55%	58%	47%
Self-Advocate	70%	61%	55%	48%

\*Participants were asked to check all that apply

## REASONS NOT TO GET THE VACCINE



Not Safe/  
Effective



Fear Long  
Term Effects



Need  
Info



No Belief  
In Vaccines



All of  
These

ALL Participants	20%	23%	5%	16%	7%
Direct Sup Prof	18%	23%	2%	22%	0%
Parent/Guardian	20%	24%	6%	16%	5%
Self-Advocate	24%	15%	6%	12%	6%

\*Participants were asked to check all that apply

## DECISION BY RACE



BLACK Participants

YES	UNSURE	NO
55%	22%	23%



HISPANIC Participants

YES	UNSURE	NO
54%	15%	31%



OTHER Participants

YES	UNSURE	NO
79%	4%	17%



WHITE Participants

YES	UNSURE	NO
75%	7%	18%



### ACCESS TO INFORMATION (comments from survey below)

I have access to good, reliable information about the COVID-19 vaccine.

83%  
AGREE

17%  
DISAGREE

- Data needed on the efficacy of the vaccine for students (5-18 years old) with autism/DD.
- Not heard information about how the vaccine affects individuals with autism.
- Not enough information regarding the vaccine and pregnancy, nursing and future fertility.
- Great deal of unknowns, inadequate reporting (false positives/negatives), and too many people listed as dying from COVID with not enough diagnostics done to determine true cause of death.



### FAIR & EQUITABLE DISTRIBUTION OF VACCINE (comments from survey below)

Fair and equitable distribution of the COVID-19 vaccine should ensure people with DD are considered a priority population to receive the vaccine?

91%  
AGREE

9%  
DISAGREE

- Yes, people with DD deserve equal access and so does my spouse who is a healthcare worker in the ED. He works part-time with 3 health care systems but wasn't prioritized because he is not full-time.
- I have already been trying to get the vaccine for my parents that it is not equitable.



### RECEIVE APPROPRIATE CARE (comments from survey below)

I believe people with developmental disabilities will receive appropriate care from medical establishments should they need it.

73%  
AGREE

27%  
DISAGREE

- The trauma of taking my son to get the vaccine isn't worth the hassle unless I know he is at high risk.
- Quality of care may suffer if the individual lacks communication skills and support is not allowed due to COVID-19.
- It would be hard for my son to be in the hospital. He would not understand and probably need to be kept sedated.
- How will medical professionals address behaviors or barriers that may occur during the vaccination process?
- I think if it came to it, they would give a vent to a person without DD before one with DD.