#VaccinateByADA:
Strategies for COVID-19 Vaccine Access and Confidence for People with Disabilities
Agenda

1. Introduction to AUCD COVID-19 Vaccine Confidence and Access Initiative
   Lauren Blachowiak

2. Maryland Center for Developmental Disabilities at Kennedy Krieger Institute
   Maureen VanStone

3. Mailman Center for Child Development at the University of Miami Miller School of Medicine
   Lydia Ocasio-Stoutenburg and Jeff Brosco

4. University of New Mexico Center for Development and Disability
   Marcia Moriarta

5. Highlights from ASTHO Disability Inclusion Specialist
   David Carey

6. Panel Discussion

7. Audience Q&A
AUCD’s COVID-19 Vaccine Access and Confidence for People with Disabilities Initiative

**The goal:** Vaccinate all eligible persons with disabilities

- Build Vaccine Confidence
- Remove barriers of access and accessibility
- Outreach directly to disability communities
  - Persons with disabilities
  - Family members
  - Direct support professionals
AUCD’s COVID-19 Vaccine Access and Confidence for People with Disabilities Initiative

#VaccinateByADA Let’s vaccinate all eligible people with disabilities by the anniversary of the Americans with Disabilities Act (ADA) on July 26th!

Vaccine Confidence Story Bank
Share your Vaccine Story!

“We wanted to ensure they would be accessible” - Bryan’s Story

with one of my ADA coordinator colleagues in that area, and we would tour the site, see what the

Why should I get the COVID vaccine?

It’s safe.

It’s free.

It works.

Why get the vaccine?

If a person with a disability asks: “Why should I get the vaccine?”

You can say...

• The COVID-19 vaccine is a shot, like the flu shot, it will protect you from getting very sick from COVID-19, just like the flu shot protects you from getting very sick from the flu.

• It is important that all people who can get the shot, get it. Getting the shot will help keep you healthy.

• Getting the shot can also help keep your family, friends, and the people you care about healthy. It is very unlikely that you can give someone else COVID-19 after you get the vaccine.

• We know that people with some disabilities are more likely to get COVID-19 or get very sick from COVID-19 because of their type of disability or disability-related medical conditions. If you have one of these disabilities, it is even more important that you get the shot to stay healthy.

• Getting the shot can help you safely do the things you enjoy, like spending time with other people, going to work, and going out in the community.

www.aucd.org
Maryland Vaccine Access and Confidence

Maureen van Stone, Esq., MS
Director, MCDD
Director, Project HEAL
Associate, Johns Hopkins Bloomberg School of Public Health

June 29, 2021
COVID-19 Vaccine Access & Confidence

Kennedy Krieger Institute created an interdisciplinary team across various departments and programs to address COVID-19 vaccine access and confidence among people with disabilities, including:

- Maryland Center for Developmental Disabilities (Maryland’s UCEDD)
- Leadership Education in Neurodevelopmental and Other Disorders (Maryland’s LEND)
- Center for Diversity in Public Health Leadership Training
- Center for Child & Family Traumatic Stress
- Self-advocates or individuals with disabilities
- Parents or legal guardians
- Trainees (MCDD, LEND, Center for Diversity in Public Health Leadership Training)
Kennedy Krieger Outreach

- Kennedy Krieger hosted free drive-through vaccination clinics at our medical-campus in downtown Baltimore. The clinics were open to our patients, students, families, and members of the community.
- The COVID-19 Vaccine Clinics were held on May 1, May 23, & June 13
  - 580 people in total received vaccines
  - Individuals 12 and older could receive their first or second dose of the vaccine
  - Accessibility promotion included language and ASL interpreters on-site, behavioral supports, and ability to handle oversized vehicles (i.e., medical transport)
- Collected success stories for receiving the COVID-19 vaccine
  - Identified persons with a disability to share their vaccine success stories
Kennedy Krieger Outreach, continued …

• Beginning on Friday, July 9, 2021, Kennedy Krieger will offer vaccines to our outpatients, parents, and caregivers on-site in the Kennedy Krieger Outpatient Center on our downtown medical campus.
  – These clinics will be held every Friday throughout the summer.
  – We will consider other community-based clinics in late summer/early fall.
Kennedy Krieger Media Coverage

- **People with Disabilities and the Covid Vaccine**
  - *WTTG-TV*, by Melanie Alnwick: Maureen van Stone, the Director of the Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger Institute, joined to discuss people with disabilities getting the COVID vaccine
  - Aired on May 11, 2021

- Kennedy Krieger press release was issued on May 20, 2021
COVID-19
COVID-19 – Ongoing MCDD Activities

- Kennedy Krieger COVID-19 Task Force
- Johns Hopkins Scarce Allocation of Resources Committee
- Kennedy Krieger CARES Act Task Force
- Kennedy Krieger Patient Vaccine Information Workgroup
- Special Education Law During the COVID-19 Pandemic (Project HEAL)
- Special Education Law During the COVID-19 School Closures (Project HEAL)
- Home and Hospital Teaching (Project HEAL)
- Kennedy Krieger Institute Advance Directive Toolkit (Project HEAL)
- Kennedy Krieger COVID-19 Task Force email resources: Taking care of yourself, your family, and others (Resource Finder)
- COVID-19 resources added to MCDD’s quarterly newsletter
- How Did the COVID-19 Pandemic Affect People with Autism and their Caregivers? (Autism Research & Engagement Core)
- Special Education Law and Advocacy During the Time of COVID-19: A Q&A with Peter Wright (Autism Research & Engagement Core)
- Recorded Webinar: Advocating for your Child during the COVID-19 Pandemic

KennedyKrieger.org
Vaccine Access and Confidence
COVID-19 Vaccine Access & Confidence

- Chris Mason-Hales, a Kennedy Krieger patient with a spinal cord injury and a community member of Kennedy Krieger’s ethics program, recorded his vaccine success stories.

- Chris’s videos are live on the National Center for Disability in Public Health website: [https://nationalcenterdphp.org/vaccine-resources/](https://nationalcenterdphp.org/vaccine-resources/)
Center for Dignity in Healthcare for People with Disabilities (CDHPD)
Center for Dignity in Healthcare for People with Disabilities

- The MCDD is one of the eight collaborators for the Center for Dignity in Healthcare for People with Disabilities

- The Center added a COVID-19 workgroup April 2020
  - Two members of the MCDD’s team
  - Currently meets biweekly (began as a weekly workgroup)

- COVID-19 Vaccine Allocation Plan for Disability Tracker
  - [Dashboard] created as a partnership between the Johns Hopkins Disability Health Research Center and the Center for Dignity in Healthcare for People with Disabilities as a starting point for understanding how each state prioritized the disability community in COVID-19 vaccine distribution and was intended to help people with disabilities determine when they qualified for a COVID-19 vaccine in their state
  - Last updated 4/21/2021
Center for Dignity in Healthcare for People with Disabilities (cont’d)

- Social Stories for the COVID-19 Vaccine
  - Videos of our social stories and Common Asked Questions documents on COVID-19
  - Getting a COVID-19 Vaccine (English)
  - Getting a COVID-19 Vaccine (Spanish) “Reciber Una Vacuna”
  - Getting a COVID-19 Vaccine Social Story Screen Reader Version (Word Format)

- Fact Sheets on COVID-19 Vaccine
  - Common Questions about the COVID-19 Vaccine
Center for Dignity in Healthcare for People with Disabilities (cont’d)

- Fact Sheets on Rights during COVID-19 Response
  - How to Safeguard Against Disability Discrimination During COVID-19
  - Do you Know Your Rights with COVID-19
  - Infographic on Disability Discrimination in Healthcare during COVID-19 Pandemic
  - Types of Discrimination and Discrimination Remedies

- Blogs
  - First to Die, Last to be Recognized: Will Vaccine Allocation be Equitable? Posted December 17, 2020
  - Steps to Develop a Disability Advocacy Response to Vaccine Roll-Out Plans, by Stephanie Meredith, posted January 17, 2021
  - Vaccine Allocation Confusion, posted March 5, 2021
  - Does it matter that the COVID-19 Vaccine is for Emergency Use Authorization Only and not Full-FDA Approval? Posted June 4, 2021
Contact Information:

Maureen van Stone, Esq., MS
Director, MCDD
Director, Project HEAL
Associate, Johns Hopkins Bloomberg School of Public Health
vanstone@kennedykrieger.org

#VaccinateByADA
To learn more, get involved, and stay connected, visit KennedyKrieger.org/Connect
Promoting Vaccine Confidence

An Initiative Supporting Individuals with IDD and those who support them
The Team

- Jeffrey P. Brosco, M.D., Ph.D. — Project Principal Investigator and Oversight
- Lydia Ocasio-Stoutenburg, Ph.D. — Project Director and Co-Investigator
- Austin Garilli, Ph.D. - Project Manager and Budget Oversight
- Shelly Baer, MSW-SALT, Lifespan and Disability Local and Statewide Connections
- Jairo Arana, B.S. - Self Advocate, Lifespan and Budget Coordinator
- Reese Triana, MPH student - Logic Models and Research
- Grace Dima, MD student - Social Media Outreach
- Michelle Schladant, Ph.D. - Faculty and AUCD Connections/outreach

LEND Trainees

Active roles & responsibilities

Preparing next generation of leaders

Promoting Vaccine Confidence: An Initiative Supporting Individuals with IDD
Diversity, Equity, and Inclusion...

...simply, who we are.

Accessible Resources  Diverse Leadership  Self-Advocates with Intersecting Identities

Promoting Vaccine Confidence: An Initiative Supporting Individuals with IDD
Vaccine Logic Model

- Emphasizes support in decision making
- Interdisciplinary expertise in development
- Extensive stakeholder involvement
Responsive Resources & Partnerships

- Partnership with Department of Health
- Resource List for Clients with Disabilities
- Puerto Rico UCEDD Collaboration
- Utilization of Emergency Communication Networks
What We've Done
REAL TALK COVID 19: ASK AN EXPERT

Have questions about COVID 19 and the Vaccine? We've got answers! Join us for an open forum Q&A for adults with Developmental Disabilities. We will have medical experts here to answer all of your questions and share up-to-date information about the state of the pandemic, personal safety and of course the COVID 19 vaccine and how to get one!

Wednesday, March 31st, 12:00pm-1:00pm

Who: This event is open to adults with Developmental Disabilities who are participants in the CARD or Mailman Center adult group programs

What: A virtual group session using the Zoom platform. We will hear a brief presentation about COVID 19 and then you can ask all of your questions

How: Email us for the zoom link: Jairo Arana at jea145@med.miami.edu or Jennifer Feinstein at jfeinstein@miami.edu

Medical Expert: Jonathan Talbot, MD, FAAP, FACP

Program Director, Combined Internal Medicine-Pediatrics Residency Program
Clinical Associate Professor, Internal Medicine and Pediatrics
Section of Med-Peds
Departments of Internal Medicine and Pediatrics
University of Miami/Jackson Memorial Hospital

Group Facilitators:

Jennifer Feinstein, MSW
Case Manager, The Daniel Jordan Fidell Foundation Transition and Adult Programs at UMmotherJF

Shelly Baer, LCSW
Director, Leadership Training Initiatives at the Mailman Center for Child Development

Jairo Arana, BA
Clinical Program Coordinator, Mailman Center for Child Development

Changing the Narrative

Promoting Vaccine Confidence: An Initiative Supporting Individuals with IDD
LAS PERSONAS CON DISCAPACIDADES TIENEN PREGUNTAS SOBRE LA VACUNA DE COVID-19

¿CUÁLES SON LOS EFECTOS A LARGO PLAZO DE LA VACUNA? ¿CUÁLES SON LAS DIFERENCIAS EN LA SEGURIDAD DE LAS DIFERENTES VACUNAS?
¿HAY QUE SEGUIR USANDO UNA MASCARILLA AUNQUE UNO YA SE HAYA VACUNADO? ¿ES POSIBLE INFECHARSE AUNQUE DESPUÉS DE VACUNARSE?
¿QUÉ OCURRE SI SE TIRA EL VACUNADOR DE UNA VACUNA DESPUÉS DE LA PRIMERA DOSIS? ¿CUÁNTAS DOSIS DE LA VACUNA SON NECESARIAS PARA QUE TENGAS EFFECTOS?
¿CUÁLES SON LOS EFECTOS SECUNDARIOS? ¿CUÁLES SON LOS EFECTOS SECUNDARIOS DESPUÉS DE UNA VACUNA?
¿QUÉ HAY SI SE VACUNA EL 2.° DÍA DESPUÉS DE UNA VACUNA?
¿NECESITAS VACUNARTE SI TÚ TUS HIJOS NO SE VACUNARON? ¿CUÁLES SON LAS INTERACCIONES CON LOS MEDICAMENTOS QUE TÚ PRESENTAS ACTUALMENTE?
¿CÓMO SE PLANIFICAN LAS VACUNAS PARA COMPRARLO? ¿CÓMO DESEAN LA VACUNACIÓN?
¿QUÉ OCURRE SI SE TIRA EL VACUNADOR DE UNA VACUNA DESPUÉS DE LA PRIMERA DOSIS? ¿CUÁLES SON LOS EFECTOS SECUNDARIOS DESPUÉS DE UNA VACUNA?
¿QUÉ HAY SI SE VACUNA EL 2.° DÍA DESPUÉS DE LA PRIMERA DOSIS?
¿NECESITAS VACUNARTE SI TÚ TUS HIJOS NO SE VACUNARON?
¿QUÉ HAY SI SE VACUNA EL 2.° DÍA DESPUÉS DE LA PRIMERA DOSIS?
¿NECESITAS VACUNARTE SI TÚ TUS HIJOS NO SE VACUNARON?

Dialogue con las personas con discapacidades. Es importante.

Traducido de PRUCEDD

REAL TALK COVID 19: ASK AN EXPERT

Have questions about COVID 19 and the Vaccine? We've got answers! Join us for an open forum Q&A for adults with Developmental Disabilities. We will have medical experts here to answer all of your questions and share up-to-date information about the state of the pandemic, personal safety and of course the COVID 19 vaccine and how to get one!

Tuesday, August 24th, 12:00pm-1:00pm

Who: This event is open to adults with Developmental Disabilities who are participants in the CARD or Mailman Center adult group programs

What: A virtual group session using the Zoom platform. We will hear a brief presentation about COVID 19 and then you can ask all of your questions

How: Email us for the zoom link: Jairo Arana at jae145@med.miami.edu or Jennifer Feinstein at jfeinstein@miami.edu

Medical Expert:

Jeffrey Brocas, MD PhD
Professor of Clinical Pediatrics, University of Miami
Director, Population Health Ethics, UM Institute for Bioethics and Health Policy
Chair, Pediatric Bioethics Committee, Holt Children's Hospital, Jackson Health System

Jennifer Feinstein, MSW
Case Manager, The Daniel Jordan Fiddle Foundation Transition and Adult Programs at UM MIND CARD

Shelly Baer, LCSW
Director, Leadership Training Institute at the Mailman Center for Child Development

Jairo Arana, BA
Clinical Program Coordinator, Mailman Center for Child Development

For any questions or for more information please email Shelly Baer at rbaer@med.miami.edu or Jennifer Feinstein at jfeinstein@miami.edu

Responsive: Real Talk 2
Dear Mayor Cava,

A little over a year after the start of the pandemic the inequities experienced by individuals with disabilities has become more evident.

As people with disabilities, we face attitudinal obstacles and accessibility barriers. We often feel invisible and are treated like second-class citizens. This pandemic has exacerbated the disparities people with disabilities face.

There will always be emergencies, be it hurricane, or pandemic, or any other crises. We are individuals with disabilities who are alumni of a leadership group and have come together to recommend future steps to prevent people with disabilities from being sidelined again.

Promoting Vaccine Confidence: An Initiative Supporting Individuals with IDD
Thank You

Jeffrey P. Brosco, MD, Ph.D.
jbroesco@med.miami.edu

Lydia Ocasio-Stoutenburg, Ph.D.
locasio-stoutenb@miami.edu
Center for Development & Disability
Collaborative Efforts In Vaccine Confidence

Marcia Moriarta, PsyD, Executive Director

Pat Osbourn, MA, CCC, Associate Director
Town Hall for Youth with Disabilities

Partnered with NM Governor’s Commission on Disability to co-host town hall

- New Mexico State Agencies Involved:
  - Aging & Long Term Services Division
  - Commission for Deaf & Hard of Hearing
  - Commission for the Blind
  - Developmental Disabilities Council
  - Department of Health
  - Parents Reaching Out
  - Public Education Department
  - Child, Youth Families Department
Town Hall for Youth with Disabilities

• Principles in Planning
  • Overall Goal:  *Provide information about vaccines so people can make decisions that are right for them about the vaccines*
  • Specifically, we wanted to:
    • Reach the entire state
    • Have a diverse panel, representing state of New Mexico
    • Have testimonials/moderation specifically from youth with disabilities and/or parents
    • Insure broad access
Town Hall for Youth with Disabilities

- Town Hall presented on Facebook live, recorded for YouTube
- Advertised widely to disability groups within New Mexico
- All advertisements were made accessible in a variety of formats
- Panelists were chosen specifically to represent state
- Scheduled after work hours for convenience of parents
- ASL, CDI interpretation provided
- Spanish Language interpretation
- Real time captioning
COVID Vaccine & Youth with Disabilities Town Hall
THURSDAY, JUNE 10, 2021
6pm to 7pm

Watch live: UNM Center for Development & Disability's
Facebook.com/UNMCDD

This event will have sign language interpreters and real-time captioning.
Send questions for panelists in advance to Travis.Davis@state.nm.us
Town Hall for Youth with Disabilities

AGENDA

**Welcome:** Marcia Moriarta, CDD Exec. Dir

**Moderators:** Katie Stone, Parent of children with disabilities, Zoie Lamure, Youth with ASD

**Jason Cornwell, NM DOH:** Vaccine Equity & How to Register for Vaccine

**Dr. Martha Muller, UNM Pediatrics:** Overview of the science behind vaccine & vaccination efforts
Town Hall for Youth with Disabilities

AGENDA (cont.)

Testimonials: Panelists discuss why they or their children decided to get vaccinated and any concerns they had

Lynette Torivio: Mother, member of Pueblo of Acoma
JoJo Lopez: Youth, Deaf advocate/activist
Dana Mullen: Mother, parent of young adult who is medically fragile
Kaity Ellis: Youth, Blind advocate/activist

Questions & Answers
Questions Submitted During Town Hall

- Primarily medical, so “scientific expert” was important
  - Is the vaccine safe and effective for children?
  - What are the side effects for children who get the vaccine?
  - Does the vaccine alter children’ DNA or cause infertility?
  - Is there a risk for heart problems in children who get the vaccine?
  - If COVID does not cause children to get really sick, why should they get vaccinated?
  - When will children under the age of 12 be eligible for the vaccine?
  - If my children are under 12 years old, are they safe to go back to school?
Lessons Learned

- Need as much planning time as possible
- Working with many state agencies is powerful and takes much more time
- Youth voice was critical as was parent voice
- Youth may need preparation
  - Our moderator had never been in such a role
  - Needed rehearsal and also negotiations about what she personally wanted to present and what felt overwhelming to her
Next Steps/Plans

- Continued partnerships with NM Governor’s Commission
- Specific partnership with NM Developmental Disability Council
- Podcasts/radio broadcasts specific for the Navajo nation (one of our panelists was unable to connect to the internet after hours)
- CDD’s Community Advisory Council will continue to be our “on the ground” group who will advise us about next steps for their community
David Carey
COVID-19 Inclusivity Educator
Arizona Statewide Independent Living Council (AZSILC)
#VaccinateByADA

Arizona Statewide Independent Living Council (AZSILC) is an organization which promotes resources, supports, and services which empower people who have disabilities to live independently.

There is a Statewide Independent Living Council in each state, which works closely with the network of Centers for Independent Living, partner agencies, and other organizations in the State on behalf of people who have disabilities.
Arizona Statewide Independent Living Council is a longtime partner of the Arizona Department of Health Services (ADHS) regarding Emergency and Disaster Preparedness for individuals who have disabilities in Arizona.

This year, AZSILC is also partnering with The Association of State and Territorial Health Officials (ASTHO).

ASTHO, through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), is providing one-year funded Disability and Preparedness Specialist positions in select jurisdictions.

AZSILC was selected to receive funding for a specialist, and I was hired as its COVID-19 Inclusivity Educator.
ASTHO aims to assist jurisdictions and build capacity to plan for and respond to the needs of people who have disabilities during the COVID-19 pandemic and beyond.

COVID-19 has both created and spotlighted many barriers to health equity for people with disabilities.

Through a data-driven process, ASTHO identified 15 jurisdictions that may benefit from participation in this program. ASTHO selected jurisdictions based on the level of additional burden COVID-19 may add in that jurisdiction, particularly on those with disabilities.
My role is to be an integral part of the COVID-19 response and emergency planning process, and to advocate and protect the rights, health, and well-being of people who have disabilities throughout Arizona’s COVID-19 public health emergency planning. Special attention to disability rights and health equity are essential to the emergency planning process.

My duties include coordinating with both public health and disability advocates, and participating in an ASTHO-hosted community of practice and relevant agency workgroups to build capacity.
Successful Strategies for Disability Inclusion

COVID-19 information gathering to better serve the disability community

- Disability Community Forum  (Individuals)
- Disability Lifeline Pulse Check  (Partner Organizations)
- ADHS Quarterly Address

ASL Interpreters and CART provided for all webinars
Successful Strategies for Disability Inclusion

Partnering with local agencies to provide vaccinations to the disability community

- Site must be accessible, both structurally and by transit
  - Dial-A-Ride, buses, light rail, etc.
  - Bathrooms, ramps, etc.
- Provided volunteers to assist individuals with vaccination registration
- Provided ASL interpreters
- More than 2,000 vaccinations since April
Lessons Learned

Home Vaccinations:
Criteria for in-home vaccinations too stringent; would have liked to see more vaccinations offered in the home to those with:

- Limited mobility
- Limited access to accessible transportation
- Compromised health
- Mental health (anxiety of leaving the home because of the pandemic, fear of getting Covid-19)
Lessons Learned

Transportation:

Transportation always presents as a barrier for people living with disabilities.

- Many individuals in Arizona don’t qualify for Dial-A-Ride (door-to-door transportation for those that are ADA qualified)
- Many in especially rural communities do not have access to transportation, including public transportation
- Many are not on Medicaid, and therefore do not qualify for medical transportation through their health plan, and are medically fragile, with no means to access a lifesaving vaccine.
David Carey
COVID-19 Inclusivity Educator
Arizona Statewide Independent Living Council (AZSILC)
david@azsilc.org
What are your strategies for working with public health policy makers to sustain disability inclusion in emergency responses?
Audience Q&A
Thank you for attending!

Adriane Griffen  
agriffen@aucd.org

Denise Rozell  
drozell@aucd.org

Cassandra Thompson  
cthompson@astho.org

So, the reason why I went to get my COVID-19 vaccine is that I wanted to stay healthy for a lifetime.