COVID-19 Public Health Webinar Series

Session 3: Advice from People who have a Disability on Dealing with COVID-19

April 29, 2020
Facilitators:

Ilka Riddle, PhD - University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD)
Adriane Griffen, DrPH, MPH, MCHES - Association of University Centers on Disabilities (AUCD)

Speakers:

Max Barrows - Outreach Director for Green Mountain Self-Advocates
Kara Ayers, PhD - PhD, Director of the University of Cincinnati Center for Excellence in Developmental Disabilities
Sherice Smith – Disabilities Program Coordinator/Specialist for the Arkansas Disability and Health Program and the Safety Project at Partners for Inclusive Communities
Julia Atkinson - Center for Human Development, University of Alaska Anchorage

Discussants:

Liz Weintraub – Senior Advocacy Specialist / Association of University Centers on Disabilities (AUCD)
Mark Smith - Munroe-Meyer Institute / Nebraska Medical Center, University Center for Excellence in Developmental Disabilities (UCEDD)

Q&A Marshal:

Jeiri Flores – Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Self-Advocacy Co-Discipline Coordinator / Strong University Center for Excellence in Developmental Disabilities (UCEDD)
Welcome

Ilka Riddle, PhD

University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD)
Introduction: What is public health?

Adriane Griffen, DrPH, MPH, MCHES
Association of University Centers on Disabilities (AUCD)
Public health...

• Promotes and protects the health of people and communities
  - Everywhere: where you live, learn, work and play
• Prevents people from getting sick or injured
• Promotes wellness by encouraging healthy behaviors
• Practice of science and art

American Public Health Association: [www.apha.org/what-is-public-health](http://www.apha.org/what-is-public-health)
Public health is for everyone.

• Everyone! #PHis4Everyone
• Shares tools for managing change
• Thinking creatively and doing things differently
• Motto / Framework for AUCD’s National Center on Disability in Public Health

Public health is for everyone.

Work with us!

- AUCD works in every state and Territory
  - UCEDDS
  - LENDS
  - IDDRCs

- Advance policies and practices that improve the health, education, social, and economic well-being of all people with developmental and other disabilities, their families, and their communities.
Advice from People who have a Disability on Dealing with COVID-19

Max Barrows
Outreach Director for Green Mountain Self-Advocates
Information about the Coronavirus is complicated
Change is fast and constant.
GMSA and SARTAC made documents written in plain language for people with disabilities to understand.
We run 2 zoom meetings a week with self-advocates from more than 20 states.
Tips For Working With Support Staff During COVID-19

Nothing About Us, Without Us

What To Do If Someone You Live With Gets Sick?

Make a Written Plan

Protecting Rights
Ideas for Self Care

- Teach ways to be outside during Stay-at-Home orders
- Enjoy nature if you can
- Finding new strengths and interests
- Teach new ways to connect online
- Make sure people know how to call or text Crisis Lines and Disability Rights Organizations
Kara Ayers, PhD

- Associate Director of the University of Cincinnati UCEDD
- Co-founder of the Disabled Parenting Project
- Director of newly formed Center for Dignity in Healthcare for People with Disabilities
Adapting to changes in supports

• Loss of typical formal and informal supports
  • How can we make it work?
  • For how long?
• What ways can our disability community help each other?
Advocacy in Action

• Advocacy is happening everywhere
• Know your rights
  • Keywords: discrimination, equal access, and reasonable accommodation
• Stay informed
• Stay well
Collective toll on our community

• Recognizing and validating the fear in our community
• Hearing others (even inadvertently) express beliefs that our lives are less valued takes a toll.
• How can we care for each other?

“….but did she have a pre-existing condition?”
Are we still in this together?

Many states have announced plans to reopen.

• Watch for sidelining of “vulnerable” populations
• Will supports that have helped us all live at distance continue?

“Well the sick or vulnerable will just have to stay home.”
What comes next? Into the Unknown...

- Social distancing
- Wearing a mask
- Reducing risk to exposure

......are complicated for many people with disabilities.

Our individual plans for re-entry may vary. Our rights and community membership do not.
Center for Dignity in Healthcare for People with Disabilities created a fact sheet for people with disabilities to know their rights during COVID-19 pandemic: https://tinyurl.com/yd8n9j3z

Email us at: Centerfordignity@cchmc.org

Disability Justice Culture Club:
https://www.facebook.com/disabilityjusticecultureclub/
Advice from People Who Have a Disability on Dealing with COVID-19

Sherice Smith

Disabilities Program Coordinator/Specialist for the Arkansas Disability and Health Program and the Safety Project at Partners for Inclusive Communities
Strategies for Hygiene

- Washing your hands is very important. Especially if you use a wheelchair because you have to touch the ground.

- When washing your hands the temp of the water isn’t as important as making sure you do it for 20 secs. Sing a song make it fun.

- Favorite songs to wash my hands to: Shake, Shake, Shake Your Booties, I Saw the Sign, and Row, Row, Row Your Boat.

- Be sure to wash between your fingers, under your nails and palms.
Mental Health Illness

• Stress and anxiety during COVID has spiked. Affecting: Sleep and eating habits.

• People with disabilities who already sometimes live an isolated existence are even more isolated.

• Ways to combat it? Find a new hobby, dance or listen to music, join social media, get a pen pal or join an online support group.
Nutrition and Exercise

• Lots gym chains are now offering online classes.

• Our Arkansas and Disability Health Program will be offering online nutrition and exercise videos made by advocates designed specifically for people with disabilities.

• If you can’t go outside and walk around your yard or neighborhood try doing laps in your home. It’s better than nothing.
Steps on how to work with personal care attendants

• Make sure your support staff has protective gear like mask and gloves. If they can’t provide their own work with a disability organization to see where you can get supplies.

• Make sure that personal care staff takes their temp everyday and ask them if they have any symptoms.

• Have back up staff person. If your staff is sick, ask them not to come in and try to find a back up.

• Ask your staff to set up your meds, meals or however they support you in advance in case they can’t come in due to illness.
Social Distancing and Relationships

• Connection and relationships are important
• Social distancing has created some barriers for relationships
• There are a lot of ways we can continue to connect
Who is Around You?

- Foster relationships with those you live with
- Find things you have a common
- Take turns picking activities
- Let them know when you want time to yourself
Use Technology

• Use a messaging app to check in with your partner, friends, and family
• Video chats
• Online games or apps
• Watch a movie together through Kast or other app

• Ask for support if using a new app to understand privacy settings
No Technology, No Problem

• Call your partner, friends, and family
• Write a note, letter, or email
• Say “hi” to neighbors and friends when you are out walking
• Create a shared experience and talk about it
Stay Safe

• Social distancing will help to keep you safe

• In intimate relationships:
  - Selective kissing
  - You are your safest partner
  - Practice safe sex
Discussants:

Liz Weintraub – Senior Advocacy Specialist / Association of University Centers on Disabilities (AUCD)

Mark Smith - Munroe-Meyer Institute / Nebraska Medical Center, University Center for Excellence in Developmental Disabilities (UCEDD)

Q&A Marshal:

Jeiri Flores – Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Self-Advocacy Co-Discipline Coordinator / Strong University Center for Excellence in Developmental Disabilities (UCEDD)
Mark Smith, M.S.
Munroe-Meyer Institute / Nebraska Medical Center, University Center for Excellence in Developmental Disabilities (UCEDD)
Discussant

Jeiri Flores

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Self-Advocacy Co-Discipline Coordinator /Strong University Center for Excellence in Developmental Disabilities (UCEDD)
Thank you for participating!

Action Steps: 1. Join next session - Advice on Your Questions
2. Share resources - Public Health is for Everyone

Session 4: Advice on Your Questions
Thursday, April 30, 2020, 4pm - 5:30pm ET
Register
https://www.aucd.org/template/event.cfm?event_id=8648

Public Health is for Everyone
online toolkit that helps public health professionals create programs for everyone
www.phetoolkit.org