

COVID-19 Public Health Webinar Series

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

April 29, 2020





ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

Facilitators:

Ilka Riddle, PhD - University of Cincinnati Center for Excellence in Developmental Disabilities (UCEDD)

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)



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Public health is for everyone.

Welcome



Ilka Riddle, PhD

University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD)



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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

Winslow, C.E.A.: *The Untilled Field of Public Health*. *Modern Medicine*, 2:183-191. 1920.



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- 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

Griffen, A., Risley, K., Petros, M., and Welter, C.: *Inclusion Wheel: Tool for Building Capacity and Public Health Leaders to Serve People with Disabilities*. *Health Promotion Practice*, March 2020 Vol. 21, No. (2) 209–218.



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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.



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

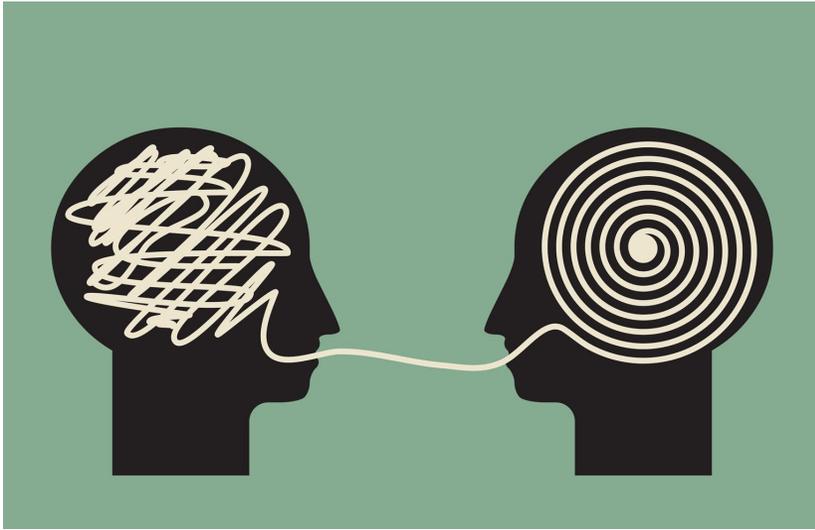


Max Barrows

Outreach Director for Green Mountain Self-Advocates



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Plain Language

- 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



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**Nothing About Us,
Without Us**



Make a Written Plan

**What To Do If
Someone You Live
With Gets Sick?**



Protecting Rights



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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



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Kara Ayers, PhD



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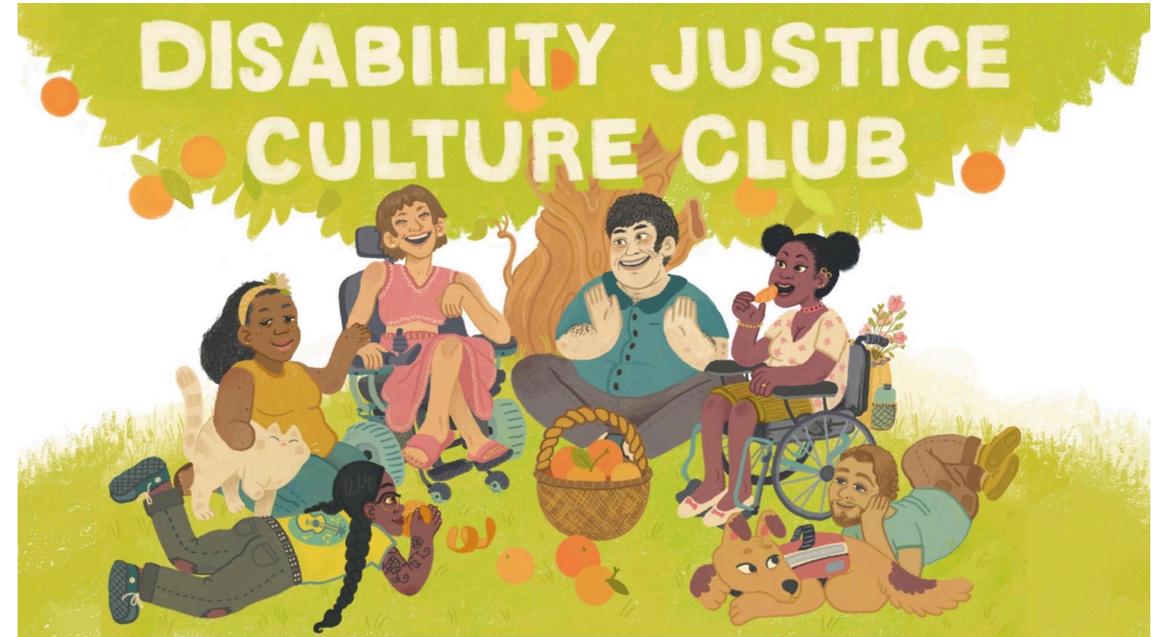


- Associate Director of the University of Cincinnati UCEDD
- Co-founder of the Disabled Parenting Project
- Director of newly formed Center for Dignity in Healthcare for People with Disabilities



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?



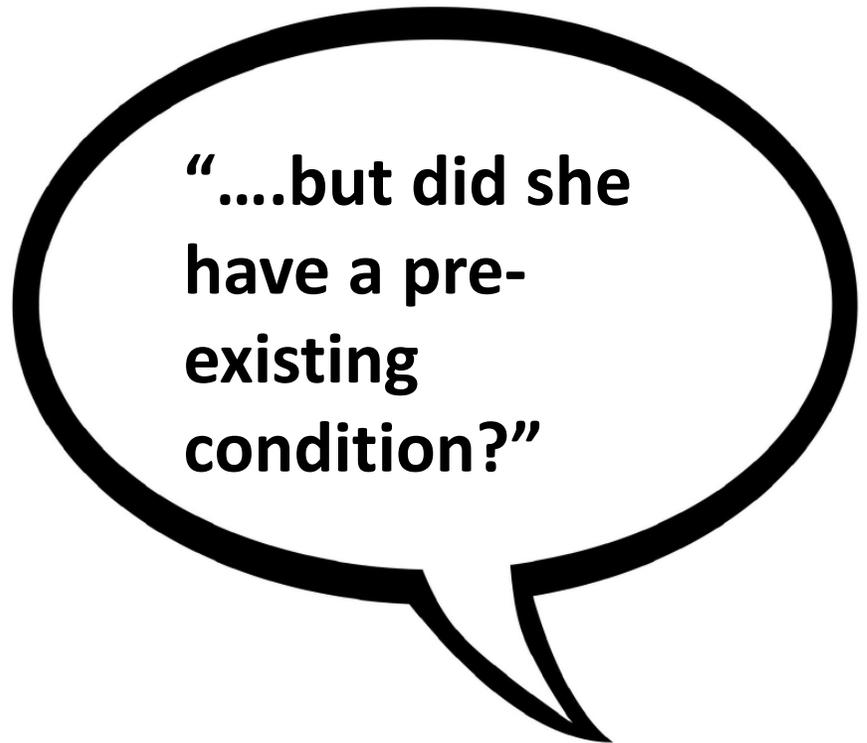
Advocacy in Action

- 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?

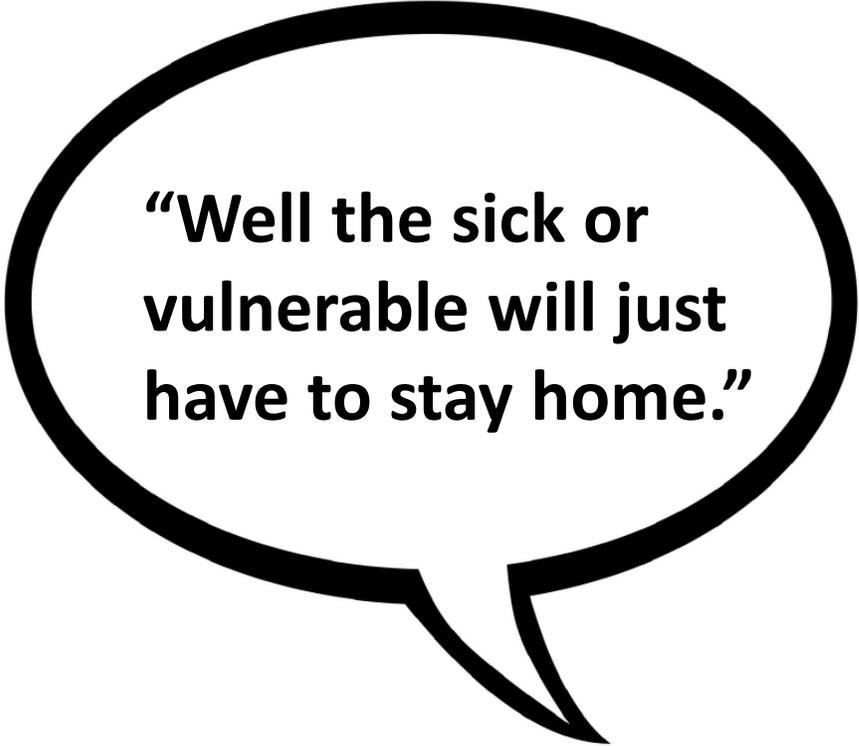


“...but did she have a pre-existing condition?”

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.



Resources

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 a 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



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- 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.



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COVID-19: Maintaining Relationships



Julia Atkinson

Center for Human Development, University of Alaska Anchorage



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



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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

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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)

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Discussant



Jeiri Flores

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

The screenshot shows the homepage of the 'Public Health is for Everyone' website. The header includes navigation links for Home, Search, About, and Contact Us, along with buttons for 'SEND Your Feedback' and 'SHARE Your Resources'. The main content area features a large graphic with the text '1 in 4 American adults has a DISABILITY' and an introduction to the toolkit. Below this are icons for 'HEALTH CARE ACCESS', 'FIRST TIME HERE?', 'ACCESSIBILITY BROWSE RESOURCES', 'VIDEO TOUR', and 'USER GUIDE'. A search bar is prominently displayed with a magnifying glass icon and a question mark. To the right, there are sections for 'RESOURCES PROVIDED BY' (listing the Federal Emergency Management Agency), 'TOP SEARCHES', and 'NEW RESOURCES'. A yellow arrow points to the search bar.



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