COVID-19 Public Health Webinar Series

Session 2: Advice from Family Members and Caregivers on Dealing with COVID-19

April 22, 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:

Joni Beasley, PhD - Center for START Services, Institute on Disability / UCEDD University of New Hampshire
Kara Ayers, PhD - PhD, Director of the University of Cincinnati Center for Excellence in Developmental Disabilities
Celia F. Schloemer, MA, University of Cincinnati Center for Excellence in Developmental Disabilities
Carol Salas Pagan, PsyD – Institute of Developmental Deficiencies at the University of Puerto Rico
Benita Shaw, BA – UC Davis MIND Institute
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 the communities where they live, learn, work and play.
• Prevents people from getting sick or injured promotes wellness by encouraging healthy behaviors.
• Practice of science and art to ...
  - help prevent disease
  - prolong life
  - promote health through an organized community effort

Public health is for everyone.

Public health shares tools for managing change, thinking creatively and doing things differently.

Meditation & Practical Tips to Keep Calm

Joni Beasley
Center for START Services, Institute on Disability / UCEDD University of New Hampshire, AUCD Mental Health SIG Co-Chair
Kara Ayers, PhD

- Associate Director of the University of Cincinnati UCEDD
- Parent of children with and without disabilities
- Co-founder of the Disabled Parenting Project
- Director of newly formed Center for Dignity in Healthcare for People with Disabilities
Multiple overlapping caregiving roles

- Misconception that disability and caregiving community are distinct
  - Parents with disabilities or increasing healthcare needs
  - Spouses with disabilities
  - Aging family members who need care/provide care
Strategies for advocacy as caregivers

• Stay informed from credible sources
• Tell or remind advocacy and policy-making organizations of our needs
• Know your rights-and recognize their current limits
  • Be especially aware of medical discrimination (i.e. rationing) and reasonable accommodations as keywords for your advocacy efforts
Start taking note of lessons learned

• Urgency of future planning
• Risks of congregate living
• Caregiver crisis exacerbated but also fast adjustments to waivers made in some states
• The need for disability and family representation on ethics committees and in medical systems (i.e. family/patient advisory councils)
• Changes to service delivery that would be helpful to maintain
The cat’s out of the bag on what’s working

• Working from home
• Increased public knowledge on health behaviors
• Telehealth
• Online dissemination of adapted exercise programs and other educational material
• Policy changes that are permanent
Are we still in this together?

• Pay attention to language from policymakers that “other” our families
  • i.e. “the vulnerable folks”
• Personal decisions among families may vary.
  • Will supports for sheltering-in-place continue?
Practical Tips for Family Support during COVID-19

Celia Schloemer, MS
Family Support Coordinator & Parent
Cincinnati Center for excellence in Developmental Disabilities
Practical Ways Families can stay afloat in the Unpredictability

Remember there is always tomorrow!!
Practical Ways Families can stay afloat in the Unpredictability

- Find the small locusts of control
- Praise strengths, raise self esteem
- Offer praise and appreciation, share feelings
- Create and honor family time
- Find some point of optimism
Recognize what is in Your “Control” and what isn’t

- Focus on how to turn your COVID-19 prevention from a crisis into an unanticipated opportunity for growth, support, health, community and family.

- Having a plan can create a sense of control and reduce stress

- If you can, have a care plan for all, but…
  - at least have one for your most vulnerable family member(s): For if you get sick or For if they get sick
Take Advantage of what’s Available
Give Yourself Space to Learn how to Do This

- Turn your focus from what you can’t do to what you can do
- Take it one step at a time
- Identify What is good enough
- What is your tipping point? What can’t happen?
Identify What is Good Enough

CHARTING the life course

Life Trajectory Worksheet: Individual

Everyone wants a good life. The tools on the right will help you think about what a good life means for you or your family member, and identifying what you know you don’t want. You can use this space around the areas to think about current or needed life experiences that help point you in the direction of your good life.

What I want in my Good Life during Shut Down
- Routine (HM set, dress to the times, maintain house, meals at the table)
- Sense of normalcy (still “see” family and friends, still have dinner plans, check in and “help” my kids)
- MAINTAIN LAUNDRY:
- Maintain Work schedule and work efficiently (schedule meetings, set up webinars, maintain deliverables, get next family input, don’t assume)
- Support Greg with more, one thing each day
- Maintain contact with Claire, help avoid isolation
- Cheer others on as we must GO to work, reduce anxiety
- Check-in on Mary, help think about new jobs and making rent
- Keep Ellen moving, setting up new room, creating a work/study space

What I DON’T Want:
- The Virus, or any other illness
- Isolation from friends and family
- To lose my sense of humor
- To feel behind in tasks at home or work
- To feel as if I cannot support my children
- To feel as if I cannot support my husband in this difficult time
- To not be able to support families where I can, or feel as if what I am offering is “noise” and not innovative or helpful

MAY 2020

MISSOURI FAMILY TO FAMILY | UARK-IMD, DCEDD
Determine your Family’s Sweet Spot for Routine

- Different for each family member
  - Make room for all the personalities and skills and value all of them

- This too needs to be flexible
  - Change and accommodate

- Encourage interdependence and independence and reward both
Practical Tools and Resources are Available

- Health Passport (English and Spanish) [http://flfcic.fmhi.usf.edu/program-areas/health.html](http://flfcic.fmhi.usf.edu/program-areas/health.html)
- UCCEDD [https://www.ucucedd.org/ctlc-tools/](https://www.ucucedd.org/ctlc-tools/)
- UMKC LifeCourse [https://www.lifecoursetools.com/](https://www.lifecoursetools.com/)
- Check your app store: Chore Monster, Landra, Mothershp to develop independence
“Sunlight is the best disinfectant!”

Justice Louise Brandeis
Puerto Rico’s UCEDD: Current Actions and Advice

Carol Salas Pagan, PsyD
Institute of Developmental Deficiencies at the University of Puerto Rico
COVID-19

• The PR-UCEDD is part of the Public Health School of the Medical Sciences Campus UPR who is in charge of the PR Task Force against Covid-19.

• People with disabilities are at increased risk of COVID-19.

• As we continue to fight this pandemic, it is essential that people with disabilities and their families are assured that their health is a priority.

• Is of most importance for them to be present, included and informed.
COVID-19: What are we doing?

- We are collaborating in the translation of diverse materials to Spanish.
- We are collaborating in making the PR Task Force information accessible and in plain language.
- We develop and submitted a protocol for COVID testing of people with disabilities with the feedback of people with disabilities and families of people with disabilities.
COVID-19: What are we doing?

• Our Family to Family Center keeps giving services through phone and email.
• We continue giving webinars on different topics.
• We participate twice a week on the Core Advisory Group calls to keep track of the handling of the needs of PWD.
COVID-19: What are some of our recommendations?

- Connect with your support networks. Stay in touch with your support networks: personal and professional in a virtual way, communicate how you feel.
- Limit the bombardment of information.
- Establish a daily routine. A routine that is real to you right now. You will likely have to restructure the routine you had before. Organize times.
- Rest, do not fall into the productivity trap.
COVID-19: What are some of our recommendations?

- Make room to do some activity for yourself.
- Listen to your body. Connect with what your body needs.
- Normalize what you feel and allow yourself to feel it.
- Explore your internal resources. How have you overcome difficult events before?
- Take this opportunity to create positive memories within adversity.
Advice From Family Members and Caregivers Dealing with COVID-19

Benita Shaw
Community Education Specialist
BENITA SHAW

I am a single mom of two amazing young men. My oldest attends UC San Diego and my youngest, with autism spectrum disorder (ASD), is in high school. I have a Bachelors degree in Psychology and Ethics. I work at UC Davis MIND Institute in the Resources Center and I am the Founder of the GIFTS Foundation. I am on the advisory committees for SCDD, Alta Regional Self-Determination, UCEDD and the AATF for SCUCD. I’m also a family advocate and a member of the board for the Supported Life Institute and the Fly Brave Foundation.
Mental Clarity

- Find time for yourself
  - Maybe this means waking up a little earlier
  - Allowing yourself to unwind by doing an activity you enjoy
- Use a schedule
  - But, allow for flexibility
- Take care of your body
- Connect with others
- Stay in the present
  - Take each day moment by moment
The Day to Day

- We all need support
  - Family, friends, community
  - What does this look like with social distancing?
  - Stay in touch virtually

- School
  - Be creative
  - Sometimes the path of least resistance is the right path

- Life skills
  - It may take more time but now we have fewer time constraints!

- Spend time outdoors
  - This allows us to feel freedom outside of our home
  - To exercise and stay healthy
Tools and Planning

- Find an outlet
- Play music throughout the day
- Read encouraging and uplifting passages
- Focus on the positive
- Stay informed on how to stay healthy and safe during this time
Resources

- California Department of Education (CDE)
  - https://www.cde.ca.gov/

- Department of Developmental Services (DDS)
  - https://www3.dds.ca.gov/

- Disability Rights California (DRC)
  - https://www.disabilityrightsca.org/

- Sankofa-Parent Support Group

- State Council of Development Disabilities (SCDD)
  - https://scdd.ca.gov/

- Wellness Together
  - https://www.wellnesstogether.org/
Fran D. Goldfarb, MA, MCHES, CPSP – CA
Leadership Education in Neurodevelopmental and Related Disabilities (CA-LEND), University of Southern California at Children’s Hospital Los Angeles
Q&A Marshal

David Deere, MSW, MTh
Retired (2020) from Partners for Inclusive Communities, Arkansas UCEDD
Thank you for participating!
Join us for sessions 3 and 4!

Session 3: Advice from People who have a Disability on Dealing with COVID-19
Wednesday, April 29, 2020, 4:00 p.m. - 5:30 p.m. ET
Register today!
https://www.aucd.org/template/event.cfm?event_id=8646

Session 4: Advice on Your Questions
Thursday, April 30, 2020, 4:00 p.m. - 5:30 p.m. ET
Register today!
https://www.aucd.org/template/event.cfm?event_id=8648