
Talking about COVID-19: Resources for People with IDD

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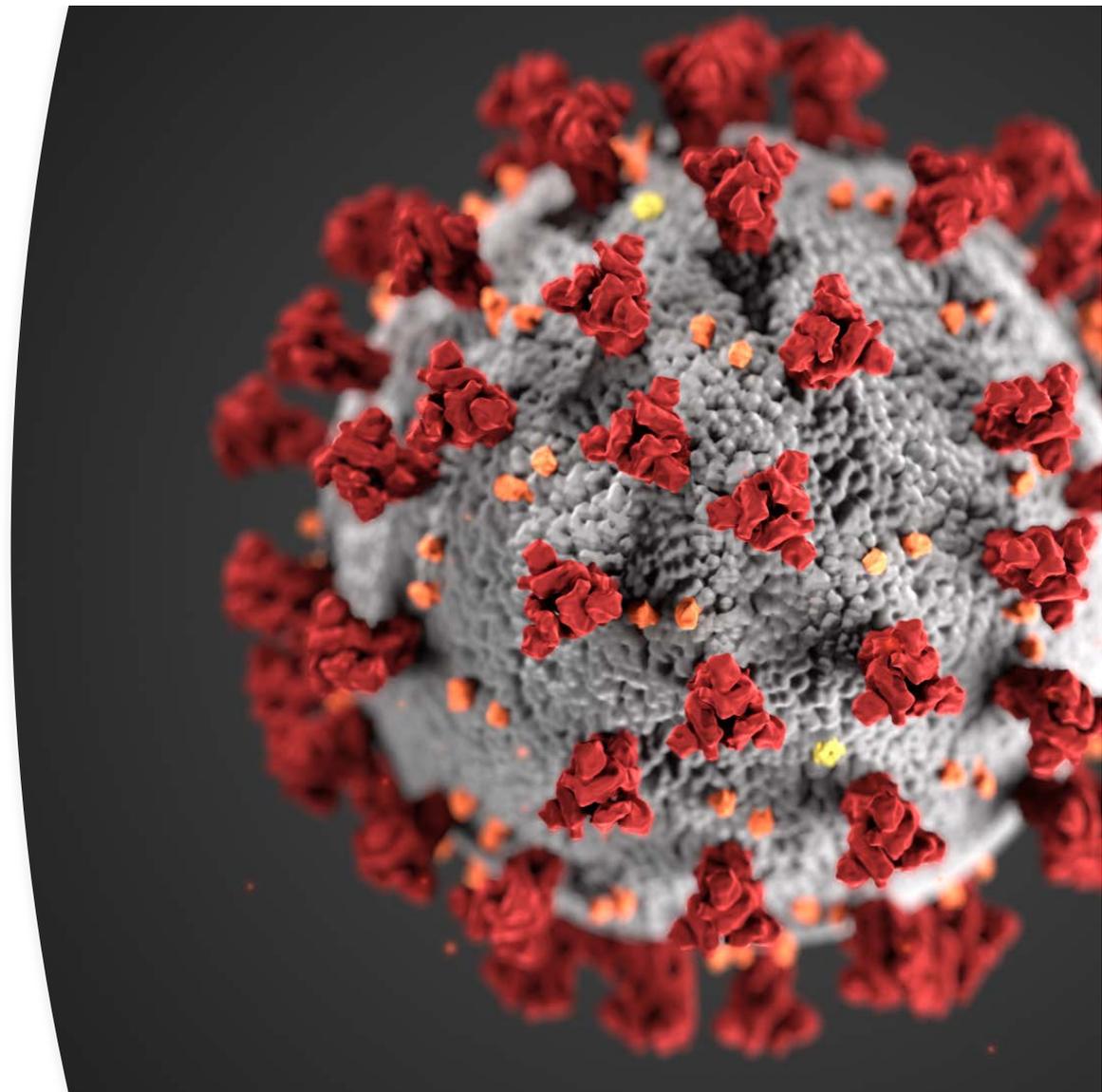
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Captioning Available:

<https://www.streamtext.net/player?event=HealthMatters>



Disclosures +

- COVID-19 is an emerging, rapidly evolving situation and is current at the time of this presentation
- Relationships with financial sponsors and potential conflict(s) of interest: none to disclose
- This information is presented for the purpose of education and should not be used in place of the advice of your and those you support health care practitioners



Talking about COVID-19: Resources for People with IDD

- **Overview:** “My staff is either panicked or thinks COVID-19 is silly.” This presentation will discuss strategies, resources, and tips to support people with IDD to understand what’s going on with COVID-19, why do we need to take precautions, and how will protections help us. *Additionally, we will discuss how to advocate for legal rights and reasonable accommodations.*



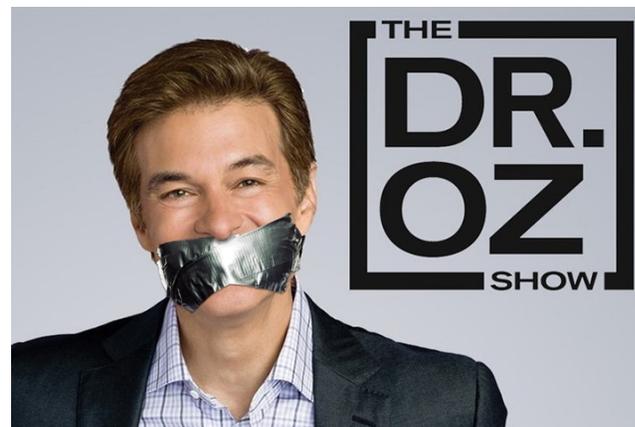
Information integrity

Navigating all these resources!!!!

Reliable Resources

- CDC, WHO
- NTG, AADMD, AUCD, AAIDD, IASSID
- State Guidelines (Overall and departments for IDD)
- City Public Health Departments

COVID-19 Resources The amount of information about COVID-19 can be overwhelming and can cause anxiety and stress. Our mental health is just as important as our physical health during this time. We recommend staying informed about the situation but also limiting the amount of time spent following the news and social media. **Adult Down Syndrome Center, Chicago**



For people with ID →



Speaking of the CDC

- **COVID-19 and Direct Service Providers for Persons with Disabilities – CDC Guidance**
<https://bit.ly/2XvzUd4>
- **Guidance for Group Homes for Individuals with Disabilities – CDC Guidance**
<https://bit.ly/2Mv02yE>
- **Guidance for Direct Service Providers, Caregivers, Parents, and People with Developmental and Behavioral Disorders – CDC Guidance**
<https://bit.ly/2U9of1Q>
- **People with Developmental and Behavioral Disorders – CDC Guidance**
<https://bit.ly/2A1VNrx>

Some possible resources:

- **Green Mountain Self Advocates** <http://www.gmsavt.org/>
 - COVID-19 Information By and For People with Disabilities
 - [*Coronavirus Plain Language Glossary – Words To Know*](#)
 - [*Tips For Working With Support Staff During COVID-19*](#)
- **IASSID:** <https://www.iassidd.org/covid-19-resources/>
- **Advocate Medical Group- Adult Down Syndrome Center**
<https://adscreources.advocatehealth.com/covid-19-resources-news/>
COMING SOON! (we hope!) Why is my staff wearing a gown and gloves and everything?

And more. . .

- **Books Beyond Words** Available for free download at <https://booksbeyondwords.co.uk/downloadshop/beating-the-virus>
 - Beating the Virus
 - Good Days and Bad Days during Lockdown
 - When someone dies from coronavirus: a guide for families and carers
 - Jack plans ahead for coronavirus: a guide for families and carers
- **Wisconsin COVID-19 Resource Tool Kit** <https://wi-bpdd.org/index.php/2020/03/25/living-well-covid-19-resource-toolkit/> A booklet for people with ID
- **Social Care Institute for Excellence** <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/carers-family>
- **Health Care Access Research & Developmental Disabilities (Canada)** <https://www.hcarddcovid.com/info>

Testing

(Source: New England Journal of Medicine)



A little about antibody tests:

- Antibody tests aren't intended to identify active SARS-CoV-2 infections. Instead of detecting viral genetic material in throat or nasal swabs, antibody tests reveal markers of immune response—the IgM and IgG antibodies that for most people show up in blood more than a week after they start to feel sick, when symptoms may already be waning.

How does PCR testing for COVID-19 work?
Polymerase chain reaction (PCR) testing can detect even very small amounts of viral genetic material in a sample by duplicating it many times over through a complex laboratory process called amplification.

- 1 A test sample is swabbed from the back of the nose and processed to isolate genetic material.
- 2 Small pieces of specifically engineered genetic material, called primers, are introduced and bind to the isolated viral genetic material, initiating amplification.
- 3 Fluorescent markers bound to the copies during PCR are released and can be detected when amplification occurs.

Positive result When there is viral genetic material in the sample, amplification occurs, releasing enough fluorescent markers to be detected.

Negative result If there is no viral genetic material in the sample, amplification will not occur and no fluorescent markers will be detected.



How to Protect Yourself & Others: An ounce of prevention is worth a pound of cure

- Know how it spreads
- Wash your hands often
- Avoid close contact
- Cover your mouth and nose with a cloth face cover when around others
- Cover coughs and sneezes
- Clean and disinfect
 - <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html>



A few ounces of prevention:

- Clean frequently touched surfaces like doorknobs, light switches, countertops, and remote controls with disinfectant products or bleach to kill COVID-19 and other germs
- If someone needs to go to the HCP or ER, call first for instructions and guidance. A virtual visit may be possible.
- If you have been exposed to COVID-19, you could be asked to self-quarantine in your home. Make plans for childcare, caregiving, and deliveries of food or medicine. Stay away from others in the household. Do not share dishes, glasses, utensils.

Phrases We Can Use

Adapted from: Patti Wade, 2020, Orange Grove Center

- We wash our hands to kill germs
- We wear masks in public and when we are sick so we don't give our germs to others
- We stand at least six feet away from people we don't live with or don't work at our homes. It makes it less likely for germs to spread.
- We stay apart from everyone to help keep each other well.
- We keep our bodies and our homes extra clean to help stop the germs.
- It's hard not to see our family and friends, but we can call or write to them or even get on the computer. We can see them again soon!
- **Help me to do this, please -PARTNER With Each Other**

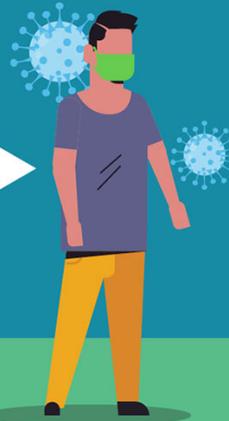
STOP THE SPREAD OF GERMS

Help prevent the spread of respiratory diseases like COVID-19.

Stay at least 6 feet (about 2 arms' length)
from other people.



6 ft



[cdc.gov/coronavirus](https://www.cdc.gov/coronavirus)

CS319178 May 12, 2020 4:01 PM

No. Regularly washing your bare hands offers more protection against catching COVID-19 than wearing rubber gloves.

You can still pick up COVID-19 contamination on rubber gloves. If you then touch your face, the contamination goes from your glove to your face and can infect you.

Is wearing rubber gloves while out in public effective in preventing the new coronavirus infection?





It's confusing. . .

<https://uhs.berkeley.edu/coronavirus/health-information/masks-information>

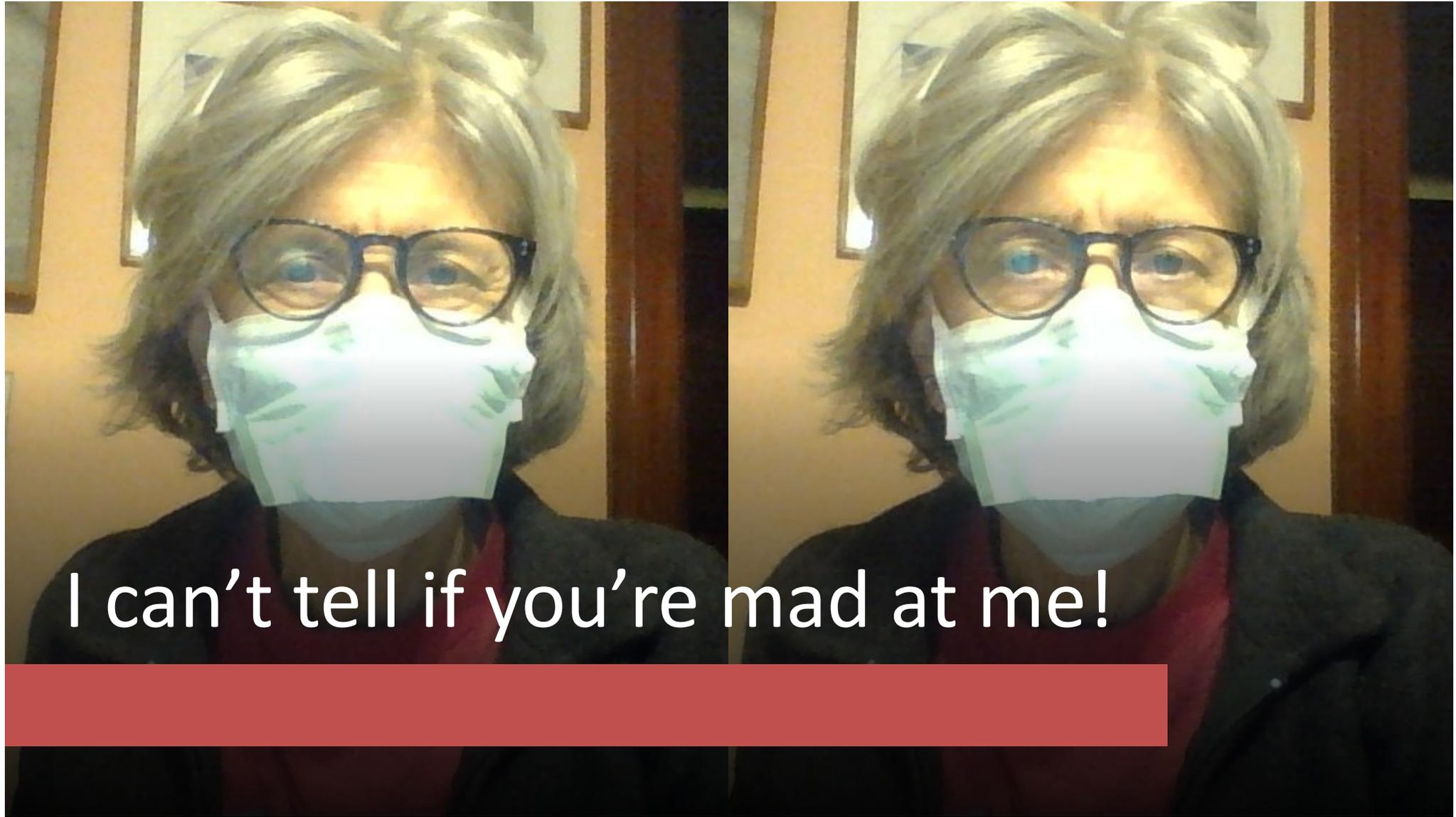
What is this about masks?

Some are mainly for health care personnel



Some such as cloth and bandanas are for some of us





I can't tell if you're mad at me!

How can we make them fun?

Mexican *lucha libre* wrestler Hijo del Soberano sews face masks since his matches have stopped due to the COVID-19 pandemic.



Making Masks Easier to Use: The Boggs Center on Developmental Disabilities -Rutgers

- If the person expresses fear over the mask, try to address what is bothering them. This may be due to fear of the mask itself, itchiness, feeling hot or difficulty breathing.
- Include the person in making the mask or even decorating it with stickers or using fun fabrics
- Have the person feel more comfortable with face masks by seeing others wear them as well
- When creating or choosing a mask, experiment with different fabric textures
- [A Parent's Guide: Helping Your Child Wear a Mask](#)
- [Help your Child Feel Good about Using and Seeing Others Wearing Face Masks](#)
- [I Can Stay Healthy by Wearing a Face Mask](#)



Other interventions:

Source: Cincinnati UCCEDD LEND Model

- Conditioning
- Use social narrative and visual support
- Use a "visual timer" technique. Put a timer on and wear a mask alongside the person. Incrementally increase the time to allow the person to get used to the feel.
- Rewards
- <https://www.youtube.com/watch?v=h6T75jZ6v3I&feature=youtu.be>

Disability COVID-19 Forms

Stony Brook University

<https://you.stonybrook.edu/disabilitycovid19forms/2020/04/08/preparing-individuals-with-intellectual-developmental-disabilities-for-medical-treatment-at-hospitals/>

- My Health Passport Florida Center for Inclusive Communities
http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf
- About My Health -Surrey Place
<https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/03/5.1-About-My-Health.pdf>

COVID-19 DISABILITY FORM
Please answer the questions on this form to help physicians provide you with proper medical treatment, in case you need to go to the hospital for COVID-19 related symptoms. Complete as many of the questions as possible.

What is your name? _____

Is this form being completed by someone else other than you? yes no
 legal guardian aide or staff member family member other
If you checked yes, what is the person's name _____ Relationship to you _____

Do you receive or have you received services from the Massachusetts Department of Developmental Services (DDS)?
 yes no I don't know

****Note to doctors: This means there may be special laws in place to protect me and a special process needs to be followed if my usual decision maker/guardian requests to withhold or withdraw life sustaining treatment. Please check in with your institution's social worker or risk management department to be sure the appropriate process is being followed.*

How do you communicate best? (check all that apply) <input type="checkbox"/> Talking <input type="checkbox"/> Writing or typing things down <input type="checkbox"/> Pictures <input type="checkbox"/> Using sign language <input type="checkbox"/> Pointing to words <input type="checkbox"/> Using a voice app <input type="checkbox"/> I cannot communicate in a way you will understand, please ask my family, staff or guardian (circle the person) <input type="checkbox"/> Other (please describe) _____	Do you need anything to help you communicate? (E.g. assistive devices) <input type="checkbox"/> no <input type="checkbox"/> yes (please describe) _____ Does anyone help you communicate? <input type="checkbox"/> no <input type="checkbox"/> yes, person's name _____ Do you use any assistive devices for mobility? <input type="checkbox"/> no <input type="checkbox"/> yes list the device(s) _____
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Do you have any triggers (e.g., being touched, trauma, doctors of a particular gender, noises, lighting, smells, textures):

What is your response to triggers?

How can you best be helped when triggered?

Do you have any medical problems that you go to the doctor for? <input type="checkbox"/> yes <input type="checkbox"/> no What are they? _____	Please list the name of the doctor you would like con you are at the hospital. Name _____ Phone Number _____
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Are there any diagnoses, medical problems or behaviors that we should consider as cautions? (e.g., aggression, biting, pica, aspiration risk):

Are there any specific modifications that could help with these cautions?

Do you take any medication at home every day? <input type="checkbox"/> yes <input type="checkbox"/> no By prescription? <input type="checkbox"/> no <input type="checkbox"/> yes, list the names and dosage _____ _____	Over the counter? <input type="checkbox"/> no <input type="checkbox"/> yes, list the names and dosage _____ _____
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Do you have any allergies? no
 yes, please list _____

Keeping Healthy

Physically ++

- **Taking care of your self**
 - Healthy Living (Eating Well, Physical Activity, Sleep, Stress management, Laughter, a Dose of Outdoors)
 - **Routines**
 - **Planning** = a sense of control
 - Understand that some things are in and some things are not in your control
- **Taking care of those you support**
 - Same as above
- **BE KIND to others and to yourself.. .**

Mentally

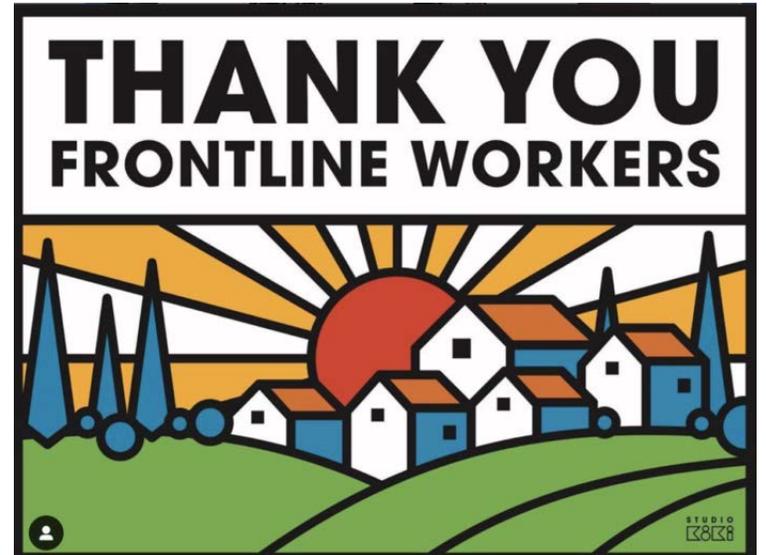
- **Mental Well-being**
- *(Source: SHRM)*
- Routine (Maintain)
- Outdoors (Sun)
- Sleep (Rest)
- Technology (Advantage)
- News (Balance)
- Positivity (Try)
- Gratitude (Pause)



From this instructor
(Kathy Service) to you
listening and all are
my best teachers
(you are!):

So what (who) really
matters. . .We all do!

Questions?



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