

**A Partnership of Golisano Institute for Developmental Disability Nursing, St. John Fisher College, Wegman School of Nursing & University of Rochester Medical Center, Division of Transitional Care Medicine, Complex Care Center**

**\*Offering Support During COVID-19**

Individuals working in and living in congregate care settings have unique needs related to maintaining health and safety during a global pandemic such as COVID-19. In addition, when individuals in congregate care have intellectual and developmental disabilities (IDD) the information and supports must be specifically tailored to the persons varied levels of understanding about the COVID-19 virus, how it spreads, and how to reduce risk of exposure.

Here are strategies to help individuals with IDD understand the concern and rationale for the changes related to this complex scenario.

1. Use **concrete language and terms** to describe the virus and current situation (e.g. cancelling activities, social distancing) and *avoid flowery or abstract phrasing*. The understanding of abstract phrases and metaphors such as “she is under the weather”, “she caught the virus”, and “he is scared stiff about this” can confuse some individuals (Lipsky, 2013). Using direct and clear language is recommended. Concrete-sounding, phrases like “The coronavirus is a type of germ. These germs are very tiny, and when they get inside your body, they can make you sick,” may be easier to understand.

<https://www.pbs.org/newshour/health/10-tips-for-talking-about-covid-19-with-your-kids>

2. Use a **social narrative**, a story that clarifies a situation to help describe the virus, the changes in schedules and activities, inability to engage in typical life activities, among other changes. Social narratives can be inclusive of modified text, photos, or the use of technology (Wong et al., 2014). Individuals with IDD or on the autism spectrum benefit from receiving information in multiple formats, as they often have receptive language deficits (Mody et al., 2013). Social narratives help individuals understand how to reduce risk, provide insight into how they may be feeling, and offer assurance that those feelings are normal. Reading the narratives to/with the individuals with an IDD diagnosis regularly across several days is helpful. Revisit and adjust as needed.

Resources for developing and using social narratives can be found at Autism Focused Intervention Resources & Modules (AFIRM):

Sam, A., & AFIRM Team. (2015). Social narratives. Chapel Hill, NC: National Professional Development Center on Autism Spectrum Disorder, FPG Child Development Center, University of North Carolina. Retrieved from <http://afirm.fpg.unc.edu/social-narratives>

3. Provide **visual supports** to offer guidance on coronavirus specific actions and behaviors. The “rules” around how we greet people (e.g. no more handshakes), how we interact with people, even family members (e.g. social distancing), and how often/when

\*Support Understanding adapted from, The University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Institute

we wash our hands (e.g. every time we come inside) are changing. Using visual cues to break down the steps of these new expectations may be helpful for staff and individuals living in congregate care. We use visuals to convey messages in every aspect of our lives. Visual cues can be used as reminders (e.g., wash hands), for social distancing (e.g., 6 feet apart), avoiding face touching, among many other important behaviors. Visuals may be especially important for persons with autism and other IDD.

Resources on visual cues can be found at Autism Focused Intervention Resources & Modules (AFIRM): Sam, A., & AFIRM Team. (2015). *Visual supports*. Chapel Hill, NC: National Professional Development Center on Autism Spectrum Disorder, FPG Child Development Center, University of North Carolina. Retrieved from <http://afirm.fpg.unc.edu/visual-supports>

4. Offering **visual cues to clarify the passage of time** may be helpful. While we do not know an “end” date to today’s uncertainty, marking the passage of time as well as including favorite activities, such as shows, online meetups, or game night on the calendar can be a helpful coping strategy. Individuals with IDD may have trouble perceiving the passage of time, an invisible concept, and the use of a monthly, weekly, and/or daily calendar may assist in tracking time out of school/in a quarantine situation

It is very important to remember that for all of us behavior change is hard. Additionally, we all learn differently. Simply stating the new expectations is not going to be enough to promote real and rapid behavior change. We all need reminders in the environment, ways to make the changes as easy as possible, and in many cases staff and persons with IDD will need to learn and practice new skills.

## **How to talk about COVID-19 with individuals with an IDD diagnosis**

There is an illness called “COVID-19” that is making some people sick. You may get sick if you are near someone who is sick. People do not mean to get each other sick, but that is how germs work – germs are tiny and we cannot see them, but they move from one person to another person. This can happen when someone coughs or sneezes and these germs come into contact with someone nearby. People can also touch something and leaves germs on the thing they touched without even knowing it. That’s why we all have to make some changes to how our days usually go - like not going to work or school. Staying home, keeping our hands to ourselves, covering our coughs and sneezes and washing our hands, are some ways we can keep ourselves and other people healthy. If you have questions about this or have any feelings about this, we can talk about it more.

### **Things we can do to stay healthy (residents and staff)**

#### **1. Social Distancing (Giving people extra room/ space)**

**STAFF Strategies:** Practice arms out without touching. Practice as a group. Use tape on floor; tape boxes together. Use behavior skills teaching video modeling what would look like, instruction, practice.

Really think about who should be in the house or other common areas and who should not. As a community, we have a no visitors policy. That makes sense - the more people, the more risk.



- Demonstrate: If we both put our arms out, we are the right amount of distance apart. This helps keep us healthy.
- It is okay to tell our friends that we care about them, but we are not touching each other or hugging right now. What are some other ways we can let our friends know we care about them?

#### **2. Hand washing**

**STAFF Strategies:** There are many steps to hand washing. Considering the resident you are supporting, you can skip or add steps as appropriate. Celebrate each success! For some individuals, putting one (or *only* one) pump of soap on their hands is a big win!

- Give choice (if possible) about where to wash hands
- Turn on the water
- Put hands under the running water so they get wet

- Get a pump of soap into one hand
- It is okay to get help with this!
- Rub hands together. Get the soap all over!
  - It is okay to leave the water running
  - Count to 20
  - Sing the Happy Birthday song
  - Ask someone else to count or sing
  - Some people like to make the soap their favorite color by putting in a few drops of “[food] coloring” (ask a staff member to help you)
- Rinse hands in the water
- Turn off water
- Dry hands
- Throw away paper towel in the trash



**Additional Strategies:** Make Video models (hand washing), Social Narratives, Task analysis with and without pictures, Teaching strategies, chain behaviors (teach one at a time); Peer modeling, Environmental cues (e.g., sign on the door, on the refrigerator, bathroom, on the tissue box)

### **3. Do not touch your face**

**STAFF Strategies:** Can also use words like, “No hands to the face” or “Keep your hands lower than your shoulders.”

- Giving people something to hold on to with each hand
  - Stress balls (no sharing, wash the object when washing hands)
- Where a facemask or bandana to help **remind us not to touch our face** (remember, this does *not* have to be a hospital-grade mask)
  - Allow for choice
    - Facemask or bandana
    - Choice of color

- If face mask, consider letting the resident put their name or initials on the mask.
- Set up a station to make your own “facemask”

**Additional Strategies:** Have a buddy! Remind each other (social awareness/habit reversal); Make it a game! Who touches least, group contingencies; Public posting, a ring or rubber band reminder (stimulus cue)

#### **4. Clothing (this mostly applies to staff members, but feel free to brainstorm about how this might help the residents too)**

**STAFF Strategies:** This virus lives in tiny droplets that come out when people sneeze, cough, blow their nose, or touch something when they have germs on their hands.

This may sound strange, but one way to think about COVID-19 is to treat everyone *as if* they have coronavirus, including yourself. (Remember, this is just a way to think about this!). *Then think - If I had this virus, how would I make sure I do not give it to anyone else?* We do this in healthcare every day - even before coronavirus (COVID-19) - we call it **standard precautions**. This protects you and protects everyone else.

- When you get ready for work, pretend you wear a “**uniform**”. Put it on for work, then take it off when you finish and wash it. Think about having 2 or 3 outfits - one you wear during work, the other you change into to go home, and one that you keep for a spare in case someone coughs or sneezes directly on to your clothes.
- This “uniform” **includes shoes**. Choose a pair of shoes that you can wear in the congregate care or group home setting, and take them off when you leave. Shoes could also be wiped down before and after shifts.
- Dedicate a private space, if possible, for staff to change into at the beginning of the day and where they can change out of their clothes on their way out. You could consider how to incorporate doing staff laundry into the laundry routine!
- Keep long hair tied up. Clothes should be close fitting-nothing flowy-practical and comfortable.
- Wash your hands as **you walk out the door** after work, and use hand sanitizer (if possible) before you get in the car.
- When you get home after a shift, always **wash your hands for at least 20 seconds FIRST** (or use hand sanitizer) before greeting everyone. You can also take a shower when you get home before greeting any family members. Throw dirty clothes in the wash - regular wash is fine.

#### **5. Cleaning**

**STAFF Strategies:** Use checklists, prompts and task analyses, make a game, clean on a schedule, visual cues for cleaning as needed (e.g., picture on the door for cleaning anything that comes into the home)

We know the virus can live on a surface for a long time. Washing hands and wiping down surfaces is the most important thing we can do to prevent the spread of germs. Pay special attention to areas that get touched a lot.

- Throughout the house
  - Door handles
  - Handrails
  - Light switches
  - Remote control
  - Desktop and drawers
  - Table tops
  - Computer mouse and keyboard
  - Telephone
  - Games, toys, craft supplies
- Kitchen
  - Tables and chairs
  - Counters and appliance surfaces
  - Faucets
  - Push plates
- Bathrooms (limit who uses which bathroom when possible)
  - Faucets
  - Toilet seat
  - Toilet handle
  - Light switch

**Additional Strategies:** Food doesn't carry the virus, but sharing food might! If someone touches your food with a fork or spoon that had their saliva on it, they could pass it on that way.

If you need to make large plates of food to share, have one person wash their hands and then serve the food. Have that person serve it in an area that does not have a lot of traffic or people. Then bring the plates to each person who is eating - think of the "lunch lady" or the person who serves food on to your plate. It is the same idea.

### **Some general comments:**

For additional motivation, make learning and new activities into a game or even competition. For example, see who can touch their face the least and use public posting for the winners. You can use self-monitoring and have people fill in squares on a board each time they clean the table or wash their hands. Organizations can designate COVID champions (both staff and residents) and provide ongoing positive feedback for high scores or game winners.

### **In case of quarantine where a mask might *need* to be worn:**

Practice wearing a mask in advance. It will be important to know whether a person will willingly wear a mask and for how long. If they will wear a mask, but for only a very short duration, work on increasing the amount of time. Set a timer for slightly more time than the first, and so on as the person is successful. If the person will not *use* a mask at all, you will need to work on systematically desensitizing them to this.

### **Acknowledging that we are all human...**

These guidelines are meant to be informative, but they are by no means an exhaustive variety of how to do this. We are all learning and it has been impressive how people have remained open to learning and able to pivot as more information becomes available. One of the ways we can keep our minds open to taking in all that is coming at us is to keep things fresh. Moving the physical location of important announcements, changing the color of paper or printing, and other variation of how we give and receive information.

### **A few words about *Behavioral Skills Teaching***

Behavior Skills Teaching (BST) can be used to teach just about anything to learners of all ages and cognition to help individuals acquire skills or a skill set(s). Although we often tell others what it is we want them to do, we know that just telling someone is not enough to be sure they understand the request, particularly under the conditions that COVID19 is such a serious health and safety threat. This method can be used to teach individuals who have an intellectual or developmental disability a variety of skills, including social and task-based skills. It is also useful in many settings, including teaching staff who work in congregate care settings.

Suggested Resource:

Hume, K., Waters, V., Sam, A., Steinbrenner, J., Perkins, Y., Dees, B., Tomaszewski, B., Rentschler, L., Szendrey, S., McIntyre, N., White, M., Nowell, S., & Odom, S. (2020). *Supporting individuals with autism through uncertain times*. Chapel Hill, NC: School of Education and Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill. Retrieved from: <https://afirm.fpg.unc.edu/supporting-individuals-autism-through-uncertain-times>

**SUGGESTIONS #1-5, as 1 PAGE VERSIONS BELOW**

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### Behavioral Skills Training

*Safe social distancing* might be taught by describing the need and rationale, visuals such as tape on the floor or arms distance, practice walking up to a person first with the visual of 6 feet present, then practice without the visual. Feedback can be provided by the person who is the teacher and by the learning partner.

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**STAFF CHECKLIST FOR COMING INTO AND OUT OF THE RESIDENCE**

THIS SHOULD BE POSTED ON EVERY DOOR

Coming into work for the shift		<input checked="" type="checkbox"/>
	Wash your hands thoroughly and/or use hand sanitizer immediately	
	Remove your home or “street” clothes and put on your work clothes	
	Place your home clothes in a bag and seal them	
	Place the bag in a location that is secure and unlikely to be opened	
Leaving home for the shift		
	Wash your hands thoroughly and/or use hand sanitizer immediately	
	Take off your work clothes. Place them on the floor.	
	Wash your hands again and/or use hand sanitizer	
	Put on home clothes	
	Place work clothes in workplace laundry (if applicable) or in bag to wash at home	
Getting to your home		
	As soon as you enter the car, use hand sanitizer	
	Remind the people at your home not to touch or hug you until you have changed your clothes and washed up	
	As soon as you enter your own home, wash your hands thoroughly and/or use hand sanitizer immediately	
	Remove your home/street clothes	
	Place the clothes immediately in the washer to be washed	
	Take a shower	
Coming back after leaving (doctor appointment, errand, etc.)		
	As soon as you enter the car, use hand sanitizer	
	Staff and resident – wash hands or use hand sanitizer	
	Assist the residents to the degree needed with their coming home routine (wash hands, change clothes)	
	Change your clothes. Place clothes in sealed bag (to be washed)	
	Wash hands thoroughly	
	Put on clean clothing	

Materials:

- Staff should have at least 2 changes of clothes at the work location
- Place plastic bags near the door in an easy to grab location
- Designate location to change as close to the door as possible
- Hand sanitizer and soap/water near the door
- Hand sanitizer in car
- Tailor these steps to the needs of the resident

- Use visual cues whenever possible. Having a stop sign on the outside of the door as a reminder to stop and check the checklist, or you can have a picture of a person looking at a list or washing their hands.
- If it would be helpful, you can have the checklist for the persons living in the home near the door with each of their names. After they wash their hands they can use a pen (a pen just for them with their name on it) or erasable marker on a white board and check off every step after they completed it.
- You can help to motivate by making a competition for all checkmarks or for everyone that checks everything off earns something preferred. Use praise and instruction as much as possible (see module on instruction)

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## **Cleaning**

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We know the virus can live on a surface for a long time. Washing hands and wiping down surfaces is the most important thing we can do to prevent the spread of germs. Pay special attention to areas that get touched a lot.

Cleaning strategies and techniques lend themselves easily to BST instruction. Teaching and learning how to and when to clean can be easily modeled and practiced. Visual supports and tasks broken down to as small steps as needed. Reminders in the environment can be built into the practice and the actual environment (e.g., timers set for each hour, visuals reminding to wipe tables after something has been put on them).

- Throughout the house
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  - Computer mouse and keyboard
  - Telephone
  - Games, toys, craft supplies
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