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A to Zs of COVID-19 for Individuals with I/DD and their Families

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insight to innovation



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This webinar is provided as part of the

Cross-Systems Navigation for Individuals with I/DD in a Managed Care Environment Initiative

Funded by the North Carolina Council on Developmental Disabilities find out more at:

https://nccdd.org/initiatives/

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To learn more, to schedule an appointment or make a referral, please call (866) 272-7826 or visit <u>www.MonarchNC.org</u> to find a Monarch location near you.

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Agenda

- Personal Health & Safety
- Information for Inpatient & Congregate Care Settings
- Our Family Experience with COVID-19
- Questions & Discussion







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Personal Safety & Health

What is COVID-19?

- COVID-19 is a new illness spreading around the world. Its nicknamed is Coronavirus.
- COVID-19 has made many people sick. COVID-19 symptoms can range from mild (or no symptoms) to severe illness. Some people have died because of it.
- COVID-19 is spread through respiratory droplets (sneezes or coughs).
- To become infected, you generally must be within six feet of someone who is contagious and come into contact with these droplets.



COVID-19 & People with Intellectual & Developmental Disabilities

We Know That:

- COVID-19 appears to present a greater risk to people with I/DD, especially at younger ages.
- People with I/DD are especially vulnerable to the physical, mental and social effects of the pandemic.
- People with I/DD have disproportionately more health problems than the general population.

Studies Are Finding:

• There is a higher mortality rates from COVID-19 for individuals with IDD between the ages of 0-74 than individuals in that age range without IDD.





SUNY Study published June 2, 2020: <u>https://www.sciencedirect.com/science/article/pii/S1936657420300674#!</u> NPR Analysis published June 9, 2020: <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3004690/</u>

Precautions & Preparations are Critical!



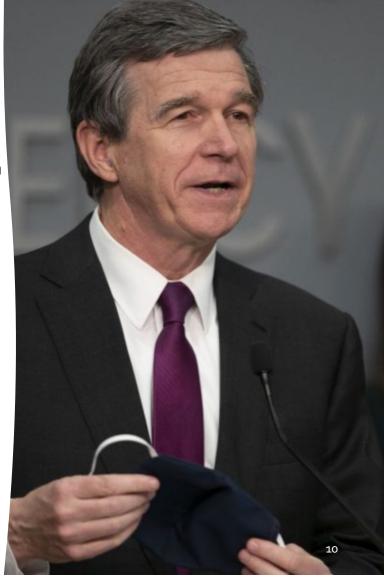
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Current Stay-at-Home Orders:

- The Governor is keeping us in Phase 2 until approximately August 7th.
- Masks are required:
 - stores
 - restaurants
 - hair salons
 - childcare facilities
 - state government
 - mass transportation
 - airports and bus stations
 - hospitals and congregate care settings
- No more than 10 people gathered indoors and 25 people outdoors.

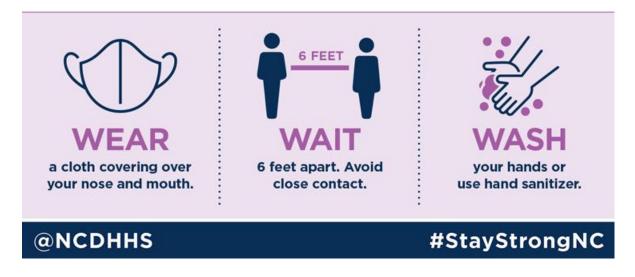
- You don't have to wear the mask if:
 - you would have difficulty with it related to a disability and that includes that you are not able to put it on or take it off without assistance,
 - you're under 11 years old,
 - actively eating or drinking, or
 - you're a child whose parent, guardian, or responsible person has been unable to place the face covering safely on your face.
 - Many business can operate but with social distancing in mind and with some limitations in capacity.

Executive Order 151: https://files.nc.gov/governor/documents/files/EO151-Phase-2-Extension-1.pdf



NC DHHS is leading the charge on addressing the virus. They recommend:

If you leave home, know your Ws!





NC DHHS COVID-19 Toolkit: https://covid19.ncdhhs.gov/materials-resources/prevent-and-protect-media-toolkit



Congestion or runny nose

- Cough
- Fever or chills
- Headache
- Shortness of breath or difficulty breathing

- Muscle pain
- Sore throat
- Loss of taste or smell
- Fatigue
- Nausea or vomiting
- Diarrhea

NC DHHS now offers a "Check My Symptoms" app and toolkit

<u>Check My Symptoms: https://ncdhhs-covid19-dtra.powerappsportals.us/en-US/</u> COVID-19 Tookit: https://covid19.ncdhhs.gov/materials-resources/prevent-and-protect-media-toolkit

Symptoms:

Calling The Doctor & Testing for COVID-19:





CENTER for INTEGRATIVE HEALTH

- Call your doctor if:
 - you are experiencing symptoms.
 - you have been out of the country.
 - you have been with someone who has the virus.
 - you have been at a place where people with COVID-19 got medical treatment.
- NC DHHS has a COVID-19 Test Site Finder at <u>https://covid19.ncdhhs.gov/about-covid-19/testing/find-my-testing-place</u>
- The site finder will provide you all of the contact information, hours of operation, as well as whether you need to schedule an appointment or you can walk-in.
- Results may take some time to get back, depending on the demand.
- If you or your family member tests positive, try to isolate as much as possible.

Isolating At Home

- Who can go food shopping for you? (delivery service, church, neighbors)
- Who will call to check in on you? (designated person, R U Ok? Program)
- Do you have personal protective equipment such as masks, face shields, gloves for you and the people who will help you (or will they have it)?
- Do you have cleaning supplies in your house that kill viruses?
- Do you have important phone numbers where you can get to them? (your doctor and direct support professional, your care coordinator, your friends and family)
- How can you ensure you won't run out of medications? (work with your doctor, set-up delivery or online)
- If you have a service animal or pet, what is your plan for their care?





If you are Isolating and Symptoms Worsen:

- Call ahead before going to your doctor's office or hospital to tell them you are isolating for COVID-19. This will help the health care personnel prepare for your arrival and protect others from getting infected.
- Do not wait in any waiting rooms and do wear a cloth face covering over your nose and mouth or mask at all times if possible.
- Do not use public transportation.
- If you call 911, first notify the dispatch and paramedics that you are under isolation for COVID-19.





Information for Inpatient & Congregate Care Settings



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COVID-19 Temporary Changes to Services

NC DHHS has made temporary changes while there is a State of Emergency (Appendix K is the main way they have received federal approval to do this). Check with your LME/MCO for more information about:

- "Relative as Provider" payments
- Allowance for increased service hours
- Retainer payments to Direct Support Providers
- Reimbursed Increased Therapeutic Leave Days from ICF-IID Facilities from 60 days to 90 days
- Temporary Alternative Service Definitions



Flexibilities during State of Emergency for IDD Waiver: https://medicaid.ncdhhs.gov/blog/2020/03/19/special-bulletin-covid-19-6-temporary-policymodifications-1915-waivers-appendix-k

Appendix K Frequently Asked Questions: https://files.nc.gov/covid/documents/guidance/healthcare/NC-Innovations-and-TBI-Waiver-Appendix-K-FAQ5.6.20.pdf

Therapeutic Leave: <u>https://medicaid.ncdhhs.gov/blog/2020/04/15/special-bulletin-covid-19-45-increase-therapeutic-leave-days-icfidd-facilities-due17</u> CDC Guidance for DSP: <u>https://www.cdc.gov/coronavirus/2019-ncov/hcp/direct-service-providers.html</u>

Your Right to Medical Care

- Hospitals and doctors must help you just like they would anyone else.
- The hospital cannot deny you emergency help (like a ventilator) just because of your disability.
- You can bring a helper or family member with you to the hospital. But they cannot come with you if they are also sick.
- You can ask for what you need for your disability.
- You can bring your service animal with you.
- You can bring what you need for your disability. You can bring your own wheelchair, ventilator or any other equipment.
- Doctors and nurses must talk with you in a way that you understand.



If you have a problem with a doctor or a hospital during COVID-19 call

Disability Rights North Carolina (DRNC) at (919) 856-2195



Source: Disability Rights North Carolina https://disabilityrightsnc.org/wp-content/uploads/2020/04/Fact_Sheet_Know-Your-Rights-Medical-Care-during-COVID-19.pdf

What to Bring to the Hospital

- Complete a medical form such as the COVID-19 Disability Form for professionals to get to know you
- Bring a list of medications and schedule for taking medications
- Bring a list of phone numbers/emails of key personal contacts
- Bring copies of your Advance Directives and other pertinent legal documents
- Have a plan for communication ready (tip sheet can help)

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?	
legal guardian aide or staff member if	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 North Caroli Abuse Services? yes no lo lon't know ***Note to doctors: This means there may be special laws in place to followed if my usual decision maker[guardian requests to withhold your institution's social worker or risk management department to l	protect me and a special process needs to be or withdraw life sustaining treatment. Please check in with
How do you communicate best? (check all that apply)	Do you need anything to help you communicate?
Talking Writing or typing things down	(E.g. assistive devices) 🔍 no
Pictures Using sign language	yes (please describe)
Pointing to words Using a voice app	Does anyone help you communicate? 🖵 no
I cannot communicate in a way you will understand, please	yes, person's name
ask my family, staff or guardian (circle the person)	Do you use any assistive devices for mobility? 🔲 no
Other (please describe)	yes list the device(s)
Do you have any triggers (e.g., being touched, trouma, doctors of a particular gender, noises, lighting, smells, textures): What is your response to triggers? How can you best be helped when triggered?	What is your typical response to a medical exam? Fully/partially cooperates Faily/partially cooperates Aggressive Resistant I like it when health professionals (please describe)
Do you have any medical problems that you go to the doctor for?	Please list the name of the doctor you would like contacted if
yes no	you are at the hospital.
What are they?	Name
	Phone Number
Are there any diagnoses, medical problems or behaviors that we should consider as cautions? (e.g., oggression, biting, pica, aspiration risk):	Do you have seizures? no yes, list the type and frequency
Are there any specific modifications that could help with these cautions?	
Do you take any medication at home every day? 🔍 yes 🔲 no	Over the counter? 🖵 no
By prescription? 🖵 no	yes, list the names and dosage
yes, list the names and dosage	
	Do you have any allergies? 🖵 no
	yes, please list



 Medical Form: https://www.autismsociety-nc.org/wp-content/uploads/COVID-19-Disability-Form_NC_April-2020.pdf

 Medical Form:
 https://spanadvocacy.org/download/health-passport-for-youth-english-spanish/?wpdmdl=52108&refresh=5cfe6abod8f1b1560177328

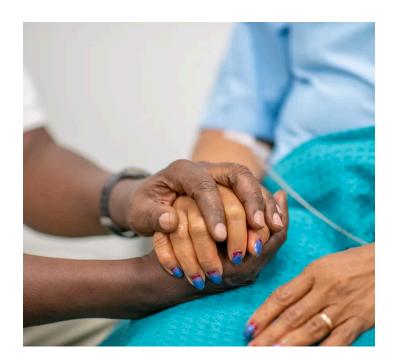
 Communication Tips:
 https://iddtoolkit.vkcsites.org/general-issues/communicating-effectively/

Can someone come with you to the hospital?

- The Americans with Disabilities Act and Section 504 of the Rehabilitation Act mandates that hospitals provide reasonable accommodations to patients with disabilities.
- <u>Section 4111 of the federal CARES Act (S. 3548)</u> authorizes I/DD direct support professionals to accompany clients on acute care hospital visits.

That said...

- Some hospitals do not allow visitors at this time.
- The hospital might need to make an exception to this rule for you. If you need your helper with you because of your disability, tell hospital workers. This is called a reasonable accommodation.
- It may help to take a **letter from your doctor** that says why you need your helper
- Your helper cannot stay with you if they are sick.
- Your helper may need to take extra precautions to prevent the spread of COVID-19.





Disability Rights of NC: https://disabilityrightsnc.org/wp-content/uploads/2020/05/Fact-Sheet-Caregivers-in-Hospitals.pdf

Being a Caregiver During this Pandemic

- CDC gives 6 general tips:
 - Be informed; Get support; Be an advocate; Be empowering; Take care of yourself; Keep balance in the family
- Have an emergency plan in place that includes provisions specific to COVID-19, e.g. have multiple options for accessing help since everyone is dealing with this pandemic.
- This may include a "Plan A" and a "Plan B", i.e.
 - Who should be involved in developing the plans or be aware of the plans?
 - What is the back-up plan if your Direct Support Professional is ill and cannot help you?

CDC Caregiving Tips: https://www.cdc.gov/ncbddd/disabilityandhealth/family.html

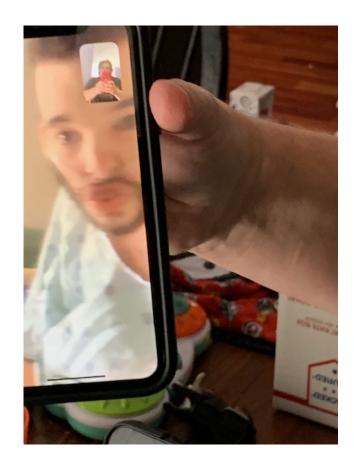




Our Family Experience with COVID 19







Things to do summer, fall, winter or spring



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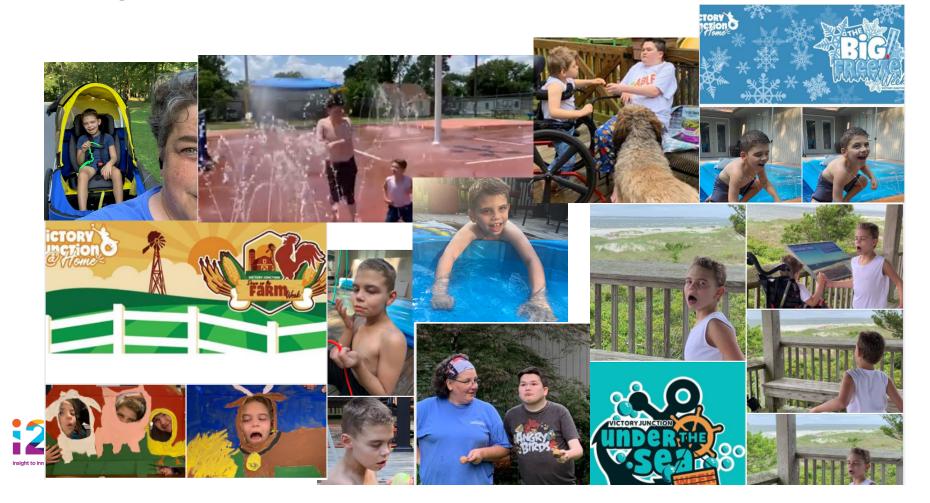
• We attended VJ@Home with Victory Junction.







Camp@Home Summer 2020



Work @ Home



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- A survey will be sent out shortly. Please complete to help up provide information that helps you!
- Questions & Answers will be sent to all registrants next week.
- Slide handouts and a recording of this webinar will be sent to all registrants and posted to izicenter.org next week.



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Keep Updated at izicenter.org

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