

# COVID-19

## More IDD-specific Stuff

Stephen Sulkes, MD

Strong Center for Developmental Disabilities

Division of Developmental-Behavioral Pediatrics

Golisano Children's Hospital Rochester

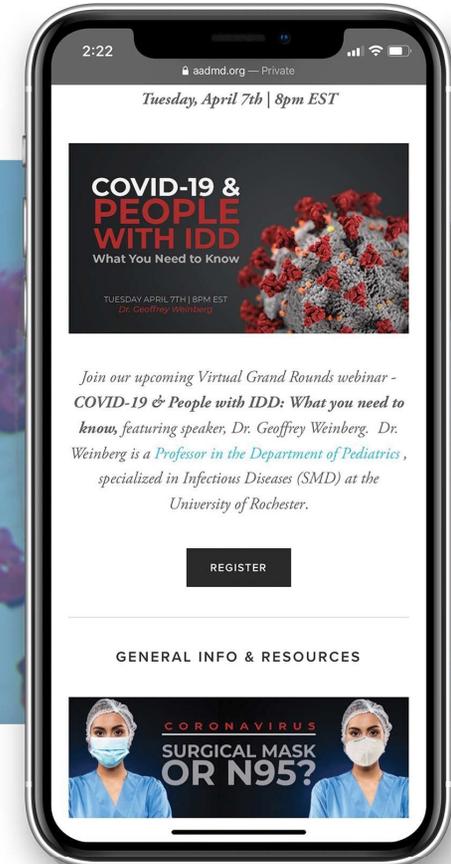
American Academy of Developmental Medicine and Dentistry





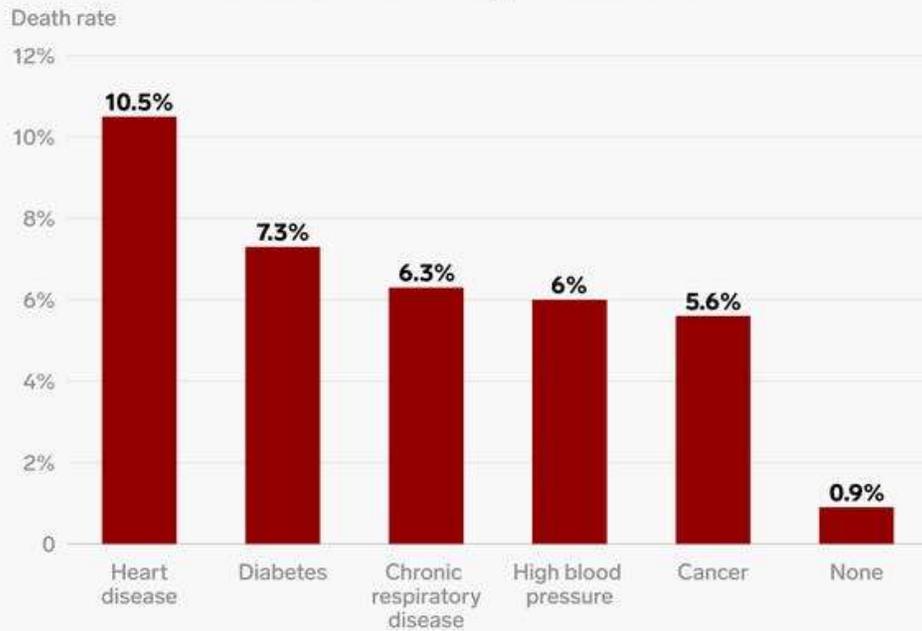
# CORONAVIRUS CENTER

[AADMD.ORG/CORONAVIRUS](https://aadmd.org/coronavirus)



# COVID-19 is worse for some than other

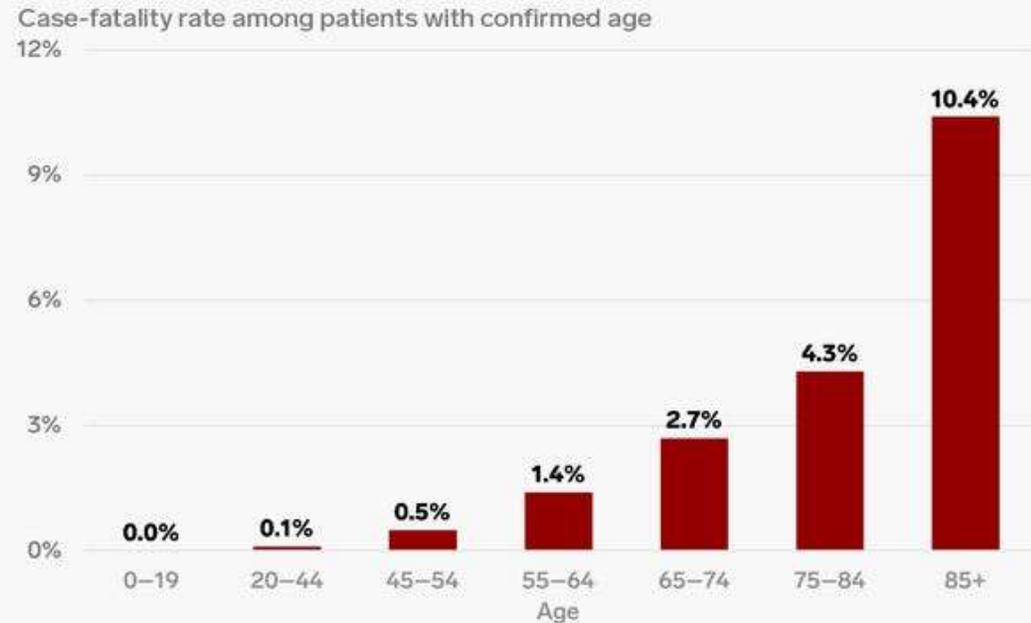
## Death rate of COVID-19 patients with preexisting conditions



Source: Chinese Center for Disease Control and Prevention

BUSINESS INSIDER

## COVID-19 death rates in US by age



Source: Centers for Disease Control and Prevention COVID-19 Response Team

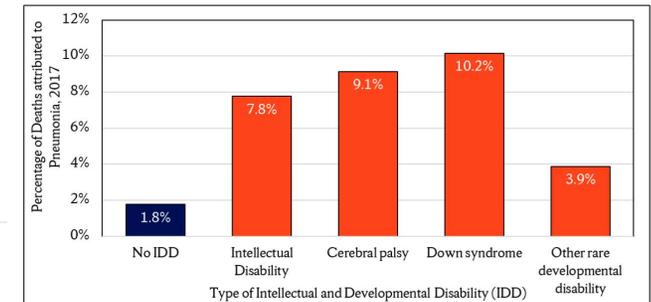
BUSINESS INSIDER

<https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6912e2-H.pdf>

# IDD/DS and COVID-19

- Breathing and swallowing difficulties; history of lung diseases (CP, aspiration)
- Sleep apnea +/- obesity (Down syndrome, Prader-Willi)
- Cardiac difficulties (Down syndrome, 22q deletion)
- Weakened immune systems (Down syndrome, 22q deletion)
- Higher degree of chronic diseases including behavioral challenges
- Autism
- Polypharmacy?
- In relatively proximity to others at risk; **congregate living**
- Ability to follow and maintain adequate hygiene guidelines
- Impact associated with caregiver issues and concerns
- Insufficient data to know for certain

## Potential Impacts of COVID-19 on Individuals with Intellectual and Developmental Disability: A Call for Accurate Cause of Death Reporting



Landes, S.D., Stevens, J.D., & Turk, M.A. (2019). Obscuring effect of coding developmental disability as the underlying cause of death on mortality trends for adults with developmental disability: A cross-sectional study using US Mortality Data from 2012 to 2016. *BMJ Open*, 9(2), 1–10.

## The New York Times

***'It's Hit Our Front Door': Homes for the Disabled See a Surge of Covid-***



<https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html>

# NY Times Data (4/8/20)

(per NY Disability Advocates)

- 1100 COVID-19 positive out of 140,000 people served by OPWDD
- 105/1100 9.5% mortality (compared with 2% general population)
- Testing limitations?

*The New York Times*

# The Timeline of COVID-19 and its Impact

- Social distancing and isolation
- Getting sick
- Going to the hospital
- Recovery

# Social distancing and isolation

- A change of routine in a restricted environment
- Stress and maintaining “normal”
- Being scared
- Keeping safe



# Maintaining Care

- Chronic conditions do not go away
- Active mental health concerns
- Ensuring caregiver supports are considered
- Telehealth
- Staying connected
- Health Promotion





# Getting sick

- Signs of the illness
- Testing; checking for fever, GI difficulties, Respiratory complaints and COVID-19 testing
- Care practices
- Quarantine
- Personal Protection Equipment (PPE)
- Deciding when a higher level of care is needed
- Stress management

# Getting Information

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## COVID-19 Information By and For People with Disabilities



**What is COVID-19?**  
It is a new illness spreading around the world. Its nickname is coronavirus.



**How do you get it?**  
Someone with COVID-19 gives you their germs. When they cough or sneeze, their germs get in the air, on you, and on things. Germs get into your body through your mouth, nose, and your eyes.



**What happens if you have it?**



A fever of 100.4 or higher



Coughing



Hard time breathing

If these things happen to you, it does not mean you have coronavirus. Lots of people get a fever or cough. You could just have a cold or the flu.



**If I am sick, when should I call a doctor?**  
Call if you have been out of the country.  
Call if you have been with someone who has the virus.  
Call if you have been at a place where people with COVID-19 got medical treatment.  
**Call your doctor, do not go to the office.**

Adapted from COVID-19 Information By and For People with Disabilities, Green Mountain Self-Advocates [www.gmsavt.org](http://www.gmsavt.org)  
To access the complete booklet visit the Green Mountain Self-Advocates website at this link:  
<https://selfadvocatesinfo.org/wp-content/uploads/2020/03/Plain-Language-Information-on-Coronavirus.pdf>



## THE ROLE OF THE DSP AND THE CORONAVIRUS



### PART THREE: LIVE

Featuring: Rick Rader, MD

April 3rd | 1:00 PM EST




<https://nadsp.org/covid-19resources/>

## Covid-19 & Down Syndrome Q & A

NTG Joins National Groups in Issuing Q&A on COVID-19 and Down Syndrome

With the constantly changing status of the COVID-19 pandemic in the United States, the NTG joined in with an effort by national organizations to produce and issue a Q&A on COVID-19 and Down Syndrome. The Q&A has two versions, one a brief series of content answers, and another longer version covering numerous questions that have arisen. The Q&A is directed toward families and others concerned with impact of COVID-19 upon persons of all ages with Down syndrome.



Download Abbreviated Version in English

Descargue la versión abreviada en español

Download Expanded Version in English

Descargue la versión ampliada en español

[www.aadmd.org/coronavirus](http://www.aadmd.org/coronavirus)



# Going to the hospital

- Testing
- Treatment
- Getting the necessary care
- Quarantine
- Communication
- Palliative Care
- Death and dying



# Improving Care in the Hospital

- Communication and Accurate Information; Health Passport/summary
- Support of the Caregiver/DSP; Cares Act Provision
- Hospital Visitation Rights; NY DOH, NJ, TN, National advocacy effort
- Ensure equity of care

[https://opwdd.ny.gov/system/files/documents/2020/04/doh\\_covid19\\_hospitalvisitation\\_4.10.20.pdf](https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf)

**CAUTION: POSSIBLE COVID-19 CASE**

**Patient Summary for Person with Developmental Disability**  
*Emergency Contacts, Abridged Medical History, Medication Regimen, Allergy Information, Assistance Needs*

I have a developmental disability. My parent/guardian or support professional believes I am showing signs of COVID-19 infection. If they cannot come with me into the hospital, please refer to the information provided here and call my guardian, service provider, and the county board of DD for any clarifications.

PERSONAL INFORMATION			
First Name:	Middle Initial:	Last Name:	DOB or Age:
Address:		City, State, ZIP:	
Name of Parent/Guardian:		Parent/Guardian Phone/Email:	
Name of Direct Support Professional (DSP):		DSP Phone/Email:	
County Board of DD Contact:		County Board Contact Phone/Email:	

CURRENT SYMPTOMS / RISK FACTORS		
<b>Current COVID-19 Symptoms:</b> <input type="checkbox"/> Temp. Over 100°F <input type="checkbox"/> Dry Cough <input type="checkbox"/> Malaise/Fatigue <input type="checkbox"/> Shortness of Breath <input type="checkbox"/> Bloodshot Eyes <input type="checkbox"/> Diarrhea <input type="checkbox"/> Loss of Smell/Taste <input type="checkbox"/> Other (please specify) <input type="checkbox"/> Other (please specify)	<b>When Did it Start?</b>       	<b>Patient's COVID-19 Severity Risk Factors (check all that apply):</b> <input type="checkbox"/> Age 60 or Older <input type="checkbox"/> Down's Syndrome <input type="checkbox"/> Bowel Disease (Crohn's, Colitis, or Divertic) <input type="checkbox"/> Hypertension <input type="checkbox"/> Cancer (Current or Previous) <input type="checkbox"/> New Chest Pain <input type="checkbox"/> Cerebral Palsy <input type="checkbox"/> Paralysis (Due to Any Cause) <input type="checkbox"/> Chemotherapy <input type="checkbox"/> Recurrent Pneumonia <input type="checkbox"/> Chronic Heart Disease <input type="checkbox"/> Severe Scoliosis <input type="checkbox"/> Chronic Lung Disease (Asthma or Emphysema) <input type="checkbox"/> Other: <input type="checkbox"/> Diabetes <input type="checkbox"/> Other: <input type="checkbox"/> On Prednisone, Dexamethasone, or any medication ending in the letters "-ab"

MEDICATIONS			
Medication:	New Medication: (added within the last 2 weeks)	Dosage/Frequency:	Preferred Form: (liquid, pill, etc.)
	<input type="checkbox"/>		

(MORE INFORMATION ON REVERSE)

MEDICAL HISTORY		
Health Issue/Diagnosis:	When Did it Start?	Notes:

PATIENT ALLERGIES	SEVERITY	PATIENT HAS DNR ORDER:
		<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> UNSURE
		If yes, list order's location if known:
		<b>PATIENT HAS LIVING WILL:</b>
		<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> UNSURE
		If yes, list will's location if known:

PERSONAL ASSISTANCE NEEDS				ADDITIONAL NOTES:
Bathroom Use:	<input type="checkbox"/> Independent	<input type="checkbox"/> Needs Assistance	<input type="checkbox"/> Needs Total Assistance	
Eating:	<input type="checkbox"/> Independent	<input type="checkbox"/> Needs Assistance	<input type="checkbox"/> Needs Total Assistance	
Mobility:	<input type="checkbox"/> Independent	<input type="checkbox"/> Needs Assistance	<input type="checkbox"/> Uses Assistive Device	
Communication:	<input type="checkbox"/> Tactile	<input type="checkbox"/> Limited Speech	<input type="checkbox"/> Non-Verbal/Uses Device	
Social Preference:	<input type="checkbox"/> Social	<input type="checkbox"/> Not Social	<input type="checkbox"/> Varies	
Sleep Schedule:	<input type="checkbox"/> Typical	<input type="checkbox"/> Inverted	<input type="checkbox"/> Intermittent/Variable	

PATIENT'S SELF EXPRESSION, LIKES, AND DISLIKES:		PATIENT HAS MASKFACE SENSITIVITY (IF YES, SPECIFY IN NOTES ABOVE):
I express myself by:		
I calm myself by:		
When I'm happy, I:		
When I'm sad, I:		
When I'm scared, I:		
When I'm angry, I:		
My likes:		<input type="checkbox"/> YES <input type="checkbox"/> NO
My dislikes:		

To download this form, visit [www.oacbdds.org/covidform](http://www.oacbdds.org/covidform)

This form has been created and distributed by the Ohio Association of County Boards of DD with additional input and guidance from Dr. Scott Arnold of the Right Care Now Project.



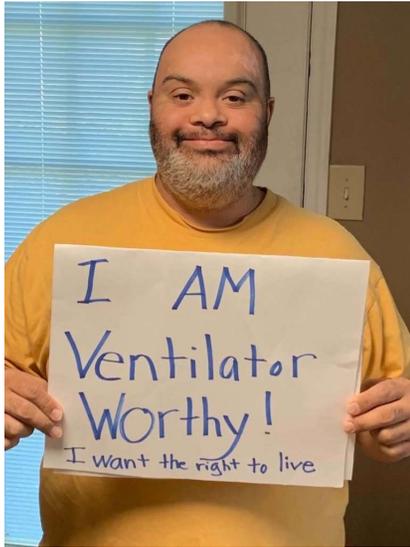

<http://www.oacbdds.org/news/2020/04/08/releases/oacb-creates-health-passport-to-assist-people-served-unable-to-enter-hospitals-with-staff-family/>

# Sounding the Alarm

CORONAVIRUS AND INEQUALITY

Published — April 8, 2020

## STATE POLICIES MAY SEND PEOPLE WITH DISABILITIES TO THE BACK OF THE LINE FOR VENTILATORS



<https://www.propublica.org/article/people-with-intellectual-disabilities-may-be-denied-lifesaving-care-under-these-plans-as-coronavirus-spreads>

### CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES



## Safeguard Against Disability Discrimination During COVID-19

Including individuals with disabilities in the COVID-19 response to ensure equitable care



### THINK EQUITABLE CARE - TAKE ACTION!

- Inform key medical personnel immediately that individuals with disabilities have equal rights to COVID-19 testing and treatment.
- Make equitable decisions to ensure that allocation of COVID-19 resources, supplies, and care are not based on inaccurate assumptions about life with a disability.
- Provide accommodations to make sure all individuals can access COVID-19 testing and treatment. This requirement includes accommodations for behavioral, intellectual, or physical disabilities that may impact someone's ability to comply during testing and treatment.



### KNOW THE BEST PRACTICES - TAKE ACTION!

- When communicating with individuals with disabilities:
  - Talk directly to them.
  - Ask permission before speaking with their caregivers, if possible.
  - Ask the caregiver for assistance if you need help communicating with a patient.
  - Use plain language to tell individuals and caregivers about COVID-19 test results and anticipated procedures.
  - Keep in mind that you may have difficulty understanding the patient, however, in most cases they understand you.
- Make these accommodations:
  - Allow a caregiver to go with a patient to ensure adequate support for decision-making and treatment.
  - Provide ramps and rooms with enough access for a wheelchair.
  - Provide qualified interpreter services for the deaf or hard of hearing.
  - Use prompts, such as picture cues, for those with limited use of verbal communication.
  - Provide the time needed for individuals to speak, respond, and understand.

### THINK EQUITABLE!

This information is based on guidance from the Department of Health and Human Services Office for Civil Rights. For more information, visit [HHS.gov/ocr](https://www.hhs.gov/ocr) and [biijr@2WXEsov](mailto:biijr@2WXEsov)

<https://www.ucucedd.org/safeguard-against-disability-discrimination-during-covid-19/>



## HHS Office for Civil Rights in Action



March 28, 2020

### BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

In light of the Public Health Emergency concerning the [coronavirus disease 2019 \(COVID-19\)](https://www.cdc.gov/coronavirus/2019-nCoV/), the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is providing this bulletin to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.<sup>1</sup>

<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>