

Part 2

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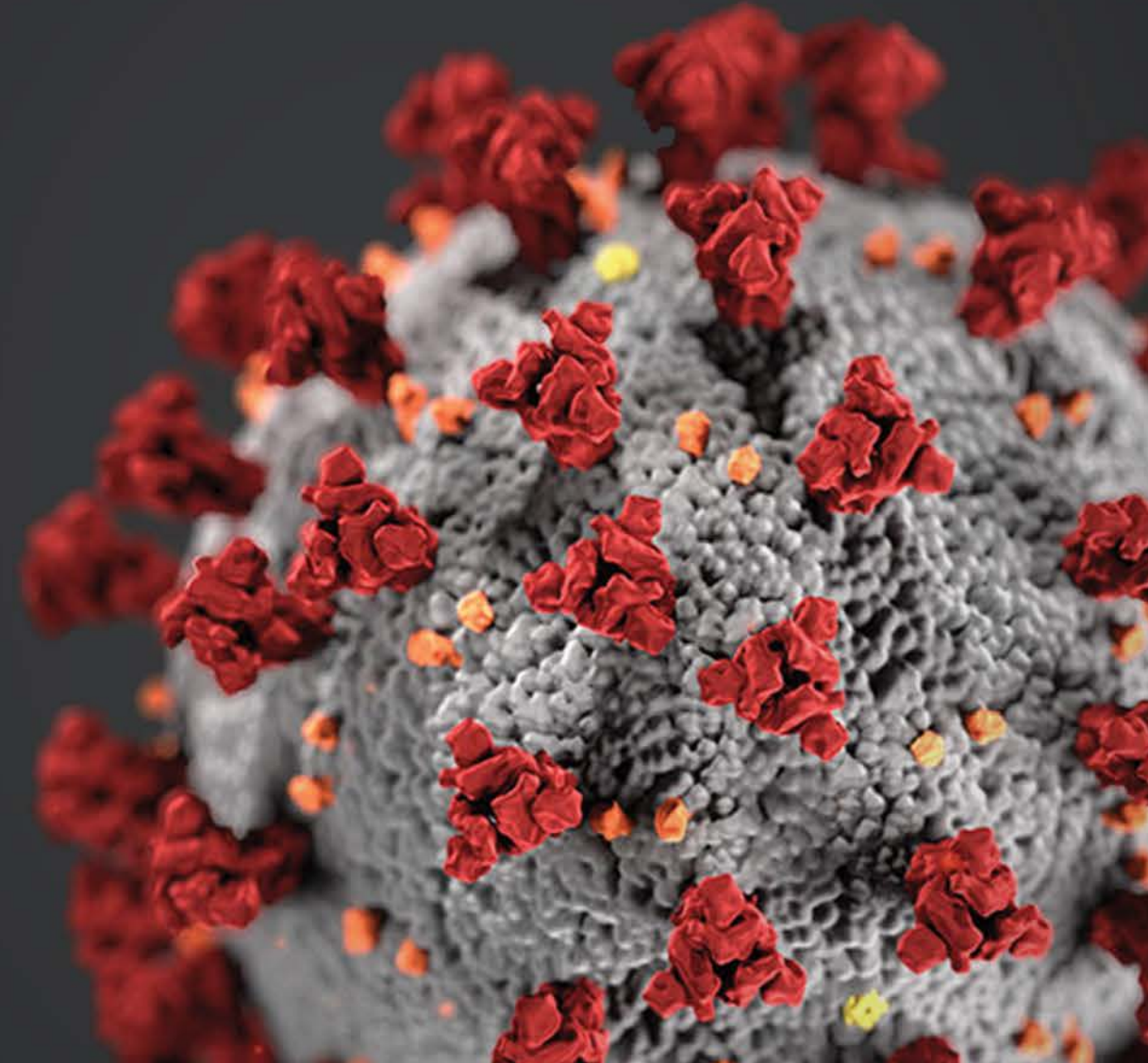


COVID-19 & PEOPLE WITH IDD

*Healthcare Concerns of People
with IDD & Dementia*

WEDNESDAY APRIL 22ND | 8PM EST

Dr. Seth Keller





VIRTUAL GRAND ROUNDS
WEBINAR

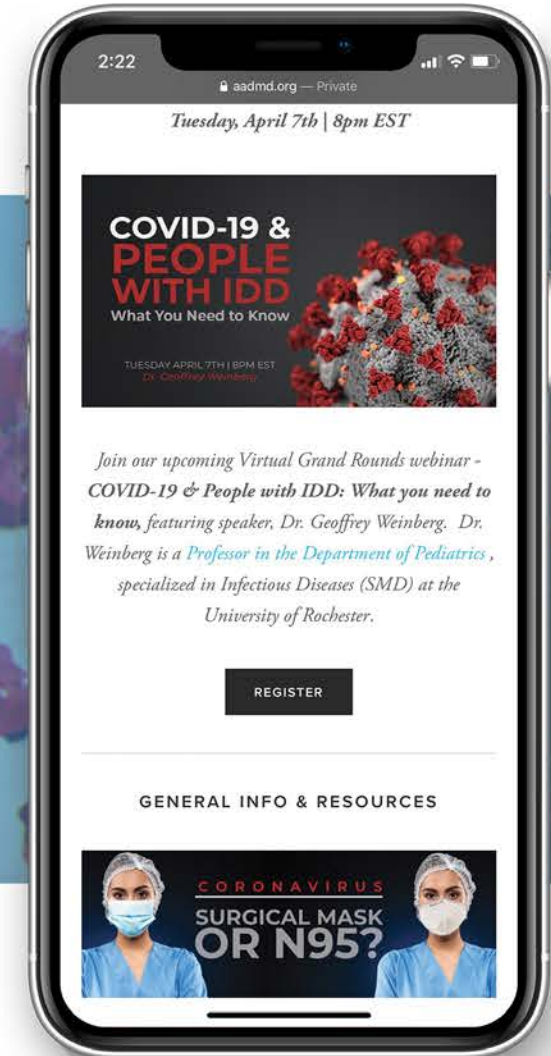
WELCOME

AADMD.ORG



CORONAVIRUS CENTER

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





Disclosures

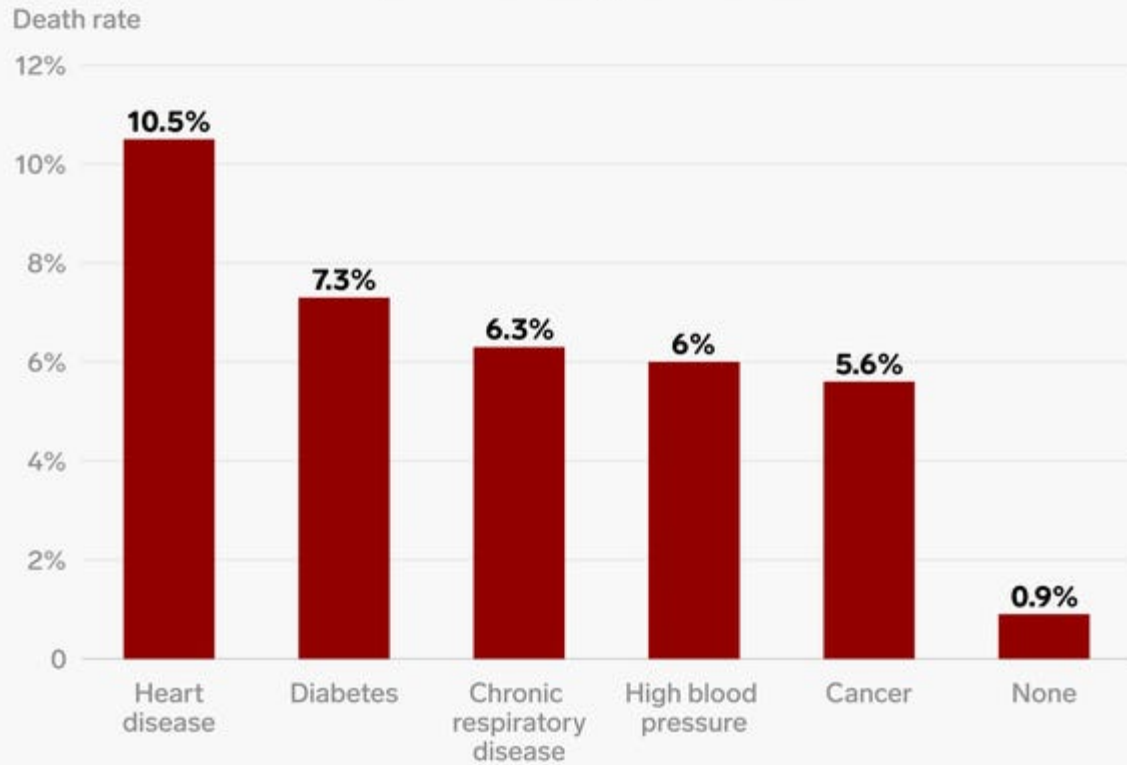
Relationships with financial sponsors: none to disclose

Potential for conflict(s) of interest: none to disclose



COVID-19 is worse for some than other

Death rate of COVID-19 patients with preexisting conditions

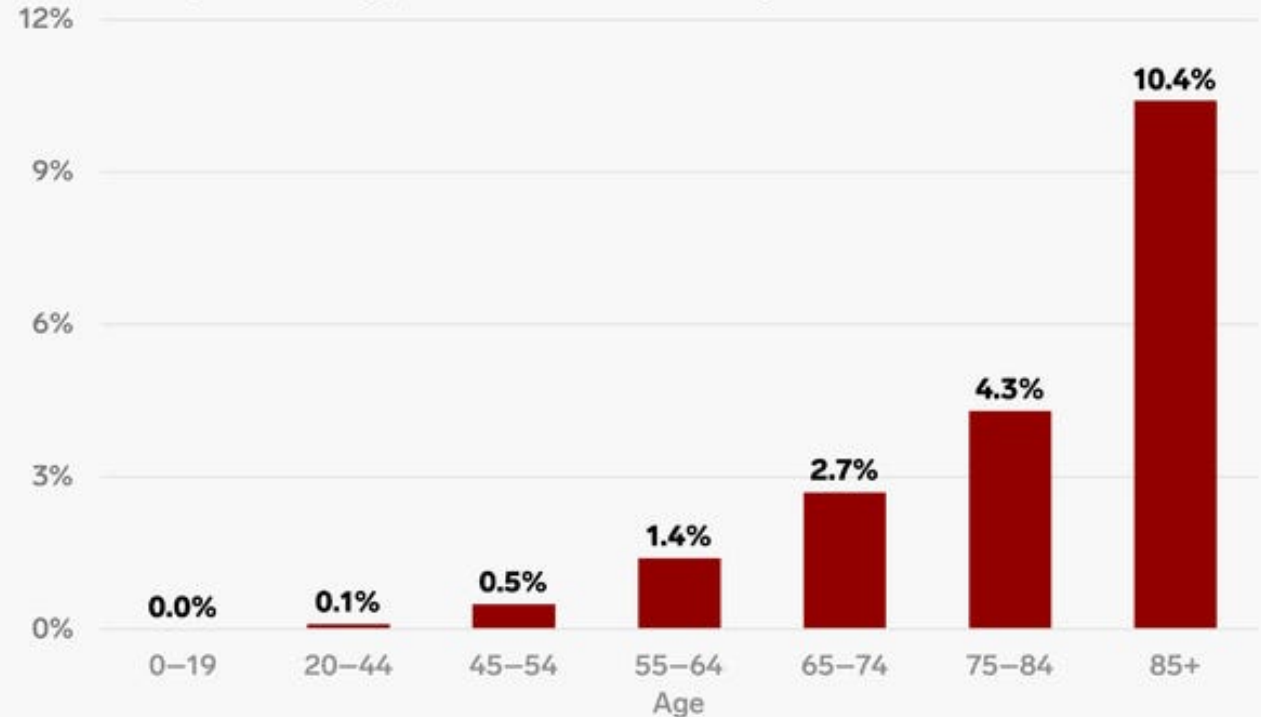


Source: Chinese Center for Disease Control and Prevention

BUSINESS INSIDER

COVID-19 death rates in US by age

Case-fatality rate among patients with confirmed age



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

BUSINESS INSIDER

Dementia and COVID-19



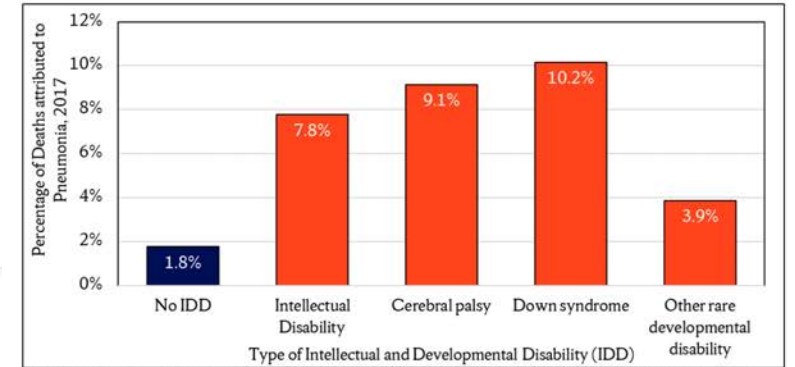
- Generally most over 65 years old, except for early-onset Alzheimer's disease
- May not be able to understand or appreciate hygiene instructions and able to follow them
- May be around others who can pass on virus;
congregate living
- Advanced disease associated with weakened immune system, breathing and swallowing difficulties
- Challenges with caregiver stress, availability and adequate PPE



IDD/DS and COVID-19

- Breathing and swallowing difficulties; history of lung diseases
- Sleep apnea, obesity in those with DS
- Cardiac difficulties
- Weakened immune systems
- 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-19



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

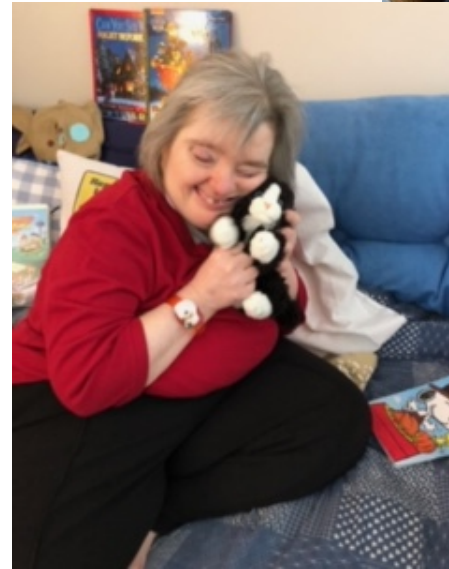


The Timeline of COVID-19 and its Impact

- 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

VOLUME 4 ISSUE 1 NTG CAREGIVER NEWS PAGE 3

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
To access the complete booklet visit the Green Mountain Self-Advocates website at this link: <https://selfadvocacyinfo.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/>



DMIG-USA
Down Syndrome Medical Interest Group-USA

GLOBAL
DOWN SYNDROME FOUNDATION

Lumind
IDSC

NATIONAL DOWN SYNDROME CONGRESS

ndss
National Down Syndrome Society

ntg
National Task Group on Intellectual Disabilities and Genetic Prenatal

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

<https://www.the-ntg.org/projects>

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

CAUTION: POSSIBLE COVID-19 CASE

Patient Summary for Person with Developmental Disability
Emergency Contacts, Allergic 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 ID 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 ID Contact: _____ County Board Contact Phone/Email: _____

CURRENT SYMPTOMS / RISK FACTORS

Current COVID-19 Symptoms: When Did it Start? _____ Patient's COVID-19 Severity Risk Factors (check all that apply):

<input type="checkbox"/> Temp. Over 100°F	<input type="checkbox"/> Age 60 or Older	<input type="checkbox"/> Diabetes	<input type="checkbox"/> Dementia Syndrome
<input type="checkbox"/> Dry Cough	<input type="checkbox"/> Blood Disease (such as anemia)	<input type="checkbox"/> Hypertension	<input type="checkbox"/> New Chest Pain
<input type="checkbox"/> Muscle Fatigue	<input type="checkbox"/> Cancer	<input type="checkbox"/> Pregnancy	<input type="checkbox"/> Family History of COVID-19
<input type="checkbox"/> Shortness of Breath	<input type="checkbox"/> Central Pulley	<input type="checkbox"/> Respiratory Precondition	<input type="checkbox"/> Tobacco
<input type="checkbox"/> Bloodshot Eyes	<input type="checkbox"/> Chemotherapy	<input type="checkbox"/> Severe Sickle Cell	<input type="checkbox"/> Other _____
<input type="checkbox"/> Diarrhea	<input type="checkbox"/> Chronic Heart Disease	<input type="checkbox"/> Other _____	
<input type="checkbox"/> Loss of Smell/Taste	<input type="checkbox"/> Chronic Lung Disease	<input type="checkbox"/> Other _____	
<input type="checkbox"/> Other (please specify) _____	<input type="checkbox"/> Diabetes	<input type="checkbox"/> Other _____	
<input type="checkbox"/> Other (please specify) _____	<input type="checkbox"/> On-Preparation, Over-the-counter, or any medication ending in the letters "ol"		

PERSONAL ASSISTANCE NEEDS

<input type="checkbox"/> Transportation	<input type="checkbox"/> Needs Assistance	<input type="checkbox"/> Needs Total Assistance
<input type="checkbox"/> Independent	<input type="checkbox"/> Needs Assistance	<input type="checkbox"/> Needs Total Assistance
<input type="checkbox"/> Independent	<input type="checkbox"/> Needs Assistance	<input type="checkbox"/> Needs Total Assistance
<input type="checkbox"/> Tobacco	<input type="checkbox"/> Limited Speech	<input type="checkbox"/> Non-Verbal/Deaf
<input type="checkbox"/> Social	<input type="checkbox"/> Not Eased	<input type="checkbox"/> Verbal
<input type="checkbox"/> Tactile	<input type="checkbox"/> Irritable	<input type="checkbox"/> Hyperactive/Anxious

PATIENT HAS DNR ORDER:
 YES NO UNSURE
If yes, list order location. If none:
PATIENT HAS LIVING WILL:
 YES NO UNSURE
If yes, list A/E's location if known.

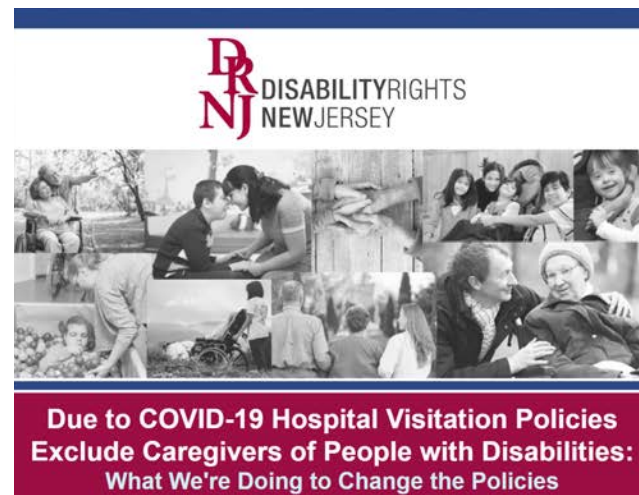
ADDITIONAL NOTES:

PATIENT HAS MASK/FACE SENSITIVITY (IF YES, SPECIFY IN NOTES ABOVE):
 YES
 NO

PATIENT HAS GENERAL TOUCH SENSITIVITY (IF YES, SPECIFY IN NOTES ABOVE):
 YES
 NO

To download this form, visit www.oacbddd.org/covidform

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



<https://myemail.constantcontact.com/--Hospital-Visitation-Policies-Exclude-Caregivers-of-People-with-Disabilities---What-We-re-Doing-To-Change-It.html?soid=1102624420023&aid=POHFyW4NBHw>

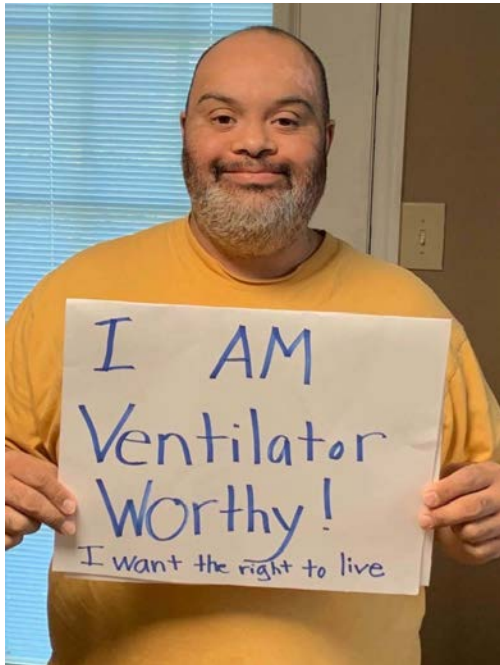
https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf

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 [btl/y/2WXEscv](https://www.hhs.gov/btl/y/2WXEscv)

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



HHS Office for Civil Rights in Action



March 28, 2020

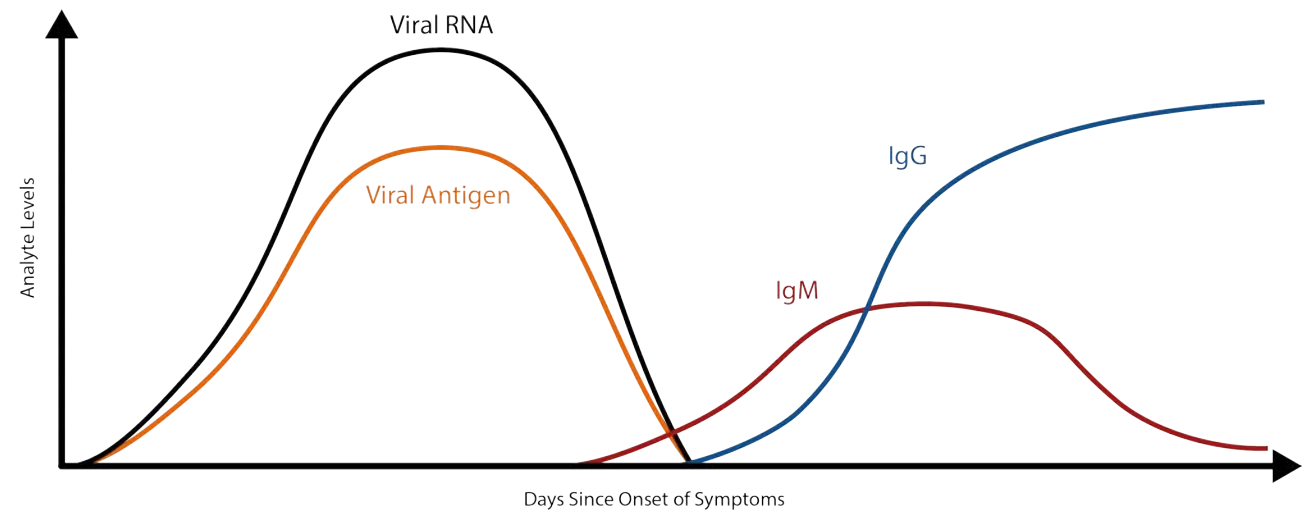
BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

In light of the Public Health Emergency concerning the coronavirus disease 2019 (COVID-19), 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.¹

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

COVID-19 Work up

- Nasal, oral, blood, fecal for evidence of the the virus
- How long to get back results
- How accurate are the tests results?
- Symptoms/signs
- Chest x-ray/CT Scan
- Blood; CRP, Ferritin, LDH, CPK, LDH
- Exclude other pathogens



<https://thenativeantigencompany.com/why-we-need-antigen-and-antibody-tests-for-covid-19/>

COVID-19 Treatment

- Prevent further spread
- Reduce fever
- Fluids/nutrition
- Respiratory and cardiac support
- Antiviral therapy; stopping the virus along its life cycle
 - ?? Hydroxychloroquine
 - ?? Remdesivir, Favipiravir
- Convalescent plasma
- Stress Management
- Communication
- Planning ahead

Prevention

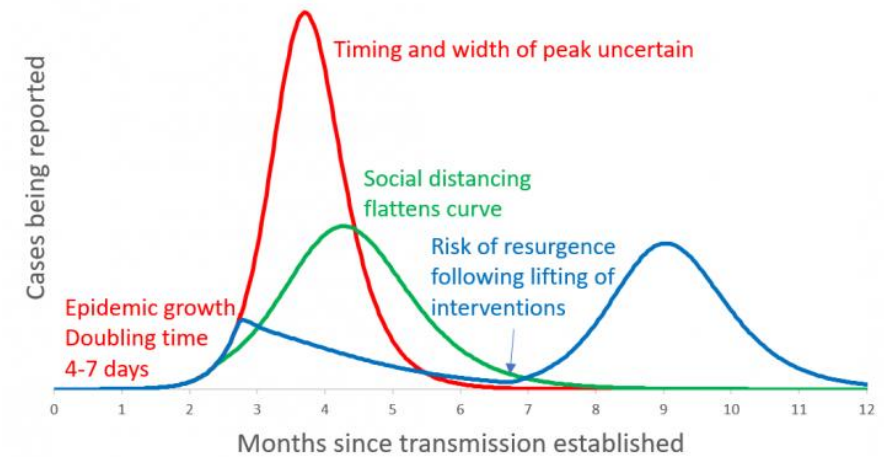


- Social distancing/hygiene
- Adequate Personal Protection Equipment (PPE)
- Vaccines



Recovery

- Post COVID-19 stress
- Transitioning and rehabilitation
- Getting back to "normal"
- Preparing for next wave
- Lessons learned



SHOCK

BETRAYAL

ENVY

FRUSTRATION

FEAR

FOREBODING

EXHAUSTION

GRIEF

TERROR

SOLIDARITY

COURAGE

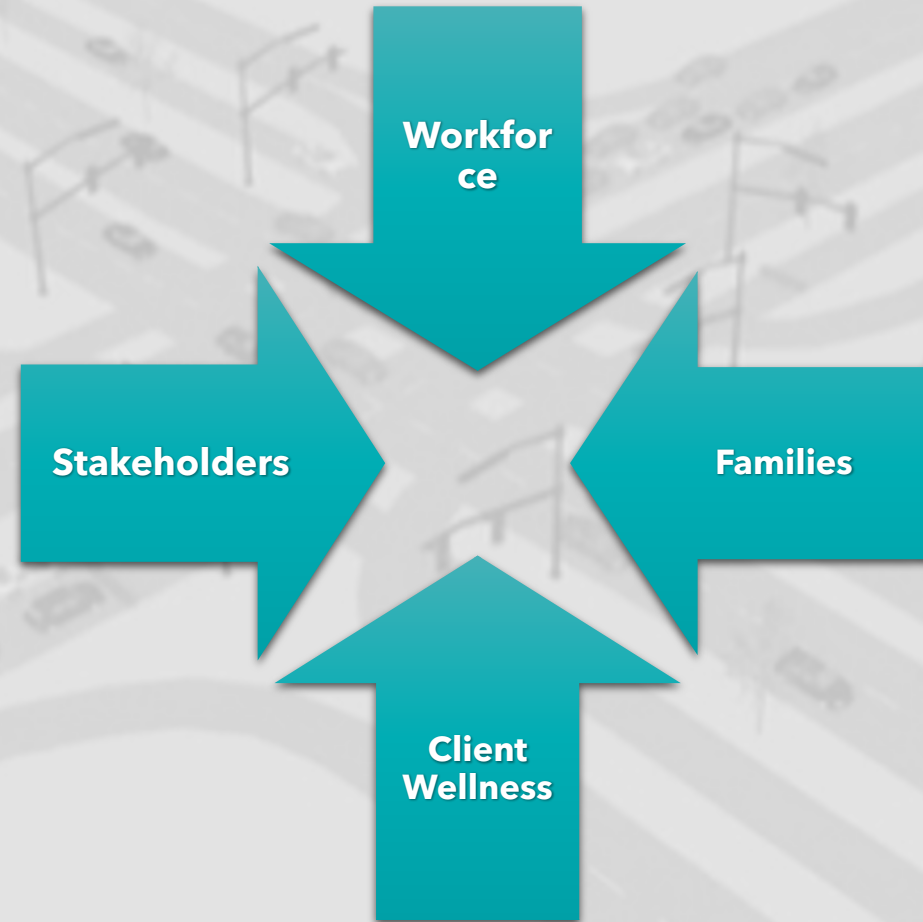
HOPE



@whiteboardpsych

**COVID - 19
SERVICE PROVIDER
ROAD MAP**

**Paul C. Landers
President and Chief Executive
Officer
Pathfinder Village, Inc**





VIRTUAL GRAND ROUNDS
WEBINAR

ROUNDTABLE

AADMD.ORG

Part 3

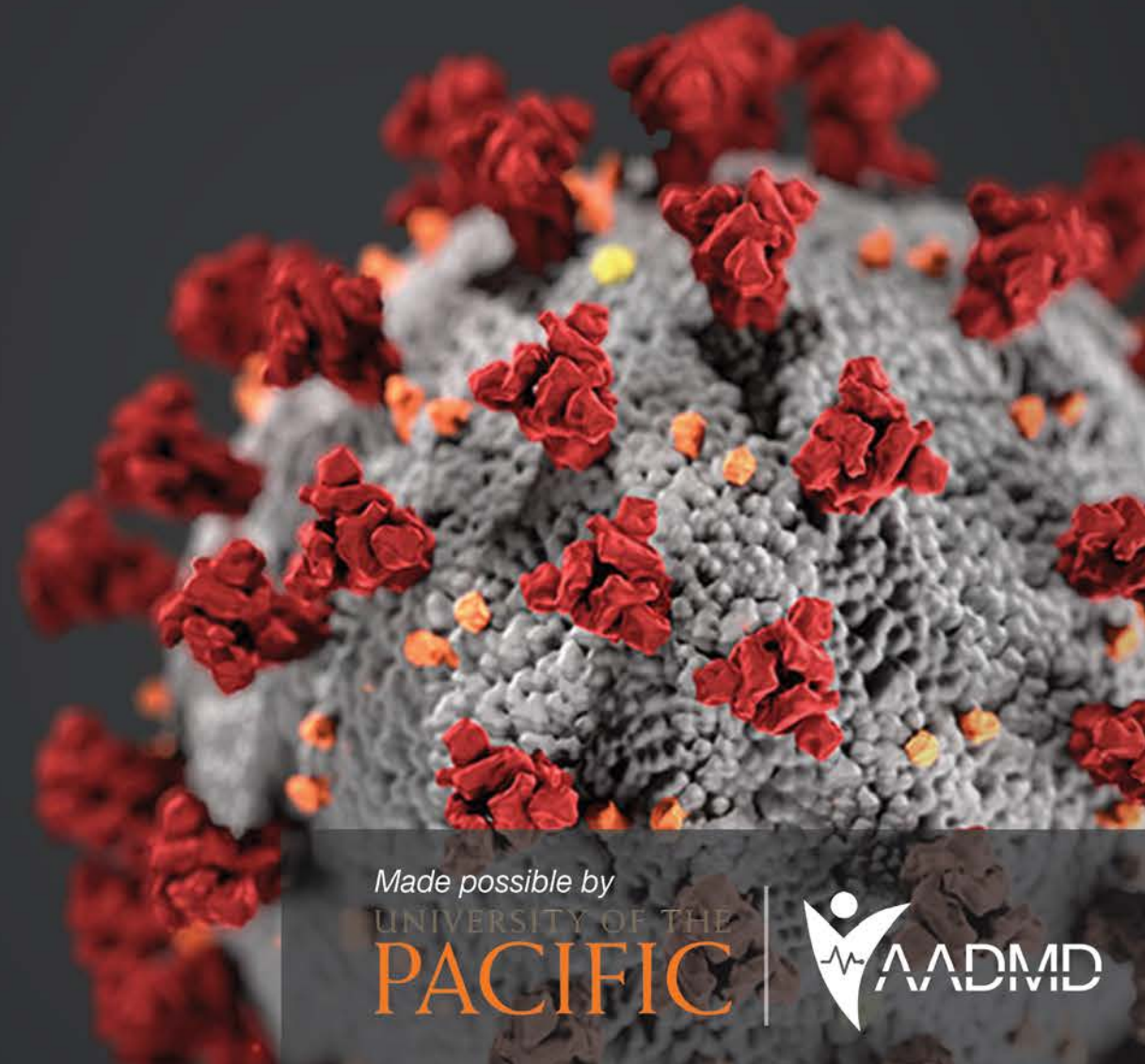


COVID-19 & PEOPLE WITH IDD

Special Olympics Responds

TUESDAY MAY 5TH | 8PM EST

Dr. Alicia Bazzano



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UNIVERSITY OF THE
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THURSDAY, APRIL 30
7PM EST

Coping during a Pandemic

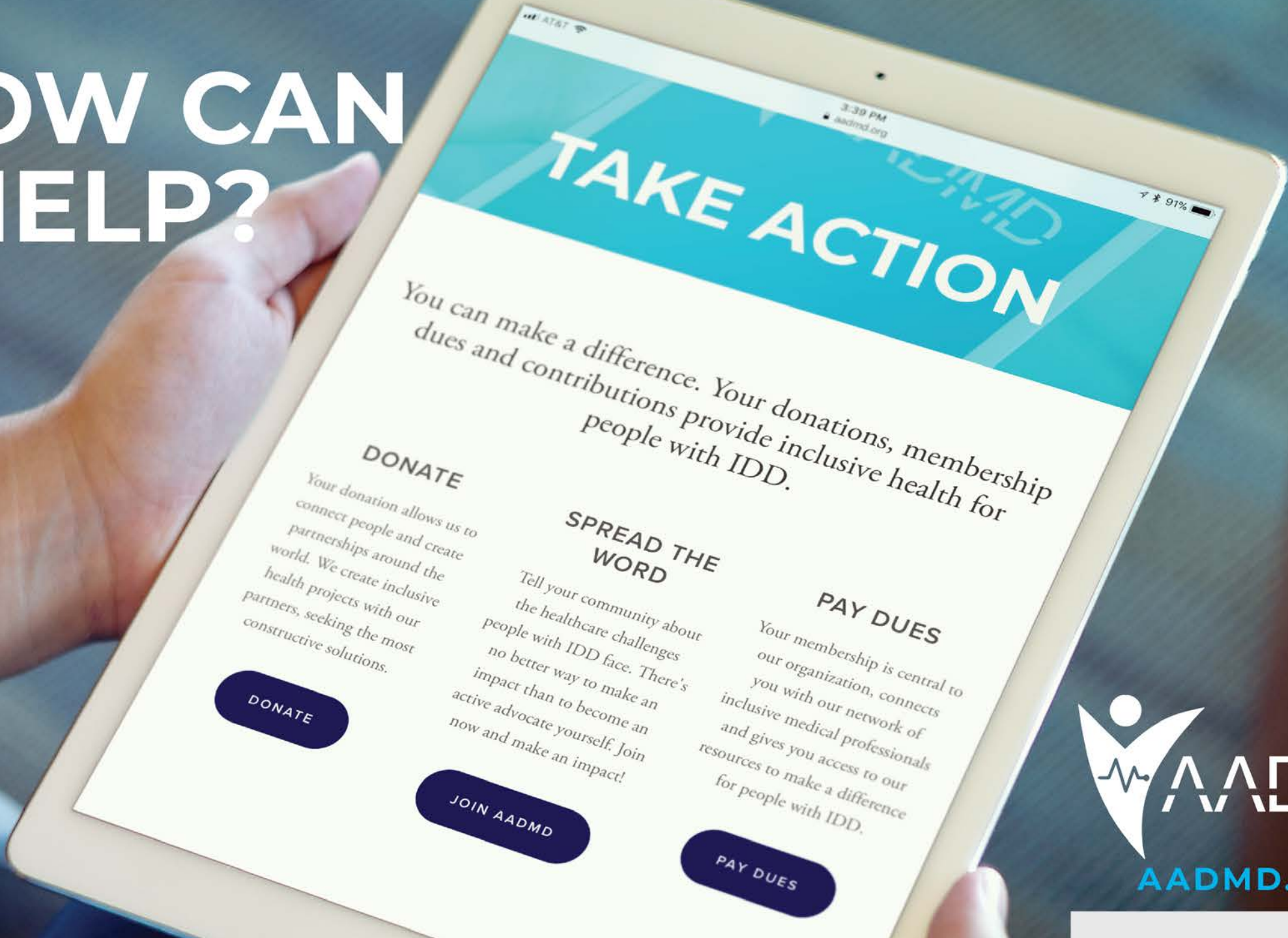


Redwood Coast
Regional Center



Making a world of difference
in people's lives

HOW CAN I HELP?



TAKE ACTION

You can make a difference. Your donations, membership dues and contributions provide inclusive health for people with IDD.

DONATE

Your donation allows us to connect people and create partnerships around the world. We create inclusive health projects with our partners, seeking the most constructive solutions.

[DONATE](#)

SPREAD THE WORD

Tell your community about the healthcare challenges people with IDD face. There's no better way to make an impact than to become an active advocate yourself. Join now and make an impact!

[JOIN AADMD](#)

PAY DUES

Your membership is central to our organization, connects you with our network of inclusive medical professionals and gives you access to our resources to make a difference for people with IDD.

[PAY DUES](#)

