COVID-19 and People with IDD: Taking Action to Mitigate Risk

Presented by:
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About the Presenter

Craig Escudé, MD

- Board-Certified Fellow of the American Academy of Family Physicians
- Fellow of the American Academy of Developmental Medicine
- Over 20 years of experience caring for people with mental illness and intellectual and developmental disabilities
- Medical Director of Hudspeth Regional Center in Whitfield, MS – Retired 2018
- Founder and Clinical Director of DETECT
- President of HRS, Inc.
What Do We Know Today

► Coronavirus - COVID-19
► Coronavirus first discovered in the 1960s likely around for hundreds or thousands of years
► Coronavirus are responsible for 15-30 percent of common colds
► Some strains like COVID-19 and SARS can be more dangerous
► There are viruses that have higher rates of death like Ebola 50%, SARS 9.6%, MERS 20-40%
► There is no vaccine for COVID-19
Risk of Serious Health Effects

► CDC
  ► Age over 65
  ► Lung disorders
  ► Heart disease
  ► Immune deficiencies
  ► Severe obesity

► Some with IDD
  ► Decreased respiratory capacity
  ► Asthma
  ► Frequent pneumonia
  ► Chronic silent aspiration

May be more susceptible to severe illnesses from COVID-19
Scenarios

► A person in a group home has been diagnosed with COVID-19
► A DSP in a group home has been diagnosed with COVID-19
► A person in a group home of 4 people has a fever of 101F and cough
► A staff member has been exposed to someone that was diagnosed with COVID-19
► 2 people are being moved to another group home with staff who do not know them to be quarantined
► Everyone is being asked to practice social distancing
Social Distancing
- Avoiding close interaction to reduce contact to reduce the spread of the disease

Quarantine
- Restricting movement of people that have been exposed

Isolation
- Separating people who are ill from those who are not
Social Distancing

► No visitors
  ► Family
  ► Friends

► No large crowds
  ► No work
  ► No school
  ► No social activities
  ► No church
  ► Eating in smaller groups or alone
SD Unwanted Effects

► Greater social isolation of a group of people that has been fighting this challenge for years

► Possibilities
  ► Anxiety, worry, fear
  ► Loneliness
  ► Anger
  ► Boredom
  ► Depression

Adverse Behaviors
SD – Reducing the Effects

► Connect with others
  ► Social Media
  ► Video Conferencing – Schedule regular time
  ► Snail Mail - HCP
  ► Xbox
  ► Phone Applications- Houseparty, Hangouts by Google

► Relaxation techniques
► Exercise - Yoga
► Virtual tours – zoos, museums etc.
► Journal writing
► Games
► Music
► Themed events and meals
► Modeling appropriate behaviors
► Keep routines the same as much as possible – cooking, cleaning, laundry, hygiene etc.

► SAMHSA.GOV - Tips for Social Distancing

Download in the “Handouts” tab in your control panel
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People Moving to a Hospital, or other Location

► Provide concise, practical information
  ► Clinical
  ► Social
  ► Environmental
  ► Anything that can help others know and better support the person
Health Passport

► Demographic
► Basic medical information
► Social and Environmental information
  ► How a person communicates
  ► How do they express pain
  ► How do they take medication best
  ► Mobility needs
  ► Calming techniques
  ► And more

► Shows that people with IDD are PEOPLE FIRST

Download in the “Handouts” tab in your control panel
My Health Passport

This document has important information so you can get to know me and better support me when I am receiving medical, dental, or other care. Please keep this information where others can easily reference it, and please READ THIS BEFORE trying to help me with care or treatment.

Demographic Information

Name: Thomas Jefferson

DOB: 4/13/1743

Address: 123 USA Street, Charlottesville, VA

Phone: 234-234-5577

Gender: Male

Race: Caucasian

Marital Status: Married

Insurance information: Medicaid number 123-456-7890

Other ID Numbers: Case number 11-23-44

Primary Care Physician:

Name: Doc Holiday, MD

Address and Phone Number: 999 9th Street, Charlottesville, VA, 222-333-4444

Psychiatrist:

Name: None

Address and Phone Number:

Dentist:

Name: Lester Tooth, DDS

Address and Phone Number: 888 8th Street, Charlottesville, VA, 111-222-3333

Preferred Hospital: George Washington Memorial

Name: Thomas Jefferson
Family contact and/or person who supports my decision-making (name and contact information):

Martha Jefferson, 123 USA Street, Charlottesville, VA cell 123-456-7890

Emergency contact: Same

**Important Clinical Information**

Diagnoses: Moderate Intellectual Disability, Hypertension, Restrictive Lung Disease

Medications and dosages: Lisinopril 5 mg PO daily, HCTZ, 25 mg PO Daily

Medication allergies or adverse reactions and type of reactions: Penicillin – rash all over body

Food allergies and type of reaction: Pickles - mouth swelling

When I experience pain I often: (describe behavior, etc.) Moan, or may pinch and pull at my ear, even if the pain is not in my ear

Usual manner and level of mobility: (Describe method, usual gait or pattern of movement and needed supports) I walk using a cane but I do get tired easily and may need a wheelchair for long distances

My diet is: (type and texture) Regular, low salt diet with no bread.

The type of assistance I need when eating: I need a curved handled spoon

The type of assistance I need when drinking: I drink better using a straw

Name: _______Thomas Jefferson_________________________
Most recent weight (and date) 156 on March 30, 2020


I take medications best in this form: (liquids, pills, mixed in pudding, etc.) I can swallow small pills with liquids but larger ones I prefer crushed up in applesauce

How I use the toilet: (Continence level, assistance, aids or products needed) I go to the bathroom alone

My usual bowel movement pattern: 1 BM every 1–2 days

Important Information About Communication

I communicate best using: (words, gestures, sign language, behaviors etc.) Some words and points to things I want: A picture card is very helpful.

Hearing: (normal, somewhat impaired, fully impaired, etc.) Normal

Vision (normal, somewhat impaired, fully impaired, etc.) I wear glasses and can see well with them

Important Social information

My friends and people who know me describe me as: (fun, likeable, smart, good at puzzles etc.) I’m friendly and I make great sandwiches! I like hugging people and smile a lot.

I Like: Watching Wheel of Fortune and going outside on the front porch

When I like something I express it by: Smiling, saying “yes!”, getting excited.

I dislike: Thunderstorms, having anyone try to undress me

Name: Thomas Jefferson
When I dislike something I express it by: Running away, or hitting at others if I am really angry.

The best way to communicate with me is: Sitting down, looking at my face and speaking in short sentences.

My usual sleep pattern is: I go to bed around 10 pm, I usually get up once to go to the bathroom and get us at 7 am ready to eat breakfast.

My favorite activities are: Watching game shows and playing kickball.

I usually interact with friends this way: (friendly, smiles, anger, fear etc.) Smile, and give a hug and a high five.

I usually interact with strangers this way: (friendly, smiles, anger, fear etc.) I like to hug everyone, even people I've never met.

When I'm angry I sometimes: Pull at my hair or ear, run away, strike at others.

When upset, the best way to help me calm down is: Speak calmly, offer a magazine or to go on a walk.

Things that I am sensitive to include: (specific sights, sounds, odors, textures/fabric, etc.) Loud noises, Thunder, and I don't like blowing my nose in a paper towel, use something softer, please.

Things that help me pass the time: Television, looking at magazines and talking with my friends.

**Health Risk Screening Tool Scores**

Name: ______ Thomas Jefferson ________________
Overall Health Care Level ______
(Levels 1 and 2 low risk, levels 3 and 4 moderate risk levels 5 and 6 high risk)

Date of most recent scoring:

Individual scores (Attach a print-out of the scoring summary)

Additional information:
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Steps

► Look at agency policies first
► Person may be sent home for quarantine
► Another option - monitor temp and signs and symptoms at least every 4 hours while at work
► No visitors
► Everyone stays 6 feet apart except when necessary for support
Agency Policies

► Julia Alleman, MSS – CEO of CADES in Swarthmore, PA has shared their policy with us today.

► CADES.org

Download their policy in the Handouts section of your control panel
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FIRST!
► Do Not Panic!
  ► Not all fevers are COVID-19
  ► Most cases are mild
► Contact your primary healthcare provider
► Utilize Telemedicine when possible
  ► Utilize clinicians that have training in IDD healthcare whenever possible
    ► StationMD (StationMD.com)
      ► Use HRS’s *Curriculum in IDD Healthcare* to train their providers
      ► HRS does not receive any financial benefit from utilization of their services
Telemedicine

- Department of Health and Human Services has expanded telehealth access
  - Medicare beneficiaries can receive a wider array of services
  - Utilize any non-public facing remote communication device
  - Reduced or waived beneficiary cost-sharing
  - Not limited to a specific diagnosis like COVID-19
  - Medicaid- states have broad flexibility of what’s covered – Check with your state office
Next

As instructed by healthcare providers or agency policies:

- Continue and increase sanitation and hygiene preventative measures
- Place a mask on the person who is ill
- Quarantine person in their room and use only one bathroom if hospitalization is not indicated
- Utilize personal protective equipment as per agency guidelines
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A note about Direct Support Providers

- The Backbone of supports for people with IDD
- Often underappreciated
- Question as to if they are considered “essential” healthcare workers
  - They are definitely essential
  - In high demand
Steps

► Person should stay home and seek medical attention

► Others in house quarantined for 14 days
  ▶ VERY DIFFICULT SITUATION
    ▶ Other support staff could be quarantined at the home or may be allowed to leave and return
When can a diagnosed person return to work?

- **Symptoms**
  - After all symptoms have resolved and no fever without the use of fever-reducing medications AND
  - Have had improvement in respiratory symptoms AND
  - At least 7 days since the onset of symptoms

- **Positive test but no symptoms**
  - After 7 days from the test and symptom-free during that time
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Steps

► Seek appropriate healthcare of the person immediately
  ► Telemedicine or local healthcare provider
  ► At this time, only those with significant symptoms including severe shortness of breath are being admitted to a hospital.
    ► Don’t risk additional exposure if it can be avoided
  ► Quarantine of others in the home
    ► Support staff may or may not be allowed to come and go
Steps

► If person remains in the home
  ► Isolation to bedroom and one bathroom
  ► All meals etc. served in the room
  ► No visitors in their room
  ► If difficulty remaining in the room, consider having staff in PPE remaining in the room with them
After a person who has been diagnosed leaves the home

► Immediately sanitize all surfaces and items
► Consider increasing the frequency of routine sanitation
► Increase monitoring frequency of others in the home- every 3-4 hours
► Utilize gloves and PPE
► Handle all laundry with gloves and PPE
► Report any fever or symptoms immediately
Where to get information

► Trusted sources for the latest information
  ► Center for Disease Control
  ► National Institute of Health
  ► World Health Organization
  ► NOT the social media outlets

► Other organizations that you have trusted before
  ► ANCOR –ANCOR.org
  ► Administration for Community Living- ACL.gov
  ► American Academy of Developmental Medicine and Dentistry – AADMD.org/prepare
  ► Developmental Disabilities Nurses Association- DDNA.org
  ► National Association of Direct Support Professionals – NADSP.org
Besides Health Risk - Risk of Losing Supports

- Family members and Support Staff
  - Become ill, themselves
  - Have an ill family member
  - Have no childcare
  - Become overworked

- Agencies
  - Lose operating funds
  - May not be able to stay open
  - May not be well-staffed
  - May not be able to return after pandemic
Risk of Reduction in Supports

- Support coordination occurring remotely
- Suspension of requirement for community time
- Reduction in accessibility to healthcare providers
Great Work Being Done

- Providers are rapidly developing protocols, policies and procedures
- Legislation is allowing for increased funding and different types of arrangements to ease financial burdens
- ANCOR.org
General Preparedness

- Monitor for signs and symptoms – notify healthcare providers if present
- Ensure adequate supply of a person’s prescription medications
- Ensure adequate supply of “cold” medications
- Have usable thermometers and other equipment available (Pulse Oximeter)
- Utilize delivery services for groceries and other household items
- All staff wear masks. People being supported wear masks as much as allowed
General Preparedness

► Have a list of emergency contacts updated and available
► Identify an area where a person might be quarantined if needed
► Present a calm and controlled appearance and environment
► Create or update a Health Passport
General Preparedness

► Model good hygiene
► Educate people with appropriate levels of information
► Teach people you support about good hygiene measures
► Create Quarantine Kits
Quarantine Kit Suggestions

- N-95 masks
- Eye goggles/protective gear
- Gloves
- Gowns
- Lysol disinfectant spray
- Alcohol wipes
- Antibacterial soap
- Additional Sanitizer wipers as well for surfaces
- Air mattresses/bed sheets
- Snacks

Thanks to FREE in NY for sharing this list - familyres.org
Education

► Green Mountain Self-Advocates
  ► Booklet about COVID-19

Download in the “Handouts” tab in your control panel
General Preparedness

► Ensure, whenever possible, that people maintain their usual routines
► Ensure access to medical care – consider telemedicine
► Take care with what is watched on television when people may become overly anxious or agitated from what is seen on the news
► Stay informed of what's happening using trusted sources
► Utilize tools you already have to identify who is at most risk - Health Risk Screening Tool
Health Risk Screening Tool

► Web-based screening instrument developed to screen for health risks associated with IDD and other vulnerabilities

► 22 item scale that identifies which individuals are at most risk of illness and health destabilization.

► The tool then responds by producing action steps

► HRSTonline.com
Changing Federal and State Requirements

► Stay up to date on regulatory changes regarding services
► Federal and State requirements may be amended or waived
► Document any actions that are made to change or reduce services or supports thoroughly as well as the reason the decision to do so
Staying updated - HRS

► Clinical Advisory Team

► HRS, Inc. Special Bulletins
  ► IDD-related COVID-19 information
  ► Free infection control video at HRSTonline.com
  ► Upcoming Bulletin - Importance of communicating that people with IDD are People, first

► Future Webinars

► My Health Passport

► eLearn and resources

► “Clinical Pearls in IDD Healthcare”
General Prevention

► Wash you hands for 20 seconds and use hand sanitizers 60% alcohol
► Keep hands away for face, especially eyes, nose and mouth
► Avoid close contact with others who are ill or infected
► Stay home if you are ill
► Cover your cough or sneeze
► Regularly clean and disinfect objects like light switches, keyboards, cell-phones, eyeglasses, etc.
Why slow down transmission?

► NOT so much
  ► To stop the disease completely

► TO
  ► “Flatten the curve”
  ► Reduce the demand on the healthcare system
  ► Reduce the death rate
Encouragement

► “There is immense power when a group of people with similar interests gets together to work toward the same goals.” Idowu Koyenikan

► “Hardships often prepare ordinary people for an extraordinary destiny.” C.S. Lewis

► “When adversity strikes, that’s when you have to be the most calm, take a step back, stay strong, stay grounded and press on.” LL Cool J

► “Your hardest times often lead to the greatest moments in your life.” Anonymous

► We will get through this, and peace, calmness, cooperation, compassion, understanding and perseverance will light the way. – Yours Truly
Questions
Thank you for joining us!

► Share the recording with others
► Visit HRSTonline.com to sign up for our newsletter
► Good Health and Wellness to all of you!