



Care for Adults with Disabilities in the Time of Covid

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Mental & Behavioral Health Supports

People with IDD, and their families, DSPs, nurses and others who provide supports to them may be experiencing higher levels of stress, anxiety, depression, and behavioral health support needs (Vindegaard & Benros, in press). Routines and long-standing structures that have allowed people to successfully predict what to expect have been radically changed because of the pandemic. DSPs and other caregivers face risks to their own health and their families' health simply by going to work. Many may face the grief that comes with losing friends, loved ones, staff, and feelings of isolation. The global community, including people with IDD, is facing these and other new emotional and mental health challenges that have arisen during the COVID-19 pandemic.

Outline

- Are there increased risks in those with intellectual disabilities from Covid? Why?
- Anything specific for Down syndrome?
- What to look for
- How to help
- Best practices

Selected references

- American Academy of Developmental Medicine and Dentistry: Covid guidelines for individuals with IDD
- Virginia Department of Behavioral Health and Developmental Service data at Covid-19 website
- The Down Syndrome Medical Interest Group Covid guidelines and Vaccine guidelines
- Dr. Kishore Vellody, Dr. Nikki Bauman

Magee Womens Hospital – Center for Women with Disabilities

 **Magee-Womens Hospital of UPMC**





Center for Women with Disabilities

The Center for Women with Disabilities at Magee-Womens Hospital of UPMC has been delivering state-of-the-art preventive health care to women with disabilities since 2001.

One of the first such services in the country, the center was designed in consultation with women with disabilities to meet their needs for accessible, regular exams and screenings.

[Learn more about our facility »](#)

We offer a comprehensive, patient-centered model of care that encourages and facilitates equal access and accommodation of physical differences.

Services We Provide

Contact Us

Center for Women with Disabilities
[300 Halket St.](#)
[Suite 5600](#)
[Pittsburgh, PA 15213](#)
Phone: 412-641-4030

Hours of Operation:
Friday - 9 a.m. to 4:30 p.m.

[Complete a contact form »](#)

Referrals

When it is necessary to refer our patients to other physicians, we refer them to physicians who also have accessible equipment.

Common types of disabilities seen

- Spinal cord injury
- Spina bifida
- Multiple Sclerosis
- Cerebral Palsy
- Intellectual and developmental disabilities
- Down syndrome
- Visual impairment
- Hearing impairment

Why more health issues in adults with intellectual disabilities?

- Those with ID – received 4 times the number of prescriptions as those without ID
- Physical disorders can be a side effect of psychotropic drugs

Medical Issues in Aging for people with disabilities

- Decreased Mobility (increased risk of stroke, diabetes, obesity)
- Loss of ADLS from pain, loss of strength, flexibility, vision
- Decreased cognitive function
- Bowel and Bladder Dysfunction
- Respiratory Complications

Common Conditions that send people with intellectual disabilities to the ER

- Dehydration
- UTI
- Skin infections
- (ENT, Respiratory issues, Epilepsy)

Hosking 2017 *Preventable Emergency Hospital Admissions*

Among Adults with Disabilities in England. Annals of Family Medicine

Down Syndrome Center of WPA



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Down Syndrome Center of WPA

- Educational Resources for:
 - New parents
 - Community primary care providers
 - Obstetricians
- Lectures and clinic observation opportunities
 - Medical students
 - Residents
 - Neurodevelopmental fellows
 - Graduate students
 - Genetic Counseling
 - Physical therapy

CASE:

A new patient presents to your clinic with her caregiver. She is 55 years old with Down Syndrome and appears older than her stated age. She has been pretty healthy although the staff has noted some decline in her abilities to participate in the life of the group home where she resides. She has co-morbidities of OSA, hypothyroidism, GERD & osteoporosis. The staff wonders if this is unusual for her to have so many problems at her age.

Hermans, H. & Evenhuis, HM. (2014).

Multimorbidity in older adults with

intellectual disabilities. *Research in*

Developmental Disabilities. 35. pp. 776-783.

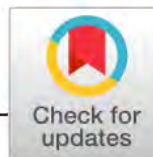
Aim: People with ID seem to have an increased risk of multimorbidity (MM). So this study was designed to establish the prevalence & associated factors of chronic MM in a broad client population, aged 50 yrs or greater of Dutch ID service providers.

Impact and Take Home Message

- Impact: It is not uncommon for anyone with a diagnosis of ID (but even more common in adults with DS) to have at least 2 or more chronic conditions. In DS it will be common to have 4 or more chronic conditions)
- Take Home Message: In adults with DS it can be expected that they will, more than likely, need to be simultaneously treated for 4 or more chronic conditions.

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CLINICAL REPORT

AMERICAN JOURNAL OF **PART**
medical genetics **A** WILEY

Clinical characteristics of individuals with Down syndrome deceased with CoVID-19 in Italy—A case series

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Manuela Tamburo de Bella⁶ | Marco Floridia⁷ | Graziano Onder³ | The Italian National
Institute of Health CoVID-19 Mortality Group

Italian Study of 16 people with Down Syndrome who died of Covid 19

- Average age 52
- 30% with bacterial superinfection
- 37% with Dementia
- 100% died of Acute Respiratory distress syndrome
- 78 in general population
- 13% with superinfection
- 16% with Dementia
- 97% with ARDS

Are people with
Disabilities at
higher risk for
developing
COVID-19?

- It does not appear that intellectual disabilities alone increase the risks of getting COVID-19

Are people with
Intellectual
Disabilities at
higher risk for
COVID-19
complications?

- For those with disabilities over 3 times the risk of death if COVID positive
- With Down syndrome 3 times the risk of hospitalization
3-10 x the risk of death
But.....

Ortega. 2020 *Lessons from Individuals with Down syndrome during Covid 19*. Lancet

Are people with
Disabilities at
higher risk for
COVID-19
complications?

Similarly to the general population, the highest risks appear to be:

- Older than 65 years of age
- Compromised immune systems (like due to chemotherapy or dialysis)
- Chronic pre-existing conditions (like heart disease, kidney disease, diabetes, chronic lung disease)
- People in group homes or long-term care facilities


Why higher risk?

- In group homes, people with IDD in close proximity to one another and to support staff
- Shared living environments may facilitate the introduction and spread of COVID.
- Higher rates of chronic health issues and poorer health status
- For many conditions: higher rates of death from flu and pneumonia


Turk 2020, Landes, 2020

Data for Virginia

- VDH department of health posts weekly data on covid outbreaks by selected exposure settings:



COVID-19 Outbreaks by Selected Exposure Settings



Locality: (All) Search Facility Name: Facility Type: Group Home Public Health Investigation Status: (All) Dashboard Updated: 1/15/2021, Data updated weekly on Fridays

Locality	Facility Name	Facility Type	Public Health Investigation Status	Date VDH Notified	Cases	Deaths
Greensville	Jackson-Feild Behavioral Health Services	Group Home	Outbreak Pending Closure	12/23/2020	7	0
Henrico	ClearVision	Group Home	Outbreak Pending Closure	12/10/2020	14	*
Henry	Community Alternatives Inc	Group Home	Outbreak Pending Closure	12/30/2020	11	0
Portsmouth	Lucas Lodge Residential	Group Home	Outbreak Pending Closure	11/5/2020	17	0
Richmond City	United Methodist Family Services	Group Home	Outbreak Pending Closure	12/21/2020	10	0
Salem	Key Living Options, Inc	Group Home	Outbreak Pending Closure	10/23/2020	10	0
Waynesboro	Community Living Services	Group Home	Outbreak Pending Closure	11/19/2020	31	0

AADMD Support guidelines

Table 1. COVID-19 Group Home Risk Stratification

Risk Level	Description
Severe	Confirmed COVID-19 case in the home.
High	Person in the home has had a direct exposure to a confirmed COVID-19 case.
Moderate	Home has had indirect contact with a confirmed COVID-19 case.
Low	No known exposure to COVID-19 in the home and among people living and working there.

AADMD Support guidelines

Table 2. COVID-19 Transmission Risk Stratification of Individuals Within a Home

Risk Level	Description
High	Individual frequently puts hands or objects in his/her mouth, or has language impairments preventing them from participating in necessary isolation. Individual's behavior could potentially expose objects or others to saliva or infectious material. Individual has significant difficulty maintaining distance from others. Individual is unable to wear a mask.
Moderate	Individual has behaviors that may make isolation more challenging such as impulsivity or difficulty maintaining physical distancing.
Low	Individual is able to communicate and participate in isolation and appropriate hand hygiene activities, and is able and willing to wear a mask.

How can we help people with disabilities
stay healthy and prevent infection?

- **Routine is key!**
 - **Social distancing**
 - **Wearing masks**
 - **Washing hands**

How much do masks help?

- 70% reduced risk of becoming infected compared with those who didn't wear masks during high risk exposures.
- wearing a mask sometimes during contact did not lower infection risk
- Maintaining >1 m distance from a person with COVID-19, having close contact for <15 minutes, and frequent handwashing were independently associated with lower risk for infection

Case-Control Study of Use of Personal Protective Measures and Risk for SARS-CoV 2 Infection, Thailand Nov 2020

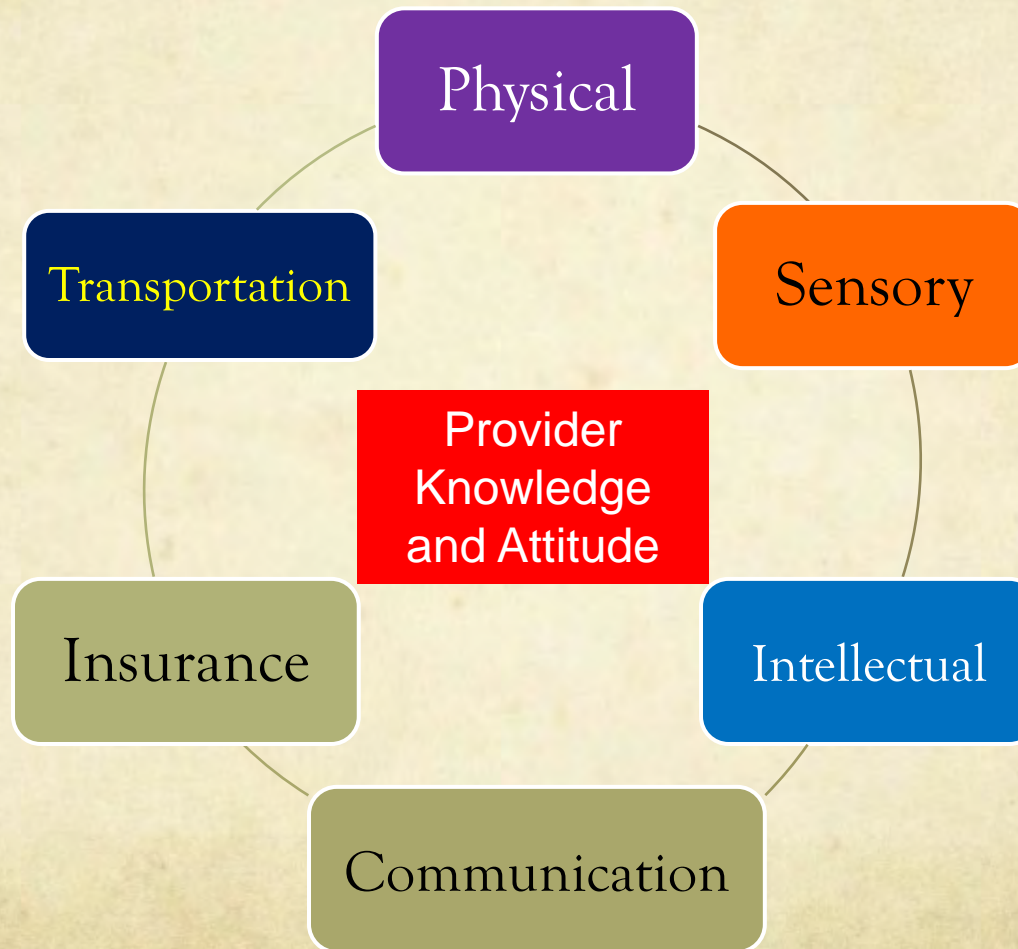
Pitfalls of isolation

- People with Down syndrome can be very sensitive to sudden changes to their routine and environment, which may cause stress and anxiety. Here are some common behaviors families/caregivers may see that could indicate a child or adult with Down syndrome is experiencing stress during the pandemic:
 - Behavioral changes or regression/loss of certain previous skills (e.g., incontinence when previously toilet trained or no longer wanting to or being able to complete activities of daily living that they previously were able to do).
 - Increase in self-talk.
 - Increased isolation or desire to be alone.
 - Rapid shifts in mood or tearfulness.
 - Disruptive behaviors or angry reactions that were not present prior to COVID.
 - Specific fears, anxieties, or phobias that were not present prior to COVID

Here are a few things families and/or caregivers can do to support a person with Down syndrome during the challenges presented by COVID:

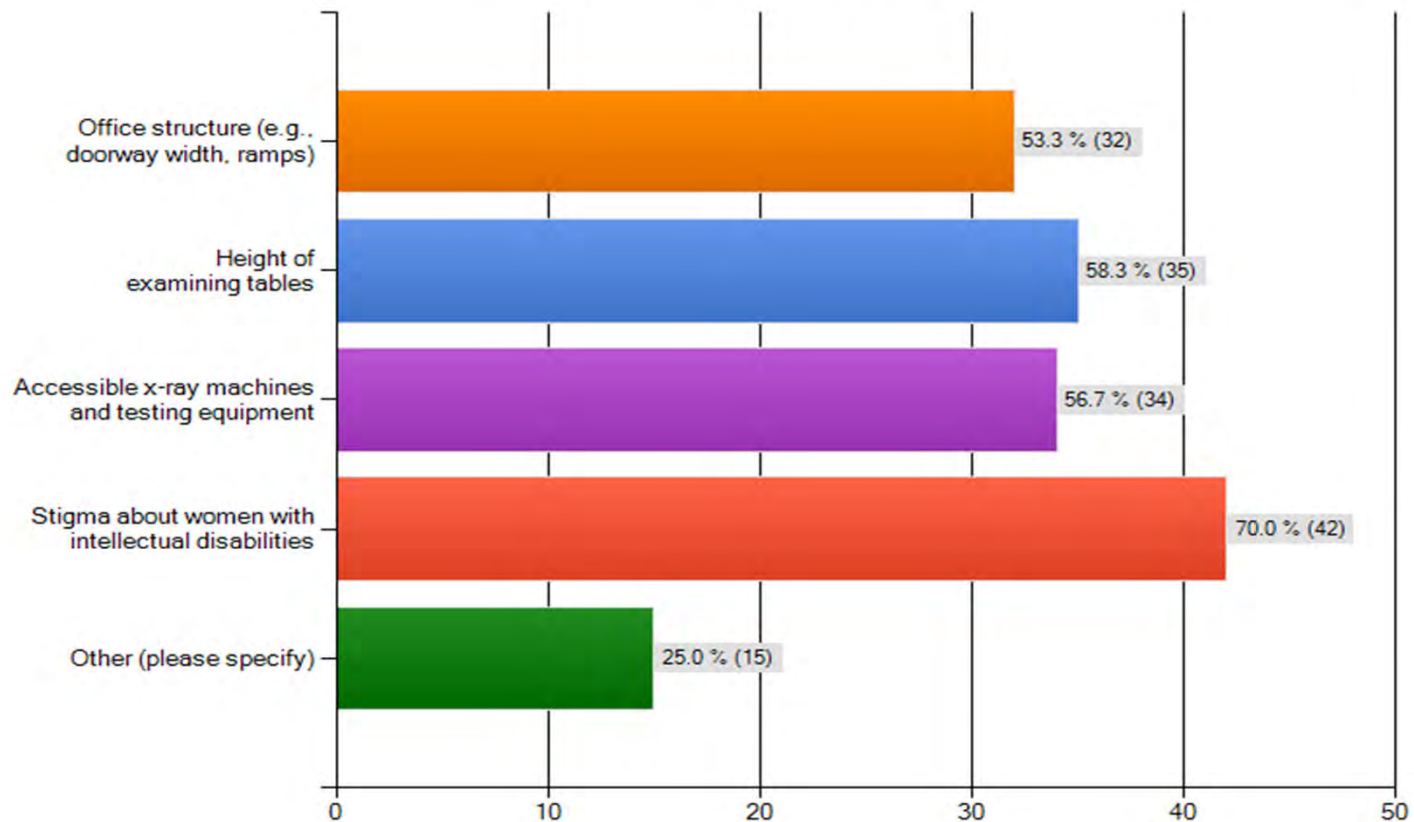
- Maintain routines/structure as much as possible with visual schedules and checklists.
- Find approved ways to help the person with Down syndrome stay connected. Video chat, texting, phone calls, letters, etc.
- Make a list of activities that *are* allowed, both indoors and outdoors, such as bike rides, or virtual dance parties where it is possible to stay physically distanced. Posting the list of activities around your home can also be a helpful reminder.
- Put together a memory photo book about the people or activities that are missed.
- Use a social story explaining the situation in simple, first-person terms.
- Validate the person's feelings, no matter what they are feeling.
- People with Down syndrome may be more easily influenced by the emotions of others, so be mindful of how your own emotions may be impacting the person with Down syndrome.
- Talk to a psychologist, therapist, or other professional familiar with your child or adult about how to help the individual with Down syndrome process the "new norm".

Barriers Limiting Access To Health Care



Access to Health Care for Women and Girls with Disabilities

Which of the following hinders access to quality community health care for women and girls with disabilities? (Check all that apply)



Communication is Key

- An 18 year old woman (accompanied by her mother) presents because of unbearable pain in her left hip. Her mother makes a plea for intensive pain treatment, as her daughter screams and hits when being washed and dressed in the morning. The daughter has a spastic tetraplegia and epilepsy. She has a grand mal seizure about once a month. She does not speak but understands gestures and communicates by facial expressions and screaming.

- At age 14 she had surgery on her left hip. After some remission, two years later, the pain increased and she seemed to have osteoarthritis. Surgical revision did not result in improvement of her complaints. Her pain increased. By that time, she had moved from her parents' house into a community living facility with five other people with intellectual disabilities. The house had been recently renovated, adapted to the needs of the residents and it was staffed by 10 part time workers, all trained in support for people with intellectual disabilities.

- One member of staff, experienced in working with people with autistic spectrum disorders wondered if she might have an autistic spectrum disorder in addition to her physical problems. Consultation with a psychologist confirmed the presence of an autistic spectrum disorder. Videotapes of individual staff members performing their morning routines with her showed great differences in behavior—for example, in how they greeted her in the morning, moved her in the lifting device, or helped her to shower and to use a wheelchair. Subsequent training in total communication, including a consistent application of this approach, diminished the screaming and hitting greatly. In the following months, the dosage of analgesics was substantially reduced.

What are special considerations for individuals living in group homes, nursing homes, or with Dementia?

- 1. Know the extent of COVID-19 in your community and the group home's community
- 2. Check how prepared the agency is who runs the group home
- 3. In those with Dementia, or are non-verbal: look for increased confusion or significant change in behavior

What are signs of
COVID-19 illness and
what do we do if they
are present in a loved
one with a disability?



Mild symptoms

- Cough, congestion, runny nose, fever *without* difficulty breathing or keeping hydrated
- ✓ Stay Home and continue recovery
- ✓ No need to seek medical care or testing
- ✓ Call your doctor's office if questions



Severe symptoms

- Significant trouble breathing, unable to keep hydrated
- ✓ Seek immediate medical care
- ✓ Notify your doctor's office or hospital Emergency Department prior to your arrival so they can prepare

What to do if someone has covid?

1. Pulse ox
2. Monitor for cough, respiratory symptoms
3. Monitor for oral intake
4. Symptomatic care (Ibuprofen, Tylenol)
5. Monitor for secondary conditions
Dehydration, UTI, skin infections, aspiration

What should be done if
someone in the
household tests positive
or is presumed to be
positive?

- Notify your doctors that you have tested positive and follow local regulations on whether others in the household should be tested
- Create a plan for alternative care in case the caregiver(s) of someone with a disability needs to be in home quarantine/isolation or need to be admitted to a hospital
 - Family member
 - Personal care worker
 - Respite worker
 - Discuss with local agency on aging or local/state disabilities agency

Strategy for Discontinuing COVID Isolation

Infection Prevention works with the nursing and physician teams to deem patients “COVID Recovered”

For Symptomatic Patients:

Symptom-based strategy

- **Mild to moderate severity AND not immunocompromised**
 - At least 24 hours since recovery defined as resolution of fever without the use of fever-reducing medications **and** improvement in symptoms; **and**,
 - At least 10 days have passed since symptoms first appeared
- **Severe to critical severity OR immunocompromised**
 - At least 24 hours since recovery defined as resolution of fever without the use of fever-reducing medications **and** improvement in symptoms; **and**,
 - 20 days have passed since symptoms first appeared

For Asymptomatic patients:

Time-based strategy

- **All patients**
 - At least 10 days have passed since the date of their first positive COVID-19 diagnostic test

COVID-Recovered

After a patient is deemed COVID recovered, treat them like any other patient:

- **No isolation precautions** specifically for COVID-19 are required
 - Remember to continue transmission-based precautions for other infectious organisms like VRE
- **Re-testing for SARs-CoV-2 is not clinically indicated** within 90 days of past infection
- Patients who are “COVID Recovered” in the banner bar may be present on other **non-COVID units**
- The **banner bar and clinical notes** are updated to reflect this and can be referenced



COVID-19 Recovered,

Do we need better access for people with disabilities?

- Access to Subspecialty Care for Patients with Mobility Impairment: A Survey
- *Annals of Internal Medicine* 19th March 2013

- Background: Three million Americans require a wheelchair. The ADA states that by federal law, they must have equal access to health care. Despite this, people in wheelchairs are at times denied care and receive less preventative services than those with normal needs. The denials of care with justifications have not been characterized.
- Methods: *Survey using a deceptive technique with no explanations or informed consent at the onset. 256 subspecialty practices were called to schedule a fictitious patient with special needs.*

Results

- 575 practices identified. Duplicated practices (138) were excluded for the second physician, 34 said the patient's problem was out of their scope of practice.
- 56 (22%) reported they could not accommodate a patient in a wheelchair.
 - Reasons lack of staff, patient too heavy, concern about liability
- 42 (26%) of 160 practices that require transfer for adequate care could not accommodate the patient.
 - Of those who could accommodate, 88 (55%) were going to lift the patient without equipment onto the examining table.
 - (5%) would make do in the wheelchair (14% could accommodate without any problem)
- Despite not requiring transfer, 25% of Ophthalmology clinics were inaccessible

When can we return to “normal”?

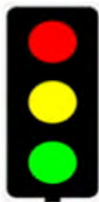
- Ability to physically distance
- Availability of personal protective equipment
- Safety / cleaning protocols
- Group size, etc.

**Environment /
Community /
Activity
Specific
Factors**

**Public Health
Considerations**

- Infection Rate / Incidence in Community
- Monitoring Ability
- Health System Capacity
- Serologic / Antibody Testing
- Vaccine / Treatment

**Individual /
Person Specific
Factors**



- Individualized decisions based on evolving knowledge and experience

Tiered plan

- “Vulnerable individuals” continue strict physical distancing / shelter in place until last phase

- Inevitably will involve new ways of socializing, educating, working

“New Normal”



Boston Children's Hospital

Nicole Baumer, MD, MEd
Neurodevelopmental Disabilities
5/2020

Thanks!!!