

The Impact of COVID-19 Among the DD Population in Higher Education March 23, 2021

Supporting and empowering people with developmental disabilities to live, learn, work and play in the community

Who We Are

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Mission: support and empower people with developmental disabilities to live, learn, work and play in the community





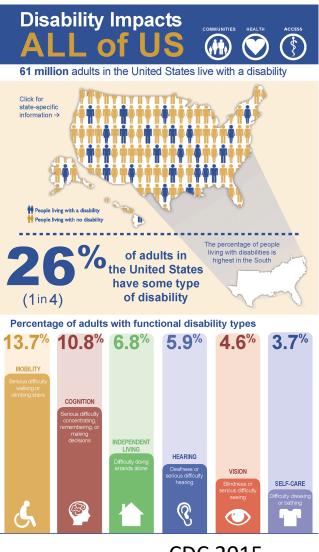
Session Objectives

- Recognize the concerns and challenges faced by the DD community during the COVID-19 pandemic including the physical, psychological, and social impacts
- Identify contributing factors to the unique challenges experienced among the DD population during the COVID-19 pandemic
- Recognize the benefits of the COVID-19 pandemic for some in the DD community
- Identify practical strategies and resources that can be utilized to better support individuals with DD through the COVID-19 pandemic



Overview

- 61 million adults in the United States live with a disability
- 26% (1 in 4) of adults in the United States have some type of disability





(Courtney-Long, Carroll, Zhang, et al., 2015)

CDC 2015

Who We Serve

- People with Developmental Disabilities (DD)
- 1 in 6, or about 17%, of children aged 3 through 17 years have one or more developmental disabilities
- A severe, chronic disability of a person that:
 - o Is attributable to a mental or physical impairment
 - Is manifested before age 22
 - Is likely to continue indefinitely
 - Person exhibits substantial functional limitations
 - Person requires a combination of lifelong treatment/services that are individually planned and coordinated

(Zablotsky et al., 2019)



DD and COVID-19

The DD population considered **one of most vulnerable groups** during the pandemic

Why?



DD and COVID-19

- Comorbidities of underlying medical conditions/ complexities of conditions
- Reliance on caregivers to help them live their lives
- Increased exposure to others
- Lack of access to PPE (especially in beginning of pandemic)

(CDC, 2020 & 2021)



DD and COVID-19

- Lack of understanding/appreciation of information regarding social distancing and other safety measures
- Limitations in practicing recommended safety precautions (e.g., hand washing and social distancing)

 Inability to tolerate/follow-through (e.g., sensory issues w/ wearing a mask, inability to remain 6 ft.)
- Unable to communicate symptoms of illness to get care in timely manner



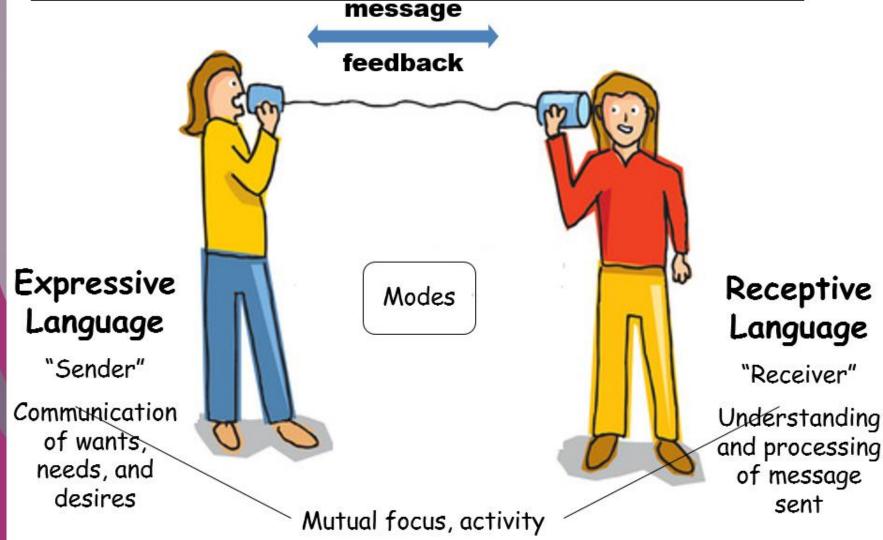
(CDC, 2020)

Communication

- People with DD may be likely to have some degree of receptive language disorder (may have difficulty understanding)
- Some may also have expressive language disorder (may have difficulty being understood)



Communication 101: The Communication Model



DD & Mental Illness

Adults with disabilities report mental distress almost 5 times as often as adults without disabilities (Cree, Okoro, Zack, & Carbone, 2020)

Mental health issues are more prevalent among the DD community than in the general population. 30%-40% of all persons with ID/IDD also have a co-occurring mental health condition (Murin, 2016)



Impact of COVID on DD Population

 Exacerbation of existing mental health symptoms

 Increase in depression, anxiety, anger, frustration, irritability, restlessness, and fear

• Why?



Psychosocial Stressors

- Increase in various factors that contribute to a greater amount of stress in a person's life
 - -Many already existing pre-pandemic



Psychosocial Stress Factors





Limited Community Resources

• Mental Health Supports/Services

- Existing issues in serving DD population pre COVID-19 exacerbated
- \circ Move to telehealth



Limited Community Resources

• Other Community Supports

- Usual community-based supports (e.g., Board of DD staff, teachers, professors, specialists, etc.) not available due to social distancing requirements
 - Not as many home visits or face-to-face visits
 - Increases vulnerabilities of abuse/mistreatment
- $\,\circ\,$ Disability/accessibility accommodations were hindered
 - Unclear for some students of where to find/obtain support (Meleo-Erwin et.al, 2021)



Communication

- Having difficulty in understanding language or expression of language can significantly impact:
 - \circ Ability to follow rules
 - Ability to understand the consequences of negative behavior
 - Ability to give "true" answers to questions
 - \circ Ability to problem-solve
 - \odot Ability to participate in conversation



Factors that Affect Understanding

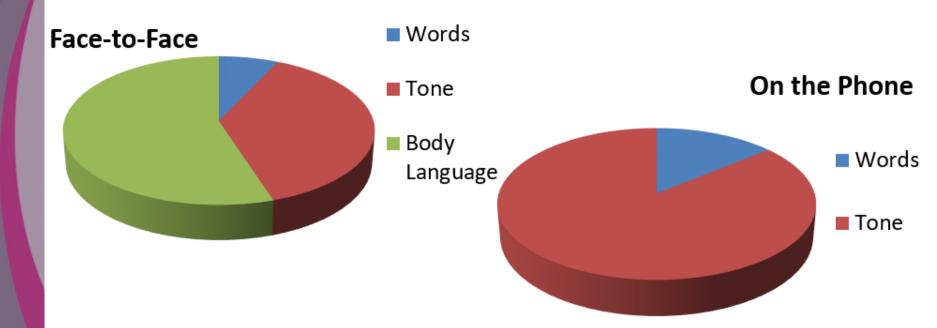
- The Message Being Sent:
 - Speed of communication
 - Length
 - Complexity
 - Word order
 - Word meaning/vocabulary
 - Vocalics (tone of voice, loudness, rate, pitch, stress)



Just because we HEAR the message does not mean we UNDERSTAND



Communication



It's not just the WORDS we use. We communicate more with HOW we say them.

Source: Dr. Albert Mehrabian, author of Silent Messages



Isolation



- Stay at home orders
- Unable to see family and friends
- Restricted access to school, work, vocational habilitation, and day supports.
- Leisure activities/groups cancelled/unable to meet in person
 - Rely on these for social involvement/community inclusion

• Lack of

understanding/appreciation for necessity of social distancing

 Perceived as a punishment or being left out



Relationship Strain

- "Lockdowns have forced those who cohabit to remain in close proximity with each other and thereby have increased the opportunity for domestic provocation and intimate partner altercations." (Boman & Gallupe, 2020)
- "Maumee Police Department demonstrate that there has in fact been an increase in substantiated intimate partner violence incidents in 2020 (73 incident by 5/26/20) compared to 55 at the same point in 2019." (Boman & Gallupe, 2020)
- "Domestic argument calls have more than doubled (2.5x higher) during the COVID-19 lockdowns compared to the same time period in the pre-COVID year of 2019." (Boman & Gallupe, 2020)
- IDD population at a greater risk of becoming a victim of crime



Relationships Continued

- Direct Service Providers have experienced a staffing crisis
 - \odot Shortage of staff
 - \odot Inconsistency of staff
 - Staff unfamiliar with individual and their communication



Major Disruptions in Routines

- Autism Spectrum Disorder
 - Rely on rigid routines to reduce anxiety
 - Ongoing ambiguity of future, perpetuates feelings of anxiety
- Continual changes in practices, policies, procedures, etc.
- Extended time to process, accept, and acclimate to changes
- Issues with new environment
 - More distractions, limited privacy, lack of structure and routine
- College or university students with cognitive and learning disabilities struggled to adapt to the new format of course delivery and the new expectations (Meleo-Erwin et.al, 2021)

Technology Issues

- Inability to afford or access technology to connect to family, friends, medical & mental health services
 Ontributes to increased feelings of isolation and loneliness
- Lack of hardware, devices, software, or subscription services needed for various learning/activities
- Individuals are confined to their residence
- Lack of technology (tablets and smart phones to stay connected to friends and family, healthcare providers, and to participate in online learning)



Financial Changes

- Loss of income (layoff, unable to get to work, vocational programs closed)
- For some, families must leave jobs to care for loved ones/assist with daily support with education
- Increase in unexpected expenses



Higher Education

- Census survey administered from May 18 to July 2020 to undergraduate students at 9 large, public research universities
- 28,311 undergraduate students
- Students with physical, learning, neurodevelopmental, or cognitive disabilities reported experiencing significantly more challenges and hardships during the COVID-19 pandemic than students without disabilities
 - Financial hardships
 - Housing insecurity (less like to live in safe environments)

• Existing issues exacerbated during pandemic (Soria, Horgos, Chirikov, & Jones-White, 2020)



Exacerbating Factors: Executive Function Challenges

- Executive function refers to a family of top-down mental processes needed when you have to concentrate and pay attention, when going on automatic or relying on instinct or intuition with be ill-advised, insufficient, or impossible (Burgess & Simmons 2005, Espy 2005, Miller & Cohen 2001) Core executive functions are:
 - $\,\circ\,$ Inhibition and interference control
 - Working Memory
 - Cognitive flexibility



Exacerbating Factors: Executive Function

- Lack of structure and/or routine has made distance learning challenging for people with DD
 - Routines decrease anxiety, increase control, maintain emotional well-being, and reduce challenging behaviors
 - Without the impetus of leaving home for school each day, some students have decreased motivation to complete ADLs (hygiene, preparing food), creating health and safety issues



Exacerbating Factors: Executive Function

- Not having immediate feedback from/access to professor
- Doing so asynchronously is challenging for students who have executive function differences



Exacerbating Factors: Sensory Issues

 Decreased sensory breaks with online learning can make focusing/attending to task challenging and fatiguing



Successes

- There are some positive outcomes
 - Remote supports and learning: preferred method for some
 - Reduces stress of social situations and expectations
 - Fewer distractions in the learning environment
 - Limited transitions throughout the week decreases anxiety



First-Hand Perspective from Grace Blatt



Introduction



Family Education Goals Role at Cuyahoga DD

Grace





The Decision Is Yours

- One has to realize that they need to meet their psychological health needs (Maslow, 1954)
- Recognize that they are stressed and have anxiety that things are not the way they used to be
- Coming to the conclusion that they need help to cope with these emotions of stress and anxiety



Positive Aspects of the Pandemic

- Not as easy to be left out of a group or group event
- More time to decompress between events
- Not worrying about getting lost in new locations
- Allows for more family time
- More control of time management for schoolwork
- Improves my test taking skills
- Less opportunities to engage in unstructured small talk and free time which can be anxiety provoking
- More predictable and consistent daily schedule and routine



Negative Aspects of the Pandemic

- Cabin fever
- Lack of social face-to-face interaction
- Loneliness
- A more sedentary lifestyle
- No change or pleasant surprises (everyday is mostly the same)
- Eating more
- More depressive thoughts and feelings (Palgi et al,.
 2020)



Enhancement of Life

- Be on more committees and help be part of more organizations due to no need of transportation
- Don't have to engage in small talk with other students before or after class
- Time to relax by crocheting, and making jewelry
- Not worrying as much about stimming or keeping my hands busy in public places
- Learn at a faster pace which is comfortable to me



Enhancement of Life (continued)

- Have been able to express my feelings and try new jokes on my family without being ridiculed for being weird or inappropriate
- More time to make decisions
- Slower paced deadline and expectations
- More planned events less spontaneous events
- Work on coping and social skills when I feel anxious right in the comfort of my own home without anyone judging me

Things That Helped

- Small landscaping job that helped me get exercise
- Made friends with my neighbors by getting their mail for them on a daily and their trash cans weekly
- Decided to take as many online courses as possible rather than in person
- Turning your webcam video stream off if you need more privacy that day
 - I know I sometime have horrible eye contact. I also sometimes rock in my chair when I am concentrating
 - This could be a neat accommodation schools and universities should have for students with disabilities



Practical Strategies to Support

Persons with a disability

- \odot Become familiar with your rights
 - \odot Check out Disability Rights Ohio for more info
- \odot Advocate for yourself
- Request support from your school's disability resource center
- \odot Connect with your local board of DD for support
- \odot Seek help for mental health
- \odot Join local support groups



Strategies Continued...

Professionals

- Make local resources readily available and easily accessible for:
 - Food, housing, financial assistance, mental health options (counseling, support group), Medical care
- Provide information in multiple modalities to meet all needs
 - Check with organizations that support people with DD for communication tools, assistive technology, and other resources related to COVID-19
- Encourage students to discuss any necessary accommodations they need for online learning with their school's disability resource center
- Check-in regularly
- Remain approachable
- Be flexible and person centered in your approach/teaching style
 Offer options
- Honor and respect communication differences



How to Communicate with People with DD

- Use SIMPLE language/vocabulary whenever possible
- Be concise Speak in black and white
- Avoid lengthy sentences
- Break down information into chunks
- When trying to establish timelines, use examples from daily routines such as lunchtime, bedtime, etc.
- Use concrete language, avoiding idioms and other figurative language
- Give choices
- Avoid yes/no whenever possible



How to Communicate with People with DD

- Progress slowly and leave pauses for the person to process your words
- Repeat messages
- Comprehension should be checked periodically, preferably before transitioning from one topic to the next
- Everyone is different



How to Check for Comprehension

DO

- "Tell me what I said?"
- "Why is it important to...?"
- "What can you change?"
- "Tell me what you did wrong."
- "Tell me what you will do differently."

DON'T

- Avoid asking, "Do you understand?"
- Avoid asking, "OK?"
- Avoid asking, "Did you hear what I just said?"
- Avoid asking, "Do you have any questions?"
- Avoid asking, "Do you know what you did wrong?"



Open-ended questions

Strategies

- Provide breaks, if possible
- Change settings- take a walk
- Give time for person to process
- Avoid using jargon
- Do not make assumptions about what the individual is saying or meaning



Supports

- Assistive Technology is any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, used to maintain or improve the functional capabilities of individuals with DD
- Cuyahoga DD's AT Department
 - Assessments for equipment
 - Lends equipment and software for trials
 - Assists with acquiring/funding equipment
 - Provides training and in-services



Supports Continued...

- Cuyahoga DD AT Specialists and SLP/AAC Specialists implemented various stopgap measures to assist individuals during the shutdown, including:
 - Loaning iPads to individuals for the purpose of maintaining the ability to connect and interact with others while quarantined, and to provide applications for games, scheduling supports, and learning



Supports Continued...

- Utilizing Cuyahoga DD's Assistive Technology Lending Library to loan equipment
- Providing education/training



Resources

For information on Developmental Disabilities

- CDC https://www.cdc.gov/ncbddd/disabilityandhealth/index.html
- Cuyahoga County Board of Developmental Disabilities
- Ohio Department of Developmental Disabilities https://dodd.ohio.gov/wps/portal/gov/dodd/

For information on DD and Mental Health

- American Association on Intellectual and Developmental Disabilities <u>https://www.aaidd.org/education/annual-conference</u>
- National Association for the Dually Diagnoses http://thenadd.org/

For information on disabilities and higher education

- Association for Higher Education and Disability <u>https://www.ahead.org/home</u>
- National Center for College Students with Disabilities <u>http://www.nccsdonline.org/</u>

For information on disability rights

- The Arc <u>https://thearc.org/covid/</u>
- Communication Bill of Rights https://www.asha.org/uploadedFiles/NJC-Communication-Bill-Rights.pdfmonash.org
- Disability Rights Ohio <u>https://www.disabilityrightsohio.org/</u>

For information on Autism Spectrum Disorder

- Milestones <u>https://www.milestones.org/</u>
- Monarch <u>https://www.monarchcenterforautism.org/webinars</u>
- Ohio Center for Autism and Low Incidence (OCALI) <u>https://www.ocali.org/</u>
- Center for Developmental Disability Health Victoria- <u>www.cddh.monash.org</u>
- https://acemh.onlinelibrary.wiley.com/doi/full/10.1111/camh.12425



Resources Continued...

Resources for people and families looking at attending higher ed...

https://thinkcollege.net/

https://www.pacer.org/transition/learning-center/postsecondary/college-options.asp

https://www.ohiohighered.org/students/prepare-for-college/students-with-disabilities



Sources of Information

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Questions?





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THANK YOU

Great minds think differently!



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