

# Pandemic Perspectives: Person-Centered Care for Individuals with Disabilities Learning Collaborative

Session One: Thursday, July 20, 2023 at 1:00 PM EST

Session Two: Thursday, July 27, 2023 at 1:00 PM EST



**NATIONAL  
NURSE-LED CARE  
CONSORTIUM**  
a PHMC affiliate



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The National Nurse-Led Care Consortium (NNCC) is a non-profit membership organization that supports nurse-led care and nurses at the front lines of care.

NNCC, in partnership with the CDC, works to support efforts to build COVID-19 vaccine confidence among nurses and the communities they serve.

Learn more at [NurseLedCare.org](https://NurseLedCare.org)

# ABOUT THE SERIES

- Free 2-part learning collaborative series for nurses on community program planning, implementation and evaluation.
- 1.5 CEU will be offered for each session attended live. An evaluation will be sent out to attendees following each session, complete the brief questionnaire to receive CEU credit. Learn more [here](#).

*This project was funded in part by a cooperative agreement with the Centers for Disease Control and Prevention (grant number NU50CK000580). The Centers for Disease Control and Prevention is an agency within the Department of Health and Human Services (HHS). The contents of this resource center do not necessarily represent the policy of CDC or HHS, and should not be considered an endorsement by the Federal Government.*

# EXPECTATIONS FOR THE SERIES

- Please mute yourself during the presentation, unless speaking to the group.
- **Participate in the discussions!**
- This session will be recorded and posted to the NNCC website
- Snacks and lunch are okay!
- Those seeking 1.5 Continuing Education Credits-- please complete the evaluation after the session
- Feedback survey following session 2.

# Disclosure Statement

The information discussed at these Learning Collaborative meetings may be used for educational purposes to inform the work of our speaker and our vaccine confidence team. All information used will remain anonymous.

# Welcome



**Brenda Fitzgerald,  
RN, BSN, MHA,  
CM/DN**  
Director of Nursing at  
The Arc

# Pandemic Perspectives: Person Centered Care for Individuals with Disabilities: Part 2

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Right To Equality

The COVID Influence

Brenda Fitzgerald, RN, BSN, MHA, CM/DN



# OBJECTIVES

Describe

Describe the daily living environment of individuals with IDD and the staff/family involvement.

Discuss

Discuss the communication and interpretation of the emotional upheavels for verbal and nonverbal individuals during the pandemic.

Describe

Describe the changes post pandemic for individuals with IDD. What we see now.



# Intellectually & Developmentally Defined

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IDD includes many severe, chronic conditions that are due to mental or physical impairments.



Developmental disability is an umbrella term for a group of conditions due to impairment in physical, learning, language, or behavior areas.



Intellectual disorders are those with cognitive difficulties such as problem solving and memory.

# Disability Rights Timeline

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- 1815-1817 Formal deaf education began. Thomas H. Gallaudet founds the Connecticut Asylum for the Education and Instruction of Deaf and Dumb. 1<sup>st</sup> permanent school for deaf in America
- 1925 Social Act signed into law by President Franklin D. Roosevelt (who was disabled himself) – establishing a program of permanent assistance for adults with disabilities.
- 1950 The ARC (Association of Retarded Citizens – named changed later to The Arc) championed the cause for people with ID and parents of children with ID. The association worked to change public perception of intellectual disability. The Arc continues today to ensure an estimated 7.2 million Americans with intellectual and developmental disabilities have the services and supports they need to grow, develop and live in communities across the nation

# Disability Rights Timeline

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- 1990 the American Disability Act was founded prohibiting the discrimination of people with disabilities in all areas of public life including jobs, transportation, schools and in all public places and private places that are open to the general public.
  - 1990 Individuals with Disabilities Education Act (IDEA). The Education for All Handicapped Children Act is renamed the Individuals with Disabilities Education Act (IDEA). Reauthorized Act requires students with disabilities to be involved in developing their transition plans, and their interests and preferences are to be considered.
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- *\*This timeline uses language that is historically correct, but no longer considered acceptable.*
  - *\*(2019 Timeline was installed outdoors at Philadelphia City Hall Courtyard at the Parkway Central Library)*

# The Arc

## Mission Statement

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**To promote and protect the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetime.**

# Normalcy

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- Individuals with IDD lived at home with their families, lived independently with supports (full-time/part-time) or in residential facilities(group homes).
- Community living with supports.
- The Person-Centered planning approach was the answer to individuals engaging in a lifestyle of their choosing within a safety net.
- Socialization with family and friends is an important part of the plan to assist with managing behaviors.
- Familiar faces and routines are stabilizing forces in everyday routines.

# Poll Question

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- Reporting symptoms is challenging for a person with IDD who may have trouble describing the problems they are experiencing. How likely is it that barriers to communication significantly impacts overall wellness and creates delays in treatment.
- A. Likely
- B. Very likely
- C. Not at all

# Supports

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- Nurse Delegation & Medical Management
- Support system: RN, LPN, DSP, Case Coordinators & Natural Supports
- Day Programs
- Respite Services

# COVID-19

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- COVID was abrupt
- Challenged methods of operation
- Individuals were kept at home and socialization stopped, lack of familiar faces
- Virtual activities-no touch
  - Appendix K Modifications
- Routines disrupted
- Families not able to visit
- Staffing was problematic
- Hardship on families to find ways to support the individuals who were normally at work or day program
- Governmental support was slow and didn't match the finesse given to nursing homes and assisted living facilities.



# COVID-19

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- **Covid-19 had a devastating impact on individuals with intellectual disabilities. Having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality.**
  - Gleason, Ross, Fossi, Blonsky, Tobias, & Stephens, 2021, p.2)

# Case Study

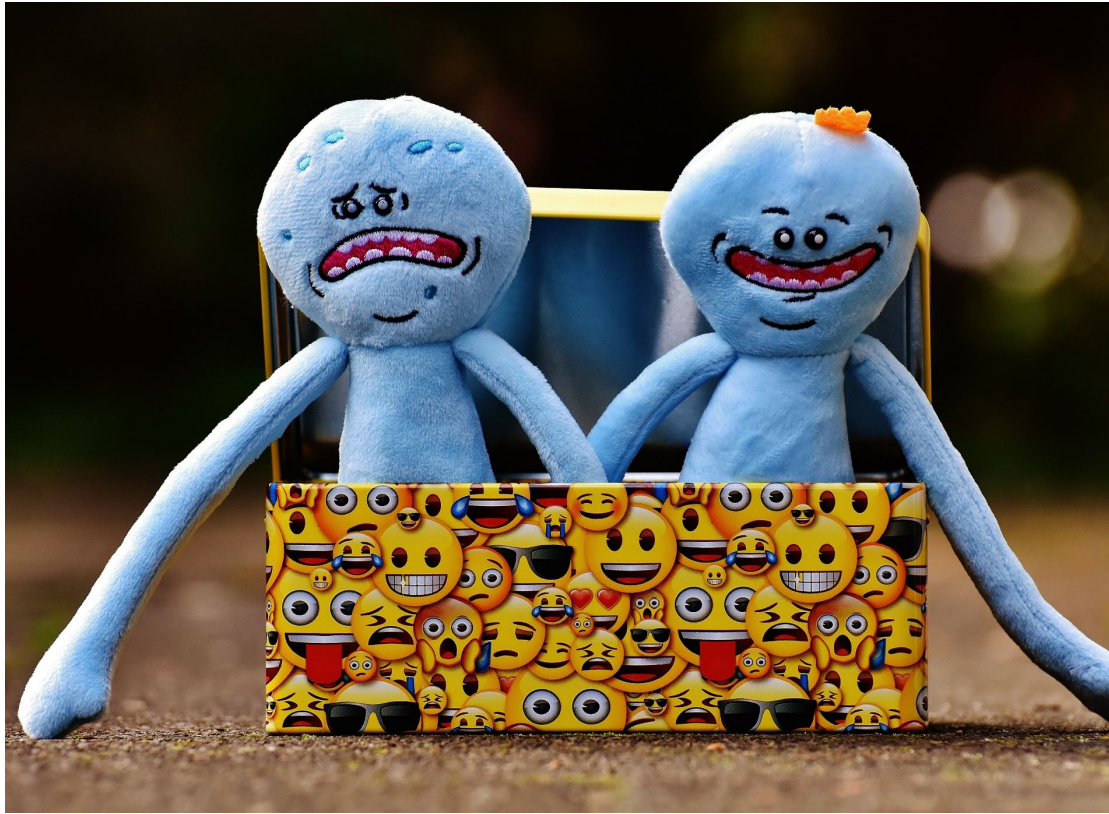
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- Sara, 22, was doing well until COVID-19 hit. She was working at a café where most employees, like her, have an intellectual disability. She'd gotten good at making lattes and had just created a video resume for a Starbucks job. She enjoyed living with her parents in a suburb of Philadelphia and participating in a local program designed to boost independence.
- But COVID-19 has created particular obstacles for Sara, who has difficulty communicating, processing information, and adapting to new situations. Some of her therapists have stopped coming to her house, and those who come wear masks that make her feel disconnected from them. She also dislikes how hot her mask feels and how often people remind her to fix it when it slips below her nose.
- Then matters got worse. Even though she was careful, Sara contracted COVID-19 and spiked a fever of 104 degrees. Once hospitalized, she struggled to explain how sick she felt. Her doctors spoke very quickly, and by the time she sorted out the questions, they had stopped waiting for her answers. She was confused about why she got moved from one room to another, and she desperately missed her parents, who could not visit her because of COVID-19 precautions.

# Case Study Question

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- What risk factors do you identify?



# Outcomes

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- Isolation
- Behaviors
- Depression
- Family anxieties
- Fear of death

# Poll Question

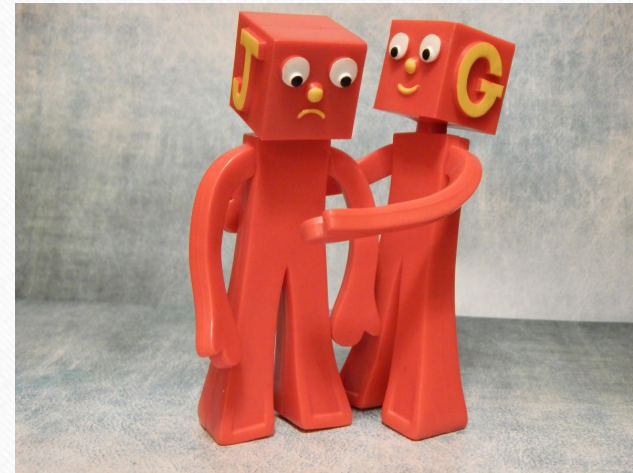
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- People with IDD are especially vulnerable to the physical, mental, and social affects related to the pandemic. Do you think the restrictions of the usual activities affected mental stress leading to challenging behaviors and an increase in the use of psychotropic medications?
- A. Yes
- B. No
- C. Unsure

# Lifestyle Modifications

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- COVID protocols
  - Hand hygiene
    - safety precautions
  - Social distancing
    - Quarantines/Isolation
  - Unable to wear mask-
    - Staff concerns
  - Visitation with families difficult
    - Breaking the rules



# Challenges

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- Barriers
  - Staffing
    - Fears
  - Virtual vs Person to Person services
    - 6 Hours virtual – attention span
  - Vaccination clinics
    - Access to vaccinations
    - Local Pharmacy participation
  - Medical Follow-up
    - Increased emergency room usage

# Are We There Yet?

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- Individuals w/ IDD were at a higher risk for COVID-19
- Mental health was most common impact for social isolation, depression, worsening anxiety
- Staffing remains a concern-vacancies are high
- Mask or no mask after the pandemic has been released
- Some families have yet to return loved ones back to day programs



# Life After Covid

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- Long COVID/Long Haulers
  - It's early to determine-communication barriers
  - Medical health services remain virtual or practices no longer in existence
  - Pneumonia and hospitalizations...Related?
  - Mental health services virtual

# Poll Question

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- With the nursing challenges in the current workforce, how likely are you to change to this environment? Would this be a place you would consider?
- A. Likely
- B. Unlikely
- C. Not at all



# Participation

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Advocacy

Get involved

Compassion not Pity

# References

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1. Gleason, J., Ross, W. Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States. NEJM Catalyst. (2021), p.1-12, DOI:10.1056/CAT. 21.0051

# Q&A



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The Children's Vaccine Education Project allowed me the educational resources to partner with ASL to teach students that are deaf or hard of hearing the importance of vaccines.

**NURSE FROM THE CHILDREN'S VACCINE EDUCATION PROJECT**

Visit <http://vaccines.fi.edu/resources>



# Reminders

- Recording and Slides available on NNCC's Resource Library
- Feedback Survey
- **Evaluation for 1.5 CEU Credit**

Find more free continuing education opportunities

**[NurseLedCare.org](https://www.nurseledcare.org)**