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

Gloria Jones Dinkins, DNP, APRN, FNP-BC, GS-C

Adjunct Assistant Professor at Howard University College of Nursing and Allied Health Sciences

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

Director of Nursing at The Arc

NATIONAL NURSE-LED CARE CONSORTIUM
a PHMC affiliate

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**

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

Adjunct Assistant Professor at Howard University College of Nursing and Allied Health Sciences

Pandemic Perspectives: Person-Centered Care for Individuals with Disabilities (Part 1)

Gloria Jones Dinkins DNP, APRN, FNP-BC, GS-C

Objectives

Provide	• Provide an overview of the population with Intellectual Developmental Disabilities (IDD).
Discuss	• Discuss the person-centered care approach to persons with disabilities.
Describe	• Describe the common barriers to disability inclusion and participation.
Highlight	• Highlight the barriers to people with disabilities in the COVID-19 response.

What is the Definition of Disability under American Disabilities Act (ADA)?

- The American Disability Act defines disability as a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.

(ADA.gov)

Intellectual Disability (ID)

- Characterized by significant limitations in both intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. Originates in the developmental period which is defined operationally as before the age of 22.

(AAIDD,2022)

Developmental Disability

- Severe, chronic disability of an individual who has a mental or physical impairment by age 22. Likely to continue indefinitely and results in substantial functional limitations in three or more areas of major life activity (self care, mobility, learning, economic self-sufficiency, capacity for independent living).

(Schalock, Lukasson, Tassè, 2021)

Intellectual Disability Community

- ID covers a wide range of impairment. Many people with ID read and write, make decisions, use telephones and computers, are employed, maintain relationships, live in their own homes, and recreate and worship in their communities. Others may need significant supports to participate fully in their communities.

- https://nationaldisabilitynavigator.org/wp-content/uploads/Materials/Population-Specific-Fact-Sheet-ID.pdf

Poll Question

As a registered nurse, what percentage of patients that you provide care (across health care settings) for have an intellectual developmental disability?

- a) <25%
- b) 50%
- c) 75%
- d) >75%

Health care Needs of the ID Community

- Like all people, the health needs of a person with ID can vary greatly based upon his/her physical and mental health and people with ID do not necessarily have ongoing health problems. However, priority health care needs include primary care, habilitative and rehabilitative services and devices, durable medical equipment, mental health and behavioral services, chronic disease management, cardio-vascular care, geriatric care, and dental and vision care. Therefore, critical providers include primary care physicians, physical and occupational therapists, orthopedists, psychologists.
- https://nationaldisabilitynavigator.org/wp-content/uploads/Materials/Population-Specific-Fact-Sheet-ID.pdf

What is a Person-Centered Approach?

- Person-centered approaches originated in the disability sector.
- In a person-centered approach, we see someone as a person first, not someone who is defined by their disability. By understanding who this person is, we see the person in terms of the person's capacities; we appreciate the person for what the person can do, for the gifts the person has, and how the person can contribute to others (Jones, L.K., 2020).

Person-Centered Approach to Care

Person-Centered Approach vs. Service/System Centered Approach

Person-centered

- Talking with the person
- Planning with the person
- Focused on strengths, abilities, skills
- Family & community members are seen as true partners

Service/System

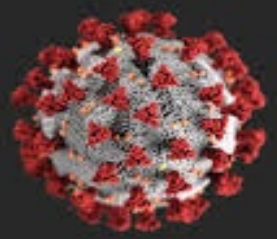
- Talking about the person
- Planning for the person
- Focused on labels/ diagnosis, deficit(s)
- Family members & community are seen as peripheral

Poll Question

How often do you practice person-centered care?

a) All the time
b) Most of the time
c) Some of the time
d) Not at all

Global Pandemic Declared



COVID-19 RESPONSE

Disparities in the COVID-19 Response Experienced by People with Disabilities

NIHCM FOUNDATION

Lack of data

Who counts depends on who is counted

- Estimates of COVID-19 cases and deaths primarily come from nursing homes, reflecting just a fraction of the population with disabilities
- Data collection is a fundamental pillar of public health and lack of information perpetuates social injustice
- Inaccurate data on COVID-19 and vaccine rates can misguide public health approaches

Inaccessible testing and vaccination

- For some people who cannot drive due to a disability, drive-through testing created accessibility challenges
- Vaccine registration websites violated disability rights laws, creating inequity for people with disabilities
- States and territories varied in vaccine prioritization for the disability community
- Vaccination sites lacked accessibility and accommodations

Obstacles to accessing information on pandemic

- Lack of captions or alternative text
- Difficult to find information relevant to variety of conditions
- Overwhelming and confusing information

Return to pre-pandemic life

The pandemic altered accessibility

Such as through work from home accommodations and grocery delivery

There is concern that returning to pre-pandemic norms will exclude people with disabilities

Poll Question

- In your area of practice, were individuals with disabilities included in the COVID-19 response?

a) Yes
b) No
c) Not sure

Poll Question

- If you answered “yes” to individuals were included in the COVID-19 response. How were they included in planning efforts?
- a) Accessibility
- b) Distribution of vaccine
- c) Messaging
- d) Personal protective equipment

Barriers to Inclusion with Disabilities in the COVID-19 Response

- Failure to ensure safety of people with disabilities in congregate living or health facilities.
- Failure to ensure access for people with disabilities to food deliveries; internet, COVID-19 testing.
- Failure to give people with disabilities or their families or support workers evidence-based priority for COVID-19 vaccination or COVID-19 treatment where required.
- Lack of or inadequate support for people with disabilities living alone or where family members or support workers are self-isolating or affected by COVID-19.
- Unclear public health messaging or lack of accessible messaging.
- Postponement of required medical treatment, including rehabilitation.
- Failure to collect data on disability to allow disaggregation.

https://www.thelancet.com/action/showPdf?pii=S0140-6736%2821%2900625-5

Strategic Priorities

Strategies to Support the Health and Well-being of People with Disabilities

NIHCM FOUNDATION

Partner
with the disability community

- Disability research should engage and include people with disabilities in the planning and decision-making process, ensuring focus on the most pressing issues

Collect
disability data

- Data should include race, gender, language, and other cultural factors
- Also collect qualitative data

Prioritize
accessibility

- Health professionals need to ensure all people receive equal access to accurate information and quality services

Include
disability in all health equity efforts

- Health equity research and policy must be holistic, intersectional, and include disability

Improve
representation and leadership

- Support the disability rights movement's call for 'Nothing About Us Without Us'

Address
stigma through medical training

- Include disability cultural competency curricula in all health care professional schools

Promote
disability employment

- Connect job seekers with disabilities to employment opportunities
- Create inclusive and accessible workplaces

Support
social participation

- Include people with disabilities in everyday activities
- Identify and remove barriers for meaningful participation based on individuals' interests

Poll Question

- As a result of this learning collaborative, I plan to

a) Receive education and training on caring for individuals with disabilities.

b) Review disaster preparedness policies (at place of employment) to ensure individuals with disabilities are included.

c) Partner with community organizations that support individuals with disabilities.

d) Advocate for legislation in support of individuals with disabilities.

Take-home Points

- A person-centered approach to care by healthcare professionals helps individuals with disabilities to manage their health that aligns with their preferences and values so they can be empowered.
- Members of the disability community are at increased vulnerability and should be prioritized in planning efforts (natural disasters, emergency preparedness, pandemics).
- Advocate for the inclusion of persons with disabilities in public health programming (identify a health and disability champion within your respective hospital, agency, organization).

References

ADA National Network (September 2022). What is the definition of disability under ADA. https://adata.org/faq/what-definition-disability-under-adaAmerican Association on Intellectual & Disability & Developmental Disabilities (n.d.). Defining criteria for intellectual disabilities. https://www.aaidd.org/intellectual-disability/definition

Disability, Health Equity & COVID-19(2021). [Infographic] https://nihcm.org/publications/disability-health-equity

Jones, L. K. (2020). Person-centered thinking in developmental disabilities–Dreaming possible dreams. Social Work Today, available online at: https://www. socialworktoday. com/archive/exc_011909. shtml.(accessed May 22, 2023).

National Disability Navigator Resource Collaborative (2022). What to know when assisting a consumer with intellectual disability.[Fact Sheet]. https://nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/population-specific-fact-sheet-intellectual-disability/

National Disability Practitioners (2021).What is a person-centered approach? [Fact Sheet] https://www.ndp.org.au/images/factsheets/346/2016-10-person-centred-approach.pdf

Schalock, L.R., Luckasson, R.,Tassè J.M., (2021). Intellectual disability: definition, diagnosis, classification and system of support, 12 Edition [Webinar]. American Association on Intellectual & Developmental Disabilities. https://www.aaidd.org/education/education-archive/2021/01/28/default-calendar/intellectual-disability-definition-diagnosis-classification-and-systems-of-supports-12th-edition

Senjam, S. S. (2021). A persons-centered approach for prevention of COVID-19 disease and its impacts in persons with disabilities. *Frontiers in Public Health*, 8, 608958.

Shakespeare, T., Ndagire, F., & Seketi, Q. E. (2021). Triple jeopardy: disabled people and the COVID-19 pandemic. *The Lancet*, 397(10282), 1331-1333.

Q&A

NATIONAL NURSE-LED CARE CONSORTIUM
a PHMC affiliate

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

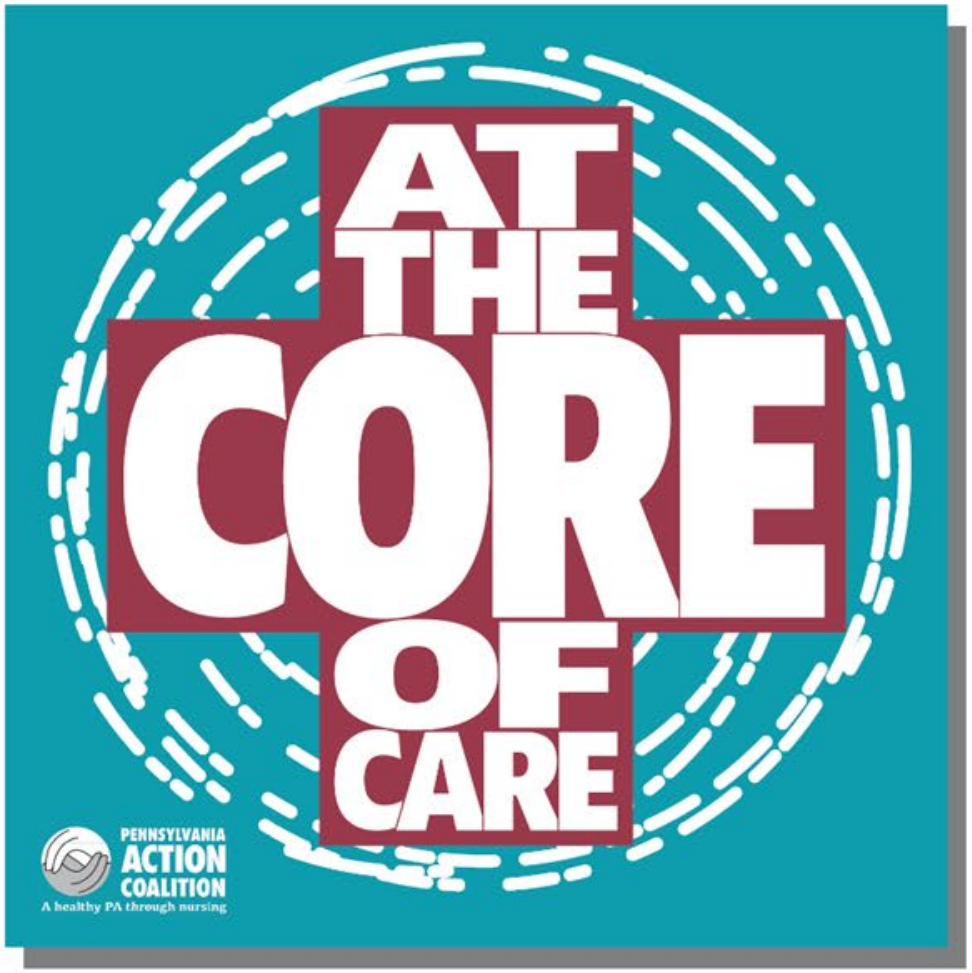
NATIONAL NURSE-LED CARE CONSORTIUM
a PHMC affiliate

Gloria Jones Dinkins, DNP, APRN, FNP-BC, GS-C

Adjunct Assistant Professor at Howard University College of Nursing and Allied Health Sciences

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

Director of Nursing at The Arc



Listen on Apple Podcasts

NURSING PODCAST

Vaccine Confidence Series

Find more free continuing education opportunities

NurseLedCare.org