

NHPCO Project ECHO 2023

Equity Where It Matters

Topic: The Unique Needs of Adults with Intellectual and Developmental Disabilities in Hospice and Palliative Care

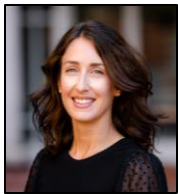
Date: December 7, 2023

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Disclosures

Disclosure

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. We ask all participants to take the survey as it will help us to improve future sessions.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today's Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

Session Faculty



Doreen Samelson, EdD, MSCP
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Didactic Presentation

What is an intellectual/developmental disability (IDD)?

- Intellectual disability starts any time before a child turns 18 and is characterized by differences with both:
 - Intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and
 - Adaptive behavior, which includes everyday social and life skills.

IDD Prevalence in the US

IDD prevalence in the US

- CDC estimate 6.5 million people in the US have ID
- 2019 Systematic review (Anderson et al.) significant gaps in surveillance for adults.

Classification/prevalence

- IQ 50 to 70: mild intellectual disability (85% of cases)
- IQ 35 to 50: moderate intellectual disability (10% of cases)
- IQ 20 to 35: severe intellectual disability (4% of cases)
- IQ below 20: Profound intellectual disability (1% of cases)

Syndromic, Non-syndromic & Idiopathic Autism

Autism is a spectrum ranging from independent to total dependence

- 30% cooccurrence of ID with Autism

Syndromic: high association with IDD

- Trisomy
- Deletions
- Prader-Willi
- Fragile-X
- Tuberous sclerosis

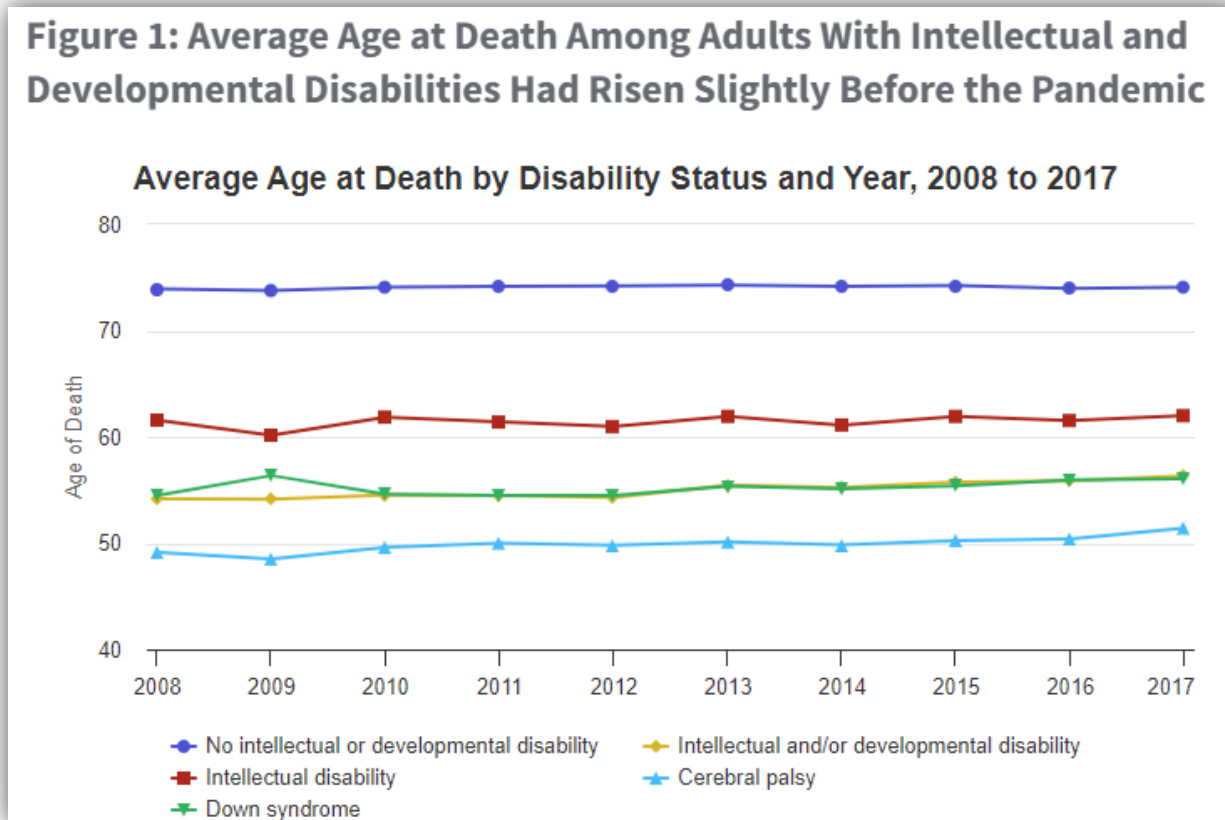
Nonsyndromic autism: well over 100 genes have been identified.
Function more likely to improve over time

IDD Adults and Wellbeing

- Special Needs Alliance: estimate 7 of 10 IDD adults live with parent or other family caregiver
- Individual housing results in higher wellbeing for IDD adults (Oliver et al., 2020)
- Guardianship vs Supported Decision making?
 - <https://supporteddecisionmaking.org/>

Life expectancy for adults with IDD was shorter and improving pre-pandemic

Figure 1: Average Age at Death Among Adults With Intellectual and Developmental Disabilities Had Risen Slightly Before the Pandemic



- Shorter life expectancy
 - Intellectual disabilities, 12 yrs
 - Down Syndrome, 18 yrs
 - Cerebral palsy, 23 yrs

Source: [2008–2017 U.S. Multiple Cause-of-Death Mortality Files, National Vital Statistics System.](https://www.cdc.gov/nchs/data/hestia/2008-2017-ucd-mortality-files.pdf)

<https://www.prb.org/articles/u-s-adults-with-intellectual-and-developmental-disabilities-are-living-longer-but-covid-threatens-to-erase-recent-gains/#:~:text=Evidence%20Shows%20Longer%20Lives%20for,than%20for%20adults%20without%20IDD.>

Adults with cognitive limitations have a higher prevalence of **diabetes and multiple comorbidities**

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

VOLUME 49, NUMBER 3: 141-154 | JUNE 2011

Diabetes Among Adults With Cognitive Limitations Compared to Individuals With No Cognitive Disabilities

Amanda Reichard and Hayley Stolze

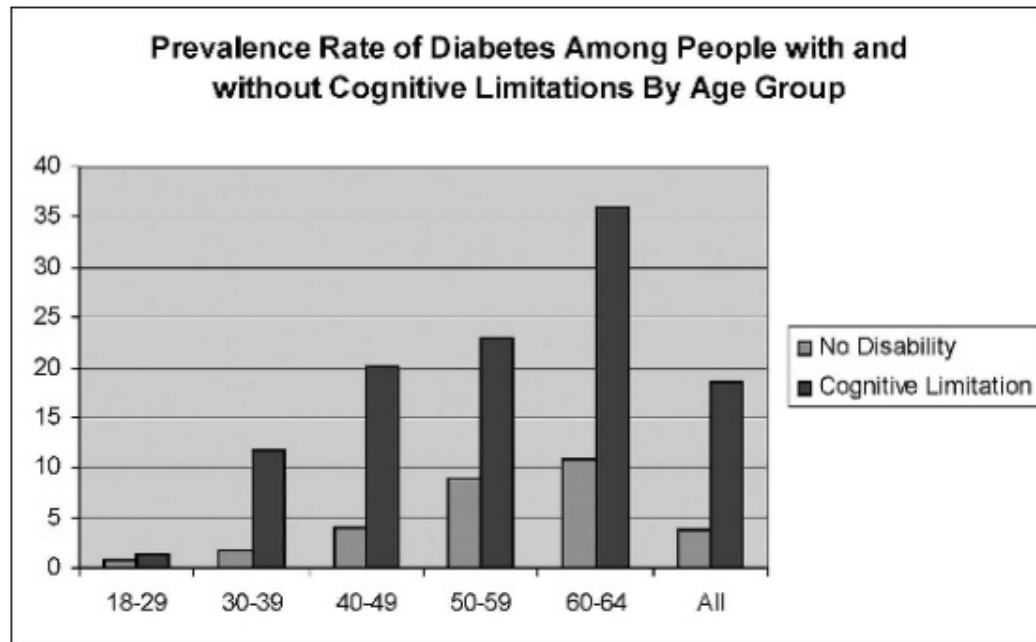


Figure 1 Prevalence rate of diabetes.

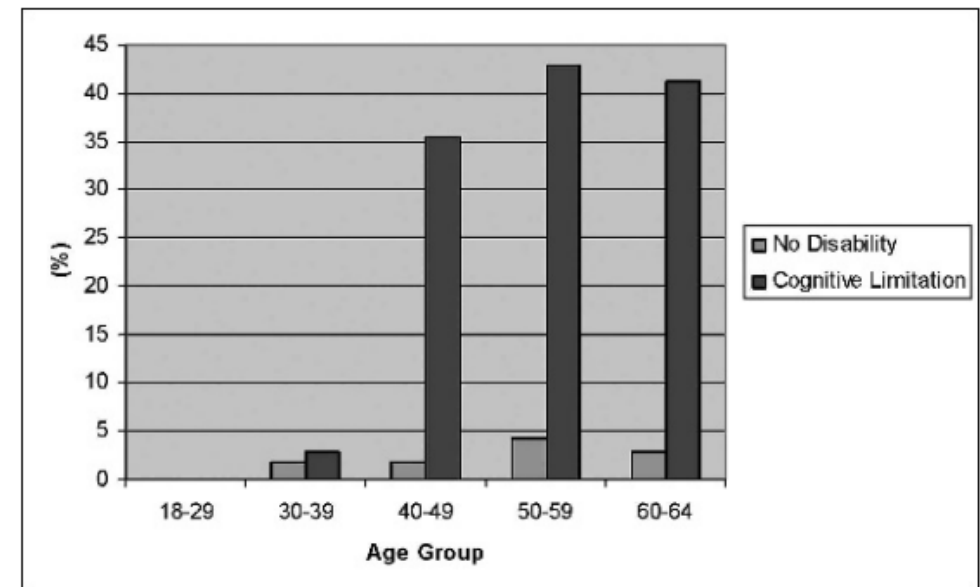


Figure 2 Prevalence of four or more comorbidities with diabetes.

Causes of death are different in the IDD population



- National Vital Statistics System 2005–2017 US Multiple Cause-of-Death Mortality files
- 22,512 deaths with ID, 32,738,229 deaths without ID
- Heart disease was leading cause of death in both groups
- Pneumonitis, influenza/pneumonia, choking – significantly higher in ID group
- Diabetes mellitus – significantly higher in mild-moderate ID group

Cancer outcomes are poorer in pts with IDD

HSR

Health Services Research

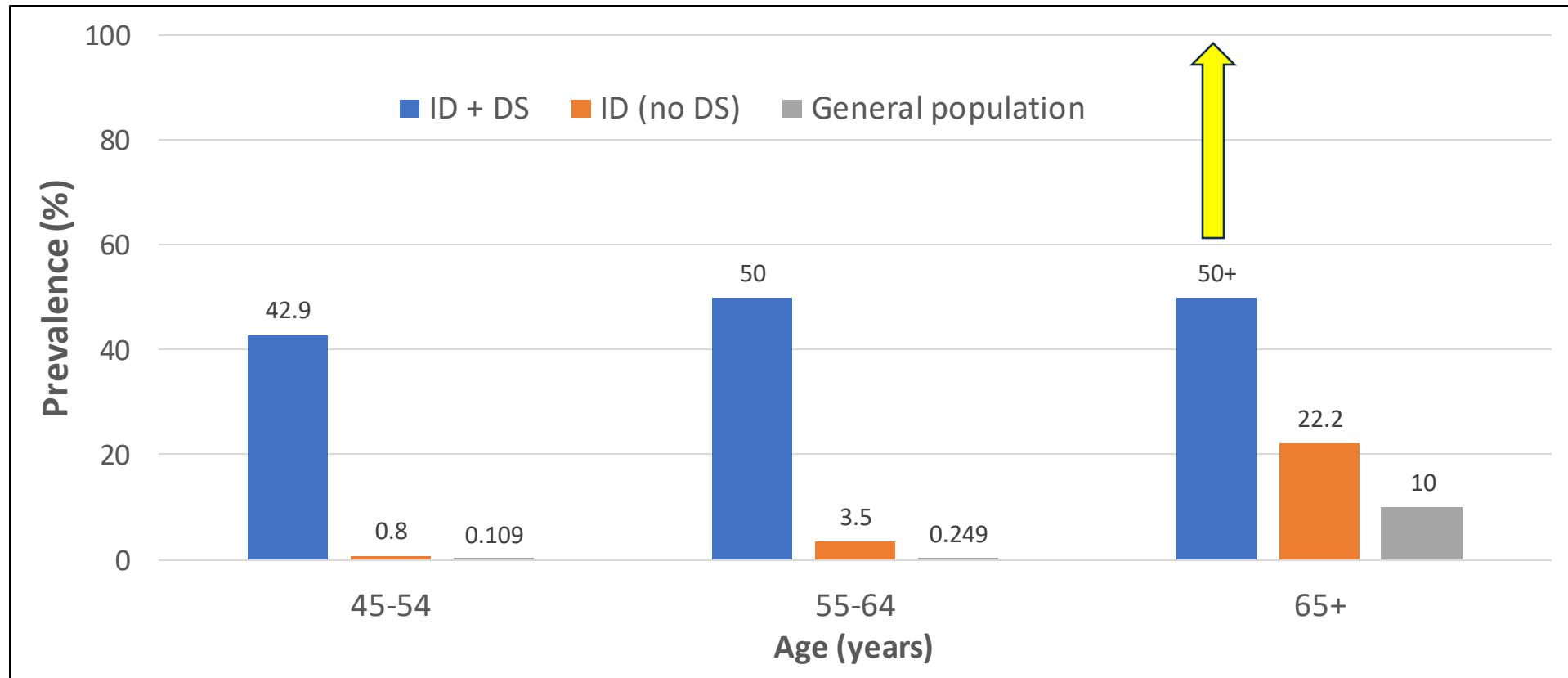
Cancer Stage at Diagnosis and Survival among Persons with Social Security Disability Insurance on Medicare

Ellen P. McCarthy, Long H. Ngo, Thomas N. Chirikos, Richard G. Roetzheim, Donglin Li, Reed E. Drews, Lisa I. Iezzoni

First published: 17 August 2006 | <https://doi.org/10.1111/j.1475-6773.2006.00619.x> | Citations: 32

- Down Syndrome – higher risk of leukemia
- Barriers to diagnosis
- Cancer all-cause mortality is higher (lung, prostate, breast, colorectal)

The IDD population has a higher prevalence of dementia, particularly the Down syndrome population



<https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.5258>

<https://www.bcbs.com/the-health-of-america/reports/early-onset-dementia-alzheimers-disease-affecting-younger-american-adults>

slido



Have you/your team ever cared for someone with IDD?

ⓘ Start presenting to display the poll results on this slide.

slido



Have you or your team ever cared for someone with an adult child with IDD?

ⓘ Start presenting to display the poll results on this slide.

Didactic Presentation Q&A

Case Study Presentation

Unique aspects of hospice in the IDD population

Global Qualitative Nursing Research

[Glob Qual Nurs Res.](#) 2022 Jan-Dec; 9: 23333936221087626. PMCID: PMC9102126
Published online 2022 May 11. doi: [10.1177/23333936221087626](https://doi.org/10.1177/23333936221087626) PMID: [35572367](https://pubmed.ncbi.nlm.nih.gov/35572367/)

A Comparative Case Study of Hospice and Hospital End-of-Life Care for Aging Adults With Developmental Disabilities

[Jacqueline M. McGinley](#)¹ and [Christina N. Marsack-Topolewski](#)²

- Underutilize hospice = no hospice, shorter hospice LOS
- Higher rates of hospital & institutional deaths
- Behavioral health needs, complex comorbidities, and polypharmacy
- People with IDD are often excluded from rituals related to death and dying
- Caregivers and medical providers can experience disenfranchised grief

Situation

- **39 yo** M with IDD and complex medical history referred by his **pediatrician** to hospice
- Medicare + Medicaid
- Advance care directive completed in 2009

- Admitted: Aug 2022
- Expired: March 2023

Background

Medical history

Leukodystrophy

Niemann - Pick Disease

Epilepsy

Scoliosis

Swallowing, protein-calorie malnutrition

Decubitus ulcers

Challenges

Minimal mobility, wheelchair user

Non-verbal

Family history

- Older sister with same conditions died at 28yo

Social history

- Attended adult day care till March 2020 (pandemic)
- Then father died of cancer later in 2020, leaving mother as patient's sole caregiver
- Mother
 - Estranged from late husband's family who desired patient in residential facility
 - Afraid to send patient back to day care during pandemic
 - Refuses any additional everyday care support

Assessment

Patient

- Needs end-of-life care
- Medically complex
- Communication barriers
- Max assist



+++ Case complexity and acuity

Mother/Caregiver

- Patient was her sole life purpose
- No immediate family
- Lacks social network



Complex anticipatory grief and bereavement needs

Patient expired after 7 months on hospice. Hospice care team attended funeral with mother. No other attendees.

Discussion and Recommendations

Discussion and Recommendations

- How would you approach caring for this patient?
- How would you support this patient's mother?
- Please share your experience with IDD patients or patients with an adult child with IDD
- How would you approach advance care planning in the IDD population?

- 4 major principles form basis for disability policy
- **Dignity:** All persons are equally valuable, with or without disability, and deserve respect consistent with human dignity.
- **Respect for autonomy:** Caregivers should always attempt, as much as possible, to discover the wishes and desires of the person with IDD and honor those wishes.
- **Life:** Caregivers should act to promote and protect the life of the person with IDD.
- **Equality:** Resources for caring at the end of life must be appropriate, sufficient, and available without discrimination.

Key Takeaways

- Our professional community needs to prioritize engaging the underserved IDD population
- Advance care planning is critical for people with IDD and their caregivers
- Patients with IDD have complex needs
- Caregivers of patients with IDD also have unique needs

Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions!
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for each session. To receive confirmation of completion, please complete the following [Project ECHO Session Evaluation and Knowledge Check](#) following each session.

NHPCO Health Equity Certificate

- Would you like to demonstrate your commitment to delivering culturally competent care across the continuum of serious illness in an equitable, inclusive, and person-centered manner?
 - NHPCO is pleased to offer a Health Equity Certificate for individuals who participate in at least 17 sessions in the *Equity Where It Matters* series
- Participants interested in earning the Health Equity Certificate must complete the [Project ECHO Session Evaluation and Knowledge Check](#) following each session.
- Effective July 20, the Session Evaluation and Knowledge Check can be completed using one link for each session.
- Session Evaluation and Knowledge Check links are unique for each Project ECHO session and do not expire. Links for each 2023 session can be found on the [NHPCO Project ECHO webpage](#).

Upcoming Sessions

Date: December 14

Topic: Equity Where It Matters: A Summary of Health Equity in Hospice and Palliative Care

Additional Information

NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

NHPCO Project ECHO session recordings and Key Takeaways:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/2023-project-echo-session-recordings/>

NHPCO Project ECHO Registration Link:

<https://nhpc.zoom.us/meeting/register/tZEsfu-trz4oGtQeKFw41UEIYNwjSli8QCBF>

For more information:

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