

## HPCO Project ECHO *Equity Where It Matters*

### Key Takeaways: The Unique Needs of Adults with Intellectual and Developmental Disabilities in Hospice and Palliative Care December 7, 2023

#### Key points:

- Intellectual disability starts any time before a child turns 18 and is characterized by differences with both:
  - Intellectual functioning or intelligence, which includes the ability to learn, reason, problem solve, and other skills.
  - Adaptive behavior, which includes everyday social and life skills.
- There are 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.
- Adults with cognitive limitations have a higher prevalence of diabetes and multiple comorbidities.
- Our professional community needs to prioritize engaging the underserved IDD population.
- Patients with IDD have complex needs. Caregivers of patients with IDD also have unique needs. Advance care planning is critical for people with IDD and their caregivers.

#### Actionable Steps:

- Engage with the IDD community to facilitate advance care planning sessions, ensuring active outreach and involvement.
- Raise organizational awareness about Intellectual and Developmental Disabilities (IDD) through targeted initiatives and campaigns.
- Implement competency training programs for staff members focused on enhancing their understanding and skills in working with individuals with IDD.

#### Conversation Starters:

1. How might intake for a person with IDD be different?
2. How might we modify the approach for family/caregivers for a person with IDD?
3. How might bereavement support be different when someone with IDD passes?



## Participant Perspectives:

- Parents of patients with IDD may be isolated from family and social circles and need additional support.
- Patients in the IDD community may need additional assistance to complete advance care planning. Resources to assist are lacking in most communities, and advance care planning conversations need to start early for individuals with IDD, just like for other patients.

## References:

- *Supported decision-making*. National Resource Center for Supported Decision-Making. (2023, March 13). <https://supporteddecisionmaking.org/>
- Stacey Oliver , Emily Z. Gosden-Kaye , Dianne Winkler & Jacinta M. Douglas (2020): The outcomes of individualized housing for people with disability and complex needs: a scoping review, *Disability and Rehabilitation*, DOI: 10.1080/09638288.2020.1785023
- Mather, M., Paola Scommegna, & Martinez, M. (2022, April 5). *U.S. adults with intellectual and developmental disabilities are living longer, but COVID threatens to erase recent gains*. PRB - Population Reference Bureau. <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%20with%20IDD.>
- Reichard, A., & Stolze, H. (2011). Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. *Intellectual and developmental disabilities*, 49(3), 141–154. <https://doi.org/10.1352/1934-9556-49.2.141>
- Landes, S. D., Stevens, J. D., & Turk, M. A. (2021). Cause of death in adults with intellectual disability in the United States. *Journal of intellectual disability research : JIDR*, 65(1), 47–59. <https://doi.org/10.1111/jir.12790>
- McCarthy, E. P., Ngo, L. H., Chirikos, T. N., Roetzheim, R. G., Li, D., Drews, R. E., & Iezzoni, L. I. (2007). Cancer stage at diagnosis and survival among persons with Social Security Disability Insurance on Medicare. *Health services research*, 42(2), 611–628. <https://doi.org/10.1111/j.1475-6773.2006.00619.x>
- Takenoshita, S, Terada, S, Kuwano, R, et al. Prevalence of dementia in people with intellectual disabilities: Cross-sectional study. *Int J Geriatr Psychiatry*. 2020; 35: 414–422. <https://doi.org/10.1002/gps.5258>
- Blue Cross Blue Shield Blue Health Intelligence. (2020, February 27). *Early-Onset Dementia and Alzheimer's Rates Grow for Younger American Adults*. Blue Cross Blue Shield. <https://www.bcbs.com/the-health-of-america/reports/early-onset-dementia-alzheimers-disease-affecting-younger-american-adults>
- Blue Cross Blue Shield Blue Health Intelligence. (2020, February 27). *Early-Onset Dementia and Alzheimer's Rates Grow for Younger American Adults*. Blue Cross Blue Shield. <https://www.bcbs.com/the-health-of-america/reports/early-onset-dementia-alzheimers-disease-affecting-younger-american-adults>
- Blue Cross Blue Shield Blue Health Intelligence. (2020, February 27). *Early-Onset Dementia and Alzheimer's Rates Grow for Younger American Adults*. Blue Cross Blue Shield.



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

- McGinley, J. M., & Marsack-Topolewski, C. N. (2022). A Comparative Case Study of Hospice and Hospital End-of-Life Care for Aging Adults with Developmental Disabilities. *Global qualitative nursing research*, 9, 23333936221087626.  
<https://doi.org/10.1177/23333936221087626>
- NHPCO Access and Inclusion - <https://www.nhpco.org/resources/access-and-inclusion/>
- *Hospice Through the DEI Lens: A Research Study Identifying Barriers to Hospice Care in Underserved Communities*, National Hospice and Palliative Care Organization.
- NHPCO Diversity Tools and Resources <https://www.nhpco.org/education/tools-and-resources/diversity>
- Culturally and Linguistically Appropriate Services (CLAS)  
<https://thinkculturalhealth.hhs.gov/clas>
- CMS Framework for Health Equity <https://www.cms.gov/about-cms/agency-information/omh/health-equity-programs/cms-framework-for-health-equity>

