

Advance Care Planning for People with Intellectual & Developmental Disabilities: A State-by-State Content Analysis of Person-centered Service Plans

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Background

Exponential growth in people aging with IDD

- Older adults are the fastest growing segment of the intellectual and developmental disabilities (IDD) population with projections forecasting a doubling by 2030 and a tripling within the foreseeable future.
- The newly emergent older cohort in the IDD population is likely one of the most significant issues facing practitioners and researchers within the field of aging and disability services, particularly as it relates to issues of inclusive decision-making in serious illness and end of life. (Hahn et al., 2015; EAPC, 2015)

Advance care planning is a best practice

- In July 2012, The American Association of Intellectual and Developmental Disability adopted a position statement, *Caring at the End of Life*. As outlined in the statement's principles and reinforced in AAIDD's 2015 *National Goal for Aging*, discussions about personal wishes for care should transpire well in advance of a serious illness and involve individuals with IDD.
- The recommendations articulated by AAIDD regarding regular and ongoing advance care planning (ACP) are strongly supported by the Institute of Medicine's 2014 consensus report, *Dying in America*, which set forth key findings and recommendations for best practices in end-of-life care for all Americans. (AAIDD, 2012; Hahn et al., 2015; IOM, 2014)

Person-centered plans may be ideal for ACP

- Required by Medicaid – Service recipients are obligated to convene regular interdisciplinary team meetings and maintain person-centered service plans for people with IDD receiving Medicaid-funded services, such as the HCBS waiver.
- The regularity and content of these meetings suggests an ideal setting for ACP; however, there is no available research to date exploring if and how these conversations transpire. (CMS, 2017)

Methods

Purpose:
Explore how state-level service plans articulate ACP for people with IDD

Aim #1:
To describe the frequency of ACP content in service plans for people with IDD

Aim #2:
to explore the specific ways in which ACP content manifests in service plans for people with IDD

Data Collection & Analysis
Five-step, Iterative Process

- 1 retrieval of publicly-available data (i.e. service plan templates and associated policies) via internet searches & queries
- 2 confirmation of the authenticity and accuracy of the data via third-party affirmation (i.e. emailed correspondence with state-level officials and developmental disability council members)
- 3 systematic analysis of the retrieved content across 10 dimension of ACP using a *researcher-developed* code book & coding sheets
- 4 co-coding and consensus building between research team members to assure intercoder reliability
- 5 synthesis of findings



Researcher-developed Dimensions of Advance Care Planning

- | | |
|-------------------------|-------------------------|
| 1. Diagnosis/ Prognosis | 6. Decision-making |
| 2. Support Needs | 7. Guardianship |
| 3. Living Arrangements | 8. Retirement |
| 4. Finances | 9. Funeral Arrangements |
| 5. Burial Funds | 10. Advance Directives |

(Preliminary) Findings

Each state's person-centered plan documents were coded on a three-point scale:



State plans articulated, at minimum, several of the 10 tenets of ACP. However, states rarely articulated these tenets specific to aging and end-of-life.

Some exemplars across the 10 dimensions of advance care planning were identified:

Dimension #1: Diagnosis & Prognosis
 • State: Virginia
 • Document: Individual Support Plan
 • "Health Topics" documentation includes chronic and communicable diseases, including onset, prognosis, and key features

Dimension #5: Burial Funds
Dimension #9: Funeral Arrangements
 • State: Connecticut
 • Document: Individual Plan
 • Presence or absence of prepaid burial and funeral plan documented

Dimension #8: Retirement
 • State: Montana
 • Document: Personal Support Plan
 • "Section IV. Lifestyle" includes opportunities to discuss wishes and plans for retirement

Dimension #10: Advance Directives
 • State: Illinois
 • Document: (405 ILCS 5/) MH & DD Code
 • Guidance provided for the documentation & use of advance directives for people in residential services

Conclusion

- There were no states that articulated all 10 of the researcher-identified dimension of advance care planning specific to aging and end-of-life within their person-centered plans.
- However, most states did articulate tenets of advance care planning more broadly suggesting opportunities for easy integration of content specific to aging and end-of-life care within person-centered plans and the semi-regular meetings that often accompany.
- States that are interested in integrating advance care planning specific to aging and end-of-life care into their person-centered plans can look to "exemplar" plans that have integrated one or more of the dimensions.



Next Steps

1. Complete steps #4-5 of data analysis
2. Disseminate findings via peer-reviewed publications and summary report to state agencies & developmental disabilities councils
3. Replicate study in Canadian Provinces
4. Develop strategy for obtain consent to "warehouse" person-centered plan documents for future studies, including methods for regular updating