

Intellectual and Developmental Disabilities

Advance Care Planning for Individuals with Intellectual Disabilities: A State-by-state Content Analysis of Person-centered Plans --Manuscript Draft--

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Title

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Abstract

Older adults are a rapidly growing segment of the intellectual and developmental disabilities (IDD) population. Advance care planning (ACP) is recommended as a best practice for adults with IDD; yet, adoption remains low. For individuals receiving Medicaid services, regular meetings maintain the person-centered planning (PCP) process. Content analysis was used to examine data from public documents across the United States to identify the frequency of ACP in PCP and the ways it manifests. Results indicate most states had evidence of ACP within the PCP process with notable variation to the extent. Findings suggest many PCP documents lack content specific to late-life transitions. Included are examples of the ways states have integrated ACP into PCP that can serve as a guide.

Key words

advance care planning; intellectual & developmental disabilities; content analysis; person-centered plans; caregiving; aging; end-of-life; decision-making

Background

The number of individuals with intellectual and developmental disabilities (IDD) who are reaching advanced age is increasing at unprecedented rates, with projections indicating a doubling by 2030 and a tripling within the foreseeable future (Acharya, Schindler, & Heller, 2016). This growing population is among one of the most significant issues facing families, practitioners, and policymakers, particularly as it relates to inclusive decision making when individuals with IDD reach advanced age and near the end of life (Friedman & Helm, 2010; Hahn, Fox, & Janicki, 2015). Within and outside the IDD community, advance care planning (ACP) is recommended as a best practice for facilitating and documenting the decision-making process; yet, adoption remains low (American Association on Intellectual & Developmental Disabilities [AAIDD], 2012; Institute of Medicine [IOM], 2014). For individuals **in the United States** receiving Medicaid-funded services, semi-annual interdisciplinary team meetings are required to maintain the person-centered planning (PCP) process (Lewis, 2014). The regularity and content of these meetings suggests an ideal setting for the promotion of ACP among individuals with IDD; however, no available research to date has explored if and how ACP occurs in the context of the PCP process.

Advance care planning is the process of preparing care plans in advance of when individuals can no longer inform care and treatment decisions for themselves (IOM, 2014). There are several ways in which ACP has been conceptualized for individuals with IDD. The Arc's Center for Future Planning (2016) provides an online tool for adults with IDD, which includes six broad components: (a) expressing wishes for the future; (b) deciding where to live; (c) financing the future; (d) determining employment and daily activities; (e) supporting daily and major life decisions; and (f) making social connections. Perkins and van Heumen (2018)

suggested principles for ACP practice, including ensuring access for the individual with IDD to have: (a) support for autonomous decision-making and self-determination; (b) the right to full inclusion across their experiences of community participation; and (c) accurate identification and involvement of family members and friends who support long-term care. When completed across the life course as a collaborative process, ACP has been found to contribute to end-of-life experiences that reflects the values and priorities of the individual with IDD (Bigby, Webber, & Bowers, 2015; Heller, Scott, & Janicki, 2017).

Person-centered planning refers to the process of articulating the care and support needs of individuals with IDD. The goal of PCP is to include the individual with IDD in a collaborative process of pursuing and achieving their goals (Heller, 2019). Thus, the PCP process is rooted in the social value of equality and access to the community for individuals with IDD, whereby decisions are based upon the principles of social inclusion, choice, and independence (Taylor & Taylor, 2013). In a longitudinal study examining efficacy and costs associated with implementing PCP, Robertson and colleagues (2005) found that participants with IDD who received a person-centered plan experienced positive changes in: (a) their social networks; (b) contact with family and friends; (c) community-based activities; (d) scheduled day activities; and (e) opportunities to engage in choice-making. Findings from a follow-up study suggested that personal characteristics, contextual factors, and process features can be used to predict individuals' access to and the efficacy of the PCP process (Robertson et al., 2007).

PCP has been widely adopted by the IDD field, both nationally and internationally, as a best practice (Claes et al., 2010). In the United States, most states have long-maintained the PCP process for individuals with IDD who are known to the service system, including those receiving Medicaid waiver services. Medicaid is a government-funded program that provides health

coverage and long-term services and supports to millions of Americans, including people with disabilities (CMS, 2018). New guidance under both the Affordable Care Act and the Centers for Medicare and Medicaid Services (CMS) require all states where individuals are residing in intermediate care facilities (ICF/IID) and/or receiving long-term services to have documented policies and procedures for PCP (Lewis, 2014; CMS, 2018).

ACP, conversely, is much less common. Approximately one-third (37%) of the United States population has completed an advance directive (Yadav et al., 2017). Emerging exploratory research from both the United States and the Netherlands suggested that people with IDD may be engaging in ACP at rates similar to people without disabilities (McGinley, Waldrop, & Clemency, 2017; Voss, et al., 2019). However, these conversations often occur on the heels of a serious illness diagnosis or medical crisis not in advance of it (Voss, et al., 2019). Family caregivers may be reluctant to engage in ACP, reporting experiences of apprehension and frustration with impediments to the planning process or “paralysis with indecision” arising from perceptions of too few care options (Lee, Burke, & Stelter, 2019; Taggart, Truesdale-Kennedy, Ryan & McConkey, 2019). In addition, healthcare providers expressed difficulties broaching this emotional topic and reported avoiding it altogether at times (McEnhill, 2008), while some people with disabilities described feeling reluctant to engage in ACP for fear that it might be misused to justify the withholding of care (Johnson, 2010).

Little is known about how ACP and PCP are used to support future planning for aging adults with IDD. To fill this gap in the literature, the present study examined how states’ PCP processes articulate ACP for individuals with IDD residing across the United States. The goals of this study were to:

- 1) identify the frequency of ACP content in PCP documents for individuals with IDD;
- and
- 2) explore the specific ways in which ACP content manifests in PCP documents for individuals with IDD.

Methods

Study Design

The research design was descriptive, using content analysis to systematically examine qualitative data derived from publicly available documents (Neuendorf, 2017). A four-person interdisciplinary research team applied the techniques of content analysis to objectively extract information from state-level PCP documents. They then categorized the text using an a priori coding scheme to determine the frequency with which categories of ACP were present for individuals with IDD during the routinely-ascribed PCP processes (Ahuvia, 2001; Smith, 2000). Additionally, within-category comparisons across states facilitated the identification of replicable best practices that appear to align with existing standards for high quality end-of-life care for individuals with IDD (AAIDD, 2012; IOM, 2014).

Data Collection

Beginning in fall 2017, the research team obtained service plan documents from state websites using search term queries, such as: “person-centered plan”; “person-centered planning”; “individual support plan”; “support plan”; “service plan”; “habilitation plan”; “plan”; and combinations of these terms. The team also used internet search engines (i.e., Google) to obtain documents using the same search terms noted above with the addition of the state name added to the query. Although service plan documents were presumed to be publicly available, the research

team recorded variability in the length of time (ranging from 5 to 60 minutes) required to locate each state's documents. State plan documents were obtained for all but 5 of 50 states, as well as the District of Columbia, from these initial efforts.

Direct communication with state-level officials and developmental disability planning council members was conducted via email to affirm the validity of documents located by the research team and/or request documentation that could not be previously located. This outreach was repeated up to three times until a response was received. These efforts yielded responses for 30 states either affirming the validity of the previously located documents or directing the research team to the most current service plan documents in use within the state. Ultimately, the research team was unable to locate plan documents for two states (Arkansas and South Carolina) after approximately nine months of this search and inquiry process.

The study data set included service plan documents for 48 states and the District of Columbia ($N = 49$). The documents provided evidence of compliance with PCP in state policies, plan templates, and/or supplemental documents (e.g. training materials, presentation slides, sample plans, and memos). Each document, regardless of type, was used as a unit of data. The dataset thus included all publicly available documents articulating PCP policies and procedures for each state to facilitate the most exhaustive and systematic analysis possible at the time of the study.

Data Analysis

The state plan documents were subjected to an iterative, three-step process: systematic analysis using coding schemes; coding and consensus building; and synthesis of findings (Neuendorf, 2017).

Systematic analysis & coding schemes. The research team began by drawing upon their collective practice experiences within the field of IDD and available research knowledge to conceptualize ACP (AAIDD, 2012; Perkins & van Heumen, 2018; The Arc, 2016). This conceptualization led to the initial operationalization of ACP into five categories: long-term care, decision making, retirement, burial account, and advance directives. This initial operationalization was presented at two interdisciplinary conferences within the respective fields of gerontology and IDD for feedback on the face validity and content validity of this process. Specifically, experts were asked if these categories were both exhaustive and mutually exclusive of ACP for individuals with IDD (Neuendorf, 2017). Based upon the feedback received, the operationalization was revised and expanded into 10 categories: diagnosis/prognosis, support needs, living arrangements, finances, burial funds, decision making, guardianship, retirement, funeral arrangements, and advance directives.

The principal investigator (PI) then created a codebook that contained definitions for each of the 10 categories and instructions for coding (Neuendorf, 2017). A code of 1 was given when the document explicitly articulated the category as defined; a code of 2 was given when the document included the category but in more general terms that were not specific to the operationalized definition; and a code of 3 was given when the plan did not articulate the category in any form. For example, the following is an excerpt from the codebook for the category of “retirement”:

Retirement (alternatives: late-life transitions; leisure activities; day service modifications; meaningful activities. and engagement)

Does the plan seek to address the person’s retirement preferences and planning?

1. Yes; the plan explicitly discusses preferences and/or plans for retirement.
2. Somewhat; the plan discusses late-life transitions or other alternative terms, but it does not explicitly use the term retirement.
3. No; the plan does not discuss retirement or its alternative terms.

Each investigator then conducted a pilot test of the codebook by independently coding a random sample of 3 state's PCP documents (12 total). Discussions were held to address process-related questions and disagreements regarding use of the codebook and associated coding form, with both documents modified accordingly.

Coding & consensus building. During the next step of data analysis, each investigator independently coded the remaining states in their assigned geographic region (i.e., south, west, midwest, northeast) with opportunities to address questions at team meetings or in individual consultation with the PI. The research team was then divided into pairs for co-coding. Each member of the pair, blind to previously assigned codes, analyzed the documents coded by their partner. Comparing the codes, using a spreadsheet for tracking and analysis, resulted in an overall agreement rate of 0.64. Pairs discussed disagreements, referring back to definitions as outlined in the codebook, until they achieved consensus. The pairs, after re-coding their states' service plan documents, reached an overall agreement rate of 0.98, which exceeded the recommended rate of 0.81 (Neuendorf, 2017).

Synthesis of findings. Descriptive statistics were calculated using SPSS v. 25 to summarize the codes during the final phase of data analysis. Specifically, the frequency of ACP content by category was calculated by dividing the number of individual states that achieved a "1" for that category by 49, the total number of states and the District of Columbia included in this analysis.

To supplement this quantitative data, the research team elected to synthesize qualitative data identified during the analysis process to illustrate the specific ways in which ACP content was made manifest in state PCP documents. When coding, members of the research team recorded the associated page number for all categories assigned a "1". This data was later

extracted to Atlas.ti 8 MAC by the principal investigator and submitted to systematic coding according to the same list of 10 concept-driven codes used to operationalize ACP. It was during this phase of analysis that the 10 concept-driven codes were collapsed into 7 categories, including the combining of several related dimensions, i.e. support needs and living arrangements, burial funds and funeral arrangements, decision making and guardianship. Axial coding was then used to define and specify the properties of each category to determine best practices in how states have expressed categories of ACP in their person-centered service planning documents (Padgett, 2008).

Findings

All but two states (Minnesota and New Hampshire) included at least one of the ACP dimensions within their publicly available documents. Variability was noted in these documents in terms of how explicitly ACP was evident within service plan policies, templates, and/or supplemental materials. Table 1 presents data on the frequency of the 10 ACP dimensions in all states' PCP documents, along with identifying "best practice" states for each dimension. The following subsections report further on these findings.

Diagnosis/Prognosis

The majority of state PCP documents required information regarding the diagnosis and/or prognosis of the person with IDD for whom the plan was being completed. For the purposes of this study, diagnosis and prognosis extended beyond qualifying disability to include serious illnesses and/or chronic conditions that may have implications for aging and/or end of life; 51% ($n = 25$) of states' PCP documents met this criterion. Arizona's *Individual Attributes Checklist* template, for example, included "Alzheimer's/dementia" among its checklist of additional diagnoses.

Other plans offered open-ended prompts that appeared designed to elicit conversation regarding the short- and long-term prognoses of the individual with IDD. For example, New Mexico's *Individual Support Plan* template articulated the following in the "Health & Safety" subsection:

Provide summary information about significant health/medical/dental/behavioral/environmental concerns (past and present) and diagnosis(es) that have implications for planning or impact on the individual's health and safety, including what has been done to date to address these concerns. If the person's health or skills are regressing, include that information here.

Similarly, California's *Individual Support Planning* template prompted a discussion about "how the individual's health compares to previous years" and required the annual updating of the individual's lifetime medical history as part of the annual PCP process.

Support Needs and Living Arrangements

Of those documents analyzed, 14.3% ($n = 7$) evidenced content related to support needs and 2% ($n = 1$) related to living arrangements that could require changes or modifications over the lifespan. Connecticut's manual, *A Guide to Individual Planning*, identified a list of age-related assessments that could be used by "[people and their support teams] who are experiencing difficulties related to their advancing age" to inform the planning process. The manual emphasized the importance of this process by stating:

A review of support options is especially important during periods of transition, such as during the transition from school-to-work, when funding resources become available to the individual, when major life changes occur, or when aging issues become apparent.

Other states' PCP documents acknowledged how support needs and living arrangements of the individual with IDD may necessitate changes in response to the illness or death of a caregiver. For example, Florida rule *65G-4.0218: Significant Additional Need Funding* authorized additional supports and services in the event of the "permanent or long-term loss or incapacity of

a caregiver.” Similarly, Louisiana’s *Guidelines for Support Planning* authorized support coordinators to submit plan changes in emergency situations that include the illness or death of a caregiver. This training manual provided an example of a woman with an intellectual disability that was living with her aging parents who were experiencing health declines. Based on this case information, the coordinator was prompted to consider both short- and long-term planning options for the individual with IDD to avoid institutionalization.

Retirement

While some documents (22.5%, $n = 11$) had subsections that had the potential to elicit information about late-life vocational transitions and day service modifications, an equal number of states (22.5%, $n = 11$) specifically used the term, “retirement”. For example, Montana’s *Personal Support Plan* template included retirement within their open-ended section on vocational and day services. Similarly, the District of Columbia’s policy *2017-DDA-POL001: Person Centered Planning Process and Individual Support Plan* stated that it is the Department of Disability Services’ goal to “integrate retirement options for adults of retirement age who are not interested in employment.” Louisiana’s *Guidelines for Support Planning* acknowledged retirement in the subsection “Planning Assumptions” with the statement, “Individuals will have meaningful work, school or other appropriate daytime activities, including retirement activities if a person is of retirement age.”

Some documents offered specific open-ended prompts to facilitate discussions about retirement preferences. As examples, Maryland’s manual entitled *Exploration and Discovery for Development of the Person-Centered Plan: A Guide for the Coordinator of Community Services* prompted coordinators to consider providing activities, such as senior’s day programs, to retired individuals with IDD. California’s *Individual Support Planning* template subsection on

“Employment/ Volunteer” prompted the inclusion of information regarding retirement plans for individuals with IDD and the types of activities they would like to pursue after leaving their employment.

Finances

Most often state PCP documents (65.3%, $n = 32$) solicited financial information in broad terms. For example, Virginia’s *Person-Centered Individual Support Plan* template asked the team to consider if the individual with IDD for whom the plan was being completed needed help from a benefits or financial advisor to plan how to retain or maximize resources.

However, some states’ PCP documents (12.2%, $n = 6$) were more explicit in addressing finances as they related to the individuals’ and/or their caregivers’ aging and end-of-life planning process, including public benefits, assets, incomes, trusts, and insurance policies. For example, under the subsection “Finances,” Connecticut’s *Guide to Individual Planning* manual inquired about finances respective of the long-term needs of the individual with IDD and/or their caregivers. The document offered the following prompts, “Do you have sufficient money to support your needs?”; “Have you looked at a special needs trust for yourself? Asset planning?”; and “Have you thought about a retirement fund?” California’s *Individual Support Planning* template had subsections dedicated to financial information, management issues, and resources. For each asset, the team was prompted to identify the resource type (e.g., government benefit, life insurance, prepaid funeral arrangements, trust/guardianship, bank accounts, burial reserve and plot, and other resources), policy numbers, contact information, and the person responsible for maintaining the original documentation.

Burial Funds and Funeral Arrangements

Regional vernacular to describe these funds varied, including the phrases: burial accounts, burial plots, burial plans, burial reserves, and burial trusts. Of the study sample, only 16.3% ($n = 8$) of states' PCP documents elicited information about burial funds, often in the form of checklists that documented the presence of the fund (yes/no) and contact information for the originator or holder of the fund information. Delaware's *Essential Lifestyle Plan Workbook* template, for example, allowed for a yes/no response to the presence of a burial plot and short-answer responses for the burial plan name and location.

Funeral arrangements, as evidenced in 12.2% ($n = 6$) of the states' PCP documents, were documented in the form of checklists for pre-paid arrangements, such as the funeral home name, contact information, and policy numbers. An exception to this was Connecticut's *Guide to Individual Planning* manual that used open-ended questions to elicit information on post-mortem wishes regarding burial funds and the identity of a person able to talk about these plans.

Decision Making and Guardianship

The analysis of states' PCP documents sought to determine if the plans addressed healthcare decision making, including successorship plans in the event the individual and/or their guardian should become incapacitated. Most states' PCP documents (63.3%, $n = 31$) required designation of a decision-making authority, including the recording of the name and contact information for anyone with legal authority to make decisions on behalf of the individual with IDD. For example, Colorado's *Support Plan* offered a template comprised of a series of forced choice and short-answer questions for identifying if a person had an individual assisting with or authorized to make decisions.

Some states' PCP documents (12.2%, $n = 6$) went further by explicitly outlined processes for designating a healthcare coordinator or surrogate. For example, Tennessee's *Department of*

Intellectual and Developmental Disabilities Provider Manual indicated a surrogate could make healthcare decisions for the individual with IDD as long as the decisions followed the wishes of the individual and were in their best interests. Suggesting an orientation toward future planning, several documents provided scenarios where decision-making authority was unestablished or at risk for change. For example, California's *Individual Support Planning* template prompted:

If substitute decision maker is not identified, then what steps will be taken to identify a substitute decision maker and by when? Enter the steps to be taken to identify a substitute decision maker, as well as when these steps need to be taken.

While New Mexico's *Individual Service Plan* template allowed the team to attribute "urgency" to the category of decision making, whereby a person was identified as having independent, guardianship status, surrogate health decision making, power of attorney/conservator, or other (specified).

Advance Directives

Approximately one-fourth (24.5%, $n = 12$) of the states' PCP documents included content related to advance directives. In some cases, state documents attempted to define advance directives for the individual and others involved in the development of the plan. For example, California's *Individual Support Planning* template stated:

Advance directives are legal documents that convey decisions about end-of-life care ahead of time. They provide a way for **individuals** who can make medical decisions to communicate wishes about their care to family, etc. in the event that they develop an end stage condition. Advance directives also can be used to document a chosen decision maker (health care proxy) for **individuals** who cannot make their own medical decisions, but is able to choose someone to make decisions for and with them. Advance directives must be made by the individual themselves not by their family or guardian. Not all will be able to complete an advance directive or choose a health care proxy.

Where policies were available regarding the PCP process, states articulated requirements for plans to include documentation of advance directives. For example, Georgia's Department of Behavioral Health and Developmental Disabilities 2018 *Provider Manual for Community*

Developmental Disability Providers indicated that “a holistic person-centered approach to care, support, and services” includes, among many other features, a “review of legal concerns including: i. Advance directives ...” Similarly, Washington DC’s policy *2017-DDA-POL001: Person Centered Planning Process and Individual Support Plan* affirmed that advance directives must be included in the service plan discussions and documentation.

State documents that included templates for advance directives often used forced-choice questions. For example, a question on California’s *Individual Support Planning* template asked: “Is there an advance directive in place? (Yes/No)”. Colorado’s *Support Plan* template was more specific, asking about the type of directive; the location of the directive; whether it had been shared with providers, family, and friends; if support was needed to create or update the directive; and information about when and with whom the directive had been last updated. Maryland’s manual entitled *Exploration and Discovery for Development of the Person-Centered Plan: A Guide for the Coordinator of Community Services* provided links to specific allowable advance directive forms, including: Maryland Advance Directives; Five Wishes; and the Arc’s Center for Future Planning.

Discussion

The frequency with which individuals with IDD engage in ACP had historically lagged far behind those rates found among the overall population (Carr & Luth, 2017; United States Department of Health and Human Services [USDHHS], 2007). Members of the research and practice community have set forth guidelines to both facilitate and improve ACP for individuals with IDD. These efforts are due in part to research that has found individuals with IDD to have both the capacity and interest in participating in ACP, especially when person-centered accommodations are made and shared decision making is facilitated by healthcare providers

(McKenzie, Mirfin-Veitch, Conder, & Brandford, 2017). King and colleagues (2004) advocated that ACP should occur over time; and, individuals with IDD and their caregivers should be educated about aging, serious illness, the full range of treatment options, legal issues, dying, and grief.

A more recent systematic review by Voss and colleagues (2017) of research from the United States, Netherlands, Switzerland, the United Kingdom, and Belgium affirmed the utility of these approaches to ACP, but they noted that additional research was still needed to determine how best to routinely implement this process among individuals with IDD and their caregivers. Due to policy changes beginning in 2014, individuals receiving Medicaid-funded services are now required to participate in person-centered planning, which includes semi-annual interdisciplinary team meetings and comprehensive plan documentation that reflects individuals' long-term care needs (Lewis, 2014). Similarly, the policies of other nations have endorsed or required PCP, including the Department of Health in the United Kingdom and the Mental Health Commission of Canada (2016) among many others (Claes et al., 2010). The regularity and content of the PCP process suggests an ideal setting for the promotion of ACP, although no prior research has been conducted to ascertain if and how this may occur internationally or nationally.

The present study sought to begin to address this gap by first examining the frequency with which states' PCP processes articulate dimensions of ACP for individuals with IDD. Findings from this study suggest that many states' PCP documents allude to the 10 categories of ACP but far fewer contain content explicitly related to late-life transitions, such as aging and end of life. The two ACP categories most frequently evidenced in the states' PCP documents were diagnosis/prognosis (yes: 51.0%, $n = 25$) and retirement (yes: 22.5%, $n = 11$). Interestingly, funeral arrangements (no: 85.8%, $n = 42$) and burial funds (no: 79.6%, $n = 39$) were the least

frequently cited ACP categories included in states' PCP documents. The analyzed documents from California had 9 out of the 10 dimensions of ACP represented, indicating it was perhaps the most comprehensive of all PCPs.

The present study also sought to identify best practices observed within states' PCP documents; specifically, data exemplifying each of the 10 dimensions of ACP were extracted from policies, plan templates, and supplemental documents to illustrate the specific ways in which ACP content manifests in PCP documents for individuals with IDD. This finding suggests that there are numerous ways in which states' PCP documents can be constructed or adapted to routinely prompt explicit conversations about ACP, including facilitating discussions about diagnosis/prognosis, support needs and living arrangements, retirement, finances, burial funds and funeral arrangements, decision making and guardianship, and advance directives respective of the individual's and/or their caregivers' aging and end of life. Of the PCP documents analyzed for this study, at least one state exemplified each of the 10 ACP dimensions, with most dimensions being represented in distinctive ways by multiple states. Once again, California was identified as a model state, providing easily-replicable ACP content throughout its PCP documents.

Limitations

This study had several limitations that are important to acknowledge. The study data was limited to what was publicly available and/or confirmed by state representatives at the time of data collection. PCP documents that were not provided and/or were updated in the time since data collection were thus not included in the present study's results. In addition, states may be utilizing alternative strategies, beyond the PCP process, to promote ACP among individuals with IDD; for example, New York State's Office for People with Developmental Disabilities (2020)

has a dedicated “Aging Information Corner” that provides information and resources on aging with an IDD. However, to ensure a consistent method for conducting the content analysis and allow for systematic within-category comparisons, the research team limited the dataset to PCP documents. This study thus represents an initial effort to describe how ACP can be integrated into services for individuals with IDD; additional research is needed to elucidate the myriad ways in which state policies and practices are evolving to support individuals with IDD and their caregivers in planning for late-life transitions, such as aging and end of life.

The use of secondary data limited the conclusions that could be drawn in terms of how states went about integrating dimensions of ACP within their PCP process. While the study methodologies were intentionally selected to elucidate best practices and facilitate opportunities for replication, the findings offer only exemplars in terms of language used within PCP documents. Prior research suggested that the topic of aging and particularly end of life can be sensitive for individuals with IDD and their caregivers (McKenzie et al., 2017; Perkins & van Heumen, 2018). It is likely that the integration of ACP conversations into the PCP process would require states to consider the legal and ethical context. The efforts of policymakers to facilitate the inclusion of explicit ACP content within PCP documents could not be accounted for in this analysis. Thus, additional research is need to lend insight into not just what states include in their PCP documents but how “best practice” states went about integrating dimensions of ACP within their policies and documents.

Additionally, this content analysis was conducted exclusively with data derived from the United States. Those seeking to extrapolated the study findings to other nations, where policies related to ACP and PCP may differ, are advised to exercise caution. While local policies related to the implementation of ACP and PCP may differ from those described in this study, the

international research and practice community have endorsed both practices (Claes et al., 2010; Kirkendall, Linton, & Farris, 2017). Future research is needed to describe how other countries and localities might regard ACP as a component of the PCP process. To this end, the research team is preparing a replication study involving Canadian provinces and territories (Blinded).

Implications for Policy and Practice

Existing literature demonstrated that individuals with IDD and their caregivers tended to be apprehensive about future planning (Perkins & van Heumen, 2018). They often did not know what options are available to them and/or found that there were too few viable options (Lee, Burke, & Stelter, 2019; Taggart et al., 2012). Exacerbating this, until recently, the literature about individuals with IDD tended to focus primarily on children and adolescents, with only emergent research focusing on the transition to adulthood and later life (Botsford & King, 2005; Kirkendall, Linton, & Farris, 2017). This recent research, coupled with grassroots advocacy, has illuminated the necessity for both practice and policy to evolve in response to the growing population of aging adults with IDD (Hahn, Fox, & Janicki, 2015).

By identifying and discussing the age-related needs that tend to arise, practitioners working with individuals with IDD and their caregivers can help to guide the planning process across the lifespan through to advanced age and end of life. Yet, professionals have expressed discomfort initiating these conversations and often reported feeling uncertain how to facilitate planning in a comprehensive manner (Carr & Luth, 2017). When ACP conversations do not occur, individuals with IDD are less likely to have their needs met and wishes honored when they reach advanced age and experience serious illness (Voss et al., 2017). By describing the ways in which states have integrated ACP into the requisite PCP process, this study offers practitioners multiple examples of language they can use to elicit information about

diagnosis/prognosis, support needs, living arrangements, finances, burial funds, decision making, guardianship, retirement, funeral arrangements, and advance directives. Further, because the PCP is not ascribed to any specific profession but rather relies of an interdisciplinary approach, any member of the team including the individual with IDD or their caregiver can use the questions and prompts identified in this study to facilitate ACP. Ultimately, the best practices elucidated by this study serve as a model for how the wishes of individuals with IDD and their caregivers can be discussed and documented so that they are ultimately carried out the end of life nears.

Policymakers have faced increasing demand for resources and services as individuals with IDD experience normative and non-normative age-related declines and changes in caregiving due to a serious illness or death of a parent (Hahn, Fox, & Janicki, 2015). Striving to align with the principles of self-determination, the United States federal government has mandated states to adopt the PCP process as a means for ensuring long-term care needs are met and institutionalization is avoided (Lewis, 2014). However, it is difficult to ensure ACP discussions are routinely facilitated absent explicit prompts within PCP documents. This may be a contributing factor as to why ACP remains low and a disproportionate number of individuals with IDD find themselves in congregate care settings in later life (Moro, Savage, & Gehlert, 2017; USDHHS, 2007). This study illuminates the feasibility of integrating ACP within the PCP process. Policymakers may consider drawing influence from the best practice presented in the study findings to amend current policies, plan templates, and supplemental documents to include content explicit to dimensions of ACP. It is these regular conversations about individuals' values and wishes that are considered to make a meaningful difference in how individuals age and experience the end of life (AAIDD, 2012; IOM, 2014).

References

- Acharya, K., Schindler, A., & Heller, T. (2016) Aging: Demographics, trajectories and health system issues. In I. L. Rubin, J. Merrick, D. E. Greydanus, & D. R. Patel (Eds.) *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*, (pp. 1423-1432), Switzerland: Springer International Publishing.
- Ahuvia, A. (2001). Traditional, interpretive, and reception based content analyses: Improving the ability of content analysis to address issues of pragmatic and theoretical concern. *Social Indicators Research*, 54(2), 139-172. doi: 10.1023/A:1011087813505
- American Association on Intellectual and Developmental Disabilities (AAIDD). (2012). Caring at the end of life. Retrieved from <http://aaID.org/news-policy/policy/positionstatements/caring-at-the-end-of-life#.V5weJ5MrKEI>
- Arnold, C., Heller, T. & Kramer, J. (2012). Support needs of siblings of individuals with developmental disabilities. *Intellectual and Developmental Disabilities*, 50, 373-382. doi:10.1352/1934-9556.50.5.373.
- Bigby, C., Webber, R., & Bowers, B. (2015). Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. *Australian Social Work*, 68(4), 453-568. doi: 10.1080/0312407X.2014.950678
- Botsford, A. L., & King, A. (2005). End-of-life care policies for individuals with an intellectual disability: Issues and strategies. *Journal of Disability Policy Studies*, 16(1), 22-30.
- Carr, D. & Luth, E. A. (2017). Advance care planning: contemporary issues and future directions. *Innovation in Aging*, 1(1), 1-10. doi:10.1093/geroni/igx012
- Claes, C., Van Hove, G., Vandeveld, S., van Loon, J., & Schalock, R. L. (2010). Person-centered planning: Analysis of research and effectiveness. *Intellectual and*

Developmental Disabilities, 48(6), 432-453. doi: <https://doi.org/10.1352/1934-9556-48.6.432>

Department of Health (2009). *Valuing People Now: A new three-year strategy for people with learning disabilities*. Retrieved from <https://webarchive.nationalarchives.gov.uk/20110503151248/http://www.valuingpeoplenow.dh.gov.uk/sites/dhvpnweb.rroom.net/files/webfm/Valuing%20People%20Now%20Launching%20Page/Valuing%20People%20Now%20Strategy%20.pdf>

Doody, C. M., Markey, K., & Doody, O. (2013). The experiences of registered intellectual disability nurses caring for the older person with intellectual disability. *Journal of Clinical Nursing*, 22(7-8), 1112-1123. doi: 10.1111/jocn.12020

Friedman, S. L. & Helm, D. T. (Eds.). (2010). *End-of-life care for children and adults with intellectual and developmental disabilities*. Washington, DC: AAIDD.

Grant, G. (1990). Elderly parents with handicapped children: Anticipating the future. *Journal of Aging Studies*, 4, 359-374. doi: 10.1016/0890-4065(90)90005-S.

Hahn, J. E., Fox, S., & Janicki, M. P. (2015). Aging among older adults with intellectual and developmental disabilities: Setting national goals to address transitions in health, retirement, and late-life. *Inclusion*, 3(4), 250-259. doi: 10.1352/2326-6988-3.4.250

Heller, T. (2019). Bridging aging and intellectual/developmental disabilities in research, policy, and practice. *Journal of Policy and Practice in Intellectual Disabilities*, 16(1), 53-7. Doi: 10.1111/jppi.12263

Heller, T., Scott, H., & Janicki, M. P. (2017). Caregiving and intellectual and developmental disabilities and dementia: Report of the pre-Summit workgroup on caregiving and intellectual and developmental disabilities. Retrieved from

[https://aadmd.org/sites/default/files/Presummit%20on%20IDD%20Brief-FINAL
8'12'17a.pdf](https://aadmd.org/sites/default/files/Presummit%20on%20IDD%20Brief-FINAL%208'12'17a.pdf)

Institute of Medicine (IOM). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.

Johnson, B. B. (2010). Practical guide to health care decision making. In S.L. Friedman & D.T. Helm (Eds.), *End-of-life care for children and adults with intellectual and developmental disabilities* (pp. 133-146). Washington, DC: AAIDD.

King, A., Janicki, M., Kissinger, K., & Lash, S. (2004). *End of life care for individuals with developmental disabilities: The last passages project*. Retrieved from www.rrtcadd.org/resources/Resources/.../End-of-Life-Care/end_life_philosophy.doc

Kirkendall, A., Linton, K., & Farris, S. (2017). Intellectual disabilities and decision making at end of life: A literature review. *Journal of Applied Research in Intellectual Disabilities*, 30(6), 982-994.

Lewis, S. (2014). *Person-centered planning and self-direction: HHS issues new guidance on implementing Section 2402(a) of the Affordable Care Act*. Retrieved from <https://acl.gov/news-and-events/acl-blog/person-centered-planning-and-self-direction-hhs-issues-new-guidance>

Lee, C. E., Burke, M. M., & Stelter, C. R. (2019). Exploring the perspectives of parents and siblings toward future planning for individuals with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 57(3), 198-211. doi: 10.1352/1934-9556-57.3.198

McEnhill, L. S. (2008). Breaking bad news of cancer to people with learning disabilities. *British Journal of Learning Disabilities*, 36(3), 157-164. doi: [https://doi.org/10.1111/j.1468-](https://doi.org/10.1111/j.1468-3156.2008.00517.x)

[3156.2008.00517.x](https://doi.org/10.1111/j.1468-3156.2008.00517.x)

McGinley, J., Waldrop, D. P., & Clemency, B. (2017). Emergency medical services providers' perspective of end-of-life decision making for individuals with intellectual disabilities.

Journal of Applied Research in Intellectual Disabilities, 30(6), 1057-1064. doi:

<https://doi.org/10.1111/jar.12363>

McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brandford, S. (2017). "I'm still here": Exploring what matters to individuals with intellectual disability during advance care planning.

Journal of Applied Research in Intellectual Disabilities, 30(6), 1089-1098. doi:

<https://doi.org/10.1111/jar.12355>

Mental Health Commission of Canada (2016). From theory to practice: An introduction to person-centered practice. Retrieved from

[https://www.mentalhealthcommission.ca/sites/default/files/2016](https://www.mentalhealthcommission.ca/sites/default/files/2016-11/An%20Introduction%20to%20Person-Centered%20Planning_oct_216_eng.pdf)

[11/An%20Introduction%20to%20Person-Centered%20Planning_oct_216_eng.pdf](https://www.mentalhealthcommission.ca/sites/default/files/2016-11/An%20Introduction%20to%20Person-Centered%20Planning_oct_216_eng.pdf)

Moro, T. T., Savage, T. A., & Gehlert, S. (2017). Agency, social and healthcare supports for adults with intellectual disability at the end of life in out-of-home, non-institutional

community residences in Western nations: A literature review. *Journal of Applied*

Research in Intellectual Disabilities, 30(6), 1045-1056. doi:

<https://doi.org/10.1111/jar.12374>

Neuendorf, K. A. (2017). *The content analysis guidebook* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

- New York State Office for Individuals with Developmental Disabilities. (2020). *Aging information corner*. Retrieved from https://opwdd.ny.gov/opwdd_community_connections/aging_information_corner
- Padgett, D. (2008). *Qualitative methods in social work research (2nd ed.)*. Thousand Oaks, CA: Sage Publications, Inc.
- Perkins, E. & van Heumen, L. (2018). When the journey ends: Parental caregiving and later life planning. In B.S. Nelson Goff & N. Piland Springer. (Eds). *Intellectual and developmental disabilities: A roadmap for families and professionals*, (pp. 216-228), New York, NY: Routledge, Taylor & Francis Group.
- Robertson, J., Emerson, E., Hatton, C., Elliot, J., McIntosh, B., Swift, P., Krijnen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P. & Joyce, T. (2005). *The Impact of Person Centred Planning*. Institute for Health Research, Lancaster University.
- Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Routledge, M., Sanderson, H., Oakes, P., & Joyce, T. (2007). Person- centred planning: Factors associated with successful outcomes for individuals with intellectual disabilities. *Journal of Intellectual Disability Research*, 51(3), 232-243. doi: 10.1111/j.1365-2788.2006.00864.
- Smith, C. P. (2000). Content analysis and narrative analysis. In H. T. Reis & C. M. Judd (Eds.), *Handbook of Research Methods in Social and Personality Psychology* (pp. 313-335). New York, NY, US: Cambridge University Press.
- Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual

disability. *Journal of Intellectual Disabilities*, 16(3), 217-234. doi:

10.1177/1744629512456465

Taylor, J. E. & Taylor, J. A. (2013). Person-centered planning: Evidence-based practice, challenges, and potential for the 21st century. *Journal of Social Work in Disability & Rehabilitation*, 12(3), 213-235. doi: <https://doi.org/10.1080/1536710X.2013.810102>

The Arc Center for Future Planning (2016). *Where to start*. Retrieved from

<https://futureplanning.thearc.org/pages/learn/where-to-start/expressing-wishes-for-the>

future

Voss, H., Vogel, A., Wagemans, A. M., Francke, A. L., Metsemakers, J. F., Courtens, A. M., & de Veer, A. J. (2017). Advance care planning in palliative care for individuals with intellectual disabilities: A systematic review. *Journal of Pain and Symptom Management*, 54(6), 938-960. doi: 10.1016/j.jpainsymman.2017.04.016

Voss, H., Vogel, A., Wagemans, A. M., Francke, A. L., Metsemakers, J. F., Courtens, A. M., & de Veer, A. J. (2019). Advance care planning in the palliative phase of people with intellectual disabilities: Analysis of medical files and interviews. *Journal of Intellectual Disability Research*, 63(10), 1262-1272.

Yadav, K. N., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., ... & Courtright, K. R. (2017). Approximately one in three US adults completes any type of advance directive for end-of-life care. *Health Affairs*, 36(7), 1244-1251. doi: 10.1377/hlthaff.2017.0175

United States Department of Health and Human Services (USDHHS). (2007). Literature review on advance directives (#HHS-100-03-0023). Washington, DC.: U.S. Government Printing Office.

Table 1

Frequency of Advance Care Planning (ACP) Categories in State Person-centered Planning (PCP) Documents (N = 49)

ACP Category & Description	ACP Category Evidenced in PCP Document, % (n)			*Best Practice States
	Yes*	Somewhat	No	
Diagnosis/Prognosis <i>Does the plan seek to identify the person's diagnosis and prognosis?</i>	51.0 (25)	16.3 (8)	32.7 (16)	Alabama, Alaska, Arizona, California, Colorado, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Kentucky, Maryland, Mississippi, Missouri, Montana, Nebraska, New Mexico, North Carolina, Oklahoma, Oregon, Utah, Virginia, Wyoming
Support Needs <i>Does the plan seek to address support needs respective of the person's aging and/or end of life?</i>	14.3 (7)	81.6 (40)	4.1 (2)	California, Connecticut, Illinois, Kentucky, Louisiana, Missouri, New Mexico
Living Arrangements <i>Does the plan seek to address the potential need to change or modify living arrangements in response to the person and/or their caregivers' aging and end of life?</i>	2.0 (1)	77.6 (38)	20.4 (10)	Louisiana
Retirement <i>Does the plan seek to address the person's retirement preferences and planning?</i>	22.5 (11)	22.5 (11)	55.0 (27)	California, Connecticut, Kentucky, Louisiana, Maryland, Mississippi, Montana, New Mexico, Oregon, Pennsylvania, Washington DC
Finances <i>Does the plan seek to address finances respective of the person and/or their caregivers' aging and/or end of life?</i>	12.2 (6)	65.3 (32)	22.5 (11)	California, Connecticut, Kentucky, Montana, Oregon, Virginia
Burial Funds <i>Does the plan seek to address the person's burial fund?</i>	16.3 (8)	4.1 (2)	79.6 (39)	California, Connecticut, Delaware, Georgia, Montana, New Jersey, Pennsylvania, Tennessee, Kentucky, Virginia
Funeral Arrangements <i>Does the plan seek to address the person's preferences for funeral arrangements?</i>	12.2 (6)	2.0 (1)	85.8 (42)	California, Connecticut, Delaware, New Jersey, Pennsylvania, Washington DC
Decision Making <i>Does the plan seek to address decision making respective of advance care planning and health care decision making for the person?</i>	12.2 (6)	63.3 (31)	24.5 (12)	California, Colorado, Connecticut, Georgia, New Mexico, Tennessee
Guardianship <i>Does the plan seek to address successorship plan in the event the guardian experiences incapacity or death?</i>	10.2 (5)	65.3 (32)	24.5 (12)	California, Colorado, Connecticut, Montana, New Mexico
Advance Directives <i>Does the plan document the presence of advance directives that express the person's and/or surrogates' wishes?</i>	24.5 (12)	--	75.5 (37)	California, Colorado, Connecticut, Florida, Georgia, Iowa, Kentucky, Maryland, New Mexico, Pennsylvania, Tennessee, Washington DC



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Supplemental Material

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