

A large orange circle is positioned on the left side of the slide, partially cut off by the edge.

We will start
shortly....

Our program will begin
promptly at 3:30 p.m. ET.

Until then, please sit back
and enjoy a moment of quiet
solitude!



NACDD

National Association of Councils
on Developmental Disabilities

Candid Conversations about End-of-Life:

*Strategies for Improving Inclusion and Access of People with IDD into
End-of-Life Planning, Strategies, and Grieving Supports*

Bridging Aging & Disability Networks (BADN) National Community of
Practice Quarterly TA Event

September 23, 2025 3:30-5:00 p.m. ET

Maximizing Your Webinar Participation: *Zoom Tips, 1/2*

- **Audio Settings:** You can change your [audio settings](#). You can also click the upward arrow (^) next to the microphone icon at the lower-left of the Zoom window to change your speaker.
- **Captioning:** Available in a separate browser window by clicking the [following page on Captioned Text](#).
- **Questions:** If you have a question for today's presenters, please type it in the Q&A box at any time during the presentation. You do not have to wait for the Q&A discussion to begin. Open the Q&A window, type in your question, and then press "send". You can also include questions in the chat box. You will receive a reply back via text in the Q&A window or the question will be answered live.

Maximizing Your Webinar Participation: *Zoom Tips, 2/2*

- **During the Interactive Discussion**
 - **Raise Hand:** [Raise your hand](#) when the interactive discussion begins if you would like to provide feedback or make a comment regarding a specific question that has been asked of the participants.
 - **Unmute/Mute:** Once the host acknowledges you, you can unmute by pressing the “Mute/Unmute” button at the task bar at the bottom of your screen, and then provide your comments. All participants will be able to hear you during this time. Be sure to mute yourself again after you have made your comments.
- **Leave meeting:** Click **Leave meeting** to leave the webinar at any time. You can rejoin if the webinar is still in progress.

What is the Bridging Aging & Disability Networks Initiative?

- The Bridging Aging & Disability Networks Initiative supports States to enhance and improve services and supports available to aging individuals with I/DD and their families
 - Brings together state government entities, federally-funded aging & disability networks, and other external partners through State Alliance Teams (SATs).
 - Provides seed funding and technical support to SATs to accelerate efforts for supporting aging adults with I/DD and their families.
 - From our shared learnings and promising practices, we then support scaling, sustaining and replicating these efforts nationally.
- Participating State Teams receive:
 - Small cash grants
 - State-specific technical assistance
 - Quarterly National COP Meetings + Quarterly TA Events
 - Annual In-Person CoP Meeting



Today's Agenda

Exploring the Topic of End of Life with People with IDD: National & International Perspectives

- **Strategies and Resources for Supporting and Encouraging Thoughtful Engagement of Individuals with IDD in Topics surrounding End-of-Life Care**
 - **Dr. Jacqueline McGinley, PhD, LMSW, FAAIDD]**
- **Exploring End of Life Care Preferences with People with ID: A Case Study in Ireland**
 - **Dr. Marissa Andréah Diaz**
- **Resource Spotlight: An Overview of the "Talking End of Life" Curriculum and Online Toolkit from Australia**

Speaker Q&A

BADN State Highlights

- ***Promising Approaches to Improving Inclusion and Access of People with IDD into End-of-Life Planning, Strategies, and Grieving Supports***

Interactive Discussion

Strategies and Resources for Supporting and Encouraging Thoughtful Engagement of Individuals with IDD in Topics Surrounding End-of-Life Care

Jacqueline McGinley, PhD, LMSW, FAAIDD
Associate Professor & MSW Program Director
Binghamton University



AGENDA

- Overview: Advance Care Planning
 - Macro-level Considerations: Policy
 - *Integrating advance care planning into the person-centered planning process*
 - Mezzo-level Considerations: Organizations
 - *Implementing an integrative care model to support aging and end-of-life care.*
 - Micro-level Considerations: Individuals & Families
 - *Resources for facilitating engagement around end-of-life care*
 - Question & Comments
-

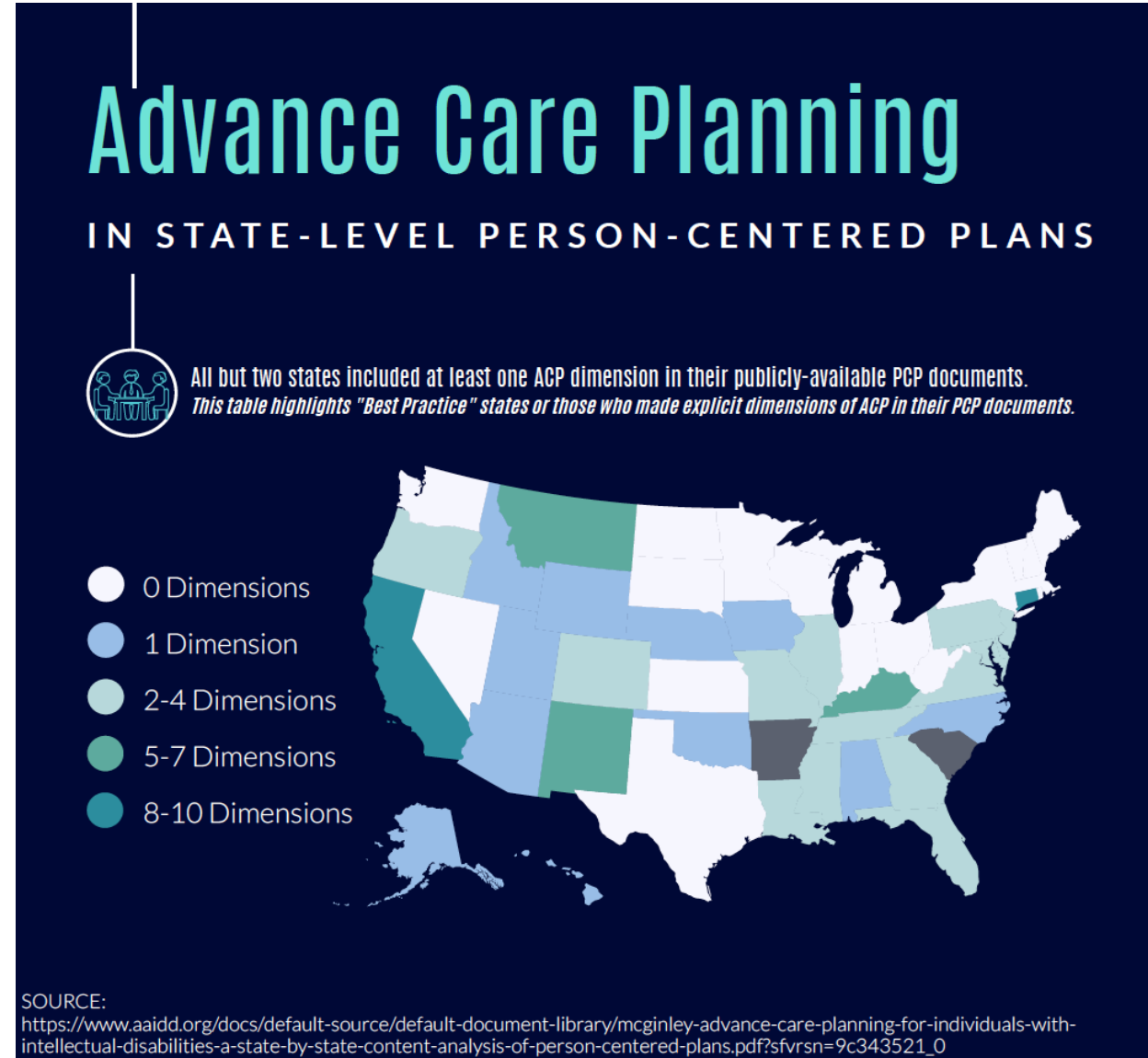


Advance Care Planning (ACP)

- “...Learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know—both your family and your healthcare providers—about your preferences” ([National Institute on Aging \[NIA\], 2022, p. 1](#)).

Macro-level Considerations: Local, State, Federal Policies

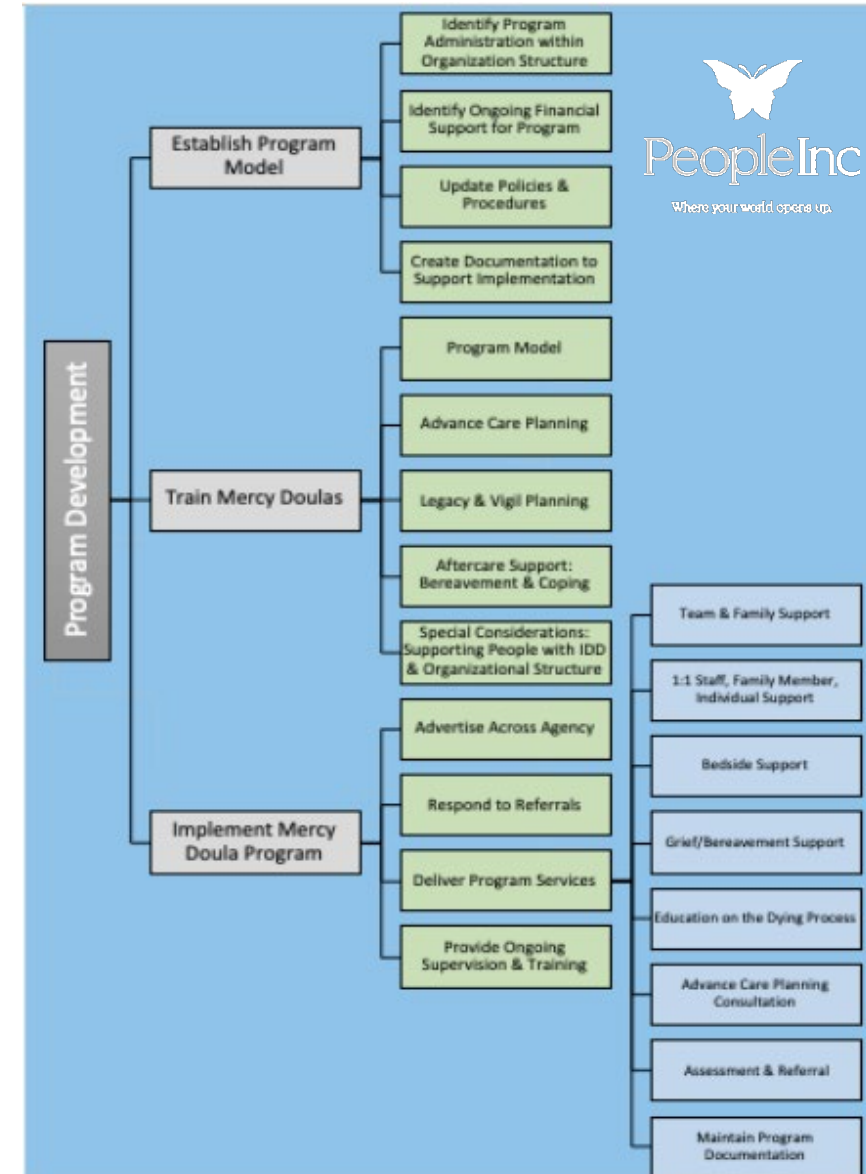
- State-level person-centered plans often articulated at least one dimension of advance care planning. However, few states articulated these specific to aging and end-of-life.
- Findings from this study suggested opportunities for the integration of content specific to aging and end-of-life care within person-centered plans and the semi-regular meetings that often accompany these plans.
- “Exemplar” plans can inform strategies for integrating tenets of ACP within existing person-centered planning processes throughout the United States and internationally.



Mezzo-level Considerations: Organizational Programs

The Mercy Doula & Life Transitions Program offers integrative care with an interdisciplinary focus:

- **Proactive** - initial diagnosis, assessment of current supports, services and needs, team discussions, build trust and rapport
- **Active** - direct support to the person/support network, care planning needs and updates
- **Reactive** - bereavement and after care supports, celebration of life, 1:1 opportunities to work through grief and loss



Micro-level Considerations: Individual & Family Supports

Organizations of Note

- [American Academy of Developmental Medicine & Dentistry](#)
- [American Association on Intellectual and Developmental Disabilities](#)
- [Alliance for Disability in Healthcare Education](#)
- [National Task Group on Intellectual Disabilities and Dementia Practices](#)
- [Palliative Care for People with Learning Disabilities \(PCPLD\)](#)

Clinical Resources and Tools

- [Coalition for Compassionate Care of California](#)
- [Talking End of Life ... with people with intellectual disability](#)
- [The ARC's Center for Future Planning](#)
- [The Victoria & Stuart Project](#)



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With thanks.

Jackie McGinley, jmcginle@binghamton.edu, (315) 460-0585

Exploring End of Life Care Preferences with People with ID: A Case Study in Ireland

Dr. Marissa Andréah Diaz

Postdoctoral Research Associate

Department of Disability and Human Development, College of Applied Sciences, University of Illinois Chicago

About Me

- PhD (Dr. Sci) Health Sciences from the University of Lucerne
 - LLM International Law from the University of Kent's Brussels School of International Studies
- Sibling of woman with ID



Perceived barriers and facilitators to good end of life care: Focusing on people with intellectual disabilities

- Published in the *Journal of Applied Research in Intellectual Disabilities* in December 2023
- Presented 17th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), focusing on online methods





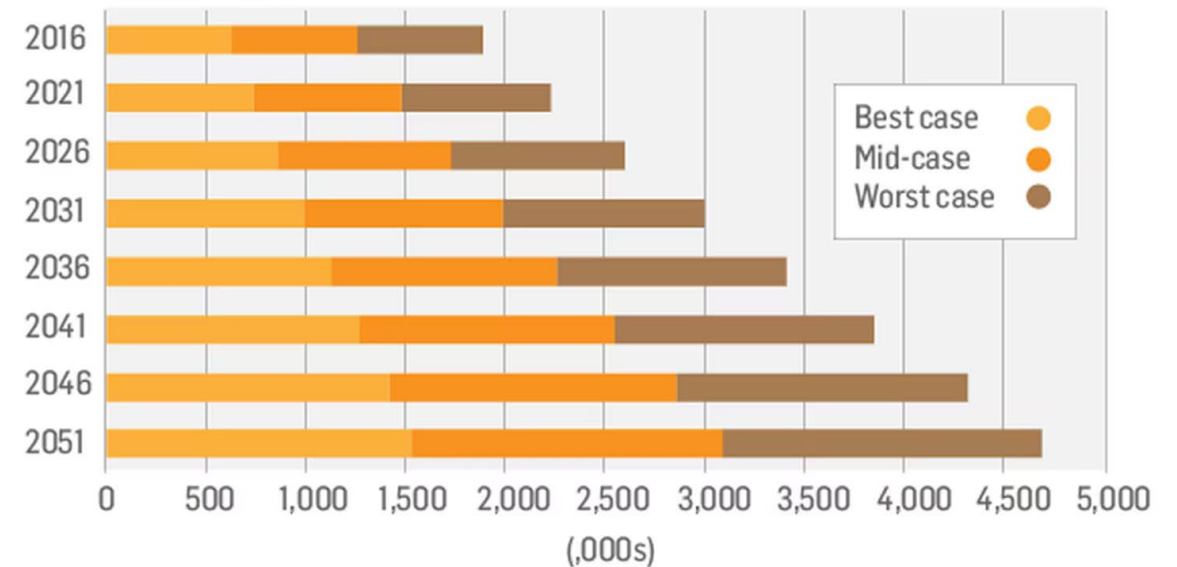
- Ireland as a Case in Point
- Study Objectives
- Method
- Data Collection
- Data Analysis
- Results
- Theme Discussions
- Preferences Derived from Focus Groups
- Conclusions

AGENDA

Background Information on Ireland

- National palliative care policy since 2001¹
- People with intellectual disabilities account for **1.4% of Ireland's population**²
 - Living longer but still dying at younger age than the general population³
- Inequities in health care access in Ireland; people with mild intellectual disabilities, those who live independently or with a family carer, and those associated with smaller agencies without healthcare professionals **have a greater risk of limited or no health care access**⁴
- There is evidence that in Ireland both intellectual disability services and palliative care services lack the confidence needed to deliver end of life care to this population, although they are willing to collaborate with each other⁵

Projected population aged 65 years and over, 2016-2051



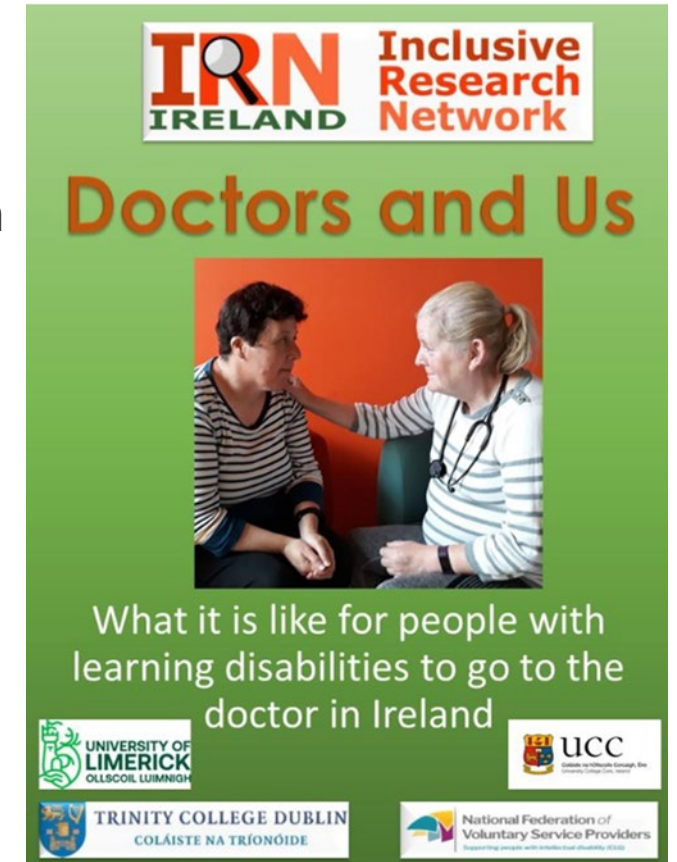
Credit: Wall and Hogan-Jones 2019 / The Irish Times

Study Objectives

- Investigate this population's perceptions on barriers and facilitators to getting good end of life care **at home and at hospice**
- Explore if there are **differences between their perceptions** of receiving care at home versus receiving care at a hospice
- Investigate their perceptions so we have evidence informed from service users that leads to **better policy and practice** that enhances facilitators and removes barriers
- **Test out the use of Zoom** for conducting qualitative research with people with intellectual disabilities, specifically on death and dying

Method Part 1

- Due to COVID-19, **Zoom was chosen to facilitate focus groups and meet with co-researchers.**
- Reached out to Inclusive Research Network **to recruit researchers with intellectual disabilities** to either work on the project with me or be a participant later on.
 - 3 people volunteered to be part of pilot study, 2 of these 3 wished to conduct the focus groups with me.
- We decided to call our group the **Researching Life's End Group** and met 1-2 times a month



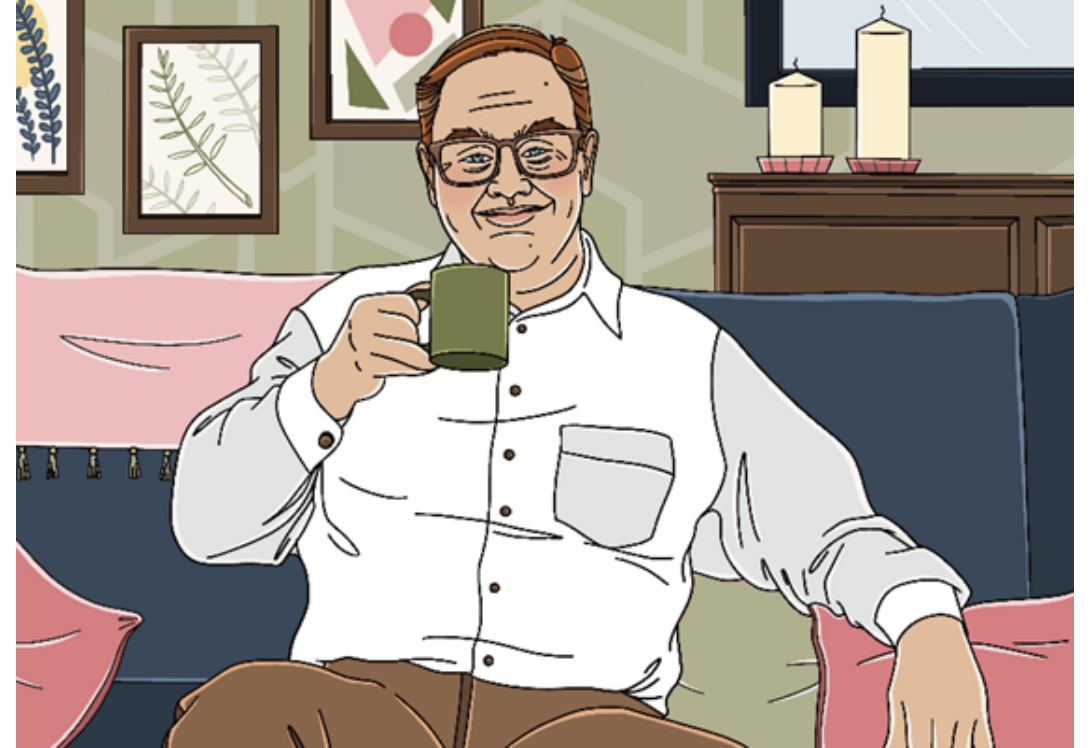
Method Part 2

- Participants had to....
 - Identify as having an intellectual disability
 - Be 18 years old or over
 - Be able to communicate in English
 - If a participant was non-verbal or had verbal communication difficulties, their supporter, interpreter, or assistive device had to be able to communicate in English.
 - Not currently live in a residential community
- In line with Article 12 of the United Nations' Convention on the Rights of Persons with Disabilities, capacity to consent in the study was assumed⁶
 - The Convention⁷ asserts that everyone enjoys legal capacity, regardless of their decision-making skills

Data Collection Part 1



“Mary”



“Colm”

Data Collection Part 2



What do you think would **help** Mary get good end of life care at home?

What would **get in the way** of Mary getting good end of life care at home?

Data Analysis

- Reflexive thematic analysis
 - Familiarization with the data was facilitated in part by making notes
 - Initial themes were generated by me after undertaking a process of **analyzing and re-analyzing the transcripts and generating codes**
 - Initial themes were discussed with Fionn before finalizing, with themes being presented via Zoom using PowerPoint for accessibility
- Validity
 - **Reflexive journal** before, during, and after data analysis
 - **Pilot study**
 - Section written by co-researcher, Fionn

Results

- Focus groups took place in March and April 2022, respectively (~60 minutes long)
- 4 participants participated in 2 focus groups (3 women and 1 man)
- None of the participants brought along a supporter to the Zoom calls
- One group had two participants in their 20's and the other group had two participants in their 50's

Discussing the "Mary" and "Colm" situations elicited reflection from participants on their own experiences with end of life and what they would want for themselves.

A variety of barriers and facilitators were highlighted and can be grouped into three broad themes: **Unsettling Transitions**, **Maintaining Familiarity**, and **Respecting People's Wishes**.

Theme 1 – Unsettling Transitions

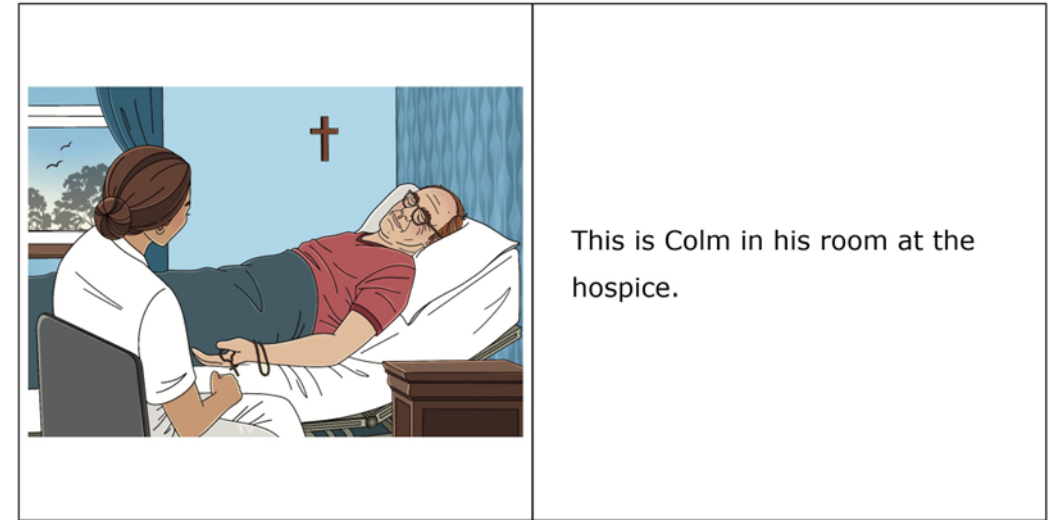
- Participants did not focus much on what "Mary" or "Colm" might be experiencing in the physical sense as they were dying (e.g. physical weakness), but rather on the surrounding environment.
 - **Financial resources** were highlighted as an important factor by participants. Hospice was generally perceived to be more expensive to participants in comparison to staying at home
- There was a perception that family alone decides when one goes to hospice, or at least are a factor that affects decisions that are made
- **Lack of family support** was acknowledged to be a barrier to good end of life care, specifically with regard to Mary and Colm being able to make informed decisions.

At least if you're at home, people would know you. And then people in a hospice, a hospital, they wouldn't know you as good as family and friends would. So, I would prefer to die at home.

"Anne"

Theme 2 – Maintaining Familiarity

- Participants highlighted the importance of having people, surroundings, and routines as unchanged as possible
- One's surroundings were considered an important aspect of getting good end of life care
 - Settings that were not reflective of the dying person's wishes and preferences were inferior
- Participants suggested that "Colm" could bring things from home such as magazines to read and art to decorate the walls
 - Despite these suggestions, hospice was in general not perceived to be as comfortable as one's home



...It'd be great to stay in touch online. And also, if their family visit[s] maybe more often, then that'd be great support, actually. I think it's [a] good idea. Because they might miss...because they might miss their family now.

"Rita"

Theme 3 – Respecting People’s Wishes

- **All participants** voiced the opinion that **one's wishes must be respected** when they are dying and discussed barriers and facilitators to achieving this aim
 - The person’s family and medical staff may affect one's wishes being respected at end of life
- Knowledge of end of life services as an important asset in helping people make sure their choices were heard.
 - **Writing down last wishes** and selecting a **next-of-kin**

They should have a system set up where they can be allowed to make their rights before dying and let somebody that ... Like, have an advocate that would talk up on behalf of them if they were too sick ... the advocate could read out what choice they made before they die.

“Deirdre”

Themes with Barriers & Facilitators

Theme Name	Barriers [to good end of life care]	Facilitators [to good end of life care]
Unsettling Transitions	<ul style="list-style-type: none">-Financial resources-Lack of family support	<ul style="list-style-type: none">-Having hospice physically close by your home
Maintaining Familiarity	<ul style="list-style-type: none">-Overcrowded hospice facilities-Unfamiliar staff	<ul style="list-style-type: none">-Using technology to stay in touch-Keeping personal effects (décor, mementos, etc.)
Respecting People's Wishes	<ul style="list-style-type: none">-Medical staff making choices for you-Family making choices for you	<ul style="list-style-type: none">-Selecting next-of-kin-Completing a will-Family making choices with you

Preferences Derived from Focus Groups

- **Family support** was perceived as crucial, but ultimately participants wanted a say in their end of life experiences
- Participants **wanted to know more** about end of life care planning
 - Some participants wanted more specific information on next steps to take
- Preferences were largely derived from previous experiences with **the deaths of their parents, spouses, or friends**

Conclusions

- People with intellectual disabilities will inevitably experience end of life and it is important that they are informed **of what will happen to them and their right to make choices**
- **Accessible advanced care planning** that responds to the wishes of the dying must be seen as an essential part of end of life care for this population
 - Accessible and thorough information must be delivered to people with intellectual disabilities and their carers
- There is potential for using Zoom to capture the view of people with intellectual disabilities, but researchers should take certain issues into consideration such as **recruiting online, establishing rapport, and maintaining privacy**



References

- [1] May, Peter, Geralyn Hynes, Philip McCallion, Sheila Payne, Philip Larkin, and Mary McCarron. 2014. "Policy Analysis: Palliative Care in Ireland." *Health Policy* 115(1):68–74. doi: 10.1016/j.healthpol.2013.07.016.
- [2] Central Statistics Office. 2016. "Types of Disability."
- [3] Doyle, Anne, Michael O'Sullivan, Sarah Craig, and Roy McConkey. 2021. "People with Intellectual Disability in Ireland Are Still Dying Young." *Journal of Applied Research in Intellectual Disabilities* 34(4):1057–65. doi: 10.1111/jar.12853.
- [4] Doyle, Anne, Michael O'Sullivan, Sarah Craig, and Roy McConkey. 2022. "Predictors of Access to Healthcare Professionals for People with Intellectual Disability in Ireland." *Journal of Intellectual Disabilities* 26(1):3–17. doi: 10.1177/1744629520937835
- [5] Ryan, Karen, Suzanne Guerin, Philip Dodd, and John McEvoy. 2011. "Exploring the Experiences of People with Intellectual Disabilities When Service Users Die: Exploring Service User Experiences of Death." *British Journal of Learning Disabilities* 39(4):259–65. doi:10.1111/j.1468-3156.2010.00662.x.
- [6] Dye, Linda, Steve Hendy, Dougal Julian Hare, and Mark Burton. 2004. "Capacity to Consent to Participate in Research – a Recontextualization." *British Journal of Learning Disabilities* 32(3):144–50. doi: 10.1111/j.1468-3156.2004.00262.x.
- [7] CRPD Committee, *General comment No. 1: Art 12: Equal recognition before the law*, 11th Sess, adopted 11 April 2014, UN Doc CRPD/GC/1, paras. 13-15.

This Project Was Supported By...

- Disability Advocacy Research in Europe
 - Marie Curie Innovative Training Network - Grant Agreement Number: 814249 - DARE - Horizon-MSCA-ITN-2018
- University of Lucerne
- Swiss Paraplegic Research
- University of Galway





Thank you!

Dr. Marissa Andréah Diaz

Postdoctoral Research Associate

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Questions?

Please share your questions with us by either:

- *Raising your hand and coming of mute to ask your question or share your thought.*
- *Writing your question or comment in the Group Chat or Q&A Feature on Zoom.*

Another Interesting International Model: Australia's Talking End-of-Life Program

- **12 modules designed around a suite of 3 topics:**
- **How do I do this?** Any or all of these 5 modules will help if you're unsure about your role, how to teach about the end of life, or how to manage cultural beliefs or feelings.
- **Teaching how to understand end of life:** Any or all of these 3 modules will help you to teach about dying, death, and loss, grief and mourning.
- **Teaching the planning options:** Any or all of these 4 modules will help if you want to teach about how to plan for dying and death.



How do I do this?

How do I do this?

5 modules which help you understand your role as a disability support worker.

Why is this important?



Facilitator's guide - Why is this important
(1.2MB pdf)

Cultural beliefs



Facilitator's guide - Cultural beliefs
(960kb pdf)

Managing feelings



Facilitator's guide - Managing feelings
(1.3MB pdf)

Your role as a DSP



Facilitator's guide - Your role as a DSP
(1.1MB pdf)

Handy teaching skills



Facilitator's guide - Handy teaching skills
(1.2MB pdf)

Teaching how to understand End-of-Life

Teaching how to understand end of life

3 modules covering the key issues about dying and death.

Dying



Facilitator's guide - Dying
(1.2MB pdf)

Death



Facilitator's guide - Death
(1.4MB pdf)

Loss, grief and mourning

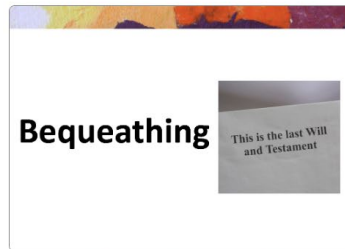


Facilitator's guide - Loss, grief and mourning
(1.5MB pdf)

Teaching the Planning Options

Teaching the planning options

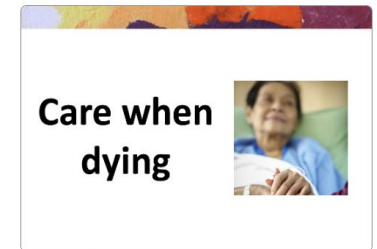
4 modules about the things people with intellectual disability might want to plan for regarding their own end of life.



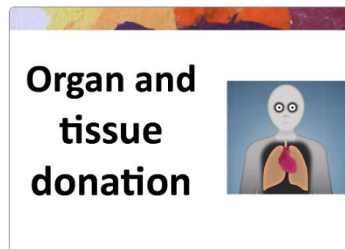
Facilitator's guide - Bequeathing
(1.2MB pdf)



Facilitator's guide - Funeral wishes
(1.4MB pdf)



Facilitator's guide - Care when dying
(1.1MB pdf)



Facilitator's guide - Organ and tissue donation
(911kb pdf)

Learn More about Australia's Talking End-of-Life Program: Resources



Home Site

<https://www.caresearch.com.au/terminal/>



Resources



Videos

<https://vimeo.com/260006132?fl=pl&fe=sh>

BADN State Highlights

- *Promising Approaches to Improving Inclusion and Access of People with IDD into End-of-Life Planning, Strategies, and Grieving Supports*
 - Kansas: Exploring Palliative/Hospice Care for Individuals with IDD
 - New Jersey: Intentionally Embedding End-of-Life Preparation into Futures Planning
 - California: Resource Spotlight – “Thinking Ahead: My Life at the End”
 - [People With Developmental Disabilities Resources](#)



Awareness to Action:

**Advancing Hospice and Palliative Care for
Individuals with Intellectual and Developmental
Disabilities (IDD)**

Allyson McCain
Deputy Director / Health Equity and Outcomes Coalition Director
Kansas Council on Developmental Disabilities (KCDD)



Eddie and Kaye's Story: The Origin of the Hospice and Palliative Care + IDD Project



Project Advisory Members



**CDDN Health Supports
Coordinator at Johnson County
Developmental Supports**



**Retired nurse with
experience serving
adults with I/DD**



**Director of Adult Health
Services**



Pediatric Palliative Care

Caregivers & Self-Advocates



**Clinical Assistant Professor of
Pediatrics, University of Missouri-
Kansas City School of Medicine**

Lived Experience Survey Results



- 11 Caregivers with lived experience with a loved one with I/DD that received hospice or palliative care responded to the survey
- The survey was sent out to the KCDD Health Equity Coalition, shared with providers and disability organizations, and on various social media channels

Lived Experience Survey Results cont'd

“Hospice nurse and aides welcomed questions and offered solutions”

“Support for the caregivers so that they didn't feel alone.”

“Actually the support and care for the staff and family. They always made sure client was kept comfortable but also kept the staff and family apprised of the situation at all times so nothing was a surprise.”

“Pain management and other health care needs”

What was most beneficial from your experience?

“Have access to a doctor 24/7 for orders to provide comfort”

“Information, options, care, safety”

“Assisting with orders to ensure person served can remain in our facility care, support to staff, support to person served, communication with providers, guidance on end of life expectation, what to look for, assistance with setting up DNR.”

More Lived Experience Survey Results

“Working with the insurance, doctors and facilities to get them the services they need.”

“We need to provide more education on the paperwork that we need from our agency.”

“In Florida, Hospice did not come out at the time of death. This was very challenging for the family.”

“Not knowing anything BEFORE we needed it.”

What were some of the challenges you or your loved one experienced utilizing hospice or palliative care?

“Perceptions of end-of-life care vary—some approaches go too far, while others honor a client’s dignity. No one should endure extreme measures like 90 minutes of CPR simply due to guardianship rules requiring two doctors to declare death. While rare abuses exist, they shouldn’t justify stripping decision-making power from most guardians and clients. It’s about dignity.”

“Some counties does not have a nurse extremely close. It does take time for a nurse to arrive onsite sometimes however they are available immediately by phone. Truly amazing people that we have experienced w/using Hospice.”



Understanding Hospice and Palliative Care



Serious illnesses can be hard for people with intellectual and developmental disabilities. Hospice and palliative care can provide support and comfort. These services help manage pain, emotions, and daily needs, making sure people get the care they deserve.

Palliative Care:

- Helps people feel better while they are sick.
- Can be given at any time during an illness.
- Works with other treatments to control pain and stress.
- Can be provided by a variety of different professions.

Examples: Cancer, heart disease, lung disease, kidney failure, and neurological conditions like Parkinson's.

Hospice Care:

- Helps people who are near the end of life.
- Focuses on comfort instead of curing the illness.
- Supports the person and their caregiver(s).
- Medical equipment may be provided.

Examples: Advanced cancer, late-stage heart failure, late-stage dementia, ALS, terminal illnesses



How These Services Can Help:

- **Pain Relief:** Doctors and nurses help manage pain and discomfort.
- **Emotional Support:** Counselors and social workers help with feelings and fears.
- **Help for Families:** Caregivers get support and guidance.
- **Comfort and Respect:** The person's choices and dignity are honored.



How to Get Hospice or Palliative Care:

1

Talk to Your Doctor

Ask if these services are right for you or your loved one.

2

Choose a Provider

Get assistance in finding a hospice or palliative care team that understands people with I/DD.

3

Make a Care Plan

Work with the team to make a plan that meets your needs.



Things to Think About:

Pain & Comfort	Routine	Emotional Needs	Advocacy
Make sure the support team knows how the person shows and communicates pain.	Keeping a familiar schedule can help the person feel safe.	The person may need help understanding what is happening.	Caregivers can speak up to make sure the person's wishes are followed.

A Guide Created by Whit Downing, VP of Policy and Programming,

KCDD- whit@kcdd.org

Provider Experience Survey Results



- 7 Hospice and Palliative Care providers completed the survey – all respondents have specifically provided care to someone with n IDD
- The survey was sent out to the KCDD Health Equity Coalition, shared with providers and disability organizations, sent to the KS state network of hospice and palliative care providers, and on various social media channels

Provider Experience Survey Results

“listen, talk, understand the underlying issue and not take that as the reason for the hospice care. Down syndrome is not the reason for hospice but dementia is. Cerebral palsy is not the reason, but chronic pain, multiple fractures, and "withering" are reasons”

“Rely on staff to get to know pt's preferences, strengths. Allow pt to get to know me slowly to build trust and understanding.”

“Having frequent communication with family.”

What strategies have you found most effective in providing compassionate and appropriate care to individuals with IDD?

“Incorporating the team that provides care to the individuals-- becoming part of the whole team for the pt”

“listening skills, along with discernment, and empathy”

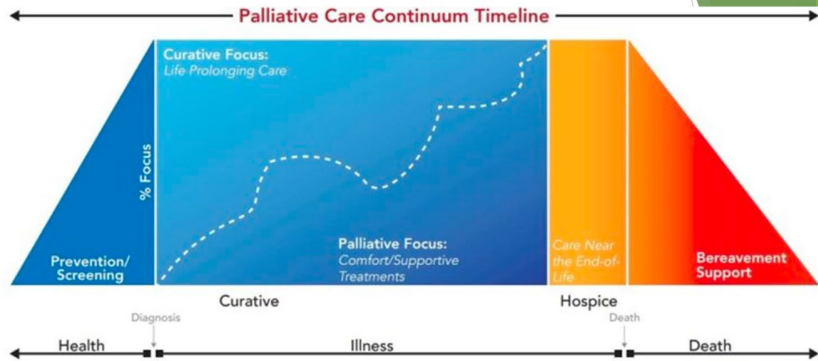
“Providing staff training is imperative. Working with the hospice company providing the care is a great way to bridge any gaps that may exist, since hospice/palliative care is not something that is provided often.”

What challenges have you encountered when providing hospice or palliative care to individuals with
IDD?



- “patient difficulty to fully understand circumstances”
- “if DNRs are not supported in the group home”
- “Number of staff requiring communication and receiving communication by email that is difficult to access.”
- “Billing and staff education/training.”
- “Facilities not honoring DNR to allow pts to die peacefully.”
- “people kicked out of hospice for not dying fast enough, physical therapy not being approved because it is palliative, not curative when a patient has physical therapy to treat pain as a baseline problem. taking PT away is not a way to treat people for pain”

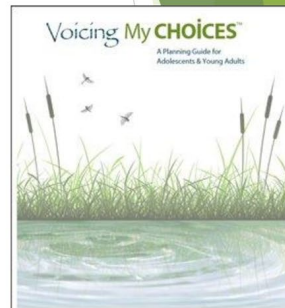
KCDD Hospice and Palliative Care for Individuals with IDD Webinar



The Palliative Care “Umbrella”

Advance Care Planning Tools

- Resources in print:
 - Five Wishes
 - Voicing My Choices
 - My Wishes



- **Speakers:** Dr. Jane Charget, the University of Michigan and Dr. Taylor Jersak, Children’s Mercy Kansas City
- **Topics covered:**
 - Review of Palliative Care and Hospice
 - Barriers to Palliative Care for individuals with IDD
 - Special Considerations for Palliative Care for the IDD population
 - Advance Care Planning (ACP): what is it, and how to approach ACP in the IDD populations
 - Palliative Care in special populations: Adolescents and Children
- **Attendees:** 344 total viewers
- **Recording up on the KCDD website:**
<https://www.kcdd.org/hospice-and-palliative-care-webinar>

Barriers to Palliative Care

- Access to care
- Provider education regarding Palliative Care as a resource for patients with disabilities.
- Communication barriers between health care providers, loved ones, caregivers, and patients.

Velepucha-Iniguez, J., et al. Barriers to Palliative Care Access in Patients with Intellectual Disability: A Scoping Review. Journal of Pain and Symptom Management. 2022 Dec; 63 (6) 337-356.

- Continue to publish and distribute educational materials
- Work with the Kansas Dept for Health and Environment and Kansas State Nurses Association to increase awareness and education around hospice and palliative care for individuals, families, clinical providers, and home healthcare workers
- Potentially a webinar on more specific topics related to hospice and palliative care for individuals with IDD

BADN State Highlights (continued)

- *Promising Approaches to Improving Inclusion and Access of People with IDD into End-of-Life Planning, Strategies, and Grieving Supports*
 - Kansas: Exploring Palliative/Hospice Care for Individuals with IDD
 - New Jersey: Intentionally Embedding End-of-Life Preparation into Futures Planning
 - California: Resource Spotlight – “Thinking Ahead: My Life at the End”

California's *Thinking Ahead: My Life at the End*

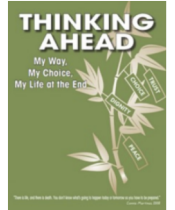
People With Developmental Disabilities Resources

People With Developmental Disabilities

The following resources were developed to address the needs of the intellectually and developmentally disabled community when preparing for the end of life.

Advance Care Planning: Workbook and Videos

Many of the conversations that surround end-of-life care include concepts and language that are challenging to follow, especially for people with developmental or intellectual disabilities. Together with our partners, CCCC created a guide that enables people with developmental disabilities to advocate for themselves and stay in control of their lives through the very end.



The [Thinking Ahead: My Life at the End \(PDF\)](#) workbook contains words, symbols, and pictures that facilitate discussion with and decision making by persons with developmental and intellectual disabilities regarding their values, goals, and treatment preferences at the end of life. The video (below) serves as an instruction manual, containing vignettes that illustrate in simple, graphic format the purpose and use of the materials.

Thinking Ahead was made possible through a Wellness grant by the California Department of Developmental Services and reflects collaboration among Alta California, Golden Gate, and Eastern Los Angeles Regional Centers, Board Resource Center, and CCCC. *Thinking Ahead* was updated in 2022 as part of a grant project funded by the WITH Foundation with assistance from Alta California Regional Center and Valley Mountain Regional Center staff and clients.

Thinking Ahead: My Life At The End Workbook

- [English](#)
- [Spanish*](#)
- [Korean*](#)
- [Chinese*](#)

*The Spanish, Korean, and Chinese translations are based on the 2007 version.

Thinking Ahead Videos+ (see below)

- Thinking Ahead: My Way, My Choice, My Life at the End (English)
- Thinking Ahead: My Way, My Choice, My Life at the End (Spanish)
- Thinking Ahead: Betty & Connie
- Remembering Donald Roberts
- Thinking Ahead: The Importance of End-of-Life Planning

+The videos are based on the 2007 version.



Discussion

Please share your reflections & questions with us by either:

- *Raising your hand and coming of mute to ask your question or share your thought.*
- *Writing your question or comment in the Group Chat or Q&A Feature on Zoom.*

Thank You!



Please take a few moments to complete today's survey – we appreciate your feedback!

https://uic.ca1.qualtrics.com/jfe/form/SV_1QPMnCXJzCkNznM



For a copy of today's presentation, please check out the launch of our updated website (to be launched in October 2025).

<https://nacdd.org/bridging-aging-disability/>



NACDD

National Association of Councils
on Developmental Disabilities

