



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)

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Sibling Advocates
KCDD Health Equity and Outcomes
Coalition



What We Will Cover Today:



- About the Kansas Council on Developmental Disabilities and the Health Equity and Outcomes Coalition
- The origin of this project – Kaye and Eddie’s Story
- Project Members and Input from HE Coalition
- Survey Results
- Educational Component – For Families + Individuals with IDD
- Training Opportunities Evaluation
- Next Steps

Our Mission: Empower individuals with intellectual and developmental disabilities (I/DD), families and caregivers to lead systems change, build capacity, and advocate for inclusive, integrated, accessible communities where everyone belongs and thrives throughout Kansas.

Our Vision: We envision a state where all people with intellectual and developmental disabilities live, learn, work, play, belong, and thrive in the community they choose.

Our Purpose: The purpose of KCDD is to support people of all ages with developmental disabilities so they have the opportunity to make choices regarding both their participation in society and their quality of life.

Allyson McCain

Deputy Director

Kansas Council on Developmental Disabilities (KCDD)

Allyson's passion for increasing health equity for individuals with I/DD began when she was a DSP for a young woman with Autism. She has several years of experience in disability services and previously served as an executive director at a Down syndrome therapeutic center outside of DC. In her role as Deputy Director and Health Equity and Outcomes Coalition Director, she has worked on legislation and policy initiatives in Kansas that seek to enhance the DSP workforce, develop a prenatal/postnatal education and support program, increase newborn screening options, and eliminate the IDD HCBS Waiver.



KCDD
Kansas Council on
Developmental Disabilities



In the fall of 2023, the Kansas Council on Developmental Disabilities launched a first of its kind statewide Intellectual & Developmental Disabilities (I/DD) Health Equity & Outcomes Coalition, with the goal of convening self-advocates, families, and caregivers, as well as Kansas state agencies and departments, healthcare professionals, researchers and providers from across Kansas.

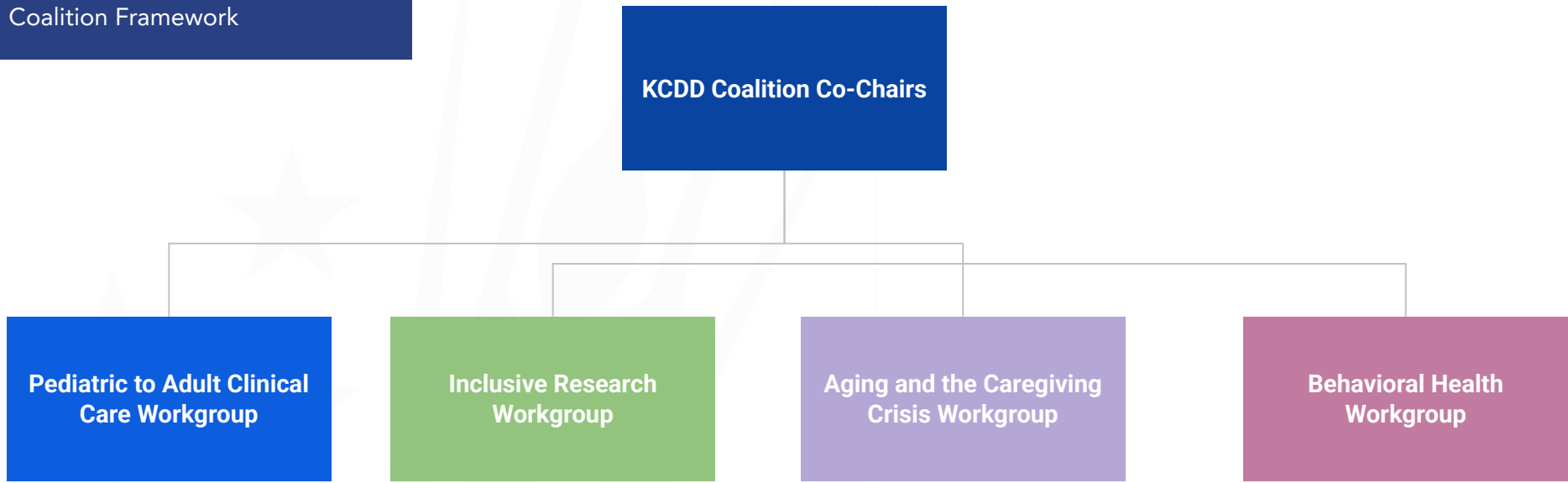
The coalition, through a series of workgroups with 60+ members, is developing an action-oriented blueprint aimed at ensuring our healthcare systems and partners throughout Kansas realize health equity for our I/DD population in our urban, rural and suburban communities. This coalition, which serves as a new national model, provides an innovative platform of stakeholder engagement and collaboration, advocacy and systems change to:

- Improve the quality of life and increase life expectancy of all Kansans with I/DD
- Address issues related to access to improving medical care access, expertise and training across all healthcare professionals and speciality areas
- Address access issues as well as supports, services and disability-related benefits across Kansas' rural, urban and suburban communities
- Address disparities in health and healthcare delivery across our state for the entire IDD population
- Enhance the workforce and establish a formal career ladder for direct support providers (DSP), healthcare providers, etc. who support and work with the IDD community

COALITION MEMBERS

Advent Health
Aetna Better Health
Alliance Rehab and Medical Equipment
Amgen
Assured Trust Company
Autism Society - The Heartland
Black Nurses Association of Kansas
Bert Nash Center
CareSource
Catholic Charities KC-SJ
Children's Mercy Hospital Kansas City
Community Health Council of Wyandotte
Developmental Services of Northwest Kansas, Inc. (DSNWK)
Down Syndrome Innovations
The Golden Scoop
Hunter Health Kansas
Institute for Advancing Medical Innovation
Johnson County Developmental Supports
Kansas Center for Autism Research and Training
Kansas City Hospice & Palliative Care
Kansas City Indian Center
Kansas Dept for Aging and Disability Services (KDADS)
Kansas Department for Children and Families
Kansas Department for Health and Environment (KDHE)
Kansas Family Support Center
Kansas LEND, University of Kansas Medical Center

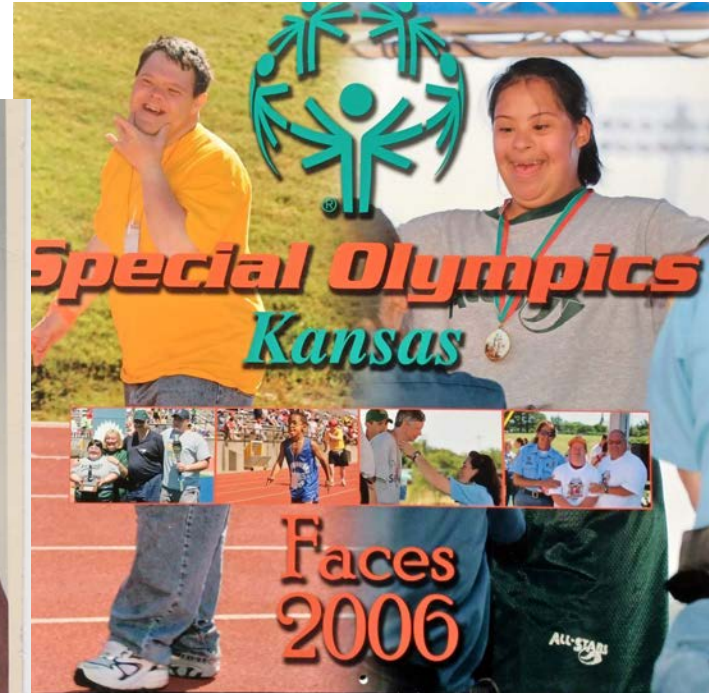
Kansas State Nurses Association
Kansas State Physician Assistant Program
KU Center on Developmental Disabilities
KUMC Girls Night Out Program
L'Arche Heartland
NAMI Kansas
New Hope Therapy Services
Onward Kansans
Optum Care
Oral Health Kansas, Inc.
Raise Health Innovations
Rush University Dept of Community, Systems and Mental Health Nursing
and PATHPWIDD
Sedgwick County Department of Aging and Disabilities
Sedgwick County Developmental Disability Organization
Special Needs Assured
Special Olympics Kansas
Sunflower health plan
UnitedHealthcare Community Plan of Kansas
University of Kansas Medical Center (UKMC)
University of Kansas School of Nursing
We Care and Connect
Whole Story Planning



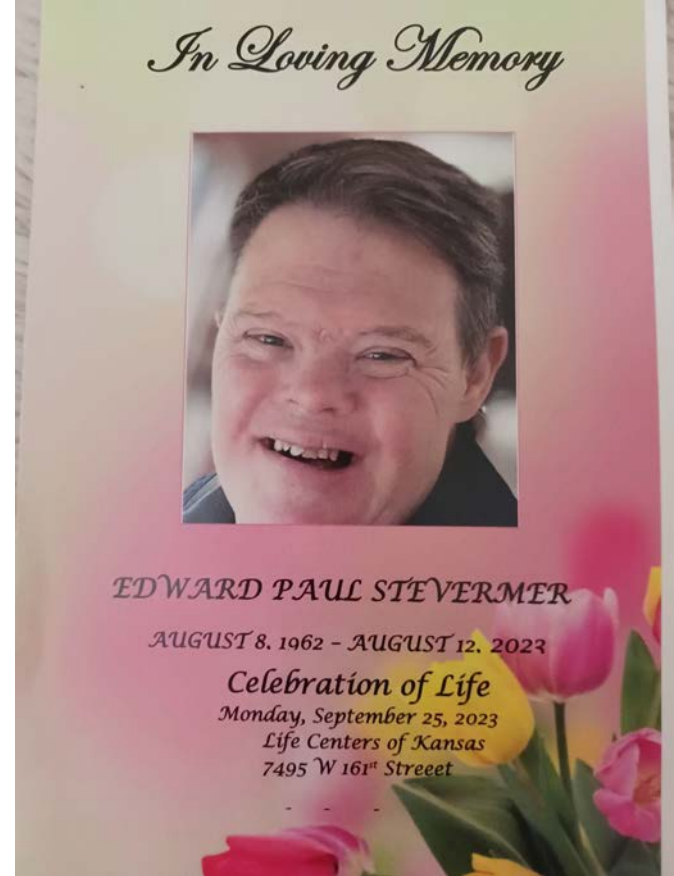
FRAMEWORK

1. Create working groups focused on each of the stated goals.
2. Within each group, undertake an assessment of progress, gaps, and opportunities for advancing health equity for people with IDD in Kansas.
3. Develop an outreach, education, advocacy and public policy strategy that seeks to address the recommended outcomes in a meaningful way.

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



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

Lakemary

Caregivers & Self-Advocates



**Children's Mercy
KANSAS CITY**

Pediatric Palliative Care



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

Lived Experience Survey Results

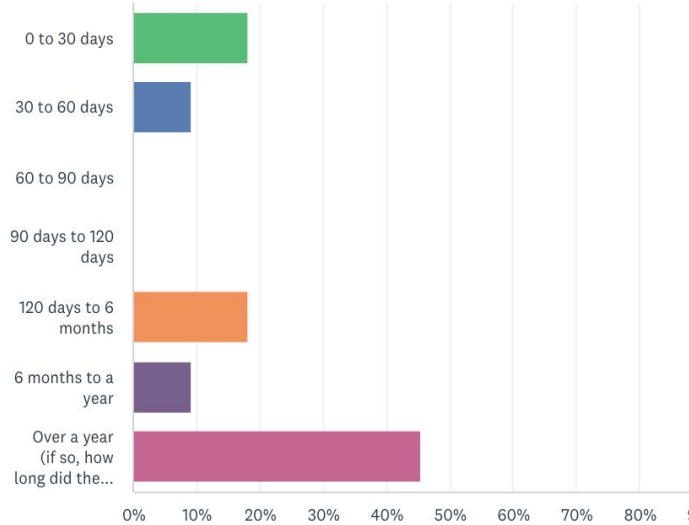


- 11 Caregivers with lived experience with a loved one with I/DD that received hospice or palliative care responded to the survey
- The survey was sent out to the KCDD Health Equity Coalition, shared with providers and disability organizations, and on various social media channels

Lived Experience Survey Results

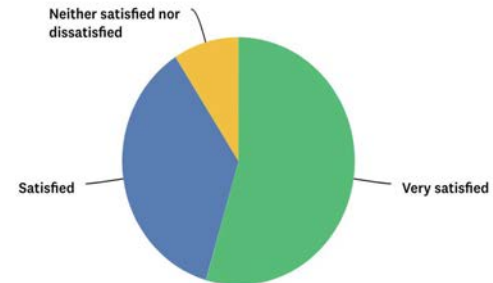
How long have you been using or have previously used hospice or palliative services?

Answered: 11 Skipped: 0



How would you describe your experience with hospice or palliative care?

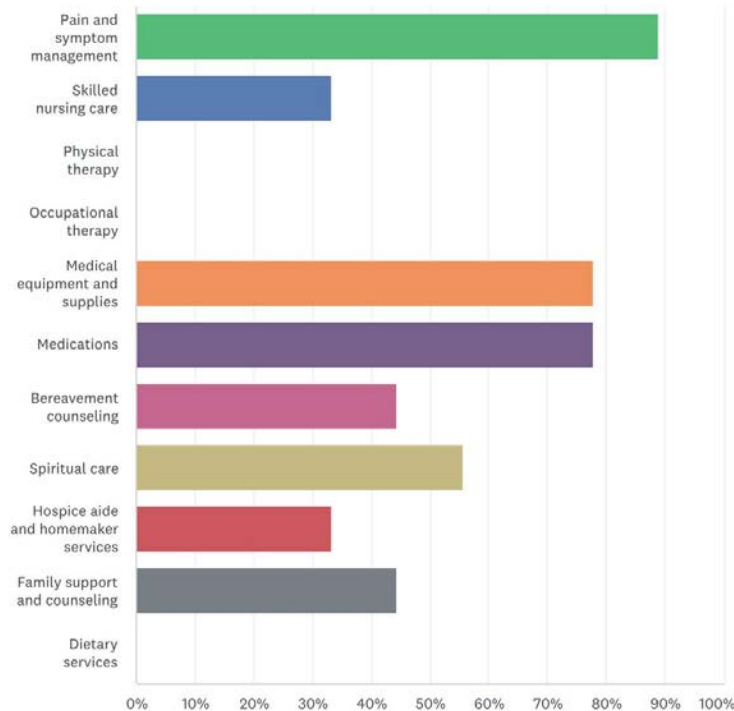
Answered: 11 Skipped: 0



Lived Experience Survey Results

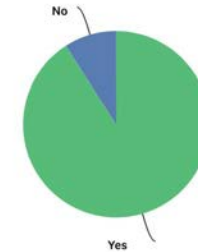
What services were provided during your hospice or palliative experience? If the service provided is not listed, please explain.

Answered: 9 Skipped: 2



Would you recommend hospice or palliative care to someone with IDD in Kansas?

Answered: 11 Skipped: 0



Lived Experience Survey Results

“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.”

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

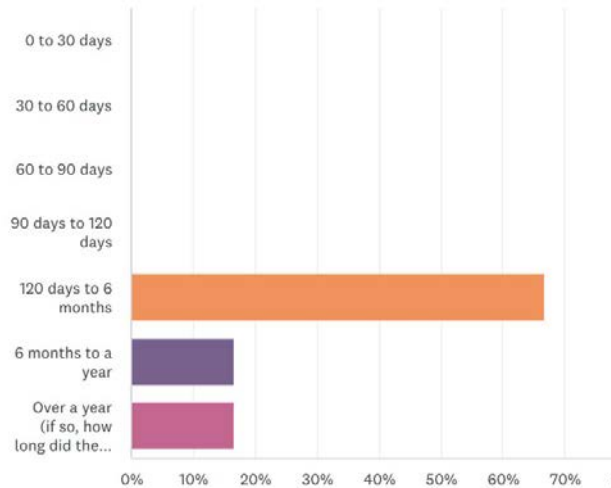


- 7 Hospice and Palliative Care providers completed the survey – all respondents have specifically provided care to someone with n IDD
- The survey was sent out to the KCDD Health Equity Coalition, shared with providers and disability organizations, sent to the KS state network of hospice and palliative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

Provider Experience Survey Results

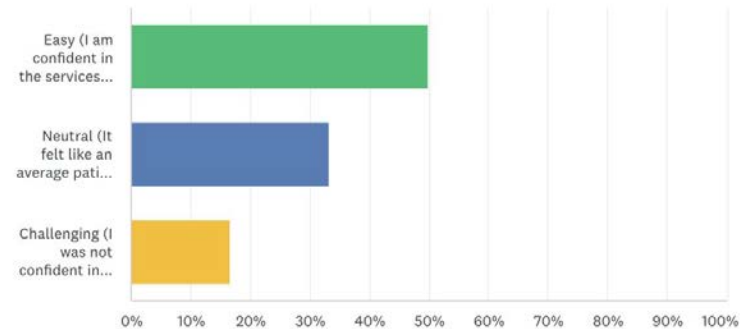
On average, how long do individuals with IDD remain in hospice or palliative care under your services?

Answered: 6 Skipped: 0



How would you describe your experience serving individuals with IDD in hospice or palliative care?

Answered: 6 Skipped: 0



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"

- The Advisory Committee evaluated 3 different training programs and provided feedback to the other members of the committee
- The 3 trainings included:
 1. Hospice and Palliative Care for Adults with Intellectual and Developmental Disabilities ([Hospice Foundation of America](#))
 2. End-of-Life Care for People with IDD ([Relias Academy](#))
 3. Palliative Care & Hospice Care for Patients with Disabilities ([MDisability Provider Webinar Series on Youtube](#))

1.5 CE hours Online CE Courses Self Study

Hospice and Palliative Care for Adults with Intellectual and Developmental Disabilities

2 Reviews >

\$25.95

Having a cognitive disability *does not mean* one is incapacitated in all decision making. People with intellectual/developmental disabilities (IDD) or other cognitive disabilities can be supported to develop advance directives, including identifying their clear wishes or values and choosing someone to honor their care preferences. This webinar will address best practices, strategies, and resources for supporting people with IDD or other cognitive disabilities in developing advance directives.

Pros:

- Effectively highlights some of the unique challenges individuals with intellectual and developmental disabilities (IDD) face regarding end-of-life care.
- Speaker brings valuable expertise as a social worker and director of a Mercy Doula program specifically designed for individuals with IDD—an innovative and meaningful model.

Areas for Improvement:

- Lack of pediatric content:
 - No mention of palliative care needs or supports for children with significant medical complexity or IDD.
 - Including pediatric perspectives would broaden the module's impact and applicability.
- Inaccurate information (for Kansas):
 - Module claims individuals with IDD living in group homes or other facilities are not eligible for palliative care.
 - This is incorrect for Kansas. Confirmed with a KU palliative care social worker that individuals with IDD do access palliative care in clinic settings.
- State-specific relevance:
 - Inaccurate information does not align with how care is delivered in our state.
 - Raises concerns about the module's overall suitability for our educational program.

HOME / BROWSE / END-OF-LIFE CARE FOR PEOPLE WITH IDD



End-of-Life Care for People with IDD

🕒 Hours: 1.00

Course Code: REL-IDD-AAIDD-ELCPIDD

\$15.00 [Add to Cart](#)

COURSE DESCRIPTION

People with intellectual and developmental disabilities (IDD) face many of the same issues at the end of life as people without such disabilities. They also face additional issues and challenges. As people with intellectual disability (ID) live longer, they outlive family caregivers more frequently. This often requires additional supports in advanced age, different service locations, and additional planning. The number of people in this situation is expected to rise as the "Baby Boomer" generation moves into this age category (Heller, Gibbons, & Fisher, 2015).

This course will introduce basic legal and ethical guidelines for decision making at the end of life. Advanced planning can provide clarity in complex, stressful situations when people are unable to communicate or provide consent. Your knowledge of an individual's preferences and rights, as well as ethics, will help you support the person you are serving and their families. This course provides basic information about some common medical decisions that are included in an end-of-life care plan, as well as information about specialized healthcare options such as palliative care and hospice.

The goal of this course is to introduce nurses, psychologists, social workers, and qualified IDD professionals to critical issues at the end of life for people with IDD.

Pros:

- Module briefly defines hospice and palliative care.
- Introduces concepts such as what constitutes a "good death" and what to expect as someone nears end of life.
- Covers basic legal topics such as living wills, power of attorney, emergency POA, competency vs. capacity, and end-of-life care planning.

Cons:

- The format is text-heavy and passive—there's no audio or interactive component, essentially making it a long article to read.
- Content is overly broad and lacks state-specific guidance, which limits its practical use.
- The bulk of the module focuses on legal paperwork, with limited discussion of actual care, systems navigation, or the human experience of end-of-life decision-making.

The screenshot shows a YouTube video player interface. At the top left is the YouTube logo and a search bar. The video content is a slide presentation. The main slide is dark blue with the University of Michigan logo and the title "Hospice and Palliative Care for Patients with Disabilities". Below the title, it lists "Jane Chargot MD, Assistant Professor, Department of Family Medicine and Palliative Care". A smaller slide on the right shows "I have no disclosures". The video player controls at the bottom show a progress bar at 4:44 / 1:02:23, indicating it is on Slide 1 of 20. A subtitle at the bottom of the video reads "ahead, Dr. Chargot, and share your slides and take over." A small video inset in the top right corner shows Jane Chargot speaking.

Pros:

- Easy to understand and potentially helpful for families learning about the differences between hospice and palliative care.

Content Strengths:

- Covers a timeline from preventive care to end-of-life, definitions of hospice and palliative care, interdisciplinary support services, and questions to guide decision-making.
- Addresses barriers such as limited access, provider bias, communication challenges, and lack of education—especially for individuals with IDD.

Suggested Additions:

- Clearer education on hospice vs. palliative care, DNR, guardianship vs. DPOA, and advance care planning.
- Emphasize the importance of involving individuals with IDD in care planning, using accessible communication tools, and honoring patient autonomy and preferences.

- Publish and distribute educational materials
 - The difference between Hospice and Palliative Care
 - How to find care for YOU
- Hosting a webinar with Dr. Charget from the University of Michigan and Dr. Taylor Jersak from UMKC and Children's Mercy to fill in Kansas specific information (September, 2025)
- 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



Thank YOU for your time!

Allyson McCain

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<https://www.kcdd.org/>

