

## Hospice Foundation of America's Program

# HOSPICE AND PALLIATIVE CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

### Self-Study ONLINE Course

#### DESCRIPTION

This webinar will explore hospice and palliative care for people who have intellectual and developmental disabilities. The program will begin with an overview of intellectual and developmental disabilities, including an exploration of the demographic imperative that has emerged as a result of the increased life expectancy of people with intellectual and developmental disabilities coupled with the persistence of health disparities that impact access to timely end-of-life care. The program will then offer insight into the challenges and opportunities that exist for increasing access to hospice and palliative care for this population, including practice, regulatory, and ethical considerations presented through real-life examples from the field.

#### PROGRAM DETAILS

Hospice Foundation of America has taken its popular webinar program and created a self-study course for professionals. The online presentation features an experienced professional offering his own expertise on the topic. On the screen, you will see the slide presentation and will be able to see and hear the expert presenter.

- RELEASE DATE:** Program originally premiered October 11, 2022  
**ON DEMAND:** Viewing available to registered individuals for 6 months after purchase.  
**LENGTH:** 90 minutes  
**CE HOURS:** 1.5 hours  
**CONTENT LEVEL:** The program is mainly for professionals already working in the field, but is practical for all levels of education – entry level, intermediate or advanced.  
**TARGET AUDIENCE:** The course is useful to Health care clinicians, social service clinicians and others working in the hospice, palliative care, counseling, hospital, nursing home, funeral home or faith community environments

#### HOW THE ONLINE SELF-STUDY PROGRAM WORKS

**Step 1** - Register/purchase the course

**Step 2** - View the course online through the link in your confirmation email or in your account.

**Step 3** - Follow the instructions provided to receive your CE certificate\*.

\*An evaluation and a short exam are a part of this process.

#### TECHNICAL REQUIREMENTS

A computer and reliable internet connection. Mobile service provider charges may apply.

#### REGISTRATION INFORMATION/FEEES

Register directly online, on HFA's website: [www.hospicefoundation.org](http://www.hospicefoundation.org).

**There are no refunds on registration.** \*Few exceptions may occur depending on the circumstance. To request a refund, a written request must be received (and granted) by HFA.

## **REGISTRATION POLICY**

### **INDIVIDUAL REGISTRATION**

Provides one person, the registrant, access to the self-study course for personal viewing and continuing education. Discounts may be available for multiple viewers. Please check HFA's website at [www.hospicefoundation.org](http://www.hospicefoundation.org) for current pricing.

### **MATERIALS AREA**

Course materials (Video, Program Slides, and Viewer Guide) are accessible to all registered individuals online immediately after registering. Download materials are available on HFA's website at <https://hospicefoundation.org/Shop-HFA/My-Account>, under "Orders/Courses."

## **LEARNING OBJECTIVES**

AT THE CONCLUSION OF THIS PROGRAM, PARTICIPANTS WILL BE ABLE TO:

1. Examine the distinct needs of aging and seriously ill adults with intellectual and developmental disabilities;
2. Identify issues of special importance that inform the experiences of people with intellectual and developmental disabilities as they age, become seriously ill, and reach the end of life.
3. Critically consider the challenges and opportunities to increase access to hospice and palliative care services for people with intellectual and developmental disabilities.

## **PROGRAM OUTLINE**

- Brief introduction to topic, speakers, and learning objectives (5 min)
- Introduction to intellectual and developmental disabilities (10 min)
- Overview of the demographic imperative, including health disparities (15 min)
- Discussion of challenge and opportunities for hospice and palliative care for people with intellectual and developmental disabilities
  - Practice considerations - overview & case example (15 min)
  - Regulatory considerations - overview & case example (15 min)
  - Ethical considerations - overview & case example (15 min)
- Brief conclusion (5 min)
- Question & Answers (10-15 min)

## **CONTINUING EDUCATION**

This program is valid for 1.5 contact hours of continuing education. View the current list of board approvals on HFA's website at [www.hospicefoundation.org](http://www.hospicefoundation.org), located on the program's registration page.

## **COURSE COMPLETION REQUIREMENTS:**

Participants must view the entire 90-minute program (online-streaming video). Partial credit is not awarded. Participants must also complete the entire CE process online before a certificate is awarded. The online CE process includes a required evaluation form and exam. The exam must be completed at 80% or above (the exam may be re-taken, if necessary).

## **EXPERT SPEAKERS**

**Jackie McGinley, PhD, LMSW**, is a licensed social worker and Assistant Professor with the Binghamton University Department of Social Work. Dr. McGinley's research focuses on the intersection of disability, aging, serious illness, and end-of-life care. Through her work, Dr. McGinley seeks to improve care for people with intellectual and developmental disabilities and their families as the end of life nears and through bereavement.

**Ashley Keagle, LMSW**, is a licensed social worker and the Director of Life Transitions - Mercy Doula program for People Inc., one of the leading agencies in services to people with intellectual and developmental disabilities. In this unique and innovative effort, Ms. Keagle has capitalized on the gap in service for end-of-life care, companionship in dying and the beauty of vulnerable space.

## REVIEWER

Angela Novas, MSN, RN, CRNP, *Senior Medical Officer*, Hospice Foundation of America

## BIBLIOGRAPHY/REFERENCES:

Wark, S, Hussain, R, Müller, A, Ryan, P, Parmenter, T. Challenges in providing end-of-life care for people with intellectual disability: Health services access. *J Appl Res Intellect Disabil*. 2017; 30: 1151– 1159. <https://doi.org/10.1111/jar.12408>

Tromans, S., Andrews, H., Wani, A. and Ganghadaran, S. (2019), The ELCIDD Project: An Audit of End-of-Life Care in Persons with Intellectual Disabilities and Dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 16: 88-92. <https://doi.org/10.1111/jppi.12286>

Jacqueline McGinley, Christina N. Marsack-Topolewski, Heather L. Church, Victoria Knoke; Advance Care Planning for Individuals With Intellectual and Developmental Disabilities: A State-by-State Content Analysis of Person-Centered Service Plans. *Intellect Dev Disabil* 1 August 2021; 59 (4): 352–364. doi: <https://doi.org/10.1352/1934-9556-59.4.352>

Adam E, Sleeman KE, Brearley S, Hunt K, Tuffrey-Wijne I. The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review. *Palliat Med*. 2020 Sep;34(8):1006-1018. doi: 10.1177/0269216320932774. Epub 2020 Jun 17. PMID: 32552409; PMCID: PMC7596767.

Hille Voss, Anique G.F.M Vogel, Annemieke M.A Wagemans, Anneke L. Francke, Job F.M. Metsemakers, Annemie M. Courtens, Anke J.E. de Veer; Development, Implementation, and Evaluation of an Advance Care Planning Program for Professionals in Palliative Care of People With Intellectual Disability. *Intellect Dev Disabil* 1 February 2021; 59 (1): 39–54. doi: <https://doi.org/10.1352/1934-9556-59.1.39>

Terry Alitio, Shirley Otis-Green, John Cagle (Eds). 2022. *The Oxford Textbook of Palliative Social Work*. Oxford University Press.

## COPYRIGHT NOTICE

**HFA's program is copyrighted. Its use and dissemination is restricted and unauthorized duplication is strictly prohibited.** HFA strictly prohibits any other dissemination of this program by any method, including internal WAN or LAN computer networks or telemedicine networks.  
**CE Certificates for this program may only be obtained through HFA.**

## SPECIAL ACCOMMODATIONS FOR DISABILITY (ADA)

Reasonable accommodation may be made available, on an individual basis. To request accommodation, please contact HFA via email at [educate@hospicefoundation.org](mailto:educate@hospicefoundation.org) or call 800-854-3402, or write to HFA, 1707 L Street NW, Suite 220, Washington, DC 20036.

## CONFLICT OF INTEREST

Planners (Panelists and Reviewers) disclose no conflict of interest relative to this educational activity.

## FOR QUESTIONS, COMMENTS, OR ADDRESSING GRIEVANCES

**PLEASE CONTACT** Hospice Foundation of America (HFA)

1707 L Street NW, Suite 220, Washington, DC 20036

[educate@hospicefoundation.org](mailto:educate@hospicefoundation.org)

1-800-854-3402 toll-free / (202) 457-5811 phone / (202) 457-5815 fax

**PRODUCED BY Hospice Foundation of America, [www.hospicefoundation.org](http://www.hospicefoundation.org)**

