PROGRAM INFORMATION

Supporting Individuals with Intellectual and Developmental Disabilities
Through Serious Illness, Grief and Loss

DESCRIPTION:

The ethical, medical management and psychosocial issues for individuals with intellectual and developmental disabilities facing death, grief and loss can be complex. This two-hour educational event focuses on the critical challenges of providing and accessing optimal end-of-life care and bereavement support for this population.

DATE AND METHOD OF PRESENTATION:

HFA’s New Perspectives program will be webcast LIVE on October 24, 2013. An archived version of the program will be available for viewing and continuing education for up to a year afterwards.

- **LIVE Event** on October 24, 2013 from 2:00pm – 4:00pm (EST)
  - Program is webcast via the Internet. You will see and hear the presenters on the screen. Questions may be submitted online during the program.
- **ARCHIVED** program is available until October 23, 2014
  - The archived version will be accessed the same way as the live program; with no interactivity.
- A DVD of the program will be mailed about a month after the live event to registered organizations only.

TEST YOUR SYSTEM:

Please test your system ahead of time to ensure you have the capabilities to view and hear the program, as HFA does not provide refunds on registration. Please be sure to test on the SAME equipment you will use on the day of the program viewing. You will need a computer and screen, reliable internet access, and speakers. If you are showing to a large group, you will need a way to project on a large screen and a sound amplification system. You must test your system as a condition of registration.

TEST LINK for Audio and Video: [http://webcast01.commpartners.com/ec2/4000/5534/5552/8225/TEST_Browser_Test/default.htm](http://webcast01.commpartners.com/ec2/4000/5534/5552/8225/TEST_Browser_Test/default.htm)

EXPERT PANELISTS:

- Kenneth J. Doka, PhD, MDiv
- Tawara D. Goode, MA
- Matthew P. Janicki, PhD
- Leigh Ann Kingsbury, MPA
- Teresa Thalia Moro, AM, LSW
- Elizabeth Perkins, PhD, RNMH
- Rick Rader, MD, FAAIDD

Self Advocate Respondents:

- Under Development
Review Committee Members:
- Marisa C. Brown, MSN, RN
- Pamela Kushner, MA, MD, FAAFP

Hosted by:
- Frank Sesno, Director, School of Media and Public Affairs, The George Washington University

* Panelist Biographies are listed under the “Panelist Bios” section, below.

TARGET AUDIENCE:
This program is practical for all levels of professionals – entry level, intermediate or advanced. The information provided by the expert panel will be useful to clergy, counselors, nurses, nursing home administrators, social workers, case managers, psychologists, physicians, funeral directors, marriage and family therapists, caregivers, and those working with death, dying, grief or bereavement.

LEARNING OBJECTIVES:
At the conclusion of this program, participants will be able to:

1. Define and differentiate intellectual and developmental disabilities and note the patterns of morbidity and mortality with populations of such individuals;
2. Describe the critical issues that emerge in the medical management of life-limiting illness in individuals with intellectual and developmental disabilities;
3. Describe the special issues that arise in the assessment and management of pain in individuals with intellectual and developmental disabilities;
4. Discuss the ethical issues that arise in end-of-life care for individuals with intellectual disability noting particularly the principle of assent;
5. Define grief and enumerate the types of losses that individuals with intellectual and developmental disabilities and their families may experience;
6. Describe the ways that grief is manifested in persons with intellectual disability;
7. Discuss interventive approaches and strategies to assist persons with intellectual and developmental disabilities who are ill or grieving, as well as their families;
8. Identify national resources and initiatives for individuals with intellectual and developmental disabilities and family members who are ill or grieving.

CE CREDITS:
This program is valid for two (2) hours of CE credit. CE credits are included through HFA with registration for the first two weeks after the live event only. After November 7, 2013, CE credits are $10/participant.

CE credits are copyrighted by HFA. Participants are attending an event of Hospice Foundation of America (HFA). All CE certificates must be obtained directly through HFA. Boards approve the content developed by HFA, not by the viewing organization. CE instructions will be provided to you on the download area online.

To view the list of professions/boards that have approved this program, please go to HFA’s registration site at https://register.hospicefoundation.org. Select the “Supporting Individuals with Intellectual and Developmental Disabilities” program, and then select "Board Approvals" on the left-hand menu.
DOWNLOAD MATERIALS:

Download materials are accessible to all registered individuals and organizations immediately after registering for the program. Download materials include your log-in information (access instructions and technical information) and CE information/instructions. Information will be posted to the download website as they become available.

PROGRAM OUTLINE:

I. Introduction: The Nature of Intellectual and Developmental Disabilities
   A. Who are persons with intellectual and developmental disabilities?
   B. Patterns of morbidity and mortality within intellectual and developmental disabilities
   C. Losses experienced by individuals with intellectual and developmental disabilities

II. Life-Limiting Illness in Persons with Intellectual and Developmental Disabilities
   A. Medical Management
   B. Pain Management
   C. Ethical Issues

III. Grief and Intellectual and Developmental Disabilities
   A. Losses and intellectual and developmental disabilities
   B. Grief in persons with intellectual and developmental disabilities
   C. Disenfranchised grief and intellectual and developmental disabilities

IV. Interventive Strategies
   A. During illness
   B. At the time of death
   C. Rituals
   D. Counseling and group support

V. Transition Training and Death Education

VI. Conclusion: Resources and Initiatives
   A. American Association of Intellectual and Developmental Disabilities, The Arc, ANCOR
   B. Last Passages
   C. Government resources

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PANELIST BIOS:

Kenneth J. Doka, PhD, MDiv, is a professor of gerontology at the Graduate School of The College of New Rochelle and senior consultant to the Hospice Foundation of America. A prolific lecturer, author and editor, Dr. Doka has served as editor of HFA’s Journeys with Grief, one of HFA’s newest books, its Living with Grief® book series, its Journeys newsletter, and numerous other books and publications. Dr. Doka has served as a panelist on HFA’s Living with Grief® video programs for 20 years and speaks world-wide on issues of grief and bereavement. He is the author of works published in academic publications concerning grief and loss in individuals with intellectual and developmental disabilities. Dr. Doka was elected president of the Association for Death Education and Counseling (ADEC) in 1993. In 1995, he was elected to the Board of Directors of the International Work Group on Death, Dying, and Bereavement and served as its chair from 1997-99. ADEC presented him with an Award for Outstanding Contributions in the Field of Death Education in 1998. In 2006, Dr. Doka is a mental health counselor under New York’s first state licensure of counselors. Dr. Doka is an ordained Lutheran minister.

Tawara Goode, MA, is an assistant professor in the Department of Pediatrics, Georgetown University Medical Center in Washington, D.C. She has been on the faculty of the Georgetown University Center for Child and Human Development (GUCCHD) for the past 30 years and has served in many capacities. She has degrees in early childhood education, and education and human development. Ms. Goode has extensive experience as a principal investigator for federal and private sector grants and contracts. She is
the Associate Director of the GUCCHD’s University Center for Excellence in Developmental Disabilities and focuses on national level efforts to advance and sustain cultural and linguistic competence in the field. She is also the director of the National Center for Cultural Competence (NCCC), an internationally recognized program at GUCCHD. The NCCC has been in existence for the past 18 years during which Ms. Goode was the director for 16 years. Ms. Goode is recognized as a thought leader in the area of cultural and linguistic competency. Ms. Goode is actively involved in the development and implementation of programs and initiatives in cultural and linguistic competency at local, national, and international levels. She serves on numerous boards, commissions and advisory groups concerned with addressing the interests and needs of culturally and linguistically diverse populations and communities.

Matthew P. Janicki, PhD, is a research associate professor in the Department of Disability and Human Development at the University of Illinois at Chicago, and serves as director for technical assistance for the Rehabilitation Research and Training Center in Aging with Developmental Disabilities—Lifespan Health and Function at the University. Formerly, he was director for aging and special populations for the New York State Office for People with Developmental Disabilities. Currently, he is leading a study of specialized group homes designed for dementia related care of adult with intellectual disabilities. Dr. Janicki was the principal investigator of studies examining how community agencies provide community supports to adults with intellectual disabilities affected by Alzheimer’s disease and how families are aided by community agencies in supporting adults with Down syndrome affected by Alzheimer’s disease. He was also the project director of an effort that provided the World Health Organization with a series of background reports on promoting longevity among adults with intellectual disabilities throughout the world. Currently he serves as the co-chair of the US National Task Group on Intellectual Disabilities and Dementia Practices and is the editor of the Journal of Policy and Practice in Intellectual Disabilities.

Leigh Ann Kingsbury, MPA, is a gerontologist who has worked with people with developmental and intellectual disabilities, psychiatric disabilities, and with seniors, for more than 30 years. She has experience in direct care, case management, senior and executive leadership. Mrs. Kingsbury has helped more than 200 individuals move from institutional settings to their home communities, including many people with labels of “challenging behavior.” She has particular interest in the growth of person-centered practices in long term care; and was recently the lead consultant on a Centers for Medicare and Medicaid Services project that focused on systems change for North Carolina seniors. Mrs. Kingsbury is also the former director of the North Carolina Person-Centered Planning Initiative. She has authored multiple articles and a planning manual on using person-centered practices for healthcare decision-making and care at end of life, including People Planning Ahead: A Guide to Communicating Healthcare and End of Life Wishes, (AAIDD 2009). She is actively involved with the American Bar Association on developing a model of supported decision-making.

Teresa Moro, LSW, is a licensed social worker in the state of Illinois. She is currently finishing her doctorate at the School of Social Service Administration at the University of Chicago. The purpose of her dissertation research is to explore the experiences of family members and agency staff with end-of-life care for adults with intellectual and developmental disabilities in order to clarify the services currently being provided, identify gaps in services, and describe implications for clinical social work practice and policy. Ms. Moro recently completed her role as project director on the End-of-Life Care for People with Intellectual and Developmental Disabilities study (P30 NR010680) working with Dr. Teresa Savage at the University of Illinois at Chicago. In addition to her research interests, Ms. Moro has co-authored several book chapters exploring unacknowledged and stigmatized loss, and social work with vulnerable populations. She is currently completing several manuscripts exploring end-of-life care with adults with intellectual and developmental disabilities. She has spent over 20 years working with adults with intellectual and developmental disabilities in a variety of roles and was fortunate to gain clinical experience in an agency offering services for individuals of all ages. In 2008, Ms. Moro was a disability ethics scholar at the Donnelley Family Disability Ethics Program at Rehabilitation Institute of Chicago.
Elizabeth Perkins, PhD, RNMH, is the Associate Director and a Research Assistant Professor at the Florida Center for Inclusive Communities (FCIC), a University Center for Excellence in Developmental Disabilities, based at the University of South Florida (USF). Dr. Perkins has a PhD in Aging Studies and a BA in Psychology, both from USF. Dr. Perkins is also an RNMH, a registered nurse specializing in mental health from the United Kingdom, where she trained specifically in the field of intellectual and developmental disabilities (IDD). Her clinical, academic, and research activities have focused on health and quality of life of aging people with IDD, and their family caregivers. She was the guest co-editor for a recent Special Issue on Aging and End of Life for the American Journal on Intellectual and Developmental Disabilities. In addition, Dr. Perkins is a co-author of the book Physical Changes and Aging: A Guide for the Helping Professions. Dr. Perkins serves on the Board of Directors of the American Association on Intellectual and Developmental Disabilities. She is the immediate past President of AAIDD’s Gerontology Division, and a former co-convener for the Special Interest Group on Developmental Disabilities for the Gerontological Society of America. Dr. Perkins represents the FCIC on the Florida Developmental Disabilities Council, and serves on the advisory board of the Disability Community Planning Group, for the Disability and Health Program, Florida Department of Health.

Rick Rader, MD, is the Director of the Morton J. Kent Habilitation Center at the Orange Grove Center, a non-profit community agency supporting individuals with intellectual and developmental disabilities. Dr. Rader is responsible for the identification, initiation and evaluation of novel and innovative healthcare programs for individuals aging with intellectual and developmental disabilities. He is the Chair of the "End of Life Care Planning Committee" and a member of TELP, Tennessee End of Life Partnership. He is a founding board member of the American Academy of Developmental Medicine and Dentistry and a member of the board of the American Association on Health and Disability. Dr. Rader has been a consultant to four former Surgeon Generals of the United States in the area of health and disability. He is the Editor in chief of Exceptional Parent Magazine and has contributed over 250 articles in developmental disabilities. He was elected to the National Academy of Practice in Medicine and is the recipient of the Exceptional Physician of the Year Award. He was a member of Last Passages, a Robert Woods Johnson program addressing end-of-life issues for individuals with intellectual disabilities. He is an adjunct professor of Human Exceptionality at the University of Tennessee-Chattanooga and a member of the Institute for Evidence Based Practice at the University of Texas Health Sciences Center, San Antonio. He is cross trained in internal medicine and medical anthropology.

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**COURSE COMPLETION REQUIREMENTS:**

Participants must attend the entire two-hour program. Partial credit is not awarded. Participants must also complete the entire CE process online, before the CE deadline of October 23, 2014. Attendees will need a unique Course Code in order to log-into the CE site (The Course Code is provided to all registered individuals in their Download Materials online). The online CE process includes a required evaluation form. Attendees will be able to choose the board from which they wish to receive credit (see Hospice Foundation of America’s list of board approvals*) and will then be able to print their CE certificate immediately after completing all requirements.

*A complete list of board approvals for this webcast program is posted to HFA’s registration site at [https://register.hospicefoundation.org](https://register.hospicefoundation.org).

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**PSYCHOLOGY CE CREDITS:**

Continuing Education (CE) credits for psychologist are being offered through PsychoEducational Resources, Inc. (PER). Participants may earn 2 CE credits.

PER is approved by the American Psychological Association to sponsor continuing education for psychologists. PER maintains responsibility for this program and its content.
For additional CE information (for psychologists) please call PER at 800-892-9249 or e-mail support@per-ce.net.

To receive CE Certification you must complete the program post test and evaluation. CE Certification will be mailed to you approximately 30 days after you complete the program.

Program Fees / Materials:

Organization Registration (A Group of 2 or more Individuals; there is no limitation on size of group or number of archive viewings for organizations following the live program. Large groups should plan to order or copy additional materials, including printed programs) - $235

Organization Registration Includes:
- Access to LIVE event
- Access to ARCHIVED program
- DVD of program (mailed 1 month after)
- 25 Printed Program Guides and 25 Printed Tip Sheets
- CE Credits for participants
  - Included for 2 weeks after live event only ($10/person after this date)
- Downloadable Materials
  - Program Guide (pdf)
  - Tip Sheet (pdf)
  - Marketing Kit documents
  - Organizer’s Manual

Individual Registration (One Individual only) - $25

Individual Registration Includes:
- Access to LIVE event
- Access to ARCHIVED program
- CE credits for one individual
  - Included for 2 weeks after live event only ($10 after this date)
- Downloadable Program Guide (pdf)
- Downloadable Tip Sheet (pdf)

Register directly online, on HFA’s registration site: https://register.hospicefoundation.org

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Special Accommodations for Disability (ADA):
This is based on individual site location(s). Site coordinators: please post all ADA instructions when advertising the program.

Conflict of Interest:
Planners (Panelists and Review Committee Members) disclose no conflict of interest relative to this educational activity.
FOR QUESTIONS, COMMENTS, OR ADDRESSING GRIEVANCES
Please contact Hospice Foundation of America (HFA)

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