



Person-Centered Decision Making in Healthcare and Care at End of Life

Summary of a webinar from February 22, 2022

Introduction

This webinar is about end-of-life care. Leigh Ann says that talking about the end of life can be uncomfortable. It is important to start talking about it early. Talk with the person and those who care about them. Start with the idea that everyone can make decisions.

There are many legal and medical terms that we use in healthcare decision making. Capacity means that the person can understand the:

- Risks,
- Benefits, and
- Consequences of a healthcare decision.

First ask, “Is the decision urgent?” If not, there is time to help the person learn about their choices.

It is important to help people build trusting relationships throughout their lives. They will have support to make decisions.

Hear from the panel

Tawara points out that we all have different views of end-of-life. Some cultures avoid talking about death. Tawara says that informed consent needs to be in the person’s language.

Diane talks about informed consent and real choices. She says that there is anti-disability bias in end-of-life decisions. She points to several laws and reports that show this. Diane advises that those who are supporting the person at the end of life have advocacy skills.

Julie talks about the importance of person-centered planning throughout all phases of life. She says we should understand our own feelings about death and keep it about the person. She explains that she works with people over several weeks fill out the advanced care directive forms. Julie tells about when she had to share the news with a person that their parent had passed away.

Bill talks about spiritual supports as part of person-centered planning. He says to start by asking, “How do you handle grief and loss in your family?” He also says that direct care workers need to know how to support someone at the end of their life.



The speakers on this webinar were:



Co-facilitator **Leigh Ann Kingsbury** is a consultant and gerontologist who has supported people with complex healthcare and disabilities for more than thirty years. She is a Certified Person-Centered Thinking Mentor Trainer, and Board Member Emeritus of The Learning Community for Person Centered Practices. Leigh Ann is the author of AAIDD's *People Planning Ahead: A Guide to Communicating Healthcare and End of Life Wishes* and a Respecting Choices Advance Care Planning Facilitator. Currently, she facilitates the Alzheimer's and Related Dementias Task Force for the state of Ohio.



Co-facilitator **Mary Beth Lepkowsky** leads Helen Sanderson Associates USA, a learning and development consultancy that developed "Living Well," a person-centered approach to supporting people to live well with a long-term condition and plan for care at the end of life. Mary Beth is a Respecting Choices Advance Care Planning Facilitator, Five Wishes Facilitator, and Mentor Trainer for Person Centered Thinking and Planning and has facilitated advance care planning workshops for families and healthcare providers in California.



Diane Coleman, J.D., MBA, is the President/CEO of Not Dead Yet, a national disability group she founded in 1996 to organize disability opposition to assisted suicide and euthanasia. Not Dead Yet (NDY) has led in filing friend of the court briefs regarding surrogate decisions, futility policies and assisted suicide, joined by other national disability organizations in several state courts and the U.S. Supreme Court. Coleman has also organized disability rights protests opposing assisted suicide laws and conducted extensive public education activities, including conference presentations, university lectures and media interviews.



Tawara Goode is an associate professor and Director of the Georgetown University National Center for Cultural Competence and the Georgetown University Center for Excellence in Developmental Disabilities. Both centers are committed to advancing equity and the mission of the NCCC has a specific focus: To increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity.



Bill Gaventa is a trainer, and consultant in the arena of faith and disability. He is the founder/Director Emeritus of the Institute of Theology and Disability. His career has included working as a chaplain, Family Support Coordinator for the GA DD Council, faculty at the Boggs Center on Developmental Disabilities in New Jersey, and the President of American Association of Intellectual and Developmental Disabilities, 2016-2017. He is author of *Spirituality and Disability: Recovering Wholeness* (Baylor University Press).



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Julie Snyder is a Life Planning Navigator for Tierra del Sol. During her 31 years with Tierra, Julie has been instrumental in delivering person-centered planning to hundreds of individuals with I/DD and their families, throughout all stages of their lives. As a Regional Trainer for The National Task Group and certified trainer in Late Life Planning, Julie's expertise has not only been essential in helping individuals and families with end-of-life plans but has also aided health care professionals in understanding how to support the needs of individuals with disabilities.