

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

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NCAPPS



Welcome to Today's Webinar



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Thank you for joining us to learn about person-centered decision-making for healthcare and care at end of life.

This webinar series is sponsored by the National Center on Advancing Person-Centered Practices and Systems. NCAPPS is funded by the Administration for Community Living and Centers for Medicare & Medicaid Services.

NCAPPS webinars are free and open to the public.

The goal of NCAPPS is to promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan.





Webinar Logistics

- Participants will be muted during this webinar. You can use the **chat** feature in Zoom to post questions and communicate with the hosts.
- Toward the end of the webinar, our speakers will have an opportunity to **respond to questions** that have been entered into **chat**.
- The webinar will be live captioned in English and Spanish. To access the Spanish captions, please use this link: <https://www.streamtext.net/player?event=HSRI>
- El seminario de web estará subtulado en vivo en Inglés y Español. Para tener acceso a los subtítulos en Español, utilice este enlace: <https://www.streamtext.net/player?event=HSRI>
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



Feedback and Follow-Up

- After the webinar, you can send follow-up questions and feedback about the webinar to NCAPPS@hsri.org.
 - Please note that this email address is not monitored during the webinar.
- The recorded webinar, along with a pdf version of the slides and a Plain Language summary, will be available within two weeks at NCAPPS.acl.gov. We will also include questions and responses in the materials that are posted following the webinar.

Who's Here?

“In what role(s) do you self-identify? Select all that apply.”

1. Person with a disability/person who uses long-term services and supports
2. Family member/loved one of a person who uses long-term services and supports
3. Self-advocate/advocate
4. Peer specialist/peer mentor
5. Social worker, counselor, or care manager
6. Researcher/analyst
7. Community or faith-based service provider organization employee
8. Government employee (federal, state, tribal, or municipal)



Meet Our Speakers



Tawara Goode



Mary Beth Lepkowsky



Leigh Ann Kingsbury



Julie Synder



Bill Gaventa



Diane Coleman



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



Person Centered Decision Making for Healthcare and Care at End of Life

Advance Care Planning Conversations
with People with Intellectual, Developmental,
and Other Disabilities



**It's not about end of
life, until it is.**



Making Healthcare Decisions

- Everybody is capable of making a decision.
- Not everyone is capable of making a complex healthcare decision.
- Capability is a clinical issue, not a legal construct.
- We should test assumptions that people with intellectual disabilities are not capable.
- Even people with guardian or conservator should be involved in the decision making
- What is the urgency? Is there time to help someone?
- If not capable, who can be power of attorney?



Building Intentional Relationships



- Having conversations about future care early and throughout life can help build intentional relationships
- If there is no time, the system will identify the process for decision making



REMEMBER...

Five tips to get started



1

Everyone makes decisions

2

Discuss early in life and throughout life

3

Consider future planning rather than end of life planning

4

Respect different values, beliefs, and preferences

5

Start with yourself



Learning more...

- Use link in chat to be notified about training on *“Having advance care planning conversations with people with intellectual and developmental disabilities and their families.”*
- Download list of resources from panelists in chat





Conversations about things we can't control can actually help to give us a sense of control.

Thank You

Julie's Pictures



D.F - in front of his PCP



K.S and her mother as she recovers from a hospitalization



Obituary for K.S written by her brother after she passed away



S. who had sudden onset of Alzheimer's disease, she is holding a picture of her younger self. The end of her life was filled with quality, love and music, while surrounded by family.



Questions?

Real-Time Evaluation Questions

- Please take a moment to respond to these six evaluation questions to help us deliver high-quality NCAPPS webinars.
- If you have suggestions on how we might improve NCAPPS webinars, or if you have ideas or requests for future webinar topics, please send us a note at NCAPPS@hsri.org

Real-Time Evaluation Questions (cont.)

- 1. Overall, how would you rate the quality of this webinar?**
- 2. How well did the webinar meet your expectations?**
- 3. Do you think the webinar was too long, too short, or about right?**
- 4. How likely are you to use this information in your work or day-to-day activities?**
- 5. How likely are you to share the recording of this webinar or the PDF slides with colleagues, people you provide services to, or friends?**
- 6. How could future webinars be improved?**

Thank You.

Register for upcoming webinars at

ncapps.acl.gov

NCAPPS is funded and led by the Administration for Community Living and the Centers for Medicare & Medicaid Services and is administered by HSRI.

The content and views expressed in this webinar are those of the presenters and do not necessarily reflect that of Centers for Medicare and Medicaid Services (CMS) or the Administration for Community Living (ACL) .

