

Person-Centered Supports for People Living with Dementia in the Community

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Welcome to Today's Webinar



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Thank you for joining us to learn about **Person-Centered Supports for People Living with Dementia in the Community.**

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-SPANISH>
- 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-SPANISH>
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



Feedback and Follow-Up

- The webinar **recording**, along with a pdf version of the **slides** and a **Plain Language summary**, will be available within two weeks at [NCAPPS.acl.gov](https://ncapps.acl.gov). We will also include questions and responses in the materials that are posted following the webinar.
- 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.)

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 or close friend of a person who uses long-term services and supports
3. Self-advocate / advocate for dementia supports
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)
9. Hospital/Hospital-affiliated clinic employee
10. HMO/Managed care organization

Meet Today's Panelists



Brian Van Buren



Cameron Camp



Elias Rodriguez



**Rev. Cynthia
Huling Hummel**

What we will cover

- Definitions for person-centered thinking, planning, and practice?
- A description of the population of people living with dementia in the United States
- Share experience of supports for people with dementia living in the community from the perspective of a provider and from people with lived-experience
- Discuss strategies for supporting people living with dementia

Person-centered approaches include person-centered thinking, planning, and practice



Person-centered thinking

- A foundational principle requiring consistency in language, values, and actions
- The person and their family and friends are experts in their own lives
- Equal emphasis on quality of life, well-being, and informed choice

Person-centered planning

- A methodology that involves learning about a person's preferences and interests for a desired life and the supports (paid and unpaid) to achieve it
- Directed by the person, supported by others selected by the person

Person-centered practices

- Alignment of services and systems to ensure the person has access to the full benefits of community living
- Service delivery that facilitates the achievement of the person's desired outcomes

Systems Focus vs Person-Centered

With a SYSTEMS focus...

- Limitations define the person
- Supports are 'services' that people become eligible for, based on the extent of their 'impairment'.
- Overemphasis on problems
- Supports are driven by the needs of the system (structure, forms, professional rules and boundaries)

A PERSON-CENTERED approach...

- Recognizes a person's unique capabilities and contributions
- Identifies strengths and preferences
- Recognizes the challenges that may come with disability in planning for a future life and identifies supports
- Person-centered system of support builds capacity of individual based on who they are

See: <https://www.youtube.com/watch?v=y77y7XW8GtE>



“

One of our most important rights as human beings and sovereign citizens is the right to pursue our goals, our dreams, our loves and the things that make us happy. This is something that all people want and need. It fulfills us and makes our lives more rich and valuable.

Person-centered planning is a thoughtful, research-based and beautiful process which helps provide the foundation for people with disabilities to also experience the joys of a living a self-determined life.”

Kimberly R. Mills, Ph.D., BCBA-D

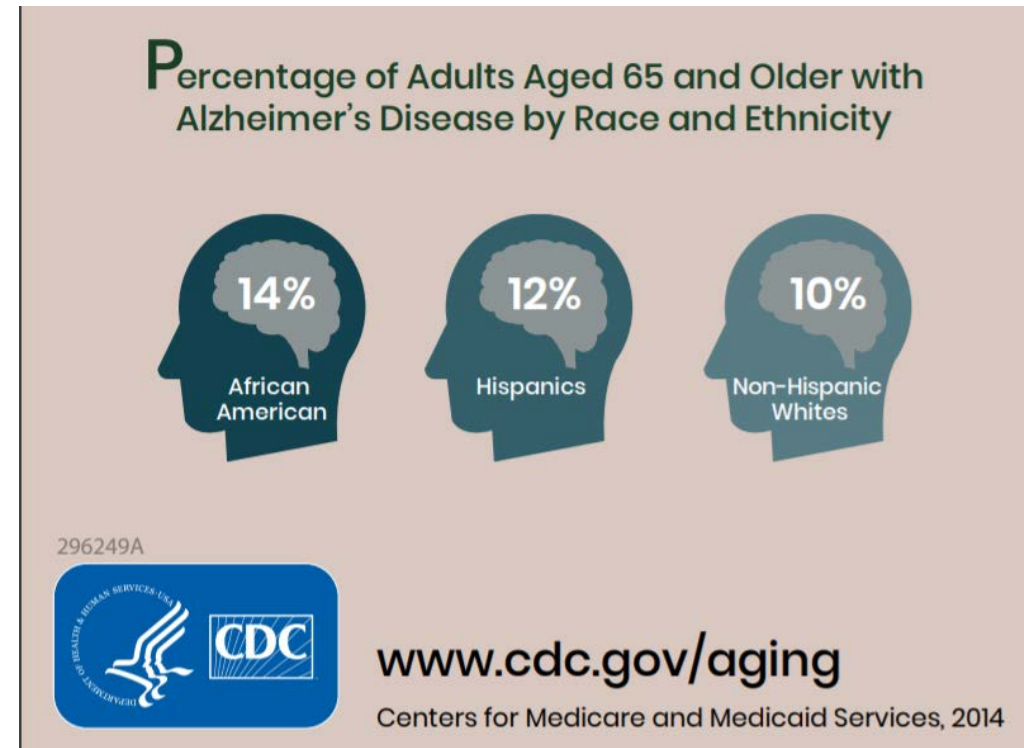
Senior Executive Director – Virgin Islands University Center for Excellence in Developmental Disabilities (VIUCEDD)

NCAPPS Person-centered Advisory and Leadership Group
(PAL Group) Member

US Population living with Alzheimer's Disease and Related Dementias

- 5.8 million Americans of all ages are living with Alzheimer's dementia in 2019.
 - This number includes an estimated 5.6 million people age 65 and older and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's Disease.
- Different causes of dementia are associated with distinct symptom patterns. It is important that individuals receive an accurate diagnosis to ensure they receive treatment and follow-up care appropriate to their specific form of dementia.

*Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2019;15(3):321-87.



Caregiving and supports

- In 2018, caregivers of people with Alzheimer's or other dementias provided an estimated 18.5 billion hours of informal (unpaid) assistance.*
- Direct care workers provide the majority of care in home or residential settings. In many cases, staff need support themselves in order to provide person centered care.
- Person centered planning, person centered thinking, provide a means to help support providers provide BOTH what is important TO the person, as well as what is important FOR the person

*Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2019;15(3):321-87.

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Questions?

References

- Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2019;15(3):321-87.
- Friedman EM, Shih RA, Langa KM, Hurd MD. U.S. prevalence and predictors of informal caregiving for dementia. *Health Aff* 2015;34(10):1637-41.
- Spillman B, Wolff J, Freedman VA, Kasper JD. Informal Caregiving for Older Americans: An Analysis of the 2011 National Health and Aging Trends Study. Available at: <https://aspe.hhs.gov/report/>

Real-Time Evaluation Questions

- Please take a moment to respond to these seven 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

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) .

