



## Expanding Access to LTSS for People Living with ADRD and their Caregivers

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## Long Term Care Needs

### Levels of LTSS

- Individual
- Family
- Community
- Residential



# Long Term Care Needs

## Caregivers

- Identify and document
- Assess needs and levels of stress
- Engage in person and family-centered care planning, consistent with “person’s” wishes
- Provide disease education and support that is culturally and literacy-level appropriate
- Connect to community-based resources



## Gaps and Barriers to Access

- Workforce
- Service delivery
- Affordability



# Gaps and Barriers to Access

## For socio-economically, racially and ethnically diverse populations

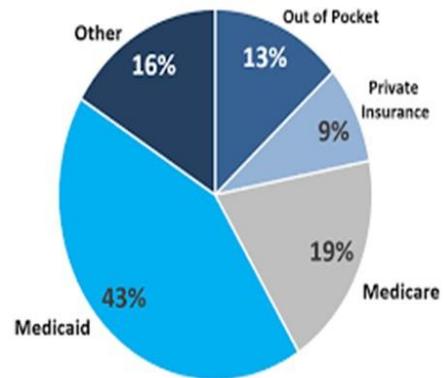
- Cultural
- Linguistic
- Literacy level
- Access to technology – wi-fi, computers and tech-savvy
- Cost



# Who pays for LTSS?

## Public Sources Outweigh Private

- Medicare
- Medicaid
- LTC Insurance
- Other (Managed Care and Unions)
- Out of Pocket Costs



Source: Health Affairs, 2017; ; [National Health Expenditures Data, 2015](#). Centers for Medicare and Medicaid Services.



# How expensive are LTSS?

**These costs can impoverish a middle-class family.**

The average retirement savings for baby boomers is about \$75,000 while the cost of providing LTSS is significant. In 2017, the average annual cost of a community-based adult day-care center was \$16,900; a home health aide was \$49,000; and the cost to live in a nursing facility was \$97,455.

American Medical Assn., 2018

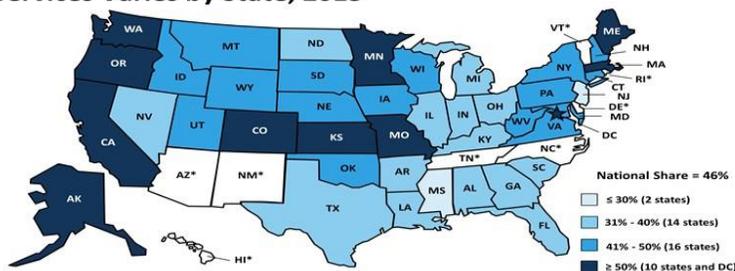


# Who pays for LTSS?

**For Lower Income Families, Medicaid Spending on LTSS and the Available Benefits Vary by State**

Figure 4

**The Proportion of Medicaid Long-Term Services and Supports Spending For Home and Community-Based Services Varies by State, 2013**



NOTE: All spending includes state and federal expenditures. HCBS expenditures include state plan home health services, state plan personal care, targeted case management, hospice, home and community-based care for the functionally-disabled elderly, and services provided under HCBS waivers. Expenditures do not include administrative costs, accounting adjustments, or expenditures in the U.S. territories.  
\*Spending for AZ, DE, HI, NC, NM, RI, TN, and VT is not shown due to their funding authority for HCBS and/or the way spending is reported.  
SOURCE: Urban Institute estimates based on data from CMS Form 64 as of September 2014.



# Impact of COVID-19 on LTSS for People Living with ADRD and their Caregivers

## Individuals, Families and Providers are Challenged

- “In England and Wales, 25% of those who died from the virus had dementia”  
The Economist, August 3, 2020
- “At least 15,000 more Americans have died in recent months from Alzheimer’s disease and dementia than otherwise would have ...”  
The Wall Street Journal, June 28, 2020
- Most adult day centers are closed
- Many families fear bringing a worker into the home
- Many services are offered online, but are not accessible to all



## Learning from the Past to Inform Future NAPA Recommendations

**Venoreen Browne-Boatswain – Lived experience**

**Gretchen Alkema – Where we've been**

**Panel: Where states are now and suggestions for the future**

Moderated by Carrie Molke

Speakers: Marc Cohn, Center for Consumer Engagement in Healthcare Innovation  
Martha Roherty, Advancing States  
Kitty Purrington, National Academy for State Health Policy  
Jenn Rosen, Alzheimer's Association

**Vignettes: Effective ACL-funded models for increasing access to HCBS for ethnically diverse groups**

Moderated by Maria Ordonez

Featuring: Madeline Michel, Haitian Memory Café  
Constantina Mizis, Promotores de Salud

**Gretchen Alkema – Future directions and recommended strategies**

