

Long-Term Services and Support (LTSS) Subcommittee Recommendations

Helen B. Medsger
Chair, LTSS Subcommittee

1

LTSS Subcommittee Members

Non-Federal Members

- Deke Cateau
- Fawn Cothran
- Roberta J. Cruz
- Susan DeMarois
- Keun Kim
- Helen B. Medsger (Chair)
- Adrienne Mims
- John-Richard Pagan

Federal Members

- Arlene Bierman - AHRQ
- Ellen Blackwell - CMS
- Elena Fazio - NIA
- Melinda Kelley - NIA
- Greta Kilmer - CDC
- Nicole Kidwiler - NIA
- Helen Lamont - ASPE
- Shari Ling - CMS
- Erin Long - ACL
- Lisa McGuire - CDC
- Emma Nye - ASPE
- Maria-Theresa Okafor - ASPE
- Latrice Vinson - AHRQ
- Joan Weiss - HRSA

2

Recommendation 1:

Reauthorization of and Budget Appropriations for NAPA

Congress should reauthorize NAPA for another ten years. Congress and HHS should fund NAPA organizers, including ASPE, to have increased resources and authority to accomplish the following:

- A. For FY2025, fund and appoint at least 1 FTE for federal coordinator(s) with the authority to prioritize, organize, implement, and follow up on cross-stakeholder recommendations.
- B. Track the progress and milestones of prior NAPA recommendations with a goal to prioritize those recommendations with the largest potential impact.
- C. Assist NAPA Council and its Chair in determining the level of appropriate resources for NAPA to track and convey recommendations optimally.

3

Recommendation 2:

Amend the OAA age eligibility requirements and increase funding to expand delivery of services in the OAA for people of all ages living with AD/ADRD and their family caregivers.

- A. Congress should increase current appropriations for OAA services and support programs which would impact the existing program waiting lists and increase capacity to expand delivery of services. This expansion should also require the development of a system of tracking the timely utilization of services and evaluation of the impact.
- B. Congress should authorize delivery of services under the OAA for family caregivers of people of all ages living with AD/ADRD and expand delivery of AD/ADRD education, training, and respite care through the National Caregiver Support Program (NFCSP) under the OAA.
- C. Congress should increase funding from \$205,000,000 to \$360,000,000 to the States under NFCSP to reduce existing wait lists and expand service delivery.
- D. Congress should increase funding from \$12,000,000 to \$20,000,000 to further States' compliance with the Civil Rights Laws Applicable to Persons with Disabilities (Title VI. C.) to be respective of those with AD/ADRD.

4

Recommendation 3:

Expand the availability of dementia-capable HCBS available to PLWD and their unpaid caregivers.

- A. The Government Accountability Office should evaluate the impact of the American Rescue Plan Act (ARPA) and other investments to further build and sustain dementia capable initiatives.
- B. NAPA recommends the following respite options:
 1. States should make at-home and community-based day and overnight respite services available to dementia caregivers through LTSS programs.
 2. HRSA should study the impact of direct care workforce recruitment, sustenance, and education challenges have on respite care options and make recommendations for addressing the issues identified in the study.
 3. CMS should expand the caregiver training benefit in outpatient settings to include funded respite care for all caregivers comparable to that of the GUIDE model.
 4. States should explore Medicaid waiver options to fund respite support (e.g., HCBS waiver program).
 5. Congress should increase funding from \$10,000,000 to \$20,000,000 to the Lifespan Respite Care and Lifespan Respite Care Enhanced Grants Programs to provide more respite opportunities for all family caregivers.

5

Recommendation 4:

Define needs and expand LTSS to people living with young-onset AD/ADRD (PLWYO) and their families/caregivers.

- A. Congress should authorize and fund ASPE to gather nationwide data on the number of PLWYO.
- B. Congress should approve legislation that exempts PLWYO from the 24-month "Medicare Waiting Period" requiring people with disabilities to first receive SSDI for 24 months before they receive Medicare benefits.
- C. Congress should appropriate funding to ACL to provide grants to LTSS providers to develop tools and programs that assist PLWYO and their caregivers to address short- and long-term housing, legal, and financial concerns.
- D. Congress should appropriate additional funding to ACL for grants to the aging and disability networks to provide comprehensive support and resources for caregivers of individuals with Down syndrome who may be at risk of or already experiencing AD.
- E. SAMHSA should conduct a study to gather nationwide statistics to determine the suicide rate of people diagnosed with dementia by age and highlight those of PLWYO within the first year of dementia diagnosis.

6

Recommendation 4 (continued):

Define needs and expand LTSS to people living with young-onset AD/ADRD and their families/caregivers.

- F. A variety of barriers continue to exist that affect the ability of people with IDD to receive the LTSS required to live their fullest life.
1. NAPA recommends interventions to address barriers these barriers:
 - a. States should reduce/eliminate Medicaid wait lists for HCBS to meet needs of those with IDD before/after dementia diagnosis.
 - b. Address unmet needs through the following:
 - i. Develop a system of comprehensive community HCBS.
 - ii. States and local systems must develop programs to actively reach out to individuals with IDD and their caregivers.
 - iii. States must develop systems to prioritize service delivery to those on the waiting list.
 - c. LTSS Workforce (in addition to topics under Recommendation 7)
 - i. IDD and AD/ADRD competency-based training must be developed and available to all LTSS providers and direct care workers.
 - ii. States must utilize a nationwide system for criminal and related background checks, for all agencies providing LTSS.
 - d. CMS should encourage states to revise their existing Medicaid policies to allow redirection of funding from institutional care to person-centered home and community-based supports.

7

Recommendation 4 (continued):

Define needs and expand LTSS to people living with young-onset AD/ADRD and their families/caregivers.

2. NIH and ACL should continue to support the development and scaling of culturally appropriate evidence-based interventions designed to support people with IDD and dementia and those at high risk. The interventions should:
 - a. Include tailored dementia education and training for LTSS providers on the unique needs of these populations.
 - b. Strengths-based person-centered support for caregivers.
 - c. Tailored education programs, support groups, and information specifically addressing the intersection of IDD and AD.
 - d. Promote tailored HCBS including (but not limited to) respite care, day programs, and shared living models.

8

Recommendation 5:

Expand the availability of culturally and linguistically tailored LTSS to high risk populations inclusive of those with the most social and economic need, including (but not limited to) rural and tribal communities, those with limited English proficiency, and LGBTQ+ populations

- A. Congress should appropriate funding to ACL to provide state grants for the purpose of expanding CHWs within the aging network.
- B. Federal agencies should encourage collaboration amongst CHWs employed by community health clinics, managed care plans, public health, and community-based organizations to provide holistic and system-integrated services to populations disproportionately impacted by dementia.
- C. ASPE should conduct and publish a study on the impact and return on investment that CHWs can have on underserved communities.
- D. Congress should provide financial incentives for diverse business owners and not-for-profit organizations to become dementia-capable LTSS service providers.
- E. Congress should increase funding for the Aging and Disability Resource Centers (ADRCs)/No Wrong Door systems to create quality ADRCs across the country.
- F. Congress should provide funding to private and non-profit organizations for the development and implementation of innovative multi-lingual technology solutions.

9

Recommendation 6:

Identify adults with a diagnosis of AD/ADRD living alone and develop and implement strategies to address their LTSS Needs.

- A. ACL should encourage the participation of all states and interested parties in developing and disseminating ASPE's national survey, "Identify Adults with Long-Term Services and Supports Needs," and include a question to determine "number in household."
- B. Create an interagency workgroup to build capacity to support people with cognitive impairment living alone including ACL, CDC, CMS, ASPE, HRSA, SAMHSA, HUD, DOT, as well as the Building Our Largest Dementia Infrastructure (BOLD) Public Health Center of Excellence on Dementia Caregiving.
- C. Develop programs to help older adults who live alone to be prepared in case they develop cognitive impairment (See Recommendation 10.A.).
- D. ACL and CDC should continue to collaboratively promote and fund the expansion of dementia-friendly communities' efforts and other strategies that help address social isolation and loneliness and encourage inclusion of such efforts in State Unit on Aging and State Health Improvement Plans.

10

Recommendation 6 (continued):

Identify adults with a diagnosis of AD/ADRD living alone and develop and implement strategies to address their LTSS Needs.

- E. CMS should increase the number of hours permitted for in-home caregivers.
- F. CMS should encourage more states to expand eligibility to persons with cognitive impairment or dementia living alone who are low income and close to Medicaid “spend-down” limits through demonstration waivers.
- G. CMS should encourage Medicare Advantage Plans that provide Special Supplemental Services for the Chronically Ill to add services that specifically support persons with cognitive impairment or dementia living alone.
- H. CMS/CMMI should substitute the GUIDE model respite benefit to allow people with cognitive impairment or dementia living alone and enrolled in a GUIDE model without caregivers, to hire home care services as an equivalent benefit.
- I. Congress should pass legislation for tax credits (including refundable tax credits for low-income individuals who do not pay taxes) to persons with cognitive impairment or dementia living alone to defray costs of hiring direct support workers.
- J. Congress should pass legislation to allow the Social Security Administration to permit family caregivers of persons with cognitive impairment or dementia living to earn Social Security credits as part of their employment history.

11

Recommendation 7:

Implement solutions to address the LTSS workforce crisis.

- A. Congress should allocate an additional \$25,000,000 in funding for HRSA and CDC to support geriatric workforce training in AD/ADRD.
 - 1. HRSA should continue to allocate a portion of Geriatric Workforce Enhancement Program funding, not less than \$230,000 per grantee, toward workforce training in AD/ADRD, and encourage participation of students and trainees of color, with needed language skills, and those from diverse communities.
 - 2. CDC should continue to allocate a portion of Behavioral Health Integration and BOLD funding toward public health workforce training in AD/ADRD.
- B. Increase efforts and implement systems solutions at the federal level to address the workforce crisis.
 - 1. HHS should create a Direct Care Workforce Task Force that will make recommendations and develop a national strategy for addressing the LTSS workforce crisis.
 - 2. The U.S. Department of Labor (DoL) should award specific funding for long-term care workforce development and to establish one Direct Care Workforce Development Centers of Excellence per state.
 - 3. Congress should fund the ARPA 10% enhanced federal matching funds to states, beyond the current timeframe, with focus on improving the LTSS workforce.

12

Recommendation 7
(continued):

Implement solutions
to address the LTSS
workforce crisis.

- C. Establish a national caregiver career pathway for career advancement.
 1. HRSA should establish a national health professions pathway and commission development of national standards and certifications for direct care workers.
 2. States that create career pathways should consider regulatory parity and certification portability across settings where PLWD reside.
- D. Provide incentives for people to enter the workforce.
 1. Congress should appropriate funds to HRSA to provide grants to representative payees and clinics, hospitals, private duty nursing organizations, home health, disability, and other clinical providers for loan repayment, sign-on bonuses, training, and certification costs for direct care staff.
 2. Congress should pass legislation and appropriate funds to DoL to establish a program providing affordable health insurance, free/low-cost childcare, paid sick, family, and medical leave, and retirement savings options.
 3. LTSS payors should provide a minimum base rate to employers that adequately cover wages, benefits, and other workforce investments.
 4. The federal government should fund public education campaigns about the direct care workforce, serving aging populations, and conduct a national recruitment campaign encouraging people to enter the workforce.
 5. Congress should consider ways laws can be changed to attract and retain immigrants within the direct care workforce.
 6. Congress should provide pathways to citizenship for immigrants who commit to work within LTSS systems.

13

Recommendation 7
(continued):

Implement solutions
to address the LTSS
workforce crisis.

- E. Increase availability and improve training and supervisory support for people providing direct care to PLWD.
 1. States and the federal government should encourage high schools, community colleges, colleges, universities, professional societies, and non-governmental organizations to develop and provide on and off-campus programs for training direct care workers and increase internship and supervision support for the direct care workforce.
 2. States should explore ways to require or incentivize LTSS systems to provide culturally competent dementia and dementia care training to all staff who interact with PLWD.
 3. Federal and state agencies and LTSS industry associations should explore options for making no-cost training available to nursing homes, assisted living facilities, home care and other LTSS providers with guidance on dementia and dementia care training requirements for enhancing workforce competency.
 4. Federal and state agencies and LTSS industry associations should encourage the uptake of education and training to identify and manage AD/ABRD behaviors that are disruptive to care. Use of non-pharmacological evidence-based, -informed, and -supported models should be widely adopted.

14

Recommendation 8:

Expand awareness and engagement in the public and private sectors about AD/ADRD.

- A. The Federal government should encourage all states to secure an Executive Order or legislation to create government support for a Multisector Plan for Aging to align state and local priorities and encourage public-private partnerships.
- B. The federal government should strengthen its collaboration with the AD Council to expand communication around AD/ADRD through public service campaigns beyond the internet.
- C. Congress should reauthorize the BOLD Alzheimer's Act for another five years and appropriate a minimum of \$35m in FY 2025 for the CDC to implement the goals under the Act.
- D. The federal government should develop crisis care/response standards that are inclusive of AD/ADRD.
- E. The federal government should encourage states to develop and implement their 988 programs and include dementia awareness training for first responders.

15

Recommendation 9:

Increase funding to implement strategies to reduce risk of homelessness among older adults living with dementia or cognitive impairment and to respond to the needs of those already experiencing it.

- A. Congress should increase funding to the States to expand Adult Protective Services to enhance services for people at risk of homelessness.
- B. Congress should expand funding for residential care for very low-income people most at-risk for homelessness.
- C. Congress should increase funding to develop permanent supportive housing for older adults facing homelessness.

16

Recommendation 10:

Implement strategies that create the conditions for high quality-person-centered and strengths-based long-term services and supports throughout the course of the disease.

- A. HHS should continue to develop and enhance distribution of information to the public on the importance of advance care planning, financial and health care decision-making options, types of long-term care settings, their payment models and services, environment modifications, and where people can turn for assistance with these topics. HHS should define the role that health care and LTSS providers could play in distributing this information and supporting planning early in the dementia-journey.
- B. HHS should develop a strategy for broadening the public awareness palliative care benefits.

17

Recommendation 11:

Develop and implement systems and programs that support PLWD while incarcerated to provide appropriate treatment from diagnosis through to end-of-life

- A. Convene a taskforce to develop standardized criteria for compassionate release for PLWD while incarcerated, to provide guidance to all states on eligibility for release, and consider supportive approaches such as: 1) establish a system of regular formalized AD/ADRD screenings for those with evidence of cognitive decline, 2) develop an advocate program to assist PLWD while incarcerated to start the compassionate release process (if unable to do so), and 3) provide a legal advocate for representation (if necessary) throughout parole board hearings.
- B. Encourage all prison systems to offer access to advocates trained to assist PLWD while incarcerated to apply for eligible benefits prior to compassionate release.
- C. Federal Bureau of Prisons and state Departments of Corrections should develop and implement mandatory dementia training for all personnel and members of parole review boards.
- D. For PLWD while incarcerated deemed ineligible for compassionate release, programs should be developed and implemented within prison systems, and include peer-to-peer support models and safe spaces for end-of-life/memory care.
- E. Prison systems nationwide should employ case managers trained and assigned to assist PLWD while incarcerated, granted compassionate release, to develop a post-release plan.

18