The Social and Economic Impact of Alzheimer’s and Related Dementias

Council of State Governments
Southern Regional Conference
July 12, 2021 • Nashville, Tennessee
Alzheimer’s Prevalence and Costs

In Millions of People; In Billions of 2020 Dollars

In 2021…
6.2 Million People
Costing $355 Billion
Gender and Racial Differences in Alzheimer’s Prevalence

• Almost two-thirds of Americans with Alzheimer’s are women.
• Older blacks/African Americans and Hispanics/Latinos are disproportionately more likely than older whites to have Alzheimer’s or other dementias.
The 2021 Facts and Figures special report shines a bright light on barriers facing non-White racial/ethnic population in accessing dementia care. The data suggest that discrimination and lack of diversity in the health care profession are significant barriers that demand attention. The already devastating burden of Alzheimer’s must not be made worse by discrimination and health inequities in the current system.
The Progression of Alzheimer’s is Slow and Burdensome

- People age 65+ survive an average of four to eight years after a diagnosis, yet some live as long as 20 years.
- Individuals who live from age 70 to age 80 with Alzheimer’s dementia will spend an average of 40% of this time in dementia’s most severe stage.
- The long duration of the disease contributes significantly to the public health impact of Alzheimer’s.
Who Are the Alzheimer’s Caregivers?

In 2020, more than 11 million Americans provided an estimated 15.3 billion hours of unpaid care, valued at nearly $257 billion.

- Two-thirds of caregivers are women
- About one in three caregivers is age 65 or older
- Over half of primary caregivers take care of their parents
- One quarter of dementia caregivers are “sandwich generation” caregivers, taking care of both an aging parent and child
- 41% of caregivers have a household income of $50,000 or less
- 66% live with the care recipient in the community
State Government Infrastructure for Alzheimer’s

Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act – State Implementation

• New federal funding for state health departments to promote a strong public health approach to dementia.
• 9 states received 3-year Core Capacity Grants in September 2020 - CO, HI, ID, ME, MS, NV, NC, OK, VT – and 4 states received Enhanced Grants for programmatic work – GA, MN, RI, VA, WI.
• **Additional state awards to be announced any day now!**
• Focusing on changing systems, environments and policies to promote risk reduction, to improve early diagnosis, to prevent and manage comorbidities, and to avoid hospitalizations.
• Core Capacity recipients establish statewide dementia coalitions and develop/update State Alzheimer’s Plans Enhanced recipients focus activity on State Plan implementation.
Increasing Support for Family Caregivers

**MISSOURI** Structured Family Caregiving Program
Established to serve 300 people w/dementia allowing them to live in the home of their choice with the caregiver of their choice, which may include family caregivers who would be paid by Medicaid. *(Medicaid)*

**WISCONSIN** Dementia Care Specialists Program
Provides full time positions dedicated to supporting people with dementia and their families by providing dementia-specific information, care planning, case management, and consumer-directed personal care. As of 2021, there are 51 dementia care specialists across the Aging and Disability Resource Centers and local tribes. *(Non-Medicaid, mostly)*
Use and Costs of Health Care, Long-term Care and Hospice

- In 2021, the total national cost of caring for people with Alzheimer’s and other dementias is projected to reach $355 billion.
- Total annual payments projected to increase from $355 billion in 2021 to more than $1.1 trillion in 2050.

Total cost of care for Alzheimer’s will continue to rise
Alzheimer’s and Dementia Deaths Surge During COVID-19

- **42,000 more deaths** attributed to Alzheimer’s and dementia during COVID-19 in 2020 — 16% increase.

- Inaccurate reporting, comorbidities, LTC communal living, reduced access to healthcare, social isolation — all potential reasons.
The Impact of COVID-19

48% of nursing home residents and 42% of assisted living residents have dementia.

People w/dementia are twice as likely to get COVID and four times more likely to die from it.

172,000+ residents and workers have died from COVID at LTC facilities making up 34% of all COVID deaths in the U.S.

Risk was greater for African Americans with dementia, who were close to three times as likely to be infected with COVID.
Pre-Existing Challenges in Long-Term Care Communities

- Staff shortages and training
- Low reimbursement
- Infection control
- Quality improvement
- Emergency preparedness

The pandemic has amplified the need to identify solutions that aid our partners in care to deliver critical services.
Growing the Dementia Care Workforce

• Growing **shortage of direct care workers** hinders the ability for people with dementia to access care.

• It’s estimated that over the next decade, the direct care workforce will be the **largest growing occupation**.

• U.S. Bureau of Labor Statistics originally estimated **7.8 million direct care job openings** between 2016 to 2026, with 2.8 million leaving this workforce for other jobs and 1.4 million new positions created due to rising demand.

• Pool of potential workers to fill these positions, which are usually women ages 25 to 64, only expected to grow 1%.

**This is a crisis.**
Improving Standards for Care Providers

KENTUCKY: In 2019 legislative leadership established the Alzheimer’s and Dementia Workforce Assessment Task Force to identify recommendations to increase and retain the number of care professionals supporting people with Alzheimer’s. In 2021 established dementia training standards for home health and personal care workers.

VIRGINIA: In 2018 memory care and assisted living facility regulations updated to require new dementia training standards. For each year of the biennium, $70,000 was approved to help deliver dementia training to long-term care staff.
# Georgia’s Path to Improved Residential Care

## HB 987 Key Provisions

### Personal Care Home & ALF

PCHs (25+ beds) & Assisted Living Facilities "shall not admit or retain an individual who is in need of continuous medical or nursing care," but the law allows provision of limited nursing services, therefore, allowing expanded aging in place options.

### Staffing

1 to 15 during waking hours
1 to 20 during non-waking hours
however, that such ratio must be adequate to meet the specific needs of the residents

### Memory Care Centers

New code section regulating "memory care" and requiring certification by the department to operate.

### Training

- All Staff, regardless of role, at least 4 hours of dementia-specific training
- Direct Care Staff 16 hours of specialized dementia training within 30 days of hire.
- New Rules & Requirements established for Personal Care Home Administrator and Assisted Living Administrator

### Staffing

1 to 12 during waking hours
1 to 15 during non-waking hours
however, that such ratio must be adequate to meet the specific needs of the residents

One registered professional nurse, licensed practical nurse, or certified medication aide on-site at all times (Hours based on average monthly census)

- **Infectious disease reporting & PPE stockpile requirements** were added to this bill as it was passed during the COVID-19 pandemic.
Representative John LaHood
Georgia, District 175
John.LaHood@house.ga.gov
(404) 656-0188

Jennifer Rosen
Sr. Director, State Affairs
Alzheimer’s Association/AIM
jrosen@alz-aim.org
(202) 638-7043