Planning for Alzheimer’s Disease in California from the Ground Up: Development of the State Plan

CSG – Aging and Alzheimer’s Health Policy Academy – October 19, 2011

Bellevue, WA
Why develop a state plan for Alzheimer’s Disease?

“The truth is, we simply must put Alzheimer’s on the front burner because if we don’t, Alzheimer’s will not just devour our memories. It will also break our women, cripple our families, devastate our healthcare system and decimate the legacy of our generation.”

Maria Shriver
Why develop a state plan for Alzheimer’s disease?

Alzheimer’s Disease Facts and Figures in California
Funded by The Rosalinde and Arthur Gilbert Foundation
Need to plan for the future:

By 2030, the number of people living with Alzheimer’s disease in California will nearly double to over 1.1 million people.

California is home to roughly 10% of our nation’s people with Alzheimer’s disease.
Prevalence of Alzheimer’s in Diverse Communities

While numbers of people with Alzheimer’s disease will double in African American and Caucasian populations, Asian/Pacific Islander and Latino communities will see a tripling in the numbers of people diagnosed with Alzheimer’s.
Public Costs of Caring for People with Alzheimer’s

Figure 13: Medi-Cal Costs per Beneficiary 60 Years of Age and Older with AD and Other Dementias Compared to Other Medi-Cal Beneficiaries: 2007 Dollars

Source: See Report
State Government Alzheimer’s Disease Plans

- Published a State Alzheimer’s Plan. (20)
- Task Force established to develop a State Alzheimer’s Plan. (8)
- Legislation pending or working with Executive Branch to establish a State Alzheimer's Plan Task Force. (5)
- No Legislation filed or Executive Branch activity pending. (19)

Updated April 13, 2011
National Alzheimer’s Project (NAPA)

• Signed by President Obama December 2010
  • Creates a national Alzheimer’s plan
  • Establishes an inter-agency Advisory Council to coordinate and evaluate all federal efforts in Alzheimer’s research, care, institutional services and HCBS
• Ultimate goal of NAPA: End Alzheimer’s
  • For every $25,000 spent on Medicare and Medicaid services for people with AD, the government spends less than $100 on AD research
Laying the Foundation for Developing a State Plan

- Data: projections
- Special legislative hearing
- Legislation
- Building support in the Administration
Model: Public-Private Partnership Launched to Fund State Plan

**Public Partners**
- California State Legislature
- California Health and Human Services Agency
- Alzheimer’s Disease and Related Disorders Advisory Committee

**Private Partners**
- The Rosalinde and Arthur Gilbert Foundation
- The SCAN Foundation
- The California Endowment
- Archstone Foundation
  - Alzheimer’s Association
Model: Building for Leadership

• Task Force

• Subcommittees:
  1) Public Awareness, Professional Education, Workforce Development and Consumer Outreach
  2) Care in the Home, Community and Residential Settings
  3) Medical Care, Health Services and Scientific Research

• Executive Committee

• Project Director
Model: Gathering Input through Targeted Listening Sessions
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- “I earn $8.50 an hour and the caregivers for my wife cost $21.50/hr. You figure it out”

- “It is just very overwhelming. Even with a paid caregiver for my mom, I still do all the food shopping, money management, doctor appointments, etc., while working a full time job.”
“It didn’t take long before my regular lunch group stopped calling. Soon, the phone stopped ringing altogether and it was just my husband and me all alone. “

“My wife was seen by five different doctors before we finally got a diagnosis after nearly two years of pushing for answers.”
Model: Web-based Family Caregiver Survey

- Chinese, English, Korean, Spanish and Vietnamese
- 1320 respondents; 800 comments
- Distributed at listening sessions

“In addition to the sadness, depression, financial sacrifice and exhaustion that I experience caring for a loved one, I also cannot make plans for my future. My own life is on hold.”

“I am plagued by feelings of grief, anger and depression.”
Take away messages:

• Investing in caregiver training and support is not only humane but wise financially because they are the backbone of the long-term care system

• To contain costs, avoiding hospitalization and forestalling nursing home placement is key

• Improving financial integration will yield better coordinated services and improve care delivery
Cross-cutting Issues

- Financing
- Integration
- Caregiving
- Data
- Technology
- Legal
- Diversity
Guiding Principles: California Alzheimer’s Disease State Plan

- Promote person-centered care that is responsive to individual need
- Address the broad cultural, ethnic, racial, socio-economic and demographic diversity of California’s population.
- Integrate the social and medical needs of this and other aging populations living with multiple chronic diseases and disabling conditions.
GOALS

Eliminate Stigma

Recommendations:

• Heighten public awareness through culturally appropriate public education campaigns

• Ensure established clearinghouses have reliable information
Ensure Access to high quality, coordinated care in the setting of choice

Recommendations:

• Develop a comprehensive, accessible network of medical care and long-term services and support from diagnosis through end-of-life

• Advocate for accessible transportation systems

• Address the affordability of services across the long-term care continuum
Establish a comprehensive approach to support family caregivers

Recommendations:

• Acknowledge and invest in the informal, unpaid caregivers as a vital participant in care

• Sustain and expand California’s statewide caregiver support network
Develop an Alzheimer’s proficient, culturally competent workforce

Recommendations:

• Build and expand on workforce capacity and competency throughout the continuum of care

• Improve dementia care capacity and competency of primary care providers
Advance research

Recommendations:

• Sustain and expand existing research efforts

• Increase participation in research
Create a coordinated state infrastructure that enhances the delivery of care

Recommendations:

• Implement a statewide strategy to coordinate, integrate, deliver and monitor the continuum of care and services

• Incorporate public health approaches to prepare for significant growth in Alzheimer’s disease

• Collect and use data to drive service development and delivery
Financing Experts Interviewed

- Utilize public funds more efficiently
- Take advantage of national emphasis on innovation
  - Advance person investment strategies
  - Rally private sector support
- Establish dedicated Alzheimer’s funding
Model: Living Document

Action Plan for 2011-2021

• Media event and Alzheimer’s Advocacy Day in the State Capitol
  – March 9, 2011
• Policy briefings
• Alzheimer’s Association leadership retreat
• Alzheimer’s Disease and Related Disorders Advisory Committee
Lessons Learned

- Design your plan development scope of work to include policy briefings
- Document the issues in your State – Alzheimer’s prevalence, costs, how the disease affects caregivers and different ethnic groups
- Develop and pass legislation in support of the plan to legitimize its development
- Be inclusive in the state plan development. Bring a diverse group of stakeholders to the table.
Lessons Learned

• Develop a nimble, “living” plan – build in a review process, be prepared for changing science, technology, political and budgetary landscapes

• Build public and private partnerships in funding, planning, and implementation

• Develop creative funding strategies for implementation

• Solutions do not have to be regulatory or legislatively based

• Ensure communication at every level (e.g. with agency leadership and community stakeholders) during the process and ensure follow-up during implementation phase
Lessons Learned

• Recognize the difficulty of planning during challenging budgetary times and plan for solutions that do not rely entirely on state support/resources

• Plan for a dissemination phase and consider how to finance that endeavor

• Consider a media event involving policy leaders

• Determine which entities are accountable for monitoring, updating and implementation
Discussion Questions

• How can state Alzheimer’s disease plans contribute to addressing the needs of persons with Alzheimer’s disease and their caregivers?

• What leadership is needed at the state and national levels to put Alzheimer’s disease “on the front burner”?

• Do you have any remaining questions?
Resources

- California’s State Plan for Alzheimer’s Disease: An Action Plan for 2011-2021
- Alzheimer’s Disease Facts and Figures in California: Current Status and Future Projections

Both reports available at www.caalz.org
Resources

- Alzheimer’s Association: [www.alz.org](http://www.alz.org), 24-7 helpline: 1.800.272.3900
- California Alzheimer’s Disease Centers: [http://cadc.ucf.edu/cadc](http://cadc.ucf.edu/cadc)
- Family Caregiver Alliance: [www.caregiver.org](http://www.caregiver.org)
- Alzheimer’s Disease and Related Disorders Advisory Committee: [www.chhs.ca.gov](http://www.chhs.ca.gov)
Thank you!

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Chair, Alzheimer’s Advisory Committee