

Alzheimer's Disease Digest

Communication from the Alzheimer's State Plan Task Force

Volume III - June 2010

Public Weighs in on California's State Plan for Alzheimer's Disease

The past few months have focused on community meetings intended to reach members of the public who have lived with Alzheimer's disease, who have questions or concerns about a loved one with memory loss, or who work with these families. It is essential that people from throughout the state with varied experiences and diverse viewpoints shape the final plan. Their collective voices were heard in different settings, allowing for individual and large group conversations about current and future issues facing people with Alzheimer's disease and their caregivers.

More than 1,000 members of the public had the opportunity to contribute their first-hand experiences, hopes, disappointments, ideas, criticisms and solutions in the following ways:

Online Survey of current and former family caregivers about their personal experience with a loved one at home or placed in a care facility. The statewide survey was available in English, Korean, Vietnamese, Chinese and Spanish. The response was overwhelming – highlighting the need for improved diagnosis, care coordination and support services for the entire informal/unpaid care team.

Experts Panel and Community Dialogue on End-of-Life Care for people with Alzheimer's disease and related dementias. A group of 60 local leaders and caregivers met jointly in Orange County to discuss the barriers to accessing hospice and palliative care for this population. Advanced care planning in the form of POLST and other tools was highly recommended. Communication, coordination and collaboration were identified as key elements in successful end-of-life care for families living with Alzheimer's disease.

Underrepresented Populations and Their Unique Perspectives on Alzheimer's disease and related dementias. In the first of a three part series, more than 50 members of the African American community met at Graceful Senescence Adult Day Health Care Center in Los Angeles to discuss their own experiences with

memory loss, dementia, forgetting and Alzheimer's disease. In this setting, the challenges of caregiving were revealed as husbands, wives, daughters, sons, siblings, cousins, nieces and nephews described the difficulties they face in managing physical limitations, behavioral problems and the coordination of medical, social and informal care. In June and July, the series continues with an Asian-Pacific Islander forum at On Lok in San Francisco and a Latino session at San Ysidro Healthcare Center south of San Diego.

Conversations with people in the early stages of the disease around the state focused on meaningful activities and effective strategies for involvement over the initial course of the disease. Participants offered keen insights into the challenges faced by people living with a diagnosis of Alzheimer's disease or a related dementia.

Financing expert interviews were conducted with 16 state and national leaders with expertise in the areas of healthcare financing and long-term care coverage. Together, they identified five areas for further exploration:

1. Utilize public funding more efficiently,
2. Take advantage of national emphasis on innovation,
3. Advance personal investment strategies,
4. Rally private sector support, and
5. Establish dedicated funding.

This important public input has been summarized and will be integrated into the work of the three subcommittees: Awareness, Care and Medical. The next full meeting of the Alzheimer's Disease State Plan Task Force is Friday, July 16, 2010, in Los Angeles.

To learn more about State Plan development, a partnership between the Alzheimer's Association, California Health and Human Services Agency and the State Alzheimer's Advisory Committee, visit <http://www.caalz.org/stateplan.htm> or call 916-447-2731, susan_demarois@yahoo.com.

Funding for the Alzheimer's Disease State Plan is made possible by the generous support of The SCAN Foundation, The California Endowment, The Rosalinde and Arthur Gilbert Foundation, and Archstone Foundation.