



CCAL

Advancing Person-Centered Living

**Comments Submitted on the
Draft Framework for the National Plan to Address
Alzheimer's disease
February 3, 2012**

Dear Secretary Sebelius:

Thank you for the opportunity to provide comments on the *Draft Framework for the National Plan to Address Alzheimer's disease*. CCAL is a national advocacy organization working to ensure that person-centered practices are always the foundation of all aging services and supports. Ensuring that person-centeredness is integrated into healthcare practices elevates the experience from a clinical one to a humanistic one. The human emotional experience is important to achieving well-being as are clinical outcomes. The bond between the person receiving services and the individual (as well as the organizations' culture) that provides a healthcare service must be based on the following four principles all working in harmony:

Relationships - valuing the uniqueness of each person

Compassion - caring to build a connection and bond with the person

Empowerment - providing information and options to the person and their caregiver(s)

Autonomy/Choice - respecting the right of the person and their caregiver(s) to make their own choices

Global Recommendations:

Person-Centeredness

Nowhere can principles and practices of honoring the personhood of each individual be more significant than in a National Plan to Address Alzheimer's Disease, yet the draft framework is silent on person-centeredness. We respectfully submit that this National Plan should include person-centeredness in its philosophical foundation, core principles, strategies and goals as does the Department of Health and Human Services' National Health Care Quality Strategy and Plan (NHCQS): "Person-centeredness and family engagement will guide all strategies, goals, and improvement efforts". This is "one of the core principles intended to serve as the underpinning of NHCQS and should be reflected not only in the framework, but in how goals, targets, and plans are developed across health care and long-term care settings."

Person-centered language should be used throughout the National Plan. To honor the personhood of each individual and recognize that patient only refers to clinical services and not the broader holistic context, the term "patient" should be changed to "person" throughout the Plan; i.e., "Educate and Support the *Person* and their Family Members Upon Diagnosis". Indeed, person-centeredness should

be a fundamental component of all prevention and treatment plans; i.e. Strategy 2.D – “Guidelines for delivery of high-quality *person-centered* care and measures of quality are needed...”

Enhancing Quality of Life as well as Quality of Care

This framework does not reflect our national commitment to providing meaningful lives for all older Americans. Enhancing quality of life and meaningful engagement for individuals with Alzheimers and related dementias must be a fundamental principle and a goal, implemented through training, education, and outreach strategies in tandem with, and comparable to, those for Goal 2 Enhancing High Quality of Care.

Meaningful relationships, purposeful engagement, social interactions and impromptu conversations all serve to enhance the individual’s psychological, social and emotional well-being. All should incorporate the person’s interests, preferences, strengths, and skills to best maintain their sense of self and to slow down the deleterious effects of the disease. The National Plan should include training for family, caregivers, and staff to heighten their sensitivity to and understanding of positive pathways for communication, interactions, relationships, and meaningful engagement.

Family Engagement

For those of us who care for loved ones with Alzheimers’ and related dementias, we know this National Plan must move beyond encouraging “family engagement” to encouraging caregiver/family/ provider partnerships to best guide and enhance person-centered quality of care and quality of life.

Individuals and families should be empowered through interactions and resources so that they are prepared to make informed choices and be active participants and decision-makers regarding their loved one’s care. We recommend the following goals and approach from “Partnering with Patients and Families to Design a Patient and Family-centered Health Care System: A Roadmap for the Future, A Work in Progress” (2006, *Institute for Family-centered Care and the Institute for Healthcare Improvement*)

“...Develop a shared vision and action plan for improving health care by advancing the practice of patient-and family-centered care and creating partnerships with patients and families in all health care settings and within the organizations and agencies having an impact on health care”

Utilize Community-Based Participatory Research (CBPR) Methodological Approach

We suggest adopting the CBPR methodological approach to AD applied research efforts to best inform the work through multiple perspectives and expertise of community-based partners (representing key stakeholders, including family members, direct care staff, practitioners, social workers, long-term service providers, etc.) to inform the research, ensure its relevancy, and enhance understanding and dissemination across research, policy and practice sectors.

Public Education Campaign

We firmly believe that any public education campaign should highlight non-pharmacologic psychosocial treatment options for enhanced quality of life and care.

We would encourage sustained community-based outreach to the general public through the creation of a “Real People; Real Life with AD” component of this campaign to enable the general public to

meet, greet and hear from regular individuals and families who are going through this journey of AD-related life experiences and challenges. We are not suggesting celebrities or authors who have written about family caregiving. We do suggest including the voices, perspectives, and insights of individuals who are living with AD or whose loved one has AD.

Improve Coordinated Dissemination of Information

We suggest adding this goal as there is no national coordinated network of information about Alzheimer's and related Dementias for professionals or non-professionals. DHHS funds numerous AD research centers, Aging and Disability Resource Centers, and initiatives throughout the country, i.e., Administration on Aging's AD Demonstration Grants; but information and findings are not networked and easily made available.

Specific Recommendations:

Goal 1 – Prevent and treat Alzheimer's disease

Psychosocial treatment modalities (non-pharmacologic) for AD should also be included in the framework for the national plan

1.A Ensure that invited expert participants to NIH's May 2012 summit include an appropriate number of non-research, non-clinical dementia experts as well as family caregivers in order to best inform and shape the national plan.

1.C Consider : a) ethical issues related to such efforts; and b) the potential psychological, social-emotional, medical and economic impact (and unintended consequences) on individuals and their families receiving a diagnosis 10 years prior to emergence of symptoms.

1.E Consider educational campaign on appropriate and safe use of psychoactive drugs and sedatives and non-pharmacologic psychosocial treatment modalities as related to individual's quality of life

Goal 2 – Enhance Care Quality and Efficiency

2. A The plan should address solutions for recruiting and retaining high-quality direct care and paraprofessional workers. Best-practice models for AD training should be noted.

2.C & 2.D The plan should address how individuals and families can be actively engaged in decision making and act as partners on the care team if they so choose. Some individuals and families may just wish to receive counseling, support and information. Both should be addressed.

Palliative care and end-of-life care should be addressed. What interventions are available; what decisions need to be made to have personal wishes carried out by healthcare and long-term support system(s); i.e., individuals with Alzheimer's may want to leave a living will; families should understand the decisions that they may need to make.

2. D CCAL suggests using a community-based participatory process in which individuals, families, and direct care staff can be partners with experts in developing the guidelines.

We suggest examining the national Center for Excellence in Assisted Living (CEAL) “Person-centered Care Domains of Practice” for HCBS which identifies domains of: personhood, relationships and community, governance/ownership, leadership, workforce practices, meaningful life and engagement, services, environment, and accountability.

2.E Even “safe and effective” transitions can be traumatic for people with Alzheimer’s disease, particularly for people with advanced Alzheimer’s who are sent to emergency rooms for relatively minor conditions. Emphasis should be on: 1) limiting transitions; and 2) when transitions are necessary—how to make them safe and effective.

Goal 3. Expand Patient and Family Support

We strongly recommend including families and direct care staff as active partners in the process of Expanding Person & Family Support, from creating and disseminating culturally sensitive education and support materials to serving as Person & Family Support Guides.

CCAL commends all who were involved in creating the framework for a National Plan to Address Alzheimer’s Disease and related dementias; and appreciates the opportunity to contribute to the process by providing person-centered feedback on its contents.

Sincerely,

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Jackie Pinkowitz

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