

NAPA -- FACA 2013 Public Comments
(January Comments Only)
February 7, 2013

JANUARY 2013 COMMENTS

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JANUARY 2013 COMMENTS

DATE: January 14, 2013

SUBJECT: January 2013 meeting - comments from Minnesota

I would like to submit the following comments to be shared at the January 14, 2013 meeting on behalf of Jean Wood.

Dear Members of the Advisory Council on Alzheimer's Research, Care, and Services:

On behalf of my collaborators in ACT on Alzheimers, the implementation group for the Minnesota Alzheimer's Plan, the Minnesota Board on Aging and the Alzheimer's Association MN ND, we would like to express our deepest appreciation for the work of NAPA and the recommendations to dedicate \$10.5 million to seed the development of state action plans, restore ADSSP funding to \$13.5 million and fully fund the National Family Caregivers Act. Minnesota using its own private and public resources has not only developed a legislatively approved Alzheimer's Plan but a powerful collaboration that has moved forward to implement the plan. ADSSP funding has been key to this effort as well as enabling Minnesota to implement important evidence-based interventions such as the New York University Caregiver Intervention. Minnesota relies on a network of dementia capable caregiver consultants many funded through the National Family Caregivers program to support Alzheimer's caregivers in the community. Minnesota has dedicated significant state and private dollars to building a dementia capable medical care and community care system of the highest quality. With the national coordination and funding that is being recommended by NAPA our work and that of other states would be greatly magnified and impact many more lives.

Jean Wood
Director, Aging and Adult Services Division
Minnesota Department of Human Services
Executive Director
Minnesota Board on Aging

Donna Walberg
Integrated Systems -- Dementia Capability
Minnesota Board on Aging
St. Paul, MN

DATE: January 13, 2013

SUBJECT: Person with Alzheimer's should be on the Advisory Council

While I thank you and appreciate all that you are doing, I find it shocking and appalling that no person with the actual disease that you are discussing is on your council.

I cannot think of another disease where this might happen.

From my extensive experience working with people with dementia who are advocates for themselves and other people with the disease, I know firsthand that the best people from whom to learn about the disease are the people with it.

People in the early and mid stages of the disease are able to communicate in a language that the rest of us can understand (I believe that it's up to the rest of us to learn how to communicate with people who lose the ability to communicate in a way that we understand), and they already appreciate much of the difficulties and challenges faced by people in all stages of the disease. In addition, people with early onset Alzheimer's can report firsthand the unique challenges that they face by losing their jobs, taking on new expenses, and yet in many cases still putting children through college and saving for retirement.

In addition, people with dementia must be given the opportunity to advocate for themselves, as the plans that you are recommending will be impacting them directly. It is their future that you are deciding, and yet they have no direct input into these plans.

While there are many many people with dementia across the USA who are active advocates, standing up and speaking out about dementia, you need look no further than Michael Ellenbogen as a passionate, knowledgeable, and outspoken individual, whose hard work and perseverance is already changing the way Alzheimer's disease is viewed by society in general. Michael would make an excellent addition to the Advisory Council.

Thank you for your consideration,

Laura Bowley,

Mindset Memory Centre

Editor of I CAN! I WILL! Stand Up and Speak Out about Dementia

(<http://www.alz.co.uk/icaniwill>)

Facilitator of A Meeting of the Minds virtual meeting of people with dementia

(<http://www.dementiasupportnetworks.com>)

DATE: January 13, 2013
SUBJECT: Talking points and Recommendations for Meeting

Attached are my talking points and recommendation for tomorrow's NAPA meeting. I want to make sure they are also in the public record. I look forward to meeting with you and Don afterwards.

Regards,

Michael Ellenbogen
Author of "The Insider's Guide To Saving Money"
<http://www.michaelellenbogen.com>
<http://www.michaelellenbogenmovement.com/>

ATTACHMENT: NAPA 14_2013_TalkingPoints.docx

Available as separate links:	
January 14 Talking Points	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach164.pdf

DATE: January 13, 2013
SUBJECT: Comments RE the Advisory Council

As a former caregiver and an ardent advocate in the fight against Alzheimer's, I want to thank you for the excellent work that has been done thus far regarding NAPA. I'm hopeful that this year we will see adequate support and funding to implement your recommendations and turn our shared dream of NAPA and a world without dementia into a reality.

I understand that the Advisory Council consists of at least 22 members and meets quarterly to discuss the efficacy of government programs targeting the needs of individuals and caregivers coping with the consequences of Alzheimer's and related disorders. My request and hope is that the Advisory Council can be expanded to add/include individuals who have been diagnosed with dementia.

We know that stigma is a tremendous obstacle for individuals and families living with this disease. I personally experienced the very painful and isolating results of this in caring for both my father and my husband from 1984 to 2012. It is my personal belief that, if we truly hope to reduce stigma, improve care, and help the public fight against ADRD, we must have someone who is living with the disease on the Advisory Council.

I trust that you will act upon this recommendation and set an example for all that those with dementia continue to contribute and have capabilities, not just disabilities.

Thank you.

Lynda Everman

DATE: January 12, 2013
SUBJECT: Representation of ALS patients on NAPA

There's an old Middle Eastern saying, "If you want to know how good the medicine is, don't ask the doctor, ask the patient." I believe the same wise saying should apply to advisory committees.

For eight years I have counseled, wrote about, cared for Alzheimer's patients, and have done research in human information processing. I can attest that the perspective of someone with the disease is different from those who know the illnesses at arms length. This includes researchers, caregivers, and medical personnel.

I believe it is important to have someone on your committee who has Alzheimer's. Life as seen through any illness is different from life without it. It can provide a unique perspective to other committee members. The inclusion of Alzheimer's patients in the United Kingdom advisory committees has met with great success.

Having someone with Alzheimer's can give the committee a type of perspective that isn't possible from those without it. I suggest Michael Ellenbogen for your consideration.

Sincerely,

Stan Goldberg, Ph.D.