NAPA -- FACA 2012 Public Comments

(March Comments Only)

June 22, 2012

MARCH 2012 COMMENTS

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DATE: March 31, 2012
SUBJECT: NAPA Strategic Plan Input

This is an excellent document and we applaud your initiative and efforts to make this comprehensive and inclusive. It is with that objective in mind that we make the following observations:

Under Action 1.B.5 you note the importance of clinical trials on "Pharmacologic interventions." In B.6. you mention the importance of these for "lifestyle interventions." However, another **key area** is **dietary or nutritional interventions**. While this is often assumed by some under lifestyle, it is **not always understood as such**, especially by the public, and in light of recent research seems significant enough to warrant it's own mention. At least in terms of prevention, diet and nutrition is arguably <u>at least as important</u>, if not much more so, than any pharmaceutical intervention yet devised. (see evidence below). The rationale for it not being assumed under lifestyle is as follows:

Dictionary.com defines lifestyle as: *the habits, attitudes, tastes, moral standards, economic level, etc., that together constitute the mode of living of an individual or group*.

While tastes may imply dietary choices, that's not necessarily so, as they could imply one's taste for clothing, cars, companionship, etc., which do not equate to food or nutritional choices. Dictionary.com provides this example of it's use in a sentence: *Much of what we're told about diet,* ***lifestyle*** *and disease is based on epidemiologic studies*.

Here you see they clearly do not consider "diet" to be synonymous with "lifestyle."
Perhaps this oversight, or confounding of the variables, is due to the heavily biased and fretfully flawed FDA tendency to lump anything therapeutic under the heading of pharmaceutical or "drug." That however is confusing and misleading to the public, and we feel a disservice to the thousands of great scientists who have worked and are working with nutrition and nutritional formulas -- many of whom your agencies have funded, who in the past **have made better inroads** into preventing or arresting AD symptoms than the pharmaceutical industry. In fact, Dr. William Grant in his landmark epidemiological study of "what causes Alzheimer's," including studies from 11 different countries, argued strongly that Alzheimer's disease was "primarily caused" not by genetics, which you pay great attention to, but by **unhealthy dietary choices**.[1] Moreover, the experimental peer reviewed studies, also show that findings in the field of nutrition have been more promising to date,[2], [3], [4], [5], [6], [7], [8], [9] at least for the prevention of Alzheimer's than the much more costly pharmaceutical trials. It is logically inconsistent therefore to emphasize pharmaceutical trials in the context of prevention and neglect to even use the words **diet, nutrition** or exercise in this proposal.

So, wouldn't it be appropriate in light of the above noted research, to include here "nutritional" or "dietary" in para 1.B.6 before "lifestyle" as the dictionary has above. In other words to note "the importance of clinical trials on nutritional or dietary interventions." And encourage the FDA to expedite the approval, implementation and public awareness of positive outcomes in these areas, instead of dragging their feet as they historically have done, in this area. Or worse yet proposing a moratorium on new formulations, as they recently have proposed. (If you would like evidence of this let me know.)

We recommend, as you discuss prevention and early intervention, that you at least make mention of the fact that Alzheimer's is seen by many good researchers as a condition of elderly malnutrition,[10], [11] and there is a great deal of good research, such as that conducted by Dr. Suzanne Craft at the University of Washington, which the Alzheimer's 'Association highlighted in their 2010 ICAD conference and in their HBO series, which suggests that healthy foods and the nutrients they contain, may be among the **most** important factors to consider in our efforts to prevent Alzheimer's. In fact in that video she notes that by following some simple dietary guidelines people "could at the least delay the onset of Alzheimer's" and by doing so "reduce the number of Alzheimer's cases nearly in half" -- thus enabling you to achieve your objective.

Of course we're just using Dr. Craft as an example. In fact that Assoc and NIH have sponsored many good studies which suggest that various nutrients, like folic acid, grape seed and other antioxidants, key amino acids, etc can make a major dent in preventing Alzheimer's. Remember the famous Cache Senior memory study where they found that high consumption of antioxidants -- C and E "reduced AD prevalence by about 78% (adjusted odds ratio, 0.22; 95% confidence interval [CI], 0.05 - 0.60) and incidence by about 64% (adjusted hazard ratio, 0.36; 95% CI, 0.09 - 0.99)."[12] Then there were the Chicago fish studies5 and the MIDAS study presented in the 2009 ICAD conference which showed fish and DHA's potential to reduce risk by more than half. And we could go on -- see the references noted above.

You get our point. If you are going to specify pharmaceutical and lifestyle trials, we feel you should also note dietary or nutritional trials.

p.s. please reply so that I know you received this.

David R. Larsen, MFHD
Independent Alzheimer's Researcher and National Post Graduate Instructor for Health Education Network
Writing for Innovations in Health Associates

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DATE: March 31, 2012
SUBJECT: We need a bold plan to stop Alzheimer's!

My dad died with dementia. It's not a pleasant thought to look forward to!

Thank you.

Elizabeth Haviland
Ellensburg, WA

DATE: March 31, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

Unless you have cared for a family member throughout their demise due to Alzheimer's, you cannot possibly imagine the horror and sadness this disease inflicts upon a family. It took eleven years for our beloved mother to finally succumb to this wretched disease. It completely destroyed our father, as the primary caregiver, depleted ALL of our parents' savings, and left our family penniless and in a shambles. Our dear father's health was so comprised as her caregiver, that he is now in a nursing home, dying. I cannot stop crying. We have not only lost both parents, but also all hope of any chance of happiness for their children and grandchildren. I hope you do not have to experience this first hand before you understand how devastating Alzheimer's truly is. Turning your back on an opportunity to stop this dreadful disease will surely prove to be a failure to act to save someone in your OWN family from this tragedy. Alzheimer's is no respecter of persons. Please help.

Sharon Russell
Oakland, CA

DATE: March 31, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

I had worked in nursing homes as an Activities Assistant for years, and saw the debillitating effects of the disease on the people who had the disease, as well as their loved ones. I also have an aunt with the disease, and know of the toll this is taking on her children. We need the HHS to take action to find a way to prevent this disease and cure it.

There needs to be more research done on Alzheimer's Disease, so that this disease may be combatted.

Respectfully yours,

Ellen Hely
St. Louis, MO

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer's!

Dr. Oz backs the research behind this existing drug to treat Alzheimers. This article explains it better than I can. My mother was recently diagnosed and it is a painful disease to watch. The mental decline in someone so vibrant and otherwise very healthy is devastating. Please support an aggressive pursuit of this new promising treatment for Alzheimers.

http://www.doctoroz.com/blog/mike-roizen-md/alzheimer-s-breakthrough-shows-promise

Thank you very much.

Dr. Jessica L. Madsen
Cincinnati, OH

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

My father died a slow death from Altzheimer's, essentially losing his life before it actually killed him. In the process, it drained my mother's life to the point where she neglected her own health to devote 100% of her time to his care, and she died soon after. It drained me and my brother's as well, and now we live in fear of developing this disease ourselves.

The current NAPA plan, though well intentioned, is as effective as a Get Well Soon card. Please work to make the next version of the plan effective by putting some muscle behind it. It is hard to believe even in the current partisan environment that it would not receive bi-partisan support.

Thank you.

Nicholas Kouros
Harvard, MA

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

My mother once spoke four languages, got her master's from Tufts School of International Law and Diplomacy and had one of the sharpest wits ever.

She's 89 now, and think she thinks I'm an overly friendly nursing home staffer who kisses her and tells her how much Istill love her. She has disappeared so slowly, I'm not even sure when I said goodbye to the mother I once knew.

I am saddened and scared. I am scared now that I, too, will suffer this fate. And that my children will one day wonder where I went and who is this apparition is who looks like me but seems lost at sea.

I am heartened by the commitment to a 2025 deadline in the draft NAPA plan to fight Alzheimer's. The clinical trial are crucial and I am strong believer in targeted research and coordinating resources. We cannot afford to waste resources!

But I fear good intentions without benchmakrs will mean wasted time, effort and money. We need timelines, deadlines and accountability.

I hope that HHS will tackle this issue in the coming months the only way to address this disease -- with courage, coordination and bold action.

Sincerely,

Karen Lowe
Glendale, CA

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

Alzheimer's is a cruel disease. It slowly steals one's intellect, ability to communicate, independence, and dignity, even control over basic bodily functions like eating and caring for personal hygiene. It also places an overwhelming burden on caregivers -- emotionally, physically, and financially.

Sadly it seems the Republican party is inflicted with this horrible disease. If for no other reason, do it for the GOP!

Michael Berg
San Francisco, CA

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

I feel sure you have been exposed to Alzheimers there are very few people now that haven't been affected by it, so there is no need to explain what it does, all we need is help.

Once the damage is done it can't be reversed, so please encourage urgent research to stop Alzheimers.

Sue Smith
Canton, NC

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

For the past 3 years I've watched my partner of 48 year decline into the darkness of Alzheimer's disease. His physical condition is to the point that I must place him in a nursing home. This is by far the most difficult decision I have ever made. I want a time to come that no one must make such a decision because of Alzheimer's disease.

I am pleased that your draft plan recognizes the need for increasing enrollment in clinical trials, compressing the drug development process, accelerating targeted research, and better coordinating activities with other countries.

From what I can tell there needs to be more resources promised and some more explanation of the steps to be taken.

I hope that HHS will address these issues in the coming months so that the next version of the plan will be bolder. Our nation cannot afford the costs of inaction.

Thank you.

Alan Baker
Alpine, TX

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

Alzheimer's is a traumatic way to end one's sacred time here on this planet. The disease is paralleled with strong (negative) personality shifts and loss of memory related cognitive abilities in all types of memory. Further fueling this disease is the social treatment of it. Family members interact cautiously, and the person suffering Alzheimer's disease often witnesses their social structures disappear. My grandma, who suffers Alzheimer's, has been fighting with my grandfather for two years now, convinced that he is slyly stealing all of her things. My grandfather cannot even be in the same room alone with her anymore without being emotionally trampled. This is not her, and this is not the person my whole family grew up with. This has happened with both my grandmothers.

This needs to be dealt with, and it can. Research has identified many of the neural and microbiological mechanisms behind this neurodegenerative disease. If we can learn to cure this, that would be amazing. However, more funding can allow us to really treat it, which involves both traditional AND preventative medicine. Education of our public is highly important. Teaching appropriate and healthy behaviors (nutrition, physical AND mental exercise, having social relationships, etc.) which are highly linked to prevention are important. Funding of projects both in research and education is of extreme importance, especially given the future financial costs all of us will be covering for these individuals.

It is our national duty to fix this. Please take the necessary steps forward! Thank you for your time.

Glenn Carson
Candidate for B.A. in Intensive Psychology and B.S. in Neuroscience at UC Santa Cruz
Santa Cruz, CA

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

The devastation caused by Alzheimer's disease to so many families is well known. Please see to it that the resources needed to really push this plan forward are made available. We're depending on you.

Thank you.

Toby Horowitz
Brooklyn, NY

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

My Mother died of Alzheimer's, it was a long, cruel and horrible spiral to death....so sad.

Thank you.

Dale Novak
Saginaw, MI

DATE: March 30, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

Alzheimer's is a cruel disease. I saw my Grandma go from an active, sweet person to a woman who thought the person reflected in her mirror was another woman. I saw my Grandpa's heart break as the person he planned to spend the rest of his life with dwindled away to a woman who thought he was her father.

It's time for something to be done to eradicate this disease. It is a cruel disease that robs a person of their dignity and leaves the family feeling angry and cheated.

Please do what is needed to stop this disease.

Thank you.

Tami Sutton
Austin, TX

DATE: March 30, 2012
SUBJECT: Comments on Draft National Plan to Address Alzheimer's Disease

Having been associated with the Alzheimer Society of Washington for thirty years I have seen many changes in the recognition, support and care for person affected by dementia. The scope of the Draft National Plan makes it clear that leaders in the nation have recognized the need to bring together governmental and private agencies to develop a plan. I applaud the work that has been done and have only a few comments:

1. Even though the prevalence of Alzheimer's disease and related dementias (AD) increases with age ***it is not an "aging" issue***. AD is a chronic disease and designating many of the programs that serve people affected by dementia to, or through, the National Institutes on Aging or through Older Americans Act programs shifts a chronic health problem to an aging issue. The National Institutes of Health (NIH) could be assigned to oversee all Chronic Disease and Disability programs – then AD supportive services could fall under the auspices of NIH. This action would make AD more likely to be seen as a chronic disease and should elicit preventive health-related responses, even though there is not currently a cure for AD.

2. While this report addresses reducing stigma and bringing better understanding to the needs of people with dementia, it still reflects the medical bias that can occur in so much of health care. In the *Draft National Plan, Action 2.A.4: Strengthen the direct-care workforce it says, "The training will be released in Spring 2012, and will be available to all* ***nursing homes to share with their staff***." I recommend the language be changed to say,"…will be available to all "***organizations providing dementia care***." My reason for expanding the beneficiaries of the training is that many organizations in the community provide care to people with dementia. Offering training to all organizations that provide supportive services, daycare and home care, and less medically-oriented care, and not limiting the training to nursing homes, can help the person with dementia remain in the community longer -- and reduce healthcare costs.

3. Funds designated for ***research*** should specifically include ***Social Innovations***. As I indicated in the paragraph above, there are many organizations that are providing support to people affected by dementia.

Our organization has sponsored two such innovative social programs:

A. The Early Memory Loss (EML) program, conducted at least yearly, is for the person with dementia and his/her care partner(s). The initial program lasts ten weeks. Participants gather, then are divided. People with dementia are in one group; the family care partners are in another. The same topic is addressed in each group, but in a way that is appropriate for the person with dementia or the family members. Upon completion of the weekly EML program the group "graduates" into a follow-up support group that is made up of attendees from previous classes and meets monthly.

B. The second program is called "Staying Connected" and is for people with early memory loss. Participants attend a small (up to 8 people) 3-hour weekly group that provides physical, social and mental stimulation. Over the past three years many of the participants have retained their mental capacity and have continued to benefit from the program. Their care partners have benefitted, too, by having this supportive community program.

Research into ***Social Innovations*** could help provide credibility and more support for these kinds of programs.

Thank you for asking for comments from the public.

Josselyn Winslow
Alzheimer Society of Washington Board Member
Bellingham, WA

DATE: March 30, 2012
SUBJECT: NASUAD Comments on the Draft National Plan to Address Alzheimer's Disease

The National Association of States United for Aging and Disabilities (NASUAD) appreciates the opportunity to comment on the Department of Health and Human Services (HHS) Draft National Plan to Address Alzheimer's Disease, as published on February 22, 2012.

NASUAD represents the nation's 56 state and territorial agencies on aging and disabilities. As part of the National Aging Network, each of our members oversees the implementation of the Older Americans Act (OAA), through funds awarded by the Administration on Aging (AoA). Additionally, many member-states also serve as the operating agency for Medicaid home and community based services (HCBS) waivers that serve older adults, and in some cases, individuals with disabilities. The Association's principal mission is to design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability, and their caregivers.

The enactment of the National Alzheimer's Project Act (NAPA) has created a long-overdue opportunity to focus the nation's attention on Alzheimer's disease, and the Association applauds the Administration's recognition of both the vital need to address the many challenges facing people with the disease, their families, and caregivers; and the urgency with which this must be done. Additionally, we find the draft plan's guiding principles, which seek to optimize existing resources and improve and coordinate ongoing activities, to support public-private partnerships, and to transform the way we approach Alzheimer's disease, to be an appropriate reflection of the ambitious, yet attainable, goals embodied by the plan itself.

Guided by a vision of a nation free of Alzheimer's disease, the Draft National Plan to Address Alzheimer's Disease outlines goals, strategies and actions that directly affect the Aging Network. Consequently, NASAUD respectfully submits for your consideration the following comments and recommendations.

Action 2.A.5: Strengthen state aging workforces.
NASUAD applauds the Department's efforts to strengthen state aging workforces that are "capable and culturally competent" through AoA. While implementing this action, it is important that efforts to improve state strategies do not further burden states' abilities to apply for and utilize funds from AoA. States should maintain flexibility to implement strategies that address the unique needs of the state populations through their state infrastructures.

Action 2.A.6: Support state and local Alzheimer's strategies.
NASUAD applauds states for recognizing the need to develop comprehensive plans to address Alzheimer's disease, but we are concerned that these plans are being conceptualized and developed without involvement from the Aging Network. State agencies on aging and disabilities play a critical role in the oversight and delivery of services that are designed to support older adults, including those with Alzheimer's disease, in their homes and communities. For these reasons, NASUAD recommends that state agencies on aging and disabilities, and other relevant stakeholders, should be involved at all stages of Alzheimer's state plan development.

Additionally, in accordance with the Older Americans Act, state agencies must develop a State Plan on Aging, which is envisioned by AoA as a comprehensive plan document that articulates the direction in which state long-term care efforts are moving, key strategies to address the strong desires of the rapidly growing new generation of long-term care consumers to be served in their homes and communities, and how the state will address the challenges of America's budgetary constraints and competing priorities in today's society. Given these existing requirements, State Plans on Aging may be the most appropriate place for states to describe their short and long-term strategies for addressing Alzheimer's disease. The integration of Alzheimer's state plans into State Plans on Aging would align with the need for a holistic approach to combatting the disease itself, as well as AoA's intent that State Plans serve as valuable tools for planning and tracking all of the state's efforts on behalf of older adults.

Action 2.B.1: Link the public to diagnostic and treatment services.
NASUAD supports the Department's approach of expanding linkages between existing disease support and community information centers supported by AoA and the National Institutes of Health (NIH). In order to successfully connect members of the public with the necessary services and supports, NASUAD recommends that HHS also examine the capacity of these existing structures, particularly those within the Aging Network, such as ADRCs, I&R/A, and SHIPs, to ensure that these resources are adequately funded to meet the needs of this growing population.

Action 2.C.2: Enhance assistance for people with AD and their caregivers to prepare for care needs.
NASUAD recommends that any strategy to strengthen the Aging Network's capacity to provide families and people with AD access to appropriate services and specialized long-term care planning should be implemented in such a manner that does not overly burden these existing systems. Rather, any approach should provide the Aging Network with the necessary resources to meet these unique needs and to develop innovative practices for doing so. In addition, HHS should compile an inventory of tools to assist caregivers from federal and state agencies, as well as patient advocacy organizations, and make these tools readily available within the next year for distribution through the Aging Network.

Action 2.F.2: Implement and evaluate new care models to support effective care transitions for people with Alzheimer's disease.
NASAUD supports the Department's recognition of the potential for the ADRC Evidence Based Care Transitions program to implement evidence-based care transition models that meaningfully engage older adults, individuals with disabilities, and their informal caregivers. Throughout this evaluation process, NASUAD recommends that HHS consider the impact that additional resources could have on the ability of ADRCs to build their capacity and successfully support effective care transitions for people with Alzheimer's disease.

Action 2.F.3: Develop an AD-specific toolkit on care transitions.
NASUAD recommends that this toolkit be developed in consultation with state agencies on aging and disabilities, and be available for distribution throughout the Aging Network within the year.

Action 2.H.2: Identify steps to ensure access to long-term services and supports for younger people with AD.
NASUAD supports the proposed collaboration between the Administration on Aging (AoA), the Office on Disability, and Administration on Developmental Disabilities (ADD) to address access to long-term services and supports across the lifespan, and believes these agencies should be consulted as stakeholders throughout the plan's development and implementation.

Action 3.A.1: Identify culturally sensitive materials and training.
NASUAD supports HHS efforts to give caregivers the information and training that they need in a culturally sensitive manner, and recommends that plans to do so include input from the Aging

Network. To facilitate the identification and distribution of culturally-appropriate materials to caregivers, NASUAD recommends that within the year, HHS should convene an expert panel to develop an inventory of culturally-sensitive materials and trainings that are currently available, and identify gaps that should be filled by government and patient advocacy organizations.

Action 3.A.2: Distribute materials to caregivers.
NASUAD recommends that HHS utilize its current inventory of federal agency programs and materials and make these resources readily available to all caregivers through the Aging Network.

Action 3.B.2: Identify and disseminate best practices for caregiver assessment and referral through the long-term services and supports system.
NASUAD recommends that HHS distribute the identified best practices in a manner that recognizes the variance in long-term services and supports systems across, and within, states. Since what may be a promising practice in one state may be ineffective in another, NASUAD encourages HHS to recognize the importance of state flexibility in meeting the unique needs of individuals within each state.

Action 3.B.3: Review the state of the art of evidence-based interventions that can be delivered by community-based organizations.
NASUAD recommends that this action include identifying interventions that are successful in improving the health and wellness of people with Alzheimer's disease and other dementias. Many successful evidence based programs have been proven to work for both people with Alzheimer's and other dementias, so it is important that the evaluation of such programs not be limited to only Alzheimer's specific interventions.

Action 3.B.4: Develop and disseminate evidence-based interventions for people with Alzheimer's disease and their caregivers.
To successfully implement the strategies defined in Action 3.B.3, NASUAD recommends that HHS quickly work to ensure that more people with Alzheimer's disease, and their families, have access to successful evidence based intervention programs. There are existing programs that NASUAD recommends HHS should expand as part of this effort:

- <u>Older Americans Act</u> -- Reauthorization of this legislation would ensure grants to states for community planning and social services, research and development projects, and personnel training in the field of aging. Funding should also be increased for the programs funded by the Act.

- <u>Lifespan Respite Care Act</u> -- Reauthorization of this legislation would authorize grants to statewide respite care service providers. Grants can be used for various purposes, including training and recruiting workers and volunteers, training family caregivers and providing information about available services. Additional funds should be allocated to the Act.

- <u>National Family Caregivers Support Program</u> -- At a minimum, funding levels should meet the recommended levels of the President's FY12 budget ($192 million). This program provides grants to states and territories to pay for a range of programs assisting family and informal caregivers to care for loved ones at home and for as long as possible.

Action 3.B.5: Provide effective caregiver interventions through AD-capable systems.
As HHS works to connect caregivers with appropriate supportive services, NASUAD recommends that HHS build upon the existing capacity of ADRCs to serve as "No Wrong Doors" through which individuals, their families, and caregivers can access available services and programs.

Action 3.B.6: Share lessons learned through VA caregiver support strategies with federal partners.
NASUAD recognizes and applauds the successes of the VA in providing home and community based care, and realizes the importance of sharing lessons learned from the implementation of these programs across agency and state lines. NASUAD recommends that the quarterly meetings identified in this action step commence as soon as possible, so that important information is gathered and shared not only among federal programs, but also throughout the Aging Network.

Action 3.C.1: Examine awareness of long-term care needs and barriers to planning for these needs.
Once HHS completes this barrier-identification process, NASUAD recommends that HHS work with federal stakeholders, including CMS and AoA, as well as state and local agencies on aging, to develop and implement solutions to the identified obstacles.

Action 3.C.2: Expand long-term care awareness efforts.
In looking to expand public outreach and awareness about Alzheimer's disease and the importance of long-term care planning, NASUAD recommends that HHS build upon the successes of the Aging Network in providing outreach and education, such those achieved by ADRCs, I&R/A, SHIPs, and state and local agencies.

Strategy 3.D: Maintain the dignity, safety and rights of people with Alzheimer's disease.
To successfully implement this strategy, NASUAD recommends that HHS consider implementing the Elder Justice Act (EJA), as established by the Affordable Care Act (ACA). The EJA fully realizes the need to protect our most vulnerable citizens from financial exploitation, as well as from physical and emotional abuse and neglect, and it creates structures and programs for doing so. Though the EJA was signed into law in 2010, it has yet to receive any federal dollars. Without a strong financial commitment to address the growing problem of abuse and neglect among older adults, it will be impossible to fully secure the dignity, safety, and rights of people with Alzheimer's disease. NASUAD recommends that HHS work with Congress to fully fund the Elder Justice Act.

Action 3.D.1: Educate legal professionals about working with people with Alzheimer's disease.
NASAUD recommends that these efforts take into consideration the existing framework and resources for legal services that are available through the OAA. Additionally, training should be offered to legal professionals throughout the Aging Network, and the curriculum should address the importance of cultural competence. Training should also be extended to state Adult Protective Services workers as well as to other individuals as appropriate.

Action 3.D.2: Monitor, report, and reduce inappropriate use of anti-psychotics in nursing homes.
To leverage existing successful systems, NASUAD recommends that federal and state representatives from AoA's National Long-Term Care Ombudsman Program be involved in this collaborative effort.

Action 3.E.1: Explore affordable housing models.
NASUAD recommends that this action include the evaluation of innovative interventions aimed at helping older adults and individuals with disabilities, including those with Alzheimer's and other dementias, remain in the community rather than in institutional settings. With a focus on programs and strategies undertaken by AoA, state agencies on aging and disabilities, and area agencies on aging, NASUAD recommends that HUD and HHS work with the Aging Network to identify innovative practices, barriers to success, and solutions to these barriers.

New Recommendation: ***Ensure adequate resources for programs and services supported by AoA's Alzheimer's Disease Supportive Services Program (ADSSP)***.
ADSSP's focus is to expand the availability of diagnostic and support services for persons with Alzheimer's disease and other dementias and their caregivers, as well as to improve the responsiveness of the home and community based care systems to persons with dementia. The program focuses on serving hard-to-reach and underserved persons using proven and innovative models. In order to achieve Goal 3 in the Draft Plan, funding for ADSSP should be increased rather than reduced so that evidence based programs can continue to support the growing number of people with Alzheimer's disease and other dementias and their families at the community level.

New Recommendation***: Include services for mental and behavioral health services***.
Mental and behavioral health services must be included in the wide array of necessary health services available to individuals with Alzheimer's and other dementias, their families, and their caregivers. Mental and behavioral health providers should be represented on interdisciplinary health care teams that work with these individuals, their families, and caregivers in primary care, institutional, and home and community based settings. Cognitive impairment alone does not preclude the ability to benefit from various forms of effective behavioral and mental health interventions.

Action 4.A.1: Design and conduct a national education and outreach initiative.
NASUAD recommends that HHS use existing "No Wrong Door" systems, such as ADRCs, to link individuals to accurate information, resources, services, and supports, in a manner that recognizes the potential need to enhance the capacity of ADRCs.

Action 4.B.1: Convene leaders from state and local governments.
NASUAD recommends that HHS include state directors on aging and disabilities in this collaboration, as well as state long-term care directors.

On behalf of NASUAD, I thank you for the opportunity to comment on this proposed rule. We look forward to continuing to work with HHS to develop a National Plan to Address Alzheimer's Disease that seeks to achieve the vision of a nation free of the disease, while maintaining the dignity and independence of those with Alzheimer's disease, their families and their caregivers. Please do not hesitate to contact me, or Lindsey Copeland, NASUAD's Director of Policy and Legislative Affairs to further discuss any of these issues.

Sincerely,

Martha A. Roherty
Executive Director
National Association of States United for Aging and Disabilities
Washington, DC

Lindsey Copeland
Director of Policy and Legislative Affairs
National Association of States United for Aging and Disabilities
Washington, DC

ATTACHMENT: NASUAD Comments on Draft National Plan to Address Alzheimer's Disease.pdf

Available as separate links:	
Comments on the Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach148.pdf

DATE: March 30, 2012
SUBJECT: Comments on NAPA draft from NP with 30 years in Alzheimer's

Please confirm that you received this message. I know today is the last day for submission.

I was hoping to get it in earlier, but my dad passed away recently.

Thank you for this opportunity to include our comments!

Warmest regards,

Susan Scanland

ATTACHMENT: 033012 Susan Scanland NAPA comments.docx

Available as separate links:	
Comments on NAPA from an Alzheimer's Expert with 30 years of Dementia Experience	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach146.pdf

DATE: March 30, 2012
SUBJECT: Alzheimer’s Poetry Project

Please find attached a letter for the public comments on the National Alzheimer's Project Act.

Sincerely,

Gary Glazner
Executive Director
Alzheimer's Poetry Project
Brooklyn, NY
http://www.alzpoetry.com

ATTACHMENT: Letter NAPA.pdf

Available as separate links:	
Arts and Aging Research	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach145.pdf

DATE: March 30, 2012
SUBJECT: Comments on draft National Plan to Address Alzheimer's Disease from Researcher & former Alz Assn leader

Thank you so much for signing NAPA and putting creation of our first National Plan to Address Alzheimer's Disease on the fast track.

I preface my comments with brief personal history.

I joined the national Alzheimer's Association early in 1980, co-founded both the Chicago and Detroit area chapters as I moved around the country, joined the National Board of Directors circa 1981 and rose to become a national Vice Chair and Chair of the Public Policy Committee. In 1984 I co-founded the Alzheimer's Disease International. I am also proud to have single-handedly suggested the idea of what became the federally funded program to states to create innovative Alzheimer's programs with special emphasis on serving minority populations. While Chair of the Public Policy Committee for the national Alzheimer's Association I was also successful in getting our board to hire full time professional public policy staff, create our annual spring "Public Policy Forum" to bring our citizen advocates to Washington DC to be educated and meet with their Congressional representatives. We also developed our first coalition efforts, e.g. with the then Long Term Care campaign, and the National Citizen's Coalition for Nursing Home Reform and helped support the nursing home reform bill that became law (OBRA 1987). We also held our first meetings with members of the CBO and Medicare/Medicaid administration officials to examine what information was needed to start developing a plan for how to meet the service and funding needs of people with dementia and their families. Later, in the 1990's while at Wellesley Centers for Women we looked at the scary prospects of the diminished numbers of people available (the baby bust era e.g. my children's birth cohort) to serve as care partners to those baby boomers who would be developing Alzheimer's and other brain/body diseases in 2040-2050. I then was asked to join Boston University's NIH funded Alzheimer's Disease Center and Department of Neurology to continue my clinical intervention studies; I currently have a small phase I trial of nutritional supplements underway, funded by the U.S. Alzheimer's Association.

My work over the past 30 plus years on behalf of Alzheimer's disease and now the broader field of brain health, is all inspired by my mother Frances Fink Emerson who developed Alzheimer's disease in her early 50's, lived 25 years and died in 1990 with no ability for willed action or movement of any sort, and a brain shrunk to half its original size. She received great care both at home -9 years-and in a nursing home -- 16 years- (and thus lived a long time despite her disabilities….no other health issues) in an era when we knew only a fraction of what we know now, thanks primarily to the work of the Alzheimer's Association, and research funding by NIH, Alzheimer's Association and WHO and other organizations and caring people around the world.

Today I am an Alzheimer's researcher connected with Boston University School of Medicine, actively serve on my local chapter board (Alz. Assn of Massachusetts and New Hampshire) as member of the Medical Scientific Advisory Committee, serve as a Board Member Emeritus of the national Alzheimer's Association (an inactive role), and actively attend and present scientific papers or posters at the Alzheimer's Disease International. I also have a small business that brings evidence-based knowledge about brain healthy lifestyles to organizations and individuals and families. My centerpiece is the evidence-based Memory Preservation Nutrition program, which I am proud to be bringing to 6 Boston area Assisted Living communities to help them improve the healthfulness of the foods their residents are served and eating. I am also a popular speaker, mainly on the topic of "Healthy Eating for a Healthy Brain and Body." And was featured as part of a Medical Journal TV news report on Boston Channel 5’s Chronicle on March 20, 2012 and November 18, 2011.

I am excited by the breadth and content of the draft national Alzheimer’s plan and want to make just a few pointed comments about moving forward. I am also attaching a couple documents that might be of interest in summarizing some of the recent work related to brain healthy lifestyles and reducing risk of Alzheimer’s and other brain diseases. Here also is the direct link to the article I wrote for Sage Encyclopedia 'Alzheimer's Disease: Encyclopedia of Lifestyle Medicine and Health' See it at: http://www.sage-ereference.com/abstract/lifestylemedicinehealth/n18.xml

First, I am gratified that the draft plan calls for research and program development in the realm of healthy lifestyles, not just innovations in the realm of pharmaceutical and medical research, which of course is needed as we would all like to find the magic bullet(s) to prevent and cure this disease. But given the complexity of this mysterious disease and the delicacy and intricacy of the brain, such magic bullets may not exist. Alzheimer’s may be as challenging to reduce risk as has been heart disease, stroke and diabetes, since they are all interrelated in ways we are still seeking to understand. Thus major public health initiatives based on evidence uncovered in the fields of nutrition, physical exercise, sleep, stress reduction and much more may be what works to help our society avoid the catastrophe of doubling, then quadrupling the numbers of Americans with Alzheimer’s disease as the numbers of people who could serve as care partners and paid professional providers shrinks in relative numbers.

Second, as an active member of the international Alzheimer’s research and practice communities I strongly urge that the HHS Administrative offices charged with designing, refining and implementing the plan be in close liaison with international efforts to combat Alzheimer’s disease. People in the US are often very parochial and have no idea of the great strides being made elsewhere. Also, because our healthcare system is presently dominated by for-profit organizations and pharmaceutical companies, it is harder for us to see clearly public health priorities that might be the best use of resources. The international community faces graver restraints in resources but at the same time has the power of being able to find collective solutions that benefit the most people. For instance at our most recent conference of ADI, held in London, the closing debate was whether enough evidence now exists to mount a major public health initiative targeting improvements in healthy lifestyles for middle-aged adults….vs. an even broader public health initiative to improve the health and wellbeing, especially nutrition, of babies and pregnant women and through that route decrease the numbers of future adults with brain diseases. Meanwhile we are all gearing up to try to be ready to serve the millions of adults who already have Alzheimer’s, who will develop it if we don’t find a way to slow down the progression and delay the age of onset.

Alzheimer’s Disease International’s small but very competent staff (Mark Wortman is the CEO, based at the UK Alzheimer’s offices in London) and with several groups of collaborative research groups who are keyed in on finding practical solutions to this world wide crisis we are all facing together.

One of these research groups is called “10-66” which receives both NIH and WHO funding to conduct important cross-cultural studies in the developing world to establish true and comparable prevalence/incidence rates of both Alzheimer’s disease and Mild Cognitive Impairment, has conducted international clinical trials of caregiver interventions to determine usefulness and costs in a variety of different countries and financial settings, and is now looking at some broader public policy and public health issues. Their annual reports can be found on the ADI website:

In addition, there is a collaborative effort of several country based large research projects examining whether certain lifestyle interventions could help reduce the incidence and prevalence of Alzheimer's disease, or delay the age of initial symptoms. Each initiative has different founding sources and different specific research objectives and methods, but by combining and collaborating they hope to increase the robustness of their findings. One of the three studies is taking place in Finland, led by Miia Kivipelto with major funding from Finland's Health Department, and some additional funding from the U.S. Alzheimer's Association and perhaps other sources as well. I touch on that study in one of the two papers I have attached to this email.

Another perspective that was discussed at this last London meeting was, how best to proceed in planning CARE in the depressing scenario that we can't prevent most of the cases of Alzheimer's. What public policy is best. One that is disease specific, or that is based on disabilities, across diseases and health conditions. This was very interesting to me arising among a group of people who has fought hard for over 25 years to get their home countries to give proper recognition to Alzheimer's disease and other dementias, and to develop national plans. But once one has raised awareness, achieved sufficient specific research dollars and developed specific care programs, then one is freer to look at the broader public policy perspectives and see what is the best use of resources for a country, and what is most likely to be politicall feasible.

As you could gather from my resume, I stand ready to volunteer my time and attention to helping you in your efforts should you see a way I could be helpful.

In the meantime I applaud all the work you are doing and say THANK YOU. You all are fulfilling a dream I've held since the 1980's of a true national effort to combat Alzheimer's disease, both through research, public health and programmatic efforts at the local, state and federal levels.

Sincerely,

Nancy B. Emerson Lombardo, Ph.D.
President
HealthCare Insights, LLC
Acton, MA

Adjunct Research Assistant Professor of Neurology
Boston University School of Medicine
Dept. of Neurology
http://buedu/alzresearch
http://healthcareinsights.net

ATTACHMENT: Alzheimer’s Disease, by Nancy Emerson Lombardo.doc
Memory Impact of Foods March 2012.doc

Available as separate links:	
Alzheimer’s Disease and Lifestyle	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach143.pdf
Memory and Cognitive Impact of Foods	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach144.pdf

DATE: March 30, 2012
SUBJECT: Adult Day Care for Alzheimer’s

My wish would be that all persons with Alzheimer's could have a safe haven. This would be a great benefit for all family members that have this disease in their lives. I hope we can get something past that will give them a safe haven.

Sincerely,

Valecia Floyd

DATE: March 30, 2012
SUBJECT: Comments from the Pennsylvania Department of Aging

Attached please find comments from the Pennsylvania Department of Aging on the Draft National Plan to Address Alzheimer's Disease.

We are grateful for the opportunity to offer comments.

Pennsylvania is a state with an increasing population of older persons and is home to persons and families living with Alzheimer's Disease.

The Commonwealth is also home to leading researchers and providers of care across the continuum.

We look forward to opportunities to join in the dialogue and planning process.

Please let me know if we can offer any further information or clarification.

Thank you.

Sincerely,

Brian M. Duke
Secretary
Commonwealth of Pennsylvania
Department of Aging
Harrisburg, PA

ATTACHMENT: Pennsylvania Department of Aging Comments on Draft National Plan to Address Alzheimer's Disease.pdf

Available as separate links:	
Comments on the Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach142.pdf

DATE: March 30, 2012
SUBJECT: Comments on the National Plan to Address Alzheimer's Disease

Please accept this comment letter on behalf of the Partnership to Fight Chronic Disease.

Many thanks --

Candace DeMatteis
Policy Director
Partnership to Fight Chronic Disease
http://www.fightchronicdisease.org

ATTACHMENT: March 2012 Draft Comments on National Plan to Address Alz Disease Final.docx

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach141.pdf

DATE: March 30, 2012
SUBJECT: EWA Comments on Draft National Plan

Thank you for the opportunity to provide comments on the Draft National Plan to Address Alzheimer's Disease. We appreciate the work of the Advisory Council and the recognition of the need for a well-trained workforce.

If you have any questions, please do not hesitate to contact me.

Best,

Caitlin Connolly
Project Manager
Eldercare Workforce Alliance
http://www.eldercareworkforce.org

ATTACHMENT: EWA Comments on Draft Plan- 033012 - FINAL.pdf

Available as separate links:	
Comments on the Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach140.pdf

DATE: March 30, 2012
SUBJECT: AOTA Comments re Draft National Plan to Address Alzheimer's Disease

Attached please find comments from the American Occupational Therapy Association (AOTA) in response to the US Department of Health and Human Services ' Draft National Plan to address Alzheimer's Disease pursuant to the National Alzheimer's Project Act (NAPA). Should you have any questions or need additional documentation, please do not hesitate to contact me.

Sincerely,

Jennifer Hitchon, JD, MHA
Regulatory Counsel
American Occupational Therapy Association
Bethesda, MD

ATTACHMENT: AOTA Comments re Draft Natl Plan to Address Alzhiemers Disease (March 30, 2012).pdf

Available as separate links:	
Draft National Plan to Address Alzheimer's Disease Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach139.pdf

DATE: March 30, 2012
SUBJECT: Comments of the Alzheimer's Association on the Draft National Plan to Access Alzheimer's Disease

Thank you for the opportunity to comment on the Draft National Plan to Address Alzheimer's Disease. The comments of the Alzheimer's Association are attached.

If you wish to discuss this or any other Alzheimer's issue, please feel free to reach out to Rachel Conant, Alzheimer's Association Director of Federal Affairs.

Best,

Christopher J Adamec
Specialist, Federal Affairs
Alzheimer's Association
Public Policy Office
Washington, DC

ATTACHMENT: Alzhiemers Association comments on the Draft National Alzheimer's Plan.pdf

Available as separate links:	
Alzheimer's Association comments on the Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach138.pdf

DATE: March 30, 2012
SUBJECT: American Geriatrics Society Comments on Draft National Plan to Address Alzheimer's

Please accept the attached comments from the American Geriatrics Society on the Draft National Plan to address Alzheimer's disease. Should you have any questions, please don't hesitate to get in touch.

Sincere Regards,

Alanna Goldstein, MPH
Assistant Director, Public Affairs & Advocacy
The American Geriatrics Society
New York, NY

ATTACHMENT: AGS Comments on National Alzheimer's Plan FINAL.pdf

Available as separate links:	
Comments on National Alzheimer's Project Act (NAPA) - Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach137.pdf

DATE: March 30, 2012
SUBJECT: Society of Nuclear Medicine's Comments on the National Alzheimer's Plan

On behalf of Dr. George Segall, President, please find attached the Society of Nuclear Medicine's comments on the National Plan To Address Alzheimer's Disease.

Respectfully,

Saima K. Hedrick, MPH
SNM
Advancing Molecular Imaging & Therapy
Associate Manager of Outreach
http://www.snm.org
http://www.snm.org/cmiit
http://www.discovermi.org

ATTACHMENT: Society of Nuclear Medicine_Comments on the National Plan for Alzheimer's_3_30_12.pdf

Available as separate links:	
Society of Nuclear Medicine Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach136.pdf

DATE: March 30, 2012
SUBJECT: NAPA feedback

Here is the feedback from the UCI group.

Sincerely,

Frank M. LaFerla, Ph.D.
Chancellor's Professor
Chair, Neurobiology and Behavior
Director, Institute for Memory Impairments and Neurological Disorders
University of California, Irvine
Irvine, CA
http://neurobiology.uci.edu/faculty/laferla/

ATTACHMENT: UCI NAPA questionnaire 2 2012[1].pdf

Available as separate links:	
Questions for the ADC Directors -- National Alzheimer's Project Act	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach135.pdf

DATE: March 30, 2012
SUBJECT: Mental Health America Comments on Draft National Alzheimer's Plan

Attached is the comments letter from David Shern.

Regards,

F. Michael King
Executive Office Assistant to David L. Shern, Ph.D., President and CEO
Mental Health America
Alexandria, VA

ATTACHMENT: Helen Lamont, Ph.D. - Alzheimer's Plan.pdf

Available as separate links:	
Mental Health American Comments on Draft National Alzheimer's Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach134.pdf

DATE: March 30, 2012
SUBJECT: Fw: Comments have been submitted

As I mentioned, there is now an Industry Working group on Alzheimer's supportive of the 2025 goal. I will be working to expand the size of this group in the coming months so that HHS has a strong partner in executing our National Plan.

Here are their comments on the draft plan.

George Vradenburg

==========

From: Manetto, Nicholas P.
Sent: Fri, 30 Mar 2012 18:32:09 +0000
Subject: FW: Comments have been submitted

Patrick --

Attached is a set of comments submitted on the draft plan by the Ad Hoc Industry Working Group

ATTACHMENT: Industry Working Group Comments to NAPA.PDF

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach133.pdf

DATE: March 30, 2012
SUBJECT: NDSS NAPA Letter

On behalf of the National Down Syndrome Society (NDSS), please find our letter (attached) commenting on the “National Plan” to address Alzheimer's disease and related dementias (ADRD). Please do not hesitate to contact us with any questions.

We look forward to hearing from you.

Sincerely,

Sara Hart Weir
Vice President, Advocacy & Affiliate Relations
National Down Syndrome Society
Washington, DC

ATTACHMENT: NDSS NAPA Letter FINAL.pdf

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach132.pdf

DATE: March 30, 2012

SUBJECT: NYS Office for the Aging Comments on the Draft Framework for the National Plan to Address Alzheimer's Disease

Attached are comments from the NYS Office for the Aging on the above subject matter. If you have any questions, please feel free to email me or call me.

Thank you,

Greg Olsen, MSW
Acting Director
New York State Office for the Aging
Albany NY

ATTACHMENT: National Plan to Address Alzheimer's Disease.docx

Available as separate links:	
New York State Office for the Aging comments on the Draft Framework for the National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach147.pdf

DATE: March 30, 2012
SUBJECT: Fw: Comments on Draft National Plan

George Vradenburg

==========

From: LEAD Coalition
Sent: Fri, 30 Mar 2012 14:17:10 -0400
Subject: Comments on Draft National Plan

Attached please find comments from Leaders Engaged on Alzheimer's Disease (LEAD) on the draft National Plan. Please do not hesitate to contact me if you have any questions.

Patrick Fritz
Project Manager
LEAD

ATTACHMENT: LEAD Comments on NAPA Draft National Plan.pdf
data standards appendix2.pdf
Informed consent appendix1.pdf
Public Private Partnerships appendix 3.pdf

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach118.pdf
Data Standards Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach119.pdf
Common Informed Consent Form for AD Clinical Studies Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach120.pdf
Making the Case for Public Private Partnerships for NAPA	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach121.pdf

DATE: March 30, 2012
SUBJECT: RE: Industry Working Group Comments

Thanks Mike! I will advise the whole group.

Nicholas P. Manetto

==========

From: James Michael Simmons Jr
Sent: Friday, March 30, 2012 2:23 PM
Subject: Industry Working Group Comments

Please find attached comments from an industry working group regarding the current draft of the National plan.

Mike Simmons
Director, Global Advocacy and Professional Relations
Eli Lilly and Company Corporate Affairs

DATE: March 30, 2012
SUBJECT: Industry Working Group Comments

Please find attached comments from an industry working group regarding the current draft of the National plan.

Mike Simmons
Director, Global Advocacy and Professional Relations
Eli Lilly and Company Corporate Affairs

ATTACHMENT: Industry Working Group Comments to NAPA.pdf

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach130.pdf

DATE: March 30, 2012
SUBJECT: Alzheimer’s Disease International response to NAPA

Alzheimer's Disease International is the worldwide federation of 78 national Alzheimer associations. Attached you may find a letter with our comments to the draft NAPA Act for your consideration.

I have also attached an overview of previous publications by the World Health Organization (WHO) that have any relationship with Alzheimer's disease and related disorders. The WHO will come out with a comprehensive report on 11 April.

Thanks very much,

Marc Wortmann
Executive director
Alzheimer's Disease International
London
http://www.alz.co.uk
http://www.adi2012.org

ATTACHMENT: ADI comments to NAPA - March2012.pdf
ADRD WHO publications summary chart.pdf

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach128.pdf
Summary of Publications	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach129.pdf

DATE: March 30, 2012
SUBJECT: My grandmother

Currently lies in bed at the home she's lived in for many years with my grandfather. I remember christmas with her, going over for sunday breakfast. She helped me study for school. Looked after me when I was small.

Now all she can do all day is lay in her bed and stare at the ceiling. She doesn't remember more then 5 minutes at a time. Gone are all the things I used to love about going to that house, and my poor grandfather has to take care of her, pay for her medical bills and do his best for her even though she's only a shell of his wife. A shell of the once-strong woman who beat cancer numerous times only to have her life taken from her slowly and minutes at a time.

Alzheimer's took my grandmother from me, and I want to support development and research on curing this horrible problem so others don't have to see their families hurt like mine does.

Sincerely,

Sam Langan
Brooklyn, NY

DATE: March 30, 2012
SUBJECT: AAGP's Comments on Draft National Plan to Address Alzheimer's Disease

Please note the attached document is the American Association for Geriatric Psychiatry's comments on the Draft National Plan to Address Alzheimer's Disease. If you have any questions, please don't hesitate to contact me at:

Christine M. deVries
Chief Executive Officer/Executive Vice-President
American Association for Geriatric Psychiatry
Bethesda, MD

ATTACHMENT: AAGP Comments on Draft National Plan for AD.pdf

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach127.pdf

DATE: March 30, 2012
SUBJECT: AFTD Comments on draft National Plan to Address Alzheimer's Disease

Attached please find comments on the draft plan from the Association for Frontotemporal Degeneration.

We appreciate the opportunity to offer our input on this important project.

Matthew F. Sharp, M.S.S
Program Coordinator
The Association for Frontotemporal Degeneration
http://www.theaftd.org

ATTACHMENT: AFTD reply to Alzheimer's Plan.pdf

Available as separate links:	
Association for Frontotemporal Degeneration Comments on the Draft Framework for the National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach126.pdf

DATE: March 30, 2012
SUBJECT: AstraZeneca Comments on Draft Framework on the National Plan to Address Alzheimer's Disease

Attached please find feedback from AstraZeneca Pharmaceuticals LP on the Draft Framework of the National Plan to Address Alzheimer's Disease. We thank you in advance for your consideration.

Please do not hesitate to contact us if you have any questions.

Kind regards,

Alice L. Pomponio
Leader, Americas Science Relations
AstraZeneca
Waltham, MA

ATTACHMENT: 20120330 AstraZeneca NAPA Comments.pdf

Available as separate links:	
Comments on Draft Framework of the National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach125.pdf

DATE: March 30, 2012
SUBJECT: Response to Draft National Alzheimer's Plan

Please find attached comments on the draft National Alzheimer's Plan from the Geriatric Mental Health Alliance of New York.

Thank you for the opportunity to comment.

Regards,

Kimberly Williams
Director
Geriatric Mental Health Alliance of New York

ATTACHMENT: GMHA Comments on Draft National Alzheimer's Plan.docx

Available as separate links:	
Geriatric Mental Health Alliance of New York Comments on the Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach124.pdf

DATE: March 30, 2012
SUBJECT: BMS Comments on NAPA

Bristol-Myers Squibb is pleased to submit the following comments on the Draft Framework for the National Plan to Address Alzheimer's Disease, released by the Assistant Secretary for Planning and Evaluation on January 9, 2012.

We recommend that the Plan include these additional elements:

Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025

1. Identify Alzheimer's Disease (AD) as a multidecade process eventuating in predementia symptoms and the functional impairments of dementia
2. Recognize biomarkers as key to diagnosis and treatment
   a. Support partnerships advancing biomarker development and qualification
   b. Develop medical infrastructure for clinical use of biomarkers
   c. Set access standards to ensure access to biomarkers in clinical practice
3. Ensure that diagnosis and treatment algorithms reflect patient differences, to support individualized treatment for each patient
4. Promote partnerships of government, academe, industry, and advocacy groups, to foster patient recruitment and AD treatment development programs
5. Examine routes to both accelerate development of acute treatments, learning from the HIV model, and to support long-term prevention studies.

Goal 2: Enhance Care Quality and Efficiency

1. Establish the optimum age and tests for cognitive screening for all primary care patients.
2. Evaluate the deployment of specialized memory clinics for early diagnosis, treatment, and clinical trial enrollment, as deployed in other countries
3. Ensure incentives are in place to secure a sufficient supply of qualified professional and paraprofessional care staff
4. Ensure access to innovative therapies for AD
   a. Provide comprehensive coding, coverage, and payment for new methods of preventing, diagnosing, and treating Alzheimer's disease at the predementia and dementia stages
   b. Ensure new clinical evidence is adopted into coverage and payment policies in a timely manner so that access and reimbursement is available for advanced treatment options and improved diagnostic tools
   c. Encourage adoption of new approaches to care, such as use of telehealth and increased participation in care by family members and caretakers

Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families

1. Develop and promote care infrastructure, financial planning, and behavior management strategies to support patients in their homes and in residential care.

Goal 4: Enhance Public Awareness and Engagement

1. Foster AD understanding in a campaign educating payers, patients, families, and health care professionals to recognize and overcome stigma related to AD.

Goal 5: Improve Data to Track Progress

1. Announce metrics, measureable annual goals and report on them.

We would be happy to expand on these suggestions for improving the Draft Framework to better address the social and medical needs of Americans who have Alzheimer's disease and their families. Please contact me if you would us to provide any additional information.

Yours truly,

Dr Jane Tiller MBChB, FRCPsych, MBA, MPhil
VP GDMA
Bristol-Myers Squibb Co
Princeton, NJ

DATE: March 30, 2012
SUBJECT: Letter to Dr. Helen Lamont Advisory Council on Alzheimer's Research, Care, and Services

On behalf of the Area Planning and Services Committee (APSC) on Aging with Lifelong Disabilities, I am sending a letter in response to the Draft National Plan to Address Alzheimer's Disease. We appreciate the opportunity to contribute our thoughts and congratulate you and the council on its initiative. Best wishes,

Edward F. Ansello, Ph.D.
Director
Virginia Center on Aging
Virginia Commonwealth University
Richmond, VA

ATTACHMENT: APSC letter to Advisory Council on Alzheimer's Research.pdf

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach123.pdf

DATE: March 30, 2012
SUBJECT: CMS removal of Alzheimer’s disease as a condition that can be treated with a Health Behavior Intervention

Until sometime early in 2010, patients suffering from Alzheimer's disease were allowed to receive treatment from a psychologist, in the form of a Health and Behavior Intervention Such procedures are used to modify the psychological, behavioral, emotional, cognitive, and social factors identified as important to or directly affecting the patient's physiological functioning, health and well being, or specific disease-related problems. Parkinson's disease and other chronic neurodegenerative conditions still meet criteria for medical necessity, while Azheimer's disease was removed from the list of treatable conditions. While Dementia, Alzheimer's type, or other dementias would not be appropriate to treat with a Health and Behavior Intervention, due to the patient's more severe cognitive impairment, that is not the case for patient with early- mid stage Alzheimer's disease. Advocacy is needed to ensure that these individuals who suffer for years in early stage A.D. are not deprived of the psychological support that patients with other neurodegenerative conditions are provided.

Sincerely,

Bruce Brotter, PhD

DATE: March 30, 2012
SUBJECT: NAPA comments from the CT Chapter of the Alzheimer's Association

Please accept the attached comments on behalf of the Alzheimer's Association, CT Chapter. If you have any questions or concerns, please feel free to contact me.

Laurie Julian, J.D., M.P.H.
Director of Public Policy
Connecticut Chapter
Alzheimer's Association
Rocky Hill, CT

ATTACHMENT: NAPA Comments 3-30-12 w edits.docx

Available as separate links:	
National Alzheimer's Project Act Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach122.pdf

DATE: March 30, 2012
SUBJECT: Comments on National Plan to Address Alzheimer’s Disease

2.F. Advance Coordinated and Integrated Health and Long-term Care Services and Supports for Individuals Living with Alzheimer's Disease

The Program of All-inclusive Care for the Elderly (PACE) is an outstanding model of care for persons living with Alzheimer's Disease and other memory disorders. As high as two thirds of the PACE participants have cognitive impairment. Utilizing an interdisciplinary team, PACE provides comprehensive, coordinated and integrated care to individuals age 55 and older who meet the nursing home level of care criteria. The goal is to maintain the individual in a non-instituional setting for as long as possible. This program is a three way agreement between the PACE organization, CMS and the state Medicaid agency. Although PACE is currently serving 22,000 individuals nationally, the plan is to significantly increase this program. Research supports the efficacy of this model and should be referenced in your plan.

3.B. Enable Family Caregivers to Continue to Provide Care While Maintaining Their Own Health and Well-Being

More funding is needed for individuals on Medicare that need in-home care. My father was diagnosed with dementia in September of 2010 and passed away in April 2011. During his illness, my mother had to pay out of pocket for three attendants because he did not qualify for Medicaid until the end of his life. The process took several months before a determination was made by the Medicaid Long Term Care Office. Finally, one month before his death, he was deemed eligible with a share of cost. The experience was very challenging for all our family. Moreover, funding for caregiver resources and support have been drastically cut by the State of California. This makes no sense with the anticipated increase of persons with Alzheimer's Disease and other long term illnesses. The federal government needs to step in and assess what states are doing to help caregivers. Otherwise, vulnerable populations will continue to be adversely impacted. It is important for federal entities such as CMS, HRSA and AOA to work together to address these issues and to identify the funding that is vitally needed by families across the nation.

The Napa Advisory Council has been doing excellent work to develop a comprehensive plan that addresses the nationwide epidemic of Alzheimer’s Disease

- It is critical that this plan address the needs of the growing numbers of people living with this disease and their families

- Several aspects of the plan focus on these issues but do not identify funding for implementation

- The Alzheimer’s Disease Supportive Services Program (ADSSP) which is also known and the Alzheimer’s Disease Federal-State Matching Grants Program is the one federal program that has provided focused support for this population in local communities.

- The NAPA report may want to reference AoA's support through the ADSSP program for sections of the plan including:
  - 2.C.2 Enhance assistance for people with AD and their caregivers to prepare for care needs
  - 2.H Improve care for populations disproportionately affected by Alzheimer's disease and for populations facing care challenges

Respectfully,

Marie S. Torres, Ph.D., L.C.S.W.
Senior Vice President
Government Relations and Community Research Initiatives
AltaMed Health Services Corporation
Los Angeles, CA

DATE: March 30, 2012
SUBJECT: Draft Alzheimer’s National Plan

I would like to thank the Advisory Committee for preparing an excellent draft plan. The Assisted Living Federation of America (ALFA) has submitted comments on a couple of occasions, but I would like to reiterate that our organization is a resource if HHS or the Advisory Committee would like to learn more about the role of licensed assisted living in meeting the needs of individuals with Alzheimer's and related dementia. Our providers have developed special programs that ensure residents have an improved quality of life along with quality of care. We believe these innovative programs should be used to replace the use of psychotropic and other medications that may not be needed. ALFA would just like to request that as the national plan looks ahead to helping individuals with dementia and their family and friends plan for the future, that assisted living be recognized as an appropriate and cost effective option. Thank you.

Maribeth Bersani
Senior Vice President Public Policy
ALFA
Alexandria, VA

DATE: March 30, 2012
SUBJECT: Alzheimer Research

I just came across an article stating that you are interested in ideas for understanding Alzheimers.

I have been a Clinical Psychologist and College Professor since 1950 and am interested both personally and professionally.

I try to follow the research and have attended regular conferences on Senile Dementia and it seems clear to me that medications have been minimally effective. So far physical exercise, mental stimulation and socialization have proven more effective. In working with older clients the concept of working with the positive-the resources you have -is more effective than focusing on what is lost. In addition meditative techniques are valuable in helping focus and concentration. As medications seem so limited -it would seem very important to spend some research dollars and involvement in a broad spectrum approach to dealing with Senile Dementia.Thanks for your attention.

O.B.Leibman Ph.D.
Professor Emeritus
The City University

DATE: March 30, 2012
SUBJECT: Comments on Draft National Plan

Attached please find comments from Leaders Engaged on Alzheimer's Disease (LEAD) on the draft National Plan. Please do not hesitate to contact me if you have any questions.

Patrick Fritz
Project Manager
LEAD

ATTACHMENT: LEAD Comments on NAPA Draft National Plan.pdf
data standards appendix2.pdf
Informed consent appendix1.pdf
Public Private Partnerships appendix 3.pdf

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach118.pdf
Data Standards Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach119.pdf
Common Informed Consent Form for AD Clinical Studies Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach120.pdf
Making the Case for Public Private Partnerships for NAPA	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach121.pdf

DATE: March 29, 2012
SUBJECT: Alzheimer's and Down syndrome

I would like to take this opportunity to comment on the Advisory Council on Alzheimer's Research, Care and Services draft national plan to address Alzheimer's disease. At the outset, let me express my appreciation and gratitude to everyone who is a part of this community: researchers, caregivers, affected individuals, and families who spend day in and day out caring for our loved ones.

I am providing these comments by way of my son Cole, who was born with an extra 21st chromosome. Since his birth, I have learned a great deal about the direct correlation between Down syndrome and Alzheimer's disease. For example, I have learned that Alzheimer's disease attacks adults with Down syndrome at a younger age and with increased frequency compared to the general population. I have also learned that the pathological findings of Alzheimer's disease have been described in the brains of people with Down syndrome since the 1800s and that there are genetic factors at play that, in part, explain these pathologic and clinical observations. I further understand that NIH is funding Down syndrome research using natural history and imaging techniques to identify early markers of cognitive decline. These studies will undoubtedly help people with Down syndrome, but they will also have a broader application to those individuals in the general population who are at risk for developing Alzheimer's disease.

Yet, there is so much more that can be learned from this relationship. I believe that both the Alzheimer's and Down syndrome communities would benefit greatly from additional conversations about this unique scientific correlation. To that end, I would encourage you to include a representative from the Down syndrome research community on the Advisory Council.

It has been just over one year since the National Alzheimer's Project was enacted. By recognizing the specific link between Down syndrome and Alzheimer's disease in the National Alzheimer's Project, the Council would be including all of the most current scientific data available. More importantly, millions of American's who are at risk for Alzheimer's disease will benefit from the research that is already underway in those with Down syndrome. This is truly a win-win for the entire community.

Sincerely,

Cathy McMorris Rodgers
Member of Congress
U.S. House of Representatives
Washington, DC
http://www.mcmorrisrodgers.house.gov

DATE: March 29, 2012
SUBJECT: National Alzheimer's Project Act

Attached is a letter from Anne Hinton, Executive Director of the Department of Aging & Adult Services, City and County of San Francisco.

Thank you.

La Shaun Williams
Executive Assistant to Anne Hinton
Department of Aging and Adult Services
San Francisco, CA

ATTACHMENT: National Alzheimers Project.doc

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach117.pdf

DATE: March 29, 2012
SUBJECT: Comments

I support health and well-being maintenance for family caregivers along with providing funding streams where feasible.

I support developing a plan to establish and include dementia appropriate adult day care services into the scope of long term services. This is much needed, and overdue.

Nancy Hale
alzheimer's advocate

DATE: March 29, 2012
SUBJECT: social model day centers for senior adults

I would like to share with you about our social model, senior adult day center which is certified by the state of Kentucky and is the first social model that is private pay only in Kentucky:

I own Care4Ever Senior Care Center in Elizabethtown, KY. It opened July 1st, 2009 and we have experienced caring for several dementia participants since it opened and how exciting to experience families seeing their loved one with dementia participating in activities in the center, laughing, and being active. One activity so many of those with dementia have liked is the game "Corn Hole". What a simple game, but oh the fun, laughter and exercise that can be gained by that simple bean bag and a hole in a board! Our center was designed to be "like home" and it is comfortable, beautiful and very home-like. Nothing institutional here! I have talked with the VA in Louisville several times about using social model centers for veterans, but to no avail! Medical models are all they use and approve. My other company, Tender Touch Senior Services, which provides in-home, non-medical care to senior adults here in Elizabethtown, serving Hardin Co and the surrounding counties, is in the Homemaker Program with the VA and we go into the homes of nearly 45 veterans in our area and they would get so much more out of coming to the center combined with their homemaking and personal care in their home. My vision reaches so very far, with adult social model day centers, but I get frustrated because so very many people, as they are wearing out from caregiving, only look to nursing homes. We are trying to educate as many people as we can on the wonderful offerings of the social day center, but many times by the time the family gets their loved one with dementia to our center, it is only to buy time until they can place them into a facility. Our staff cries every time someone goes into a nursing home, because we can see that many times they are not ready to go into a facility, but the family is too worn out to even think.

Thanks for reading! I could go on and on!

Dona McCurry
President/Owner
Tender Touch Senior Services, Inc.
Care4Ever Senior Care Center, Inc.
http://www.care4everseniorcare.com
http://www.tendertouchseniorservices.com

DATE: March 29, 2012
SUBJECT: Comments

We applaud the efforts of the Council and their Draft National Plan to Address Alzheimer's Disease. This Plan represents a major step forward in the development of a comprehensive strategy for addressing the impact of this devastating condition that affects millions of Americans and their families. At Genworth, we see the effect this disease has every day with our customers.

We were fortunate to have the opportunity to meet with Ms. Kathy Greenlee and her team on March 6 in Washington DC to discuss the effects of Alzheimer's and how families utilize care providers and services. At that meeting, Ms. Greenlee encouraged Genworth to comment on the NAPA. I have attached our comments in a letter from our Medical Director, Dr. Bruce Margolis.

Thank you for the opportunity to participate in this important work. Feel free to contact me if we can be of any additional assistance.

Michael D. Heard
SVP, Business Strategy & Product Support
Genworth Financial
Richmond, VA

ATTACHMENT: SRIC270B2F612032910380.pdf

Available as separate links:	
Genworth Comments on the Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach116.pdf

DATE: March 29, 2012
SUBJECT: call to action letter

Attached you will find a letter urging that people with Down syndrome be included in the national plan to address Alzheimer's Disease.

Please let me know if you have any questions.

Thank you in advance for your attention,

Janet Gora
Executive Director
iLearn
Cincinnati, OH

ATTACHMENT: letter to alz researchers.doc

Available as separate links:	
Comments on Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach115.pdf

DATE: March 29, 2012
SUBJECT: Draft HHS National Plan to Address Alzheimer's Disease - National Academy of Neuropsychology comments

If it's not too much trouble could you please confirm receipt of this document via response to this e-mail message.

Thank you,

Tim Wynkoop, Ph.D., ABPP
Diplomate, American Board of Clinical Neuropsychology (ABCN)
Clinical Assistant Professor of Psychiatry
University of Toledo Medical Campus

Fellow & Past Program Chair
Current Co-Chair, Professional Affairs & Information Committee
National Academy of Neuropsychology

ATTACHMENT: Draft HHS National Plan to Address AD.pdf

Available as separate links:	
Draft HHS National Plan to Address Alzheimer's Disease: Comments from the Professional Affairs & Information Committee, National Academy of Neuropsychology	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach112.pdf

DATE: March 29, 2012
SUBJECT: Comments for National Alzheimer's Plan

AgeOptions appreciates the opportunity to comment on the National Alzheimer's Plan. Please see the attached comments.

Anne Posner
Director of Program and Community Support
AgeOptions
Oak Park, IL
http://ageoptions.org

ATTACHMENT: AgeOptions comments on National Alzheimer's Plan.doc

Available as separate links:	
AgeOptions Comments on National Alzheimer's Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach114.pdf

DATE: March 29, 2012
SUBJECT: Comments on Draft National Plan to Address Alzheimer's Disease

Below and attached are comments I am submitting on behalf of the Healthy Brain Workgroup of the Centers for Disease Control and Prevention-funded Healthy Aging Research Network (CDC-HAN).

Sincerely,

Daniela B. Friedman, MSc, PhD
South Carolina HAN Co-Investigator and Co-Lead of the Healthy Brain Workgroup
Assistant Professor
Department of Health Promotion, Education, and Behavior (HPEB)
Arnold School of Public Health
University of South Carolina
Columbia, SC

ATTACHMENT: NAPA_Healthy Aging Research Network Response_30Mar2012_As Submitted.pdf

Available as separate links:	
Response to Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach113.pdf

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Response to Draft National Plan to Address Alzheimer's Disease: Submitted on behalf of the Health Brain Workgroup of the Centers for Disease Control and Prevention-funded Healthy Aging Research Network (CDC-HAN)

The Healthy Brain Workgroup of the Centers for Disease Control and Prevention-funded Healthy Aging Research Network (CDC-HAN) strongly supports the vision statement of the National Alzheimer's Project Act (NAPA) presented by President Barack Obama, which aims to alleviate the suffering and burden associated with Alzheimer's disease (AD) and to "*confront the challenge it poses to our public health*."

The Healthy Aging Research Network (HAN) was formed in 2001 to help develop and implement a national research and dissemination agenda related to the public health aspects of healthy aging. The HAN consists of a coordinating center, seven member and affiliate universities, and representation from and participation by over 10 national agencies with interests in the well-being of older adults, including AARP, the Alzheimer's Association, the American Medical Association, the US Administration on Aging, the National Association of Chronic Disease Directors, the National Council on Aging, and the U.S. Environmental Protection Agency. This network has played a vital role in national initiatives to ensure the inclusion of AD, cognitive impairment, and cognitive health promotion in the Healthy People 2020 Older Adult objectives. The network has also worked successfully to inform the National Public Health Road Map to Maintaining Cognitive Health, released in June 2007 by the CDC and the Alzheimer's Association [1].

Between 2005 and 2009, the HAN conducted community-based research with over 600 diverse older adults, caregivers, and healthcare providers. Interviews and focus groups were conducted in English, Spanish, Mandarin, Cantonese, and Vietnamese, with representation from African American, American Indian, Asian American, Hispanic, and Non-Hispanic White communities, in urban and rural locations across nine states. [2-4]. These older adults and those who care for older adults represent the stakeholders to whom NAPA is targeted. Findings from this large-scale, multi-site initiative (published in The Gerontologist, volume 49, supplement 1, June 2009) indicated that older adults, regardless of gender, race, ethnicity, language, or geographic region, agree that cognitive health is essential to healthy aging [5, 6]. Older adults also stated that existing media messages about cognitive health and its association with lifestyle factors can be conflicting and confusing [7]. It is imperative that researchers, educators, and policymakers continue to examine communication strategies to better inform the public about the evolving science of maintaining cognitive health and reducing the risk of cognitive impairment. Based on its strong track record, the HAN is well positioned to participate in such efforts.

As currently written, the NAPA does not explicitly state the impact of AD and other dementias on public health or the role that public health can play in this important area. We therefore strongly recommend the explicit inclusion of HAN expertise in public health research and practice in addressing each of the goals outlined in the NAPA. This document provides recommendations for roles that the HAN might fill in implementing the Plan.

1. **Prevent and Effectively Treat Alzheimer’s Disease by 2025**
   Public health has a long history of fielding prevention research and educational efforts in multiple chronic diseases such as heart disease, musculoskeletal disease, and cancer. HAN member centers have helped develop, evaluate, and implement successful health promotion programs in primary care, senior centers, and other community-based organizations. HAN researchers, in partnership with community collaborators, have developed and tested effective, evidence-based, and widely-used older adult exercise programs, including EnhanceFitness [8-9], Fit and Strong! [10, 11], and A Matter of Balance [12-14] and have demonstrated chronic illness risk reduction and improved health outcomes in these investigations. Although research is still needed about the impact of such lifestyle changes on AD [15], epidemiological and early randomized clinical trials (RCTs) show promise [16]. A cadre of experts within the HAN can help advance this work, both by conducting focused reviews of existing literature and large datasets, and by planning and implementing large scale lifestyle-enhancing initiatives. In addition, as noted above, the HAN has a proven track record in partnering with diverse groups who represent the growing numbers of racial and ethnic minorities in the US and recruiting them to participate in research and the implementation and dissemination of evidence-based findings.

2. **Optimize Care Quality and Efficiency**
   Initiatives focused on expanding dementia-specific capabilities in primary care settings are already underway within the HAN. HAN centers have examined primary care providers’ perceptions and practices regarding AD and cognitive impairment [17, 18]. A current CDC-funded Special Interest Project (SIP 10-37; PI: M. Snowden) is reviewing the scientific literature to determine the impact of cognitive impairment on co-occurring chronic illnesses, including morbidity, mortality, and how AD and dementias influence the medical care that an individual receives. The project will also identify and catalogue the elements of existing research databases for use in future studies to better understand the relationship between dementia and chronic conditions. The HAN member centers’ established associations with racial and ethnic minority, low income,

and rural populations provide resources and expertise for assessing and addressing the complications and obstacles faced by these groups who are at high risk for inadequate health care.

3. **Expand Supports for People with Alzheimer's Disease and Their Families**
   There is a need for more broadly distributed evidence-based services through involvement of a variety of service providers, including State Health Departments, Area Agencies on Aging, non-profit organizations, faith-based organizations, and other facilities within local communities. Public health has a long history of working within these organizations, and can help mobilize communities to meet these challenges. HAN members and affiliates are actively engaged in working with the Administration on Aging (AoA) in this effort (e.g., University of Washington HAN investigators are currently working with the states of Washington, Oregon, and Ohio on translating evidence-based interventions for individuals with dementia and their family caregivers into existing community health systems [19]).

4. **Enhance Public Awareness and Engagement**
   The Department of Health and Human Services should take advantage of the formative investigation already conducted by the HAN that was cited earlier [2-7]. This investigation found low health literacy and lack of access to culturally relevant information about cognitive health across all ethnic and language groups, and in both rural and urban environments. Older adults often reported that recommendations that they heard were ambiguous, contradictory, or impossible to comply with, and recommendations from health providers were often vague and lacked specific planning processes [7]. Thus, there is an urgent need for culturally and educationally appropriate materials and resources for individuals with cognitive impairment, individuals at risk for dementia, caregivers, and providers. The HAN comprehensive data set can provide guidance about messages and media that will be most effective in disseminating this information. The HAN has tremendous reach for public health and aging focused message testing and awareness campaign development, implementation, and evaluation.

   In addition, each HAN site has worked for over 10 years with community advisory groups to facilitate communication between and among state and local government agencies, nonprofit partners, racial and ethnic minority service providers, and academic public health researchers. These partnerships have actively developed and disseminated healthy aging programs, and can be leveraged to promote dementia-prevention education and intervention programs.

5. **Track Progress and Drive Improvement**
   Public health researchers have long been instrumental in evaluating large-scale programs to promote health in older adults, including both lifestyle (e.g., exercise, nutrition) and primary prevention (e.g., immunization) interventions. Any effort to measure and evaluate the impact of NAPA on health outcomes for older adults and caregivers and on policy change must be informed by public health, taking advantage of existing expertise in population-level evaluation planning, data collection, analysis, interpretation, and dissemination. The HAN has been involved in developing aging-specific questions for a number of large surveys [18, 20], and has a long history of experience and expertise in this area. It should be noted that the CDC Healthy Aging Program (funder of the HAN) developed a 10-question Behavioral Risk Factor Surveillance System (BRFSS) module on Perceived Cognitive Impairment. Twenty-two

states included the module on their state BRFSS in 2011; an additional 16 states are including the module in 2012 (total 38 states, including the District of Columbia). The CDC Healthy Aging Program is working with partners, including the states, to expand the module in 2013 to all 50 states.

In summary, to achieve the goals of NAPA, collaboration with and among public health researchers across the nation is needed. The HAN is an example of a successful and productive collaborative effort, and we look forward to helping move the science forward to address this important public health issue.

References:

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DATE: March 29, 2012
SUBJECT: NAPA input

These are thoughts and quotes from people with early dementia that are actively involved as a Early Stage Advisory member at the Minnesota-North Dakota chapter. I feel it would be helpful and important to include the voice of someone with the disease.

Advocacy:

"Advocacy is important because you know that you are not alone in this disease." Bob PWED

"Early dementia is a total change in my life-loss of independence in the way I have lived my life. It is like standing on a high mountain and not knowing if I will be able to get down safely. Being an advocate for this disease gives me empowerment over this disease and hopefully others are empowered too." Julie PWED

"Alzheimer's is a quiet disease, people who have it often don't want to talk about it. Stating the disease can often take the shame out of the shadow and it can develop connections." Dick PWED

"It is important for us to be verbal about what we are experiencing. There are times of loneliness and sadness. We need the support of care partners and others. By support I mean a genuine concern and willingness to care. "Jim, PWED

Education:

"Education helps me know what is happening to me, helps me navigate and understand this disease." Bob PWED

"This diagnosis hits you in the gut. Life stops for a time until someone comes my way, to help me learn a whole new life." Julie PWED

"More people understand the disease more clearly when it is spoken openly" Dick PWED

Support Groups:

"Support groups are helpful in learning and supporting one another." Bob PWED

"We need a time and place to learn from each other, to support each other, to learn to live again knowing that we will each hold the other up." Julie PWED

"Getting together with others and speaking openly about the disease opens up discussion that can be very helpful and connects us with others." Dick PWED

Early Stage Advisory Quotes

"It's bad enough being diagnosed," Julie said, "it feels like no one wants you anymore. I chose to get involved because I want a purpose; I want to be engaged and for my life to have meaning. I want to help others who are just like me and use the brain power I do have, for something that is good." Julie PWED

"You have to understand, life doesn't stop with diagnosis," Jim said. "This group is a testament to what it's like to live with this disease." He smiled. "And right now, this is the best period of my life. I'm going to enjoy it." Jim, PWED

“We can change the world.” Mike said. “My goal is to eradicate this disease so my children never have to deal with it again.” Jim, Dick and Julie all nod in agreement. Mike, PWED

“We’re the new faces of Alzheimer’s,” Dick said. “And we’re choosing to make a difference.” Dick, PWED

“We don’t just have a disease,” Dick said, the newest member of the Minnesota-North Dakota Early Stage Advisory Group. “We live the disease. And while I’ve accepted that this is a part of me, I’m not going to let it define who I am.”

“We’re the same people we were yesterday,” Julie said. “We haven’t changed and it’s important others know.”

Thank you,

Sara Tucker

DATE: March 29, 2012
SUBJECT: Draft HHS National Plan to Address Alzheimer's Disease

Attached please find a letter from the National Academy of Neuropsychology (NAN) regarding the Draft HHS National Plan to Address Alzheimer's Disease. Please let me know if you have any questions.

Thank you,

Allison Mendrys, CMP
Meetings & Events Manager
National Academy of Neuropsychology
Denver, CO
http://www.nanonline.org

ATTACHMENT: Draft HHS National Plan to Address AD.pdf

Available as separate links:	
Draft HHS National Plan to Address Alzheimer's Disease: Comments from the Professional Affairs & Information Committee, National Academy of Neuropsychology	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach112.pdf

DATE: March 29, 2012
SUBJECT: Comments on Draft National Plan to Address Alzheimer’s Disease

Attached are my comments. By way of background I am a caregiver for my wife who has dementia. I am also a volunteer Ambassador for the Northern AZ Region of the Desert SW Chapter of the Alzheimer's Association.

Robert Ellis

ATTACHMENT: Comments on the Draft National Plan to Address Alzheimer’s Disease - Mar2012.doc

Available as separate links:	
Comments on the Draft National Plan to Address Alzheimer’s Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach111.pdf

DATE: March 29, 2012
SUBJECT: Alliance for Aging Research comments on draft National Plan to Address Alzheimer's Disease

Attached are the Alliance for Aging Research's comments on the draft National Plan to Address Alzheimer's Disease.

Thank you for the opportunity to comment.

Best,

Susan Peschin, MHS
Chief Operating Officer
Alliance for Aging Research
Washington, DC

ATTACHMENT: Alliance for Aging Research Alz National Plan comments 03-30-12.pdf

Available as separate links:	
Comments on the Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach110.pdf

DATE: March 29, 2012
SUBJECT: GE Healthcare input to the draft National Plan to Address Alzheimers

In accordance with the solicitation in the Federal Register on 2/24/2012, please find embedded a letter of input from GE Healthcare regarding the National Plan to Address Alzheimers Disease.

A hardcopy has been sent also by courier to your attention for receipt by the deadline of March 30. Thank you for this opportunity to contribute.

Respectfully

Richard Frank, MD, PhD
VP, Global Clinical Strategy and Policy
GE Healthcare
Princeton, NJ

ATTACHMENT: GEHC Comments To HHS 3 30 2012.pdf

Available as separate links:	
Public Input on the Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach109.pdf

DATE: March 29, 2012
SUBJECT: Draft Alz Plan Comment

The University of Virginia's Office of Continuing Medical Education (CME) is working in collaboration with the Institute on Aging at the University of Virginia and the Alzheimer's Association, Central and Western Virginia Chapter and other partners to advance **Goal 1, Strategy 1.E**, to facilitate translation of research findings into medical practice, and **Goal 2, Strategy 2.A and 2B**, to build a workforce with the skills to provide high-quality care. We have developed an authoritative website for Alzheimer's *education* for physicians, nurses, and other healthcare professionals, to facilitate dissemination, translation, and implementation of the latest research findings and treatments. Called MemoryCommons:

http://www.memorycommons.org/

this web-based portal serves as a single point of access for on-line CME and training programming related to prevention, diagnosis, treatment, and public health challenges of Alzheimer's disease and related conditions, including the cognitive changes in aging and clinical differentiation of illnesses causing memory loss and dementia. Overall, MemoryCommons serves as a ***national*** resource where physicians, physicians in training, and other healthcare professionals can easily participate in educational activities and self-assessment; find tools that can support their clinical care of the aging patient; and apply the latest medical advances to their practices. We would be pleased to continue development of this tool as an existing resource upon which additional efforts can be built.

Donna L. Hearn
Executive Director, Institute on Aging
Assistant Chair
Dept of Psychology
University of Virginia
Charlottesville, VA

DATE: March 29, 2012
SUBJECT: We need a bold plan to stop Alzheimer's!

Although the official comment period has closed for the NAPA draft plan, I'm writing today to urge you to go bolder with the final plan to be released by HHS later this month.

Alzheimer's is a cruel disease. It slowly steals one's intellect, ability to communicate, independence, and dignity, even control over basic bodily functions like eating and caring for personal hygiene. It also places an overwhelming burden on caregivers -- emotionally, physically, and financially.

The commitment to a 2025 deadline in the draft NAPA plan represents a major step forward in the fight against Alzheimer's. I am pleased that the plan recognizes the need for increasing enrollment in clinical trials, compressing the drug development process, accelerating targeted research, and better coordinating activities with other countries.

However, I am one of many concerned Alzheimer's advocates who believe that this first draft fails to present a strategy aggressive enough to achieve the goal of preventing and treating Alzheimer's within 13 years. It lacks specificity in terms of timelines and deadlines, provides no path to providing significantly greater resources, and does not hold a single high-level office or individual accountable for the overall plan.

I hope that HHS will address these issues so that the next version of the plan will be bolder.

With the number of Alzheimer's patients expected to triple in the coming decades, we must embrace a plan that eschews a "business-as-usual" approach and tackles Alzheimer's with the urgency and aggressiveness it requires. If not, we stand to lose millions more lives -- and trillions of dollars -- to this disease.

Thank you.

Available as separate links:	
List of the 3,488 People Who Sent this Form Letter in March 2012	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach149.pdf

DATE: March 29, 2012
SUBJECT: Comments Draft National Plan to Address Alzheimer’s Disease

Attached please find Merck's comments regarding the Draft National Plan to Address Alzheimer's Disease.

If you have any questions, please let us know.

Thank you,

Angela M. Stewart
Director & Counsel, Public Policy and Government Relations
Merck
Washington DC

ATTACHMENT: MERCK Comments Draft NAPA Plan.pdf

Available as separate links:	
Comments on Draft National Plan to Address Alzheimer’s Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach108.pdf

DATE: March 29, 2012
SUBJECT: Oklahoma’s written comments for draft national Alzheimer’s plan

Thank you for the opportunity to submit written comments for the draft National Plan to Address Alzheimer’s Disease as part of the National Alzheimer’s Project Act.

In Oklahoma, our aging network formed an interagency workgroup to discuss the draft and make recommendations. The following agencies and their representatives were asked for their input:

Aging Services Division (ASD) Division Director
ASD Aging and Disability Resource Center (ADRC) Project Director
ASD Policy and Strategic Planning Supervisor
Oklahoma Health Care Authority representative (the state Medicaid agency)
ASD Home and Community-Based Services Program Administrator
Adult Protective Services Program Administrator
OKDHS Developmental Disabilities Division Director
ASD Older Americans Act Program Administrator
Oklahoma Mental Health Advocacy Coalition Director
ASD Legal Services Developer
ASD State Long Term Care Ombudsman

Many of these individuals also served on Oklahoma’s task force to study and make recommendations regarding the effect of Alzheimer’s Disease in our state. This task force, co-chaired by Senator Tom Ivester and Representative David Dank, met over a year and filed a final report which can be found here: http://www.oksenate.gov/publications/issue_papers/health_social_services/effect_of_alzheimers_task_force_final_report.pdf

Our group focused on Goals 2, 3, and 4 of the national draft plan.

General Thoughts:
Our group felt inclusion of the existing aging network is necessary for the success of the national plan. The aging network, through the above listed agencies and programs, already works with family caregivers, documents existing service gaps, and disseminates information statewide. Our statewide ADRC program already works to help families and caregivers to meet current needs and plan for future ones. Our Older Americans Act services specially target those individuals and their families who are facing an Alzheimer’s diagnosis through the National Family Caregiver Support Program. Including the aging network would help to optimize existing resources and coordinate implementation of the plan’s objectives. Our overarching concern is the aging network and its involvement in the rollout of this plan.

Specific Comments:

1. The draft plan references a Research Summit in May 2012 (pg. 7). We were curious if that has been scheduled, who will be participating, what will come out of that summit that could be used and in what way, etc. Likewise, the Federal Interagency Working Group referenced in the plan could be heavily leveraged to support change needed at the state level. Have the members of that group been chosen? What are differences between that group and the to-be-assembled leadership team referenced on pg. 29?

2. We really liked the references in both plans for 1) veterans 2) private sector. The private sector piece has limitless opportunity. Finally, we think for anything meaningful to happen -- either at the national or state level -- you must see legislative involvement and support.

3. In Oklahoma we have recognized the importance of providing case management to inform and coordinate services available to caregivers and their families and would like to see it as a cornerstone of services under this plan.

4. Oklahoma’s Aging Services Division works with the Oklahoma Department of Corrections and would like to see the unique needs of older prisoners addressed: (1) For those who are incarcerated, we would like to see specialized training in dementia information for prison personnel and comparative treatment options and (2) For those who have been released, more “safety net” provisions since these individuals are less likely to have a family/friend support network.

5. We would like the plan to include the following action items under a new Strategy 3.F:

   Strategy 3.F. Provide leadership in understanding legal issues, including legal opportunities and obstacles faced by persons with Alzheimer’s Disease, their family members and caregivers. Legal issues of persons with Alzheimer’s Disease emerge as the progression of the disease continues. Prompt and early legal intervention, prior to the onset of incapacity, can relieve stress on family members and caregivers who must deal with the consequences of lack of legal planning as capacity continues to diminish. AOA’s Legal Services Developers in each state address the development of local legal services and ensure that education is available to inform persons with Alzheimer’s Disease, their family members and caregivers about legal options.

   > **Action 3F.1**. Provide information to caregivers and family members regarding legal issues during life of the person with Alzheimer’s Disease as capacity diminishes. HHS will prioritize the dissemination of legal information to caregivers and family members regarding legal issues during life of the person with Alzheimer’s Disease. HHS will encourage state and local entities to work with local attorneys and legal providers to offer information related to the issues of capacity for decision making along the continuum of the progression of the disease; the uses and abuses of powers of attorney for finances and health care; the execution of advance directives, including living wills, do not resuscitate consent forms and the appointment of health care proxies; the process of legal guardianship that enables caregivers or family members to make decisions regarding the care of the person and/or the finances of the person Alzheimer's disease, and the appropriate use of “least restrictive” means to preserve the dignity of the person with Alzheimer’s Disease.
   >
   > **Action 3.F.2**. Provide information to caregivers and family members regarding legal issues upon the death of the person with Alzheimer’s Disease. HHS also recognizes that the need for quality information regarding legal issues upon the death of the person with Alzheimer’s Disease is paramount. HHS will work with states to engage local attorneys and legal providers in providing information related to estate planning documents and techniques including the execution of a will and the process of probate that addresses the need to name an executor and beneficiaries; estate planning techniques that may be available in states to avoid probate including living

trusts; transfer on death and payable on death documents and deeds; and the use and abuse of joint tenancy as an estate planning tool with finances and real property.

Jennifer K. Case
Programs Supervisor
Oklahoma City, OK

DATE: March 29, 2012
SUBJECT: Comments on Draft National Plan to Address Alzheimer's Disease; Down syndrome

I am uncertain whether my comments on the Draft National Plan to Address Alzheimer's Disease (see attached) are most appropriate to be sent to you, as liaison with the Advisory Council, and/or napa@hhs.gov (representing address for public comments), as I am unclear whether there is a distinction. I believe my comments may be most appropriate and relevant for the Advisory Council and their considerations, and therefore sending to you. Please let me know if I should also send directly to napa@hhs.gov.

I appreciate the opportunity to participate in the March 14 Advisory Council teleconference as well as the opportunity to submit my comments on the Draft National Plan to Address Alzheimer's Disease and its importance for the more than 400,000 individuals with Down syndrome in the US and their families and caregivers as well as associated stakeholders. More explicit inclusion of Down syndrome as integral to the Plan, particular concerning fundamental, translational and clinical research, will be important for accelerating progress and success not only for individuals with Down syndrome, and associated very high Alzheimer's disease neuropathology and dementia, but also for the entire population that will develop or currently have Alzheimer's disease.

Should you have any additional questions etc., please do not hesitate to contact me.

Thank you,

Michael M. Harpold, Ph.D.
Chief Scientific Officer
Chair, Scientific Advisory Board
Down Syndrome Research and Treatment Foundation

ATTACHMENT: Harpold_DSRTF_Comments on NAPA Darft Natl Alzheimers Plan 03.12.pdf

Available as separate links:	
Comments Regarding Draft National Plan To Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach107.pdf

DATE: March 29, 2012
SUBJECT: Comments re: the draft National Plan to Address Alzheimer's Disease

Thanks for writing earlier this week to clarify your group's upcoming deadlines regarding the draft National Plan to Address Alzheimer's Disease. I'm attaching written comments from my organization, Healthcentric Advisors, and the leadership team on our Medicare-funded Safe Transitions Project. After our project's Advisory Board meets next week, we'll also share a summary of the group's discussion about the draft plan.

We appreciate the opportunity to review and comment on this document--and wish you the best of luck as you finalize it!

Thanks,

Rosa Baier, MPH
Senior Scientist
Healthcentric Advisors Teaching Associate
Warren Alpert Medical School of Brown University
Providence, RI

ATTACHMENT: HCA_Draft National Plan to Address Alzheimer's Disease_032912.pdf

Available as separate links:	
Healthcentric Advisors Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach106.pdf

DATE: March 29, 2012
SUBJECT: IDoA written comments National Alzheimer's Plan

Attached please find written comments from Dr. John K. Holton, Director of the Illinois Department on Aging, supporting the role of the Aging Network in the National Alzheimer's Plan and the importance of addressing the needs of caregivers of persons with dementia.

Please contact me should you have any questions.

Sincerely,

Barbara Schwartz
Relatives Raising Children Program
Caregiver Program
Lifespan Respite
Illinois Department on Aging
Springfield, IL

ATTACHMENT: Director's letter to HHS National Alz Plan.pdf

Available as separate links:	
Illinois Department on Aging Comments on National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach105.pdf

DATE: March 29, 2012
SUBJECT: AFA’s Comments to Draft National Plan

Attached please find the Alzheimer’s Foundation of America’s (AFA’s) report, “The Time Is Now,” which serves as AFA’s comments to the draft national plan to address Alzheimer’s disease which was released February, 2012.

As always, please let me know if you have any questions or require further information.

Best,

Eric Sokol
VP,Public Policy
Alzheimer's Foundation of America

ATTACHMENT: TheTimeToActIsNow (3).pdf

Available as separate links:	
The Time to Act Is Now: Action Steps and Recommendations to the Draft National Plan to Address Alzheimer’s Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach104.pdf

DATE: March 29, 2012
SUBJECT: Comments on National Plan to Address Alzheimer’s Disease

I was quite pleased to read about the National Plan to Address Alzheimer's Disease. As a geriatrician and wound care physician, the majority of my patients are in some form of this devastating illness.

I was dismayed, however, to see absolutely no mention of the fact that currently Alzheimer's Disease is a terminal disease. In reviewing the following statement, one must get to the root cause as to how more healthcare resources are spent on these individuals:

"Caring for people with Alzheimer’s disease also strains the health and long-term care systems. Individuals with Alzheimer’s disease use a disproportionate amount of healthcare resources; for instance, they are hospitalized 2-3 times as often as people the same age who do not have the disease.[9]"

Many family members and caregivers do not understand that the natural progression of Alzheimer's Disease results in total dependency, resulting in aspiration pneumonias because of swallowing dysfunction, urosepsis and failing to thrive - despite 1:1 care by family members or caregivers.

The Institute for Aging Research at Hebrew SeniorLife has recently published "Advanced Dementia: A Guide for Families". This guide informs family members that Alzheimer's, and other forms of dementia, are terminal and that decisions can be made to enhance the quality of life rather than the quantity.

Until we find a cure for Alzheimer's, it will continue to be a terminal illness. Efforts must be made to educate the masses on the progression of this disease so that appropriate choices are made in the best interest of these patients and their families.

Sincerely,

E. Foy White-Chu, MD
Instructor in Medicine, Harvard
Director of Wound Healing Center
Hebrew Senior Life
Roslindale, MA

Primary Care Geriatrician
New Bridge on the Charles - Wellness Center
Dedham, MA

DATE: March 29, 2012
SUBJECT: NAPA comment submission

Attached please find New York Memory Centers NAPA comments for the record. Please confirm receipt of this e-mail. Thank you.

Christopher Nadeau

ATTACHMENT: NAPA Plan rec letr 03.29.12 epfnl.doc

Available as separate links:	
New York Memory Center Comments on the Draft Framework for the National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach103.pdf

DATE: March 29, 2012
SUBJECT: Alzheimers plan

Caregiver support: comment/recommendations for a caregiver "proxy" for specific recurring elements/items to obtain AZ care and/or documentation of services. For example, there is a service here in Maryland (maybe all states - but I never utilized it until I moved here). For a fee (that is well worth it) the service is automobile title/tax documentation and filing. This title service obtains the necessary information from the owner of the vehicle and then completes the necessary processes at the title/courthouse to research title, complete documents and file the title.

Something similar could/should be offered to caregivers. They lose many hours from their own work/family/life spending hours dealing with the mandatory documentation/filing/provider visits - Insurance, Medicare, SSI, finances.

Improvements could be gained through informatics and digitalization of records and bioscreen/markers. Obtain information from AZ healthcare proxy/financial proxy caregivers to write a book on a step wise process of what is required by caregivers to file Medicare, SSI, etc. and suggestions on how a business "proxy" service could do this work. And/or how to automate the procedures through functionalities through a software application and with secure/encryption.

Home/housing models: I hear repeatedly that it is cheaper for an AZ patient to live at home (if home is available) than in an institutional setting. That is not true in the current environment. The cost of maintaining 24h/7d care in an AZ patient home is more expensive that placing the AZ patient in an institution. For example, the cost of care in Alabama, is primarily due to in-house sitter/aide - minimum $12-15/hour, is the equivalent of $264-$360/day, equivalent to up to $10,000/month. This does not include cost of housing overhead, food, medications, transportation, clothing, toiletries, taxes. The cost of AZ/dementia care in an assisted living facility is about 50% of that cost (includes housing, utilities, and food). Either cost is excessive and any personal savings are rapidly consumed and then insurance (if coverage purchased), then Medicaid pays.

The only way to reduce or minimize in home care is for volunteer services and/or family live in care. Churches may be a "mission" service and should consider the care/education/services for elderly adults equivalent to the resources they invest in children services. With improvement of technology, monitoring/tracking devices, virtual monitoring, the care in house may be drastically reduced until the AZ patient is incapable of or has severe reductions in ADLs.

J. Thomas

DATE: March 28, 2012
SUBJECT: comment on National Alzheimer's Plan draft

I hope the attached serves as a useful mechanism for bringing nonpharmacological issues to the fore in the final draft of the National Alzheimer's Plan.

John Zeisel

ATTACHMENT: Letter based on Zeisel Petition.pdf

Available as separate links:	
Draft National Alzheimer's Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach102.pdf

DATE: March 28, 2012
SUBJECT: NAPA Plan comments

Hello! My name is Julie Levis. I am the Early Stage Clinical Manager for the Alzheimer's Association Greater San Fernando Valley Service Center.

We offer care consultation and early stage support groups for both the person with the memory problems and their care partners. I asked my early stage support group participants to provide suggestions for the NAPA Plan and here they are for your consideration:

- Education:
    - More emphasis on community education for people recently diagnosed
    - Opportunity to remain educationally integrated in society (taking classes to build cognitive reserve, educational institutions for cognitive impaired, etc.)

- Peer support
    - Develop support networks for early stage individuals (support groups, social clubs, etc.)

- Research
    - Greater emphasis on ES intervention- preventative treatment (what to do to avoid disease progression)

- Media
    - More AD exposure in the media to assist people in recognizing the early signs

Thank you!

Julie Levis
Alzheimer’s Association

DATE: March 28, 2012

SUBJECT: American Psychological Association Comments on Draft National Plan to Address AD

Attached please find the American Psychological Association's comments on the Draft National Plan to Address Alzheimer's Disease.

As noted in the attached, APA is eager to collaborate with the Advisory Council on Alzheimer's Research, Care, and Services, federal agencies, and other organizations in the continued planning and implementation of the National Plan.

Thank you for the opportunity to provide these comments.

Deborah DiGilio
Director, Office on Aging
Public Interest Directorate
American Psychological Association
Washington, DC
http://www.apa.org/pi/aging

ATTACHMENT: APA Comments on Draft National Plan March 28.pdf

Available as separate links:	
American Psychological Association Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach101.pdf

DATE: March 28, 2012
SUBJECT: NAPA Comment

Please accept my letter regarding the National Plan to Address Alzheimer's Disease.

Dr. Linda Levine Madori, ATR-BC, CTRS, LCAT
Professor, Clinical Internship Supervisor
Fulbright Scholar and Liaison
St. Thomas Aquinas College
Sparkill, NY
http://www.levinemadoriphd.com

ATTACHMENT: Linda Levine Madori, PhD,LCAT, ATR-BC,CTRS.docx

Available as separate links:	
Professor, Researcher and Author Comments on the Draft Framework for the National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach100.pdf

DATE: March 28, 2012
SUBJECT: Comments - Draft National Plan to Address Alzheimer's Disease

See attached for the comments submitted by AHCA.

Sandra Fitzler
American Health Care Association
Washington, DC

ATTACHMENT: National Alzheimer's Plan Comments 032812.docx

Available as separate links:	
Comments on Draft Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach99.pdf

DATE: March 27, 2012
SUBJECT: Draft National Plan to Address Alzheimer's Disease

The Down Syndrome Guild of Greater Kansas City represents 1200 families in 37 counties in Kansas and Missouri who are all caring for a loved one with Down syndrome. Many of our parents are gravely concerned about their child, teen or adult's future and the strong likelihood that they will develop dementia and Alzheimer's Disease.

I am writing to urge the Advisory Council to ensure that the population of people with Down syndrome (Ds) is specifically identified in the Draft National Plan to Address Alzheimer's Disease. Currently, this group of individuals, known to be at high risk of developing Alzheimer's and dementia, is given a fleeting reference in the Draft Plan. This omission must be rectified. We are aware that there is a lot of corollary research going on between Alzheimer's and Down syndrome and feel that more attention should be paid to this to ensure a bright future for both populations of people.

In order to better understand the Alzheimer disease process and develop early identification and other practices to treat this devastating disease which often affects individuals with DS early, research is urgently needed. Research of this type will benefit the general population as well as individuals with Down syndrome and those thousands with DS at risk for developing dementia. In addition, as a parent or family member, I am aware of the need to provide special supports for caregivers, often siblings or aging parents, who assume responsibilities for the care needs for individuals with intellectual disabilities and dementia.

It is also case that these individuals have special needs that may differ and require different supports than those provided to individuals in the general population. These needs have been identified by the National Task Group and Intellectual Disabilities and Dementia Practices in an action plan it issued as part of its report: ***My Thinker's Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports"***, which has been submitted to the Council.

Individuals with Down syndrome and their families deserve to have research and population specific clinical trials identified clearly as necessary actions in the final National Plan to Address Alzheimer's Disease. They face many challenges that require increased awareness, early recognition and supports. The National Plan to Address Alzheimer's Disease is not complete unless it fully addresses the Down syndrome population as well.

Thank you for your consideration of this request!

Sincerely,

Amy Allison
Executive Director
Down Syndrome Guild of Greater Kansas City
Shawnee Mission, KS
http://www.kcdsg.org

DATE: March 27, 2012
SUBJECT: Comments concerning National Alzheimer's Plan

Attached are comments submitted by The Arc concerning the Draft National Alzheimer's Plan.

Maureen Fitzgerald
The Arc
Washington, DC
http://www.thearc.org

ATTACHMENT: The Arc comments Draft Nat'l Alzheimer's Plan.pdf

Available as separate links:	
Comments from The Arc	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach98.pdf

DATE: March 27, 2012
SUBJECT: Comments on the National Alzheimer's Project Act Plan

Please find attached comments from the National Association of State Directors of Developmental Disabilities Services to the Advisory Council on Alzheimer's Research, Care, and Services regarding the *Draft National Plan To Address Alzheimer's Disease*.

Charles R. Moseley, Ed.D.
Associate Executive Director
NASDDDS
Alexandria, VA
http://www.nasddds.org

ATTACHMENT: NASDDDS Comments on Draft Plan 3-27-12.pdf

Available as separate links:	
Comments from the National Association of State Directors of Developmental Disabilities Services	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach97.pdf

DATE: March 27, 2012
SUBJECT: Down syndrome

Please include individuals with Down syndrome in the National Plan for Alzheimer's disease and related dementias. This group if individuals is underrepresented and under funded.

Your attention is appreciated.

Christine Lingo
Chicago Heights, IL

DATE: March 26, 2012
SUBJECT: Alzheimer Center at Parker Jewish Institute for Health Care and Rehabilitation comments on the draft National Plan to Address Alzheimer's disease

The Alzheimer Center at the Parker Jewish Institute for Health Care and Rehabilitation, located in New Hyde Park, New York, vigorously supports the draft National Plan to Address Alzheimer's disease. We are particularly supportive of the Plan's objectives to increase funding for Alzheimer's disease research and training initiatives, as well as development of state plans.

Parker is a highly acclaimed non-profit that offers inpatient short term rehabilitation, sub-acute care and nursing home care, as well as a comprehensive network of community health care services, inclusive of adult day health care, home health care, hospice care, on-site dialysis, medical transportation -and a unique Alzheimer Center that accepts participants at all stages of dementia. In 2011 alone, the Alzheimer Center at Parker served 1,085 participants. The Institute is also among the leaders in teaching and research.

Should you need additional testimony with regard to the plan, or are considering sites for pilot programs, please feel free to call upon us.

Sincerely yours,

Michael N. Rosenblut
President and CEO
Parker Jewish Institute for Health Care and Rehabilitation
New Hyde Park, NY
http://www.parkerinstitute.org

DATE: March 26, 2012
SUBJECT: National Alzheimer's Plan

The Iowa Department on Aging is encouraged by the initiation of a national plan to address Alzheimer's disease and related disorders. A diagnosis of, or in many cases just a discussion about Alzheimer's disease or related dementia can trigger a sense of fear, foreboding and uncertainty.

The National Alzheimer's plan has the potential to greatly improve and enhance the current system and help improve the quality of life and quality of care for both people diagnosed and their caregivers. But without adequate funding attached to the proposed goals, we are concerned that systems change is not possible.

1. To effectively create a system to enhance quality care and efficiency we believe the Plan should dictate minimum standards including, but not limited to the following:

    - An increased number of hours of education and training required for health care professionals and other disciplines who come in contact with people diagnosed with dementia.
    - Physician training programs that stress the importance of early detection and diagnosis.
    - Create and implement dementia unit requirements that include specially trained activity personnel, increased daily programming and adequate social work staff to meet the needs of people living in long-term care facilities.
    - Dementia care offered in hospitals must include staff with dementia training and enough staff to properly care for patients with a dementia diagnosis.

2. Expand patient and family support by enhancing existing systems.

    - Strengthen the National Family Caregiver Program to ensure that specialists are dementia capable and can provide education, referral and resource information and support to family caregivers who are caring for a person with dementia.
    - Strengthen the Lifespan Respite Program by providing adequate funds for respite care for people with dementia. Statistics show that access to respite care has a definite impact on the length of time a person can be cared for at home.
    - Provide access to evidence based programs that demonstrate effective support to all caregivers of people experiencing dementia
    - Increase psychosocial interventions for the caregiver and care receiver that offer support and assistance for people in home and community based programs.

3. Enhance public awareness and engagement through an organized, funded campaign to assist the general public in:

    - Understanding the importance of early detection, diagnosis and treatment.
    - Understanding the importance of future planning
    - Becoming knowledgeable about long term living and community support services that are available in local communities

The Iowa Department on Aging believes that a nationally funded and coordinated effort is needed to enhance care, expand caregiver support and increase awareness and we support the National Alzheimer's Plan.

Sincerely,

Donna K. Harvey
Director
Iowa Department on Aging
Des Moines, IA
http://www.aging.iowa.gov

DATE: March 26, 2012
SUBJECT: Address the Mental Health Needs of People with Dementia

The U.S. Department of Health and Human Services (HHS) should have Address the Mental Health Needs of People with Dementia and their caregivers in its ambitious plan to address Alzheimer's disease.

Unfortunately, the draft plan does not provide adequate attention to mental disorders commonly experienced by people with dementia and their caregivers.

Dementia frequently co-occurs with mental health conditions such as depression and anxiety disorders. In addition, family caregivers are at high risk for mental and physical health problems. Recognizing and treating these conditions plays a vital role in improving patients' cognitive functioning as well as the quality of life of people with dementia and their caregivers.

W. Marc Ducker, Esq. CPRP
Community Information and Benefits Specialist
Consumer Link
MHA of Nassau County
Hempstead, NY
http://www.mhanc.org

DATE: March 26, 2012
SUBJECT: Respite, Education & Training

As younger populations become increasingly urban and concentrated, persons more likely to have Alzheimer's or related dementia, become stranded in rural communities without adequate resources or family to assist them as the disease progresses. As jobs become scarce in rural communities, children of the baby boomers have moved where there are better job prospects leaving their parents alone. The community supports simply are not adequate in rural communities to address the specific needs of persons with dementia who have no informal primary caregiver's. Many of these people will end up in nursing facilities, that are ill-equipped to handle the specific care needs of an Alzheimer's patient. Nursing homes are for skilled care; however, Alzheimer's patients frequently do not need skilled care (for much of the disease progression), they simply need supervision, social stimulation, and help with minimal ADL's and IADL's. Nursing facilities have problems handling the behavior of Alzheimer's patients, because they are frequently mobile and cause disturbances with other patients. As a result nursing facilities are reluctant to accept patients with Alzheimer's disease early in disease progression. **The addition of Alzheimer's dementia specific units to nursing facilities, especially in rural communities, would alleviate some of this problem. The staffing would be smaller, and the cost per day to medicare/Medicaid could be reduced as a result**.

Additionally, for informal caregivers that do live in rural communities, support groups, educational opportunities, and training are absent. In addition, broadband internet is also difficult to obtain do inadequate infrastructure, leaving the caregiver unable to obtain information. The stress of caregiving combined with isolation shortens the amount of time an informal caregiver can increase the chance the persons are placed in nursing facilities for lack of another option. **Providing community training through religious institutions, civic organizations, and other groups would allow for wide dispersal of accurate information, as well as the infrastructure in rural communities, improving early diagnosis and extending the amount of time a person can stay at home with a caregiver by reducing their stress through knowledge and resources**. One way of accomplishing this is to certify persons at the AAAs or County Health Departments to recruit and train volunteers to provide outreach and educational events in their communities.

Another component of stress reduction is respite support. Caregiver's of persons with Alzheimer's or related diseases care for their loved ones for long periods of time. The time spent away from work, church, and family can become taxing and frequent breaks are needed. As there is increased demand for respite, and in the absence of increased funding for flexible respite support one of two options is available: 1) reduce the amount of respite per caregiver or 2) maintain lengthy waiting lists. Both options fail. At some point, respite is ineffective if it is infrequent and for very brief periods of time. If the caregiver waits too long without a break on a waiting list for respite, the caregiver will give up before the programs can provide assistance. **The solution is to increase funding for respite supports through the AAAs, V.A., as well as introduce a income needs based component to respite support programs eligibility requirements**. People that are wealthy ought to pay for their respite, or prove they have paid x amount before they can gain access to subsidized respite support each year. The reach of the programs would extend to those least likely to take a break, because they are unable to afford it.

James Patterson

DATE: March 26, 2012
SUBJECT: Submitting my COMMENT based on my telephonic statement of March 14, 2012 to the Advisory Council

This letter is very similar to my oral testimony (a few corrected typos and better words)--except for my adding a new paragraph at the beginning--to respond more fully to a public comment that preceded mine:

A person (Michael Ellenbogen?) who currently suffers from mild Alzheimer's dementia concluded his comments by recommending the Advisory Council on Alzheimer's Research, Care, and Services consider the "right-to-die" option. He thus implied that Physician-Assisted Dying could be an option for patients who suffer from dementia. Because of time limitations, I could only disagree briefly by saying that Physician-Assisted Dying will neither help nor is needed. I now explain more: (1) Why would Physician-Assisted Dying NOT help? Where Physician-Assisted Dying is legal, the law requires patients be of "sound mind" when they ask their physician to write a prescription for a lethal dose of medication. Yet dementia patients lose the mental capacity to make medical decisions early in the course of this progressive disease. Thus for dementia patients, Physician-Assisted Dying would compound their tragedy with ***premature dying***. This is because dementia patients can have much good life after they lose capacity--and they can expect more, with further research--so I and many others consider ***premature dying*** an act that violates the ***principle that life is precious***. (2) Why is Physician-Assisted Dying NOT needed? Because Living Will forms and the discussions they provoke can be both moral and effective. Combined with other clinical and strategic forms, diligent Advance Care Planning can give people peace of mind, whether they are still well or in the early stage of dementia. They need not worry about being forced to linger for months to years by enduring the huge burdens and suffering that characterize Advanced Dementia. Instead, they can feel confident that others ***will honor their Known Wishes*** after they lose the ability to speak for themselves.

Here is my original comment:

For patients who will someday suffer from Alzheimer's and related dementias, Advance Care Planning is most **urgent, most important**, and **most challenging**. The process of expressing one's end-of-life wishes in advance warrants both 1) the development of innovative planning tools that are easy, effective, and acceptable to both patients and physicians, and 2) sufficient effort to train professionals to honor Advance Directives and to recommend that their patients/clients complete them.

Why is Advance Care Planning **most urgent**? Unlike most diseases, patients who have dementia typically lose mental capacity to make end-of-life medical decisions early in the course of the disease. Once their window of opportunity to make decisions closes, they will not be able to participate in their own end-of-life planning. The reality of the huge, increasing epidemic of patients whose lives will end as they suffer from Alzheimer's disease makes Advance Care Planning even more urgent on a societal level.

Why is Advance Care Planning **most important**? Because patients can linger in the terminal stage of Alzheimer's Dementia for several years. The relentless course of their disease may frustrate the best efforts of their clinicians, their caregivers and their loved ones. The multiple burdens on others are well known. For example, more than one-third of Alzheimer's caregivers are depressed. Yet the suffering patients themselves experience is under-appreciated. For too many who have lost the ability to complain and whose behavior may be atypical, pain and suffering may go unrecognized and therefore under-treated for months, or even years

Why is Advance Care Planning **most challenging**? Unlike other terminal illnesses, often there are no life-sustaining treatments that physicians can withhold or withdraw. Typically, a strong body houses a feeble brain. Many who feel the pang of the “**Dementia Fear**” consider “*premature dying*.” They may believe: “If I don’t kill myself now, I won’t be able to kill myself later. Then, I’ll be trapped in a condition I loathe so much that I’d rather be dead.” Those who act on this fear only compound the tragedy of their disease. We must offer patients effective advance care planning so they can feel confident they can choose to avoid a prolonged dying of months to years with suffering and burdens. Then, many will ironically choose to live as long and as well as possible--and benefit from improvements in the medical and non-medical management of their disease.

Advance Care Planning for Advanced Dementia needs research funding to develop and to implement--even if other researchers discover new drugs that delay the onset of symptoms or slow down their progression. We know that changes in the brains of dementia patients begin one or more decades before clinical symptoms emerge. We also know it takes many years to prove the safety and efficacy of new drugs and to adopt a policy to implement widespread treatment. Realistically, most of the 76 million baby boomers predicted to get dementia are still likely to become demented. Even if a new drug were available today, patients afflicted with Alzheimer’s disease who do not die of another cause will eventually reach the stage of Advanced Dementia. Most importantly, when they do reach the advanced stage of dementia, these patients will then have only their Advance Directives on which they can rely, to control *how long, and how much, they must suffer* before they die.

To reduce end-of-life suffering of millions of victims of Alzheimer’s disease and their loved ones, we must thus fund research programs that will: 1) develop new Advance Directives that are easy, effective, and acceptable to both patients and physicians, and 2) train professionals to honor Advance Directives and to recommend their clients and patients have the discussions and complete the forms…now, while they still can.

Sincerely,

Stanley A. Terman, PhD, MD
Medical Director and CEO of Caring Advocates
Carlsbad, CA

DATE: March 26, 2012
SUBJECT: National Plan to Address Alzheimer's disease - Comments/Feedback

My father is the third person I know to be diagnosed with Alzheimer's disease. First was my uncle who passed away in 2005 and then my aunt or father's sister who, although 6 years younger has had it for over two years now.

The impact of this illness on the family is devastating. There is no one place to go for help or all the information you need. It takes a village to handle an aggressive, geriatric Alzheimer's family member. As a caregiver one needs to find out as much as possible as quickly as possible to get the help needed for a loved one. Nobody tells you all the challenges you will have and the financial impact it has on the family as well.

My father was normally an intelligent man, very good with mathematics, science and spoke English, Spanish, Italian and Portuguese. Now we see him unable to handle his finances, becoming increasingly aggressive, suffering from delusions and hallucinations regarding our mother who he has been married to for 62 years.

Due to the fact that a mental healthcare power of attorney was not signed since the lawyers don't mention that when you go to get your will and other papers in order, we had to apply for emergency guardianship to get my father admitted to a level one psychiatric facility. After he is there for three weeks and thoroughly evaluated we are told he cannot come home due to delusions regarding our mother. Now we have to find someplace for him and try to find resources to help us. Unfortunately we end up putting him in a group home which we think is the right thing since it is similar to his home and the advice we get from social workers as well as companies such as Care Patrol, that have familiarity with this illness. Since we have no experience we follow the guidance of these "professionals." Unfortunately in our case perhaps also due to the stressfulness of the situation we did not make the right decision. The home was nice but the caregiver, although a nurse, was not there most of the time, and the other caregivers were Pilipino and did not understand English very well.

The situation gets worse when my brother goes to visit my father and he is in bed at 7:30 since the caregivers don't seem to want to be bothered with the patients. When he arrives my father gets up from bed and falls and the door is locked and the caregivers can't seem to figure out how to get the door opened. My brother finally does and dad is on the floor. The caregivers just leave the area and my brother and his son help my father get back into the bed. My father seems to be in a drug stupor and his eyes roll back in his head. I get a frantic call from my brother and call the hospice since he was on palliative care and ask them to send a nurse immediately since the nurse who owns the group home is not there. I also leave an urgent message for her, which is never returned. I wait and then call for the nurse at the hospice that is on call to find out that she was denied entry into the home by the caregivers who told her he was sleeping and to come back the next day. When I confront the owner of the home the following morning she insists that she called me even though there is no record on my answering machine or caller id on the home or cell phones. Then she also indicates that her mother told her that nobody came to the door from the hospice, which was an outright lie. I immediately started looking for another facility but it was difficult since they are all extremely expensive and my mother is alive and living with physical disabilities at home and all of my father's social security, pension and VA benefits (which I applied for since he was a WWII veteran) have to go in their entirety to his care and we still fall short.

During the time I looked for a facility I asked the group home owner not to transport my father anywhere since there was an issue when we brought him home for lunch prior to that. I had met him at a follow-up appointment with his neurologist and she said we could try to bring him home to see how it went. The first time we tried it he seemed ok but it was after an appointment for a vision test and he refused to get in the car unless we took him home. On that occasion, he managed to get his checkbook which we later found out about since we could not locate it to pay the bills.

The following week he had a dentist appointment due to periodontal disease which we needed to attend to. After that appointment , when we brought him home, he became very agitated and pulled a knife out of a drawer, which usually had only papers(so we can only imagine he had placed it there the week before, since we did not). He sat down and said he was not going back to the group home or as he called it, a jail. Then he said he would kill my husband if he ever saw him again since he was the one who, with my sister, brought him to the hospital. I asked him to return the knife and he took it and put it under some papers behind him. This wasn’t a small knife it was a large carving knife. I asked for it back but he refused and then went out back and started cutting plants with it and ended up coming in the house without it. He had hidden it. I sent my sister out to retrieve it and she found it in a bucket outside. I took that knife and the rest that were in the house and put them in the trunk of my car. While I did that he went in the back yard and left from the gate on the side and was halfway down the block on foot. I ran to catch up with him and my sister called the police since we were very concerned and needed to get him back to the group home. When the police came he told them he would go back with us and when they left and we were a few blocks away he lunged over the back seat and grabbed my steering wheel and tried ripping the keys out of my ignition and then grabbed the gear shifter to get the car out of gear. I immediately jammed on the breaks and told my sister, who was sitting next to me, to call 911 and that is when he tried to grab the phone from her. I told him I would go back to the house and proceeded slowly to give the policemen a chance to get there. I went past the house and he became agitated and tried getting out of the car but could not since the child locks were on the doors. Unfortunately I forgot the window locks and he was able to open the window and got his body out up to his hips. I had to stop the car and get his feet back in. This is 5’8” man who weighs 158 lbs. I am only 5’3” and weigh 130. This time four police cars came and the officer ended up having to put my father in his squad car and take him back to the home.

Despite the incident that happened and the fact that the group home owner knew about what happened and was told not to take him out, her husband took my father to the bank a couple of weeks later and the bank rep called my mother and then me since my father was requesting his social security number to take out money.

When I finally found a decent place for my father that specializes in Alzheimer’s and dementia care, the group home was very rude and unprofessional with the nurse who came to assess him and asked them in front of my father if they were going to take him to a psychiatric facility. So in addition to all the stress now we had to deal with a group home that was manipulating him so he would not leave. He was also writing them checks, which I got back, but we closed the account to keep anyone from taking advantage of him. He had promised money to them, wrote checks to his attorney who was appointed by the court and was promising thousands to the staff and doctors in the hospital where he was assessed.

On top of everything we ended up getting calls from Elder abuse since the owner of the home was apparently upset that we were taking him out and kept arguing that he wasn’t ill despite the medical records from a neurologist and psychiatrist.

Our family has been going through hell. On top of all this there was a tremendous amount of paperwork to get VA benefits, get medications and other medical issues taken care of and the legal expenses for guardianship are bleeding my parent's dry. The emotional impact on our mother and the rest of us has been awful as well.

I tell you all this so you can see what it is like since none of us ever imagined how awful this would be. I don't think anyone knows what it is like until they experience it firsthand.
Waiting until 2025 is too late. In my visits to many facilities I have seen people in their 40's and 50's with the disease and it will only get worse as the baby boomers age. With twice as many of them as their parent's generation we are in for a healthcare meltdown if something isn't put in place soon. We need to do something now. I am sure we are not the only family going through this.

There should be more research into different modalities (allopathic, homeopathic, naturopathic, etc.) to address this illness. I have read that there are studies being done regarding a cancer medication that is on the market that reduces the amyloid plaque in the brain. This is the website: http://www.case.edu/think/breakingnews/breakthrough.html.

I have also read about a possible treatment or preventative in raw coconut oil by a doctor who used it on her spouse: http://www.coconutketones.com/whatifcure.pdf. Perhaps the cure or prevention lies in a combination of different modalities and all should be considered.
Families need more financial assistance and better resources where they can find all or most of the information needed with respect to legal, medical and assisted living resources as well as support groups to help families get the assistance they need as quickly as possible. Most of what is out there now is just "you are on your own" looking though websites in the midst of a crisis trying to find the help and guidance you need or other families at support groups trying to help each other. When a family is in constant crisis they need as much assistance/guidance as quickly as possible to help them navigate the system of care so they can make the right decisions for their loved one.

I agree with all of the findings but it must also be noted that some co-occurring chronic conditions such as sleep apnea (http://www.newschief.com/article/20111229/news/112295021) hearing loss (http://www.hopkinsmedicine.org/news/media/releases/hearing_loss_and_dementia_linked_in_study) and periodontal disease (http://www.breathproblems.com/link-between-periodontal-disease-and-dementia.html)should also be included in annual geriatric screenings since they can be directly linked to causing dementia and may be overlooked. In addition something should be put in place regarding hearing loss and the prohibitive cost of hearing aids. Perhaps insurance companies can increase fees by a few dollars a month on their premiums to include some coverage for hearing aids. Everyone is impacted by hearing loss of a senior citizen: family, motorists who drive on the roads along with them, and anyone who the hearing impaired interact with. Since hearing loss can be linked to dementia making hearing aids more affordable through some sort of coverage could help in part, to address this issue.

Anyone directly related to the care of a patient with dementia or Alzheimer's and affiliated with a medical facility, assisted living, or group home should need to be certified to care for a patient with this illness and display that certification where it is visible to family who are looking for care for their family member. There are people who claim to know how to handle patient s with this illness, yet do not, and tend to take advantage of the family as well as the person with the illness.

There should be clear guidelines in place as to what the group homes can and cannot do such as taking a dementia patient to the bank to take out money. I bring this up since this happened with my father.

Medical assessments in the home would help greatly as well since it can be impossible to get a dementia patient to the doctor or hospital unless you have a mental health care power of attorney. If a patient is hospitalized and determined to have dementia, a mental health care power of attorney should automatically be granted without the family having to dish out thousands of dollars to an attorney when the person has received a neurological and psychological evaluation by qualified physicians. This would save the families of these patients thousands of dollars which can be used for their care. A regular health care power of attorney is insufficient since we were told that Alzheimer's and dementia are considered physical illnesses with psychological manifestations. Without a mental health care power of attorney the family has to file for emergency guardianship and then permanent guardianship which can cost upwards of $20,000. This is a progressive disease with no known cure at this point. It is ridiculous to penalize an already suffering family to have to deplete their savings when their loved one is only going to progress in mental deterioration and obviously needs a guardian. Many times they feel that they are not ill and will continue to fight and deplete their funds further until they end up on ACCHHS (Medicaid), which in turn just depletes the government's funds further. If this is a necessity perhaps some cost containment should be put in place so families aren't hurt financially by exorbitant legal fees.

Another issue is medication. The VA indicates it can help with the cost of medication but you have to bring the patient into their facility. Once they are in a memory care facility they are not always amenable to being transported so it would be of great help to have a VA rep come to the patient facility to assess them for the medication benefits or just to have the paperwork from the doctor diagnoses serve as proof that the person needs the medication and provide it and delivery at no cost to the veteran.

The facility that my father is currently in provides dental care via mobile dentistry. It would also be beneficial to have the same with respect to mobile hearing units to help many of the residents in these facilities to get the hearing assessments and hearing aid cleaning, hearing aids, wax removal, etc. to ensure that they can hear effectively. Mobile vision care would also be a plus to ensure that the patients are seeing well or are not developing illnesses of the eye. Finally decent memory care facilities are very expensive (the one our father is now at costs $4,338/mo.) and that it would help greatly to have some sort of coverage to help as the only thing available is long term care insurance which many people do not have and once you are diagnosed with Alzheimer's, is no longer an option.

I hope you will take these suggestions into consideration in your National Plan. After going through all of this first hand I can tell you that these changes are greatly needed and would help all the families out there who are going through all of these challenges.

Thank you for your time and consideration.

Olga L Molinari
(daughter/caregiver/co-guardian to a parent with Alzheimer's disease)

DATE: March 26, 2012
SUBJECT: Public Comment on National Plan to Address Alzheimer's Disease

Thank you for the opportunity to offer public comment on this important and much needed national plan.

From my experience as a nurse working with several community hospices over the past 15 years, it's often a struggle to utilize antipsychotics (i.e. Haldol) in skilled nursing facility setting. Nursing facilities have many regulations which are well-intentioned to provide safe care for residents.

However, I would just like to offer that haloperidol is often preferred over lorazepam for agitation, terminal restlessness for many patients, especially Veterans with a history of PTSD. We have found that these patients may benefit from a medication that may help them to think more clearly, so that they feel less vulnerable by feeling more in control.

Respectfully,

Mary Zuccaro, MSN, ACHPN
Hospice Palliative Nurse Practitioner

DATE: March 26, 2012
SUBJECT: Re: Mental Health Concerns

This is to request that the Committee address the mental health concerns of persons with dementia and their caregivers.

Sincerely,

Carolyn Clemente, A.C.S.W,
Bronx, NY

DATE: March 26, 2012
SUBJECT: Dimentia

Working with individuals with dimensia requires services that are unique and tailored to address those needs which in our mental health facilities they are address all in the same, and they are not.

Solangel Griffith

DATE: March 26, 2012
SUBJECT: AAN comments on draft National Plan to Address Alzheimer's Disease

Please accept the attached comment letter from the American Academy of Neurology (AAN) on the recently released National Alzheimer's Project Act (NAPA) Draft National Plan To Address Alzheimer's Disease. The AAN is proud to support the overall Plan and fully supports the vision of a nation free of Alzheimer's disease.

The AAN stands ready to assist in these important efforts and remains committed to partnering with other organizations to prevent and reduce the burdens of this devastating disease.

Sincerely,

Katie M. Shepard
Senior Manager, Medical Economics
American Academy of Neurology
St. Paul, MN

ATTACHMENT: AAN Comments - National Plan to Address Alzheimer's Disease.docx.doc

Available as separate links:	
AAN Comments on Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach95.pdf

DATE: March 26, 2012
SUBJECT: Comment

Please make sure that the U.S. Department of Health and Human Services addresses the mental health needs of people with dementia and their caregivers in its final plan.

Miriam Schwinder
Service Coordinator, Holocaust Program
Pesach Tikvah - Hope Development, Inc.

DATE: March 26, 2012
SUBJECT: Comments to the Draft National Plan to Address Alzheimer's Disease

There are numerous improvements in the draft national plan to address Alzheimer's disease from the initial framework plan. Additional areas of the plan still need strengthening and improvement. CCAL appreciates the opportunity to submit comments to help strengthen the draft plan. The comments follow.

General

- CCAL suggests that the plan include the words "other dementias" and be known as the National Plan to Address Alzheimer's Disease and Other Dementias. The terms "Alzheimer's" and "dementia" are often used interchangeably. Many internists and family practice physicians (among others in the health care field), for example, are still not well educated about assessing and diagnosing Alzheimer's disease and use the general term "dementia" to explain cognitive decline to patients and their families. The addition of the terminology "other dementia" is more inclusionary and desirable.
- Person-centered care is the widely recognized gold standard of services and supports for people living with Alzheimer's disease and related dementias (PWD) (Alzheimer's Association, 2006; Edvardsson, et al, 2010). It is a foundational aspect of the Affordable Care Act of 2010. The draft plan is silent about person-centered care. CCAL suggests that the plan integrate the philosophy and orientation to person-centered care throughout the plan.

The Challenges Section (page 4)

- Notably missing as a national challenge is the over prescription and utilization of antipsychotic medications as a first line of management for behavioral challenges experienced by PWDs. The medical community as well as the formal and informal caregiver communities need to be educated about non-pharmacologic approaches to such behavioral challenges as agitation. Medications should be used only if and when non-pharmacologic approaches have not been effective. There is currently a dearth of readily accessible information about recommended non-pharmacologic approaches and practices.
- Also missing as a national challenge is recognition that the quality of programs and services for PWDs who reside in residential long-term care (assisted living, nursing homes) across the nation continues to be uneven and often less than optimal. There is no national focus on or effort to address quality for these long-term care programs and services despite the fact that the number of people living with dementia will increase over fifty percent by 2030.

Plan's Three Guiding Principles (page 5)

- CCAL applauds the second Guiding Principle that supports public-private partnerships. We recommend that the detail for this principle be expanded to specifically include dementia experts who represent the practice, policy, and research sectors. All too often senior executives are included on advisory panels solely because of their positions. Unfortunately they often lack actual dementia expertise and experience. It is vitally important that the national plan be developed, planned, and implemented by a diverse group of dementia experts who can provide "face validity" both to the plan and the process of its development and implementation.

References

- Alzheimer’s Association, 2006. Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes.
- Edvardsson, D., Fetherstonhaugh, D., Nay, R. 2010. Promoting a continuation of self and normality: person-centered care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing*, 111/j.1365-2702.

Thank you for the opportunity to submit comments on the draft national plan to address Alzheimer’s disease.

Sincerely,

Jackie Pinkowitz
Chair, Board of Directors
CCAL

DATE: March 25, 2012
SUBJECT: RE: Draft National Plan to Address Alzheimer's

I have just two comments on the National Alzheimer's Plan which is mostly nice sounding rhetoric that I hope helps with this devastating disease.

First, Goal 1 (an effective treatment by 2025) just seems to me arbitrary and unrealistically optimistic. Of course that would be wonderful but as a physician specializing in geriatrics and Alzheimer's I see little hope of this being accomplished in the foreseeable future or perhaps ever. How will this be done by 2025 when there are no significantly effective drugs on the market at this time -- this is only 13 years away and the drug development/approval process takes many years. Hopefully the research summits proposed will help. $50-80 million in new funding seems a pittance that can't possibly make a significant difference. We have had a "war on cancer" with much higher rates of funding for about 40-50 years now with some modest positive results but certainly no cure for cancer.

Second, in my opinion, Action 3.D.2: Monitor, report and reduce inappropriate use of anti-psychotics in nursing homes, has no place in this report. Most of the other items in this report are positive, optimistic goals. This is a narrow and arguable negative. In my opinion again as an experienced geriatrician and long term care physician, I feel the issue of antipsychotics in nursing homes is overblown and not significant enough to be a major national priority. Inappropriate use of medications is one thing that of course must be minimized, though what is appropriate is highly individualized and subjective. However the "off-label" use being considered inherently inappropriate or fraudulent is completely wrong. Physicians and nursing homes are already extensively educated and regulated on this issue. All drugs are commonly and legally used for many "off-label" scenarios and there is nothing wrong with that if the medical judgement is reasonable and the patient benefits. Unfortunately Alzheimer's patients often have uncontrollable anxiety and agitation and until a better therapy comes along, antipsychotics are often the only answer. "Conflicts of interest" among pharmacists and physicians have NOTHING to do with this issue. Clinicians simply often have no better solution for dementia related psychosis and agitation at this time. I am an active member of the American Medical Directors Association and vehemently disagree with their their "politically correct" approach to this difficult issue (they have gone along with government suggestions to more vigorously educate and crack down on physicians and nursing homes).

Perhaps a brief mention of better treatments for behavioral and psychological symptoms as well as cognitive symptoms and "cure" would be appropriate under goal 1. Otherwise I think this entire paragraph 3D2 is inappropriate in this report and should be completely deleted.

Thanks for your attention,

Todd Goldberg, MD CMD FACP
Associate Professor and Director of Geriatrics
West Virginia University
Charleston Division President
West Virginia Geriatrics Society

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From: Matheny, Helen
Sent: Tuesday, March 20, 2012 6:07 PM

Subject: Draft National Plan to Address Alzheimer's

For your information, attached is the first draft of the National Plan to Address Alzheimer's Disease. As a non federal member of the national Alzheimer's Disease Advisory Council I encourage each of you to review the draft and provide comments. Your perspective as a physician is critically important. HHS is seeking input on the draft National Plan through March 30, 2012. Please send your comments to napa@hhs.gov. Also, please feel free to copy me. I serve on the Council's Clinical Care Subcommittee and would greatly value your suggestions. I expect the second draft of the plan to be available mid-April.

I look forward to hearing from you.

Best regards,

Helen M. Matheny, MS, APR
Director
West Virginia Alzheimer’s Outreach and Registry Program
Blanchette Rockefeller Neurosciences Institute
Morgantown, WV
http://www.brni.org

DATE: March 25, 2012
SUBJECT: Alzheimer’s Disease Plan

The suffering of people with Alzheimer's Disease and their family caregivers is invariably compounded by depression and anxiety. These are among the most devastating daily effects of the disease, undermining the quality of life of both caregivers and patients and limiting their ability to contribute to society in a meaningful and economically viable way. Any effort to improve the management of the disease should therefore include a program of psychological intervention as well as medical research and therapy.

Judith Cohen
Past President
Medical Information Services, Inc.
New York, NY

DATE: March 25, 2012
SUBJECT: National Plan to address Alzheimer’s Disease

My sister died from Alzheimer's Disease on Oct. 5, 2011. My sister had Down syndrome.
The proposed plan fleetingly mentions "intellectual disabilities," which is woefully inadequate to address that fact that people with Down syndrome have a higher incidence of Alzheimer's Disease than the general population.

"Intellectual disabilities" must be replaced with Down Syndrome since it is these people who experience it at such a high rate at this time. "Down syndrome and other Intellectual disabilities" would be an acceptable term.

Sincerely,

Deborah Metzel
Waltham, MA

DATE: March 24, 2012
SUBJECT: Inclusion of Persons with IDD in NAPA

The Developmental Disabilities Nurses Association supports the specific inclusion of persons with intellectual and developmental disabilities in the National Alzheimer's Project Act (NAPA) as requested by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). In most cases, nurses assess individuals with IDD on a more frequent basis than primary health care providers, and thus may note signs and symptoms indicative of early stages of dementia in the settings in which individuals reside or spend their days. This increases the likelihood of prompt referral for diagnosis and treatment.

We sincerely hope that this medically underserved population, some of whom by the very nature of their developmental disability are at increased risk for Alzheimer's disease, are considered by the NAPA council for inclusion in its proposal.

Respectfully and on behalf of the Board of Directors of DDNA,

Mary Alice Willis, RN MSN
Executive Director
Developmental Disabilities Nurses Association
Orlando, FL

DATE: March 23, 2012
SUBJECT: Critical Path Institute Letter or support

Attached, please find C-Path's letter of support.

Kind regards,

Kimberly A. Cross for Carolyn Compton, MD, PhD.
Executive Assistant
Critical Path Institute
Tucson, AZ
http://www.c-path.org

ATTACHMENT: SKMBT_C28012032312400.pdf

Available as separate links:	
Making the Case for Public Private Partnerships for NAPA	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach96.pdf

DATE: March 23, 2012
SUBJECT: Feedback on Draft National Plan to Address Alzheimer's Disease

Please see below for my feedback on the National Plan to Address Alzheimer's Disease. I am a gerontological clinical social worker with over ten years experience in the field of dementia care. I was formerly the Director of Social Services at the Alzheimer's Foundation of America, and now I am a doctoral candidate who teaches and conducts research on dementia care at Columbia University School of Social Work.

Congratulations on creating such a progressive plan of action. I hope that my feedback is of value. I would be delighted to get involved in any of the efforts related to finalizing this national plan or taking action on any of the activities outlined within the plan. Please contact me with any questions, comments, or concerns.

Positive Feedback:

- The plan is overwhelmingly comprehensive in breadth of scope and depth of detail.
- The lists of challenges and guiding principles for the national plan are thoughtfully crafted and easily justified.
- This plan looks to make substantial achievements toward fulfilling the objectives of NAPA with both immediate and long-range potential benefits to our citizens.
- The inclusion of diverse stakeholders' input, as well as plans to coordinate efforts across federal agencies, shows dedication to setting realistic priorities and working toward meaningful outcomes.

Constructive Criticism:

Action 2.A.2: Encourage providers to pursue careers in geriatric specialties

- The professions identified in this Action Statement are surely appropriate targets of the relevant activities, but the exclusion of the social work profession is a major oversight. This oversight is not repeated in Action 2.A.3 on dementia-specific guidelines and curricula, which shows some acknowledgement on the part of NAPA representatives of the value of a competent social work workforce. Social workers are integral members of the professional care teams in every setting and program of health, mental health, and aging services. They perform essential roles which are crucial to the successful delivery of those services, and this is especially true in the context of the multidimensional, bio-psycho-social domains of need in dementia care. Look to the work of the John A. Hartford Foundation's Geriatric Social Work Initiative for information on the importance of shoring up for a gerontologically-competent social work workforce, as well as for models of successful workforce development.

Action 2.A.3: Collect and disseminate dementia-specific guidelines and curricula for all provider groups across the care spectrum

- The Action Statement suggests a plan for HHS to seek input from public and private entities to complete this activity, but it does not detail a process for identifying or selecting providers of such input. With regard to collecting social work guidelines and curricula, I gladly offer my assistance. There are few such guidelines on social work practice in dementia care, and even fewer curricula. However, this is truly my area of expertise, I have lists of the few resources available, I have developed a graduate social work course exclusively on dementia, and I know of several other experts who would also be willing to assist in this effort.

Action 2.A.4: Strengthen the direct-care workforce

- The direct-care workforce includes both those who work in private homes and those who work in facilities, yet this Action Statement is focused exclusively on nursing home personnel. Failure to include home health and home care personnel in this effort would be a tremendous oversight. The preferred location of care for nearly all citizens is their own home, the quality of home care services is known to be inadequate for the general population, and to date there are no research studies which have attempted to examine appropriate home care service models, training protocols, patient and family outcomes, and worker outcomes related to dementia care in the home environment. The home health care and home care industries must be strengthened if we are to avoid a crisis in care. Federal money and coordinated efforts among federal and state agencies, and private industry stakeholders, must be dedicated to addressing improvements in the quality of home care services for individuals living with dementia.

Action 3.D.1: Educate legal professionals about working with people with Alzheimer's disease

- The importance of reducing the abuse, neglect and exploitation of individuals with dementia cannot be overstated. Toward this end, the Action Statement should be revised to call specific attention to the need to educate District Attorneys and Assistant District Attorneys about responding to charges brought against alleged perpetrators as a result of police and Protective Services investigations. This is particularly important for victims with dementia who lack the capacity, and often the availability of capable advocates, necessary for seeking justice and protection. For example, financial exploitation charges filed by Protective Service agents are rarely addressed by District Attorneys, and, as a result, the perpetrators are not brought to justice and the elders' funds are not restored.
- Adult Protective Service programs are generally overwhelmed and understaffed. Certain states have taken the lead in developing more highly effective programs for dealing with elder mistreatment, such as the Massachusetts Executive Office of Elder Affairs which supports programs for Elder Protective Services and Elders at Risk. These elder-specific programs should be required in each state. In addition, all Protective Services agents should have access to dementia-specific education. When the victims of elder abuse are individuals with dementia, their vulnerabilities are unique, the investigations are additionally complex, and the intervention options are distinct.

Action 3.E.2: Examine patterns of housing and services

- Efforts to understand professional care services must now look beyond simple profiles of service availability and use in order to study the effectiveness and efficiency of the services. Access and use of a service are important issues to measure, but the quality of care provided by these formal service systems (most of which are regulated at the state level) needs to be studied as well. Anecdotal and research-based evidence continually suggests that consumers do not receive adequate care, families are not relieved of their burdens by using formal care services, and community-based services do not effectively postpone nursing home placement. Investments in improved quality of care would likely result in significant long-range savings due to reduced worker turnover, delayed family burnout, delayed nursing home placements, reduced hospitalizations for avoidable medical and behavioral complications, and fewer transitions between care settings.

- This Action Statement calls for an in-depth analysis of the National Survey of Residential Care Facilities, but should also include the further development and analysis of the National Home and Hospice Care Survey.

General concern-

- This plan does not provide adequate attention to mental disorders commonly experienced by people with dementia and their caregivers. Dementia frequently co-occurs with mental health conditions such as depression and anxiety disorders. In addition, family caregivers are at high risk for mental and physical health problems. Recognizing and treating these conditions plays a vital role in improving patients' cognitive functioning as well as the quality of life of people with dementia and their caregivers.

Best wishes,

Daniel B. Kaplan, LICSW, LMSW, CSW-G, QDCS

DATE: March 23, 2012
SUBJECT: Mental Health Needs of People with Dementia

Please include the mental health needs of people with dementia and their caregivers in your final plan.

Erin Vogt, LCSW, ACSW, CMC
Client Care Coordinator
Dutton & Casey, P.C., Attorneys at Law
http://www.duttoncaseylaw.com

DATE: March 23, 2012
SUBJECT: mental health care for older adults w/dementia and their caregivers

Please become more informed about the vital and large voting population who have a loved one with dementia or depression or anxiety. The Baby Boomers are one of the largest groups around and have the most voting power as well as the needs for supportive services to keep their loved ones at home. It seems when it comes to home care, respite services and other supportive case management services and counseling are the first ones to be cut. We once had an older adult program here in Illinois and that was cut (temporarily once and completely the 2nd time around). The message you are sending the public is that our government does not value the family as a place for care recipients to grow older (it is a proven statistic that family members experience less depression in the family home than in a nursing home facility). Older Adults deserve our respect and they deserve to continue to have quality care. Please do not let our government succumb to the prejudice of ageism. All people have value especially the old--who have much to still teach us.

Cathy Knowlton
Human Service Center
Red Bud, IL

ATTACHMENT: senior issue brochure.doc

Available as separate links:	
Offering Quality Care to our Seniors Brochure	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach94.pdf

DATE: March 23, 2012
SUBJECT: Mental Health Needs of People with Dementia and their Caregivers

I work with many clients with dementia and their caregivers. I am also a caregiver of a parent, my Father, with Lewy Body Dementia. I see first- hand the mental health issues that occur with dementia. My Masters' degree is in Health Sciences and I still get overwhelmed at times with things that my father experience. Please do not take this lightly, address the mental health needs of people with dementia and their caregivers in your final plan. Thank you.

Cheryl Davis, MHS, CIRS-A
Program Services Director
Lifescape Community Services, Inc.
Rockford, IL

DATE: March 23, 2012
SUBJECT: Re: Final Plan Comments

Michael,

Great letter. Send it.

==========

From: Michael Gardner
Sent: Fri, Mar 23, 2012 17:06:38 GMT+00:00
Subject: Final Plan Comments

Please see attached document, thanks.

Michael J. Gardner, MS Ed, CHES
Associate Mental Health Specialist
California Mental Health Planning Council
Sacramento, CA

THIS MESSAGE WAS SUBMITTED BY THE FOLLOWING PEOPLE DURING THE MONTH OF MARCH 2012:

- John Ryan (submitted March 23)
- Cynthia Jackson Kelartinian, PhD, Executive Director, Heritage Clinic, Pasadena, CA, http://www.heritageclinic.org (submitted March 23)
- Adrienne Cedro-Hament (submitted March 23)
- Carmen Lee (submitted March 23)

DATE: March 23, 2012
SUBJECT: Final Plan Comments

Please see attached document, thanks.

Michael J. Gardner, MS Ed, CHES
Associate Mental Health Specialist
California Mental Health Planning Council
Sacramento, CA

ATTACHMENT: 1.doc

Available as separate links:	
Comments from the California Mental Health Planning Council	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach93.pdf

DATE: March 23, 2012
SUBJECT: Include Support for MH for older patients

I understand that the present draft legislation in HHS needs to further address the MH needs of people with dementia and their care givers.

Dementia can frequently co-occur with mental conditions such as depression and anxiety disorders. Additionally family care givers carry an increased risk for mental and physical health problems. Please consider including these aspects of care for those with dementia in the current legislation.

Sincerely,

Judith Slane LCSW

DATE: March 23, 2012
SUBJECT: Alzheimer’s Disease

Please address the mental health issues to go along with Alzheimer’s Disease. My mother-in-law currently has this disease and suffers from depression and anxiety due to the frustrations that she feels in not remembering things. It is only getting worse as the disease progresses. This is a common issue. Currently she is in a skilled nursing facility because her husband passed away several years ago. He had been her caretaker. This disease takes a great toll on anyone who keeps their loved ones in their home, because constant vigilance is needed on a regular basis. This isolates the caregiver as well as the one suffering from Alzheimer’s. This can lead to depression for the caregiver. Please address the mental health aspects that accompany this disease in developing your plan regarding Alzheimer’s.

Sincerely yours,

Mary Rich
CASA Program Manager
CASA of Dutchess County
Mental Health America of Dutchess County, Inc.
Poughkeepsie, NY

DATE: March 23, 2012
SUBJECT: Personal comments on the draft National Alzheimer's Plan

Yesterday I sent you a letter regarding the draft National Alzheimer's Plan from a group of national experts on dementia and behavioral health.

Today I am sending a personal letter that is much more detailed. In it I provide comments and suggestions section by section. I hope that you will find it useful in identifying parts of the plan that need to be modified so as to reflect the behavioral health needs and opportunities of people with dementia and their families.

I would be happy to help to redraft the plan in detail.

Thank you.

Michael B. Friedman, MSW
Founder and Honorary Chair
The Geriatric Mental Health Alliance
Adjunct Associate Professor
Columbia University School of Social Work and School of Public Health
http://mf395@columbia.edu

ATTACHMENT: MBF NAP Letter final.doc

Available as separate links:	
Comments on the Draft National Alzheimer's Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach92.pdf

DATE: March 22, 2012
SUBJECT: Draft National Plan

Thank you for your efforts to develop a national plan to address the growing crisis of Alzheimer's Disease. As an elder law attorney who has worked for many years with low income caregiving families in diverse ethnic communities, I understand the urgency of your work. I applaud your efforts to be both comprehensive and realistic in the development of this plan. My own work with Alzheimer's families began through a program called El Portal -- a Latino Alzheimer's project that was funded through the Alzheimer's Disease Supportive Services Program (ADSSP), once called the Alzheimer's Federal-State Matching Grant Program. Later I worked with Asian caregivers through another ADSSP-funded program, the API Dementia Care Network. Like many other elder care professionals in this community, this grant brought me into the Alzheimer's cause where I have worked for over 20 years.

As I look over the plan, I am concerned that I do not see any reference to this program. I believe it is the only federally-funded program that uniquely targets dementia patients and their families with support and education services. Specifically, this is a program that could help to fund the part of the plan devoted to populations disproportionately affected by AD and populations facing care challenges, such as racial and ethnic minorities (Strategy 2H). It could also be referenced in section 2.C.2 as it definitely enhances assistance to people with AD and their caregivers. This program supports and educates people with the disease and caregivers, a significant concern addressed in the plan.

I have heard that there is a possibility that funding for the worthy program may be eliminated and that it has already been reduced. I urge you to use the NAPA planning process to assure that this program remains in place and continues to help develop services for under-served, at-risk populations. It may not be a perfect program but it is the ONLY federal program supporting this work for patients with AD and their families.

Thank you for attending to my feedback. I hope it will strengthen our plan to prepare for the public health crisis that is Alzheimer's Disease.

Sincerely,

Janet Morris, JD
Elder Law Attorney
Bet Tzedek Legal Services
Los Angeles, CA
http://www.bettzedek.org

DATE: March 22, 2012
SUBJECT: dementia and older people

As the baby boomers age we need to address the issues that will arise when some of them will suffer from dementia. Please include that in your bill.

Thanks,

Dr. Batya Lerner

DATE: March 22, 2012
SUBJECT: Alzheimers Draft

As you revise your policy on Alzheimer's it should also address Dementia which is the onset of this disease. Its inhumane to address one without including this illness.

Thank-you,

Monica D. Haynes,MSW

DATE: March 22, 2012
SUBJECT: Mental Health needs more attention

Please give more attention to mental health of patients with depression and other problems. There are problems that our elderly have and their family that can be helped with education, direction and other resources that the mental health has available. I am a RN and have seen the work the Mental Health Dept. is capable of giving. So please fund the necessary areas with necessary staff and information.

Dorothy Cassel
El Reno, OK

DATE: March 22, 2012
SUBJECT: plan to address Alzheimer’s disease

I applaud your efforts to address such a significant issue as Alzheimer's Disease. I am a licensed social worker who provides services to older adults in Westchester County full-time. Unfortunately, I am highly concerned about the lack of support for those individuals with Dementia and other co-occurring disorders to increase as more baby boomers turn 65.

Please consider revising your ambitious draft plan to incorporate those in need of assistance due to Dementia and other co-occurring disorders.

Best regards,

Tonia Monti

DATE: March 22, 2012
SUBJECT: Please do not forget mental health needs of those with dementia

This is my professional world, and the co-morbidity of depression, anxiety, delusional disorders, etc. runs high with dementia. Please do not ignore the needs of this sadly ever growing population.

Arleen R. Stern, LCSW, C-ASWCM
Geriatric Care Manager
Geriatric Care Management
New York,NY
http://www.arleenstern.com

DATE: March 22, 2012
SUBJECT: Comments on the Alzheimer's Draft Plan - From National Task Group on ID/DP

We, Drs. Matthew P. Janicki and Seth M. Keller, are the co-chairs of the National Task Group on Intellectual Disabilities and Dementia Practices. On behalf of the National Task Group, we wish to make our thoughts and recommendations available to the Advisory Council with respect to the Draft National Plan to Address Alzheimer's Disease. To complement the National Alzheimer's Plan Act process, the National Task Group was convened and produced a report titled, "***My Thinker's Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports***", which was designed, in part, to develop and enhance community care options for aging adults with intellectual and developmental disabilities. The National Task Group also issued the "***National Dementia and Intellectual Disabilities Action Plan***" as part of this report. The National Task Group issued this Action Plan in January 2012 in the hopes that it would promote better understanding of how adults with intellectual and developmental disabilities age and how dementia, in particular, affects them.

We note that the issues we identified in the National Task Group's report, which was submitted to the Advisory Council at its January 17th meeting, has many parallels with those raised in the Draft Plan. Our report summarized and addressed some of the challenges facing the nation due to the increasing rate of dementia found in older people with Down syndrome and other intellectual disabilities. Our report also noted that older adults with intellectual and developmental disabilities have special needs that at times require different actions than those provided for people in the general population. Alzheimer's disease affects everyone; but not everyone can be treated the same way when they are affected by this disease.

We have submitted these comments in order to clarify and provide feedback to the Advisory Council regarding its Draft Plan. First, we would like to note that the National Task Group is pleased that the Draft Plan contains mention of intellectual disabilities (in Strategy 2.H) as this group of Americans is composed of a significant number of individuals who are at exceptionally high risk for Alzheimer's disease. We also would like the Draft Plan to contain at least mention of some general issues that we have raised in our Report and also have more elaboration on some key specific issues affecting people with intellectual disabilities.

Given this, we'd like to offer the following comments:

1. **Missing mention of the significance of Down syndrome in Alzheimer's research**

   We are concerned that the text under Goal 1, neglects mention of the research with respect to the needs of people with Down syndrome, a group of individuals expressing a particular high risk for Alzheimer's disease. Certainly sustained research is warranted to better understand the etiology and course of dementia in this group of individuals. Additionally, notwithstanding the competing beliefs of whether research involving people with Down syndrome will benefit general research into the nature and cause of Alzheimer's disease, we feel that continued support of research concerning and involving people with Down syndrome will not only potentially benefit the general population, but will certainly benefit the thousands of adults aging with Down syndrome and who are at high risk for and are affected by early onset dementia. Like individuals with genetic mutations resulting in early onset Alzheimer's disease, individuals with Down syndrome also demonstrate early onset of symptoms and more research into this phenomenon is necessary. We would like to emphasize that focused research into a relatively homogeneous population such as individuals with Down syndrome and Alzheimer’s dementia can provide important clues when generalizing to the larger population of people with Alzheimer’s but absent Down syndrome.

Thus, we strongly recommend that the Draft Plan include mention that given the high risk of Alzheimer's disease among adults with Down syndrome, there is the continued need for focused basic and treatment research involving people with Down syndrome -- and this should be included under Goal 1.

2. Mention of the special programmatic and care challenges faced by people with intellectual disabilities

We note with satisfaction that the Advisory Council’s Draft Plan recognized the importance of the special programmatic and care challenges faced by people with intellectual disabilities and included mention of this in Goal 2, under Strategy 2.H (Action 2.H.1). However, we would like to recommend that mention of the special circumstances of adults with Down syndrome and other intellectual disabilities receive mention earlier in this section, so that it is clear that the Strategies included under Goal 2 apply equally to this population. We would like to see the Draft Plan recognize that Alzheimer's disease mostly impacts adults with lifelong intellectual disabilities in the same ways as it does other people, but sometimes has a more profound effect due to particular risk factors - including genetics, neurological injury, and deprivation. Further, under the Strategies noted under Goal 2, it is important to propose that any NAPA-related task forces created (as cited in the Draft Plan) not only look into improvements of care for this specific population, but also, and perhaps more importantly, increase awareness, improve screening and early recognition, and conduct population specific clinical trials involving adults with intellectual disabilities.

Thus, we strongly recommend that the Draft Plan include mention of the special circumstances of adults with Down syndrome and other intellectual disabilities earlier in the second section, so that it is clear that the Strategies included under Goal 2 apply equally to this population.

Under Strategy 2.B, we would also like to recommend that mention be made of the challenges of carrying out effective screening and diagnoses for dementia among most individuals with intellectual disabilities due to their inherently varying abilities and cognitive functions. When nationally applicable instrumentation is developed or recommended it would be highly beneficial to make mention in the Draft Plan of the need for specialized screening instruments for use with adults with intellectual disabilities. The National Task Group is currently undertaking the development of such an administrative screen, which would have specific application to people with intellectual disabilities who otherwise may not be adequately or successfully screened by tools in existence and applicable to the general population. Recognition of this special need and work by the National Task Group would go far to gain acceptance of a regularized screen applicable to adults with intellectual disabilities.

We also would recommend -- adding text under Strategy 2.E -- that the notion that community care, as noted in the 2002 Madrid International Plan of Action on Ageing, be the paramount means of long-term ‘dementia capable’ care delivery. We note specifically the growing evidence-based research that is supporting the inclusion of small group homes -- as a viable assisted living model -- and their role as a potentially powerful alternative care setting for people with dementia, and in particular those with lifelong disabilities. Research in the intellectual disabilities services area has shown this model to be particularly effective in providing quality care for those adults with intellectual disabilities affected by dementia.

Thus, we strongly recommend that the Draft Plan include consideration of the special challenges in assessing and determining the presence of dementia in adults with certain intellectual disabilities and that any national guidelines produced contain this consideration.

We also strongly recommend the consideration of the use of small group homes for the community 'dementia capable' care of adults with intellectual disabilities affected by dementia as backed by evidence-based research in the intellectual disabilities field.

3. Mention of the special support needs of aging caregivers providing long-term in-home care of adults with intellectual disabilities

As many adults with intellectual disabilities and in particular those with Down syndrome remain in their family homes living with their parents or other family caregivers as they grow older, it is crucial that under Goal 3 inclusion of the challenges faced by these caregivers -- when providing care-at-home to their relatives with intellectual disabilities and dementia -- be given due mention. These 'life-long caregivers' warrant special attention in the Draft Plan as they are providing an important and crucial bulwark against costly institutionalization and oft-times inappropriate admissions to long-term care facilities. They are also often vexed by emerging symptoms of dementia in their adult children who have successfully mastered many general activities of daily living and now are manifesting decline. Special mention to the situations of these lifelong caregivers should be made in the Draft Plan. In this context, the National Task Group also recommends that Strategy 3.C.1. be amended to recognize that in many settings concerned with adults with intellectual disabilities, decisions are often made by proxy (and not by 'middle-aged adults') and that adults with intellectual disabilities are not the ones planning for their own long-term care needs. Thus, consideration should be given to enabling parents or other family members, providing primary care, to undertake productive long-term care planning.

Thus, we strongly recommend that the Draft Plan include consideration of the special challenges faced by life-long caregivers of some persons with intellectual disabilities.

4. Mention of the enhanced public education resources related to intellectual disabilities

Under Goal 4, we strongly recommend including the needs of family caregivers and people with intellectual disabilities under public education campaigns and that the greater coordination efforts by government and the voluntary sector should get mention. As the state developmental disabilities authorities (agencies) are instrumental in helping organize state functions and programs with respect to intellectual and developmental disabilities it would be extremely beneficial to include these entities (and state developmental disabilities planning councils) in any public education efforts at the state level. Also, education and training for health professions with respect to aging individuals with dementia -- especially of the Alzheimer's type -- should be included as part of primary health care education. As there are health care disparities, an aggressive education campaign should involve universities, hospitals, emergency rooms and general medical specialists as it relates to cognitive and functional disability and its detrimental effect on caregivers and quality of life of the individuals with intellectual and developmental disabilities.

Thus, we strongly recommend that the Draft Plan include consideration of additional and targeted efforts related to public and medical education so that these efforts have a functional effect on helping people with intellectual disabilities affected by dementia.

The National Task Group recognizes that dementia has a devastating impact on all people -- including people with an intellectual disability and their friends, families and the staff who may be involved with them as advocates and caregivers. Given this, we are very pleased that the Advisory Council recognized the import of the special challenges faced by people with intellectual disabilities and included mention of this group in Strategy 2.H. We would hope for those adults with intellectual disabilities currently affected by dementia and those in the next generation who may be affected (as the timeline for the NAPA process encompasses the next 13 years) that the Advisory Council will recognize other areas of inclusion of the specific issues affecting individuals with intellectual disabilities within the Draft Plan and accept our recommendations for additional areas of mention and focus.

We trust the our comments and recommendations will be accepted in the spirit in which they are provided -- as the collective concerns and thoughts of a significant body of professionals, scientists, administrators, family caregivers and advocates, and persons personally affected by dementia -- who are represented by the National Task Group on Intellectual Disabilities and Dementia Practices.

Seth M. Keller, MD
President, American Academy of Developmental Medicine and Dentistry

Matthew P. Janicki, Ph.D.
University of Illinois at Chicago
(RRTC on Aging with Developmental Disabilities -- Lifespan Health and Function)

Co-Chairs
National Task Group on Intellectual Disabilities and Dementia Practices
http://www.aadmd.org/ntg

ATTACHMENT: NTG_comments-on_DRAFT_PLAN-3'22'12.pdf

Available as separate links:	
Draft National Plan to Address Alzheimer's Disease Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach91.pdf

DATE: March 22, 2012
SUBJECT: Mental Health Needs of Individuals with Dementia and their Caregivers

Dementia frequently co-occurs with mental health conditions such as depression and anxiety disorders. In addition, family caregivers are at high risk for mental and physical health problems. Recognizing and treating these conditions plays a vital role in improving patients' cognitive functioning as well as the quality of life of people with dementia and their caregivers.

Please provide access to mental health treatment for people with dementia and their caregivers in your final HHS Alzheimer’s Plan.

Kay Smith, JD LCSW

DATE: March 22, 2012
SUBJECT: Alzheimer’s Plan

I'd like to commend the Department of Health & Human Services for developing an ambitious plan to address Alzheimer's Disease.

I would add, however, some concern about its apparent overemphasis on biology and pharmacology. Based on my own clinicial experience, chats with colleagues, and reading of the related literature, I can confidently state this focus is necessary but not sufficient. The mental health (i.e., depression & anxiety) of patients and unpaid caregivers alike is inextricably linked to this disease and its treatment. Should these psychological components remain unaddressed, the costs (financial & human) will continue to mount. Conversely, adequate support can reduce this burden, both at the individual and societal levels.

Experts estimate it will take decades before "cures" for Alzheimer's are discovered, let alone made available (and affordable) broadly. While this remains an appropriate aspirational goal, behavioral treatment of the millions currently afflicted, and support for those trying to care for them, must not be sacrificed.

Thank you.

Benjamin A. Bensadon, Ed.M., Ph.D.
Postdoctoral Clinical Research Fellow
The University of Oklahoma Health Sciences Center
Reynolds Department of Geriatric Medicine
OU College of Medicine & OKC VAMC
Oklahoma City, OK

DATE: March 22, 2012
SUBJECT: NAPA ADSSP - BT (2)

Please see the attached.

Thank you.

Terese Bledsoe
Legal Secretary
Los Angeles, CA

ATTACHMENT: NAPA ADSSP - BT (2).pdf

Available as separate links:	
Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach90.pdf

DATE: March 22, 2012
SUBJECT: The Geriatric Mental Health Alliance of New York

Please include the impact Dementia has on caregivers. My father has Dementia and my mom's health has taken a turn for the worst. She has been to the hospital (medical) for heart problems because of the stress of taking care of my father. It is essential that you include in the draft plan attention to mental disorders commonly experienced by people with Dementia and their caregivers.

Karen Bachand, M.A.

DATE: March 22, 2012
SUBJECT: Please include provision for mental health needs of Dementia patients and their families

As a Social Worker addressing the needs of seniors with mental health issues, I see how overwhelming the diagnosis of Dementia can be for patients and the people who care for them.

Many people are in denial over the diagnosis and its consequences, and who can blame them?

There is no cure at this time, and more and more support services have been limited.

Please provide for the mental health needs of patients and their families, as the following are increasingly evident:

Dementia frequently co-occurs with mental health conditions such as depression and anxiety disorders. In addition, family caregivers are at high risk for mental and physical health problems.

Recognizing and treating these conditions plays a vital role in improving patients' cognitive functioning as well as the quality of life of people with dementia and their caregivers.

Thank you for your consideration,

Charles Anflick, LMSW
VillageCare Neighborhood NORC & Gatekeeper Program Coordinator
New York, NY

DATE: March 22, 2012
SUBJECT: Mental health needs of people with Dementia and their caregivers

Please consider the best treatment practices for people and caregivers who are struggling daily with this illness. It's becoming one of the greatest mental health challenge we must face in the future. A comprehensive approach must be considered in the treatment practices as the myriad of this illness will eventually affect us all in some way or another. The co- occurring mental conditions that are experienced by both the patients and caregivers need to be taken seriously as it greatly affect their quality of life. It is our duty as professionals to ensure that the best is offered at all times to others who rely on our expertise/training. Thank you.

Phillip Whittingham
Psychologist II
Kingsboro Psychiatric Center
Brooklyn, NY

DATE: March 22, 2012
SUBJECT: mental health needs of individuals with Alzheimers and other dementias

I am very heartened to learn that the federal government released a draft of a comprehensive plan to address Alzheimer's disease. I do want to voice my fervent hope that adequate attention is paid to the mental disorders commonly experienced by people with dementia and their caregivers in the government's plan.

I worked as a psychiatric social worker for 17 years on a locked inpatient hospital geriatric unit, where the predominant diagnoses were Alzheimers or Dementia with agitation, depression, delusions and/or hallucinations. I witnessed the range and severity of symptoms that caused elderly people with dementia to neglect themselves, to become violent, refuse help offered to them even by their own loving children, to become paranoid toward loving family members, and the devastating effects this had on families. Without access to mental health treatment provided by knowledgeable geriatric psychiatrists and other practitioners, these individuals suffering from dementia would remain in agony and distress, harmful to themselves and others.

I applaud our government for addressing Alzheimers disease and urge you to carefully consider the mental health needs of this population in planning for the future.

Sincerely,

Carol Ban, LCSW
Director of NORC Programs and Isabella Senior Resource Center
Isabella Geriatric Center
New York, NY

DATE: March 22, 2012
SUBJECT: ADDRESS MENTAL HEALTH ISSUES OF PEOPLE WITH DEMENTIA, AS WELL AS THEIR CAREGIVERS

Lydia Schwartz

DATE: March 22, 2012
SUBJECT: a mental health component

As you draw up plans to address the needs of the growing population of people with Alzheimers Disease and dimentia I ask that you would consider the *mental* health needs of both the caregivers and the patients.

My mother-in-law has been declining as a result of alzheimers, and as one of a many family member team that takes shifts caring for her I know how rough it is to maintain a positive attitude and stamina as her condition declines from one plateau to another.

If you are developing a *comprehensive* plan, I would think it would be critical to recognize the challenges of mental health and well-being as part of that overall picture, and include steps in your plan to support a mentally healthy population.

Please do not under estimate this critical aspect. The mental attitude of both the patient and the caregiver(s) can make an enormous difference in whether the patient is happy and the caregiver is attentive and loving.

Thank you for taking the time to read this and consider this aspect. People can be old and *well*.

Kathleen H. Cook

DATE: March 22, 2012
SUBJECT: mental health care for people with dementia and their families

The federal government has released a draft ambitious plan to address Alzheimer's disease.

Unfortunately, the draft plan does not provide adequate attention to mental disorders commonly experienced by people with dementia and their caregivers.

Dementia frequently co-occurs with mental health conditions such as depression and anxiety disorders. In addition, family caregivers are at high risk for mental and physical health problems. Recognizing and treating these conditions plays a vital role in improving patients' cognitive functioning as well as the quality of life of people with dementia and their caregivers.

Please address the mental health needs of people with dementia and their caregivers in the final plan.

Linda K.P. Mertz, MSW, LCSWR
Project Coordinator
Internships in Aging Project
School of Social Welfare
UAlbany
Albany, NY

DATE: March 22, 2012
SUBJECT: National Alzheimer's Plan response

I was pleased to be able to respond the the NAPA draft plan as part of the group gathered by SAMHSA in December of 2011. I support all of the comments gathered by the group and sent to you my Michael Freeman.

I also ask you to consider the additional comments that I've included in my letter, based on my 25 years experience in developing, implementing, researching and administering programs for persons with dementia.

Thank You,

Beth Meyer-Arnold
Director, Adult Day Services
Luther Manor
Wauwatosa, WI
http://www.LutherManor.org

ATTACHMENT: letter of comment for NAPA to Helen Lamont.doc

Available as separate links:	
Comments on the Draft National Alzheimer's Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach89.pdf

DATE: March 22, 2012
SUBJECT: Alzheimer’s Plan

I would like to submit a few comments regarding the Draft National Plan to Address Alzheimer's Disease. First, NAPA is a wonderful thing and long overdue. Second, thanks to the drafters who clearly state on page 3 that "Alzheimer's disease" as used also includes related dementias. My husband has Dementia with Lewy Bodies (DLB), and when someone refers to Alzheimer's, I am always the little voice that chimes in with, "...and don't forget the related dementias."

I hope that when the "experts" meet to discuss and forge the plans, they will include ideas from caregivers in the process. I've learned a tremendous amount from my experience with my husband's illness over the last several years, and believe I could provide valuable input about what it's like in the trenches.

A few items that I would like to specifically comment on:

page 4, a note that AD patients are hospitalized 2-3 times more than others: Often they are sent to the hospital and shouldn't be. The ER is a terrifying experience for them, and sometimes they are just exhibiting symptoms of their illness and don't even need the repeated MRIs, CT scans, and other tests that come back negative every time.

Throughout the document, references are made to provider education and outreach in various settings. This is my personal goal, as I have found that hospital and other staff, unless specifically trained in dementia diseases, are pretty much clueless as to caring for AD patients. One nurse in an excellent hospital in Las Vegas even told me, after caring for my husband as an inpatient, that he was "very confused." Really?

page 21, Goal 3: What does this mean? I hope the needs of caregivers will be addressed by talking to actual caregivers, and not just health care professionals who don't live this disease on a daily basis. (Also, what are "informatics?")

page 23-24, money issues: Why don't we have long-term care? For the middle class (us), it was not affordable at the time, and now it's impossible. More needs to be done to bring costs down for AD patients - they usually don't need skilled nursing care, just compassionate assistance. Also mentioned on page 25, housing options - I would be interested in participating in this discussion.

page 24, Strategy 3D: I agree that this is very important. However, I have found that sometimes the pendulum swings too far the other way, and I as a long-term spouse am viewed with suspicion. This is another goal of mine - to get government agencies and institutions at all levels to understand the difference between a person caring for their long-term spouse and someone who would exploit or abuse the AD patient.

page 26, Goal 4: Yes, we need to educate the public! But sometimes educational programs and materials are written or presented in a manner that the general public cannot understand. Short and simple is best!

page 28, Goal 5: Data is important - is there a way to also include anecdotal evidence?

Thank you for receiving comments. I guess I could summarize my thoughts by asking that the compilation of the Plan include input from real people who are experiencing the terrors of this disease each day.

Warmest regards,

Gloria Burkhart
Mesquite, NV

DATE: March 21, 2012
SUBJECT: FW: Finished Piece

Just wanted to pass along the finished article and video that was produced:
http://www.foxnews.com/health/2012/03/21/alzheimers-at-39/

Please make sure to add it to twitter, face book and your web pages.

Thanks

Michael Ellenbogen

DATE: March 20, 2012
SUBJECT: National Alzheimer's Plan

Thank you for your time in considering this document.

Regards,

Melissa Ramirez
Deputy Director
Mental Health Association in New York State
Albany, NY

ATTACHMENT: POL_20120320_Ltr2DrLamont.pdf

Available as separate links:	
Mental Health Association in New York State Response to the Draft National Alzheimer's Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach88.pdf

DATE: March 20, 2012
SUBJECT: Re: Commend and thank Bruce Lamb

I would like to thank Mr. Ellenbogen for his supportive remarks regarding my comments on the National Plan to fight Alzheimer's disease. I hope that HHS and the Secretary will consider these comments as they revise the Plan. We are truly at a unique stage in our fight against Alzheimer's that will have implications for years to come. Developing an Office that is singly focused on coordinating and organizing efforts to fight Alzheimer's disease as well as to provide feedback to HHS and the Advisory Council as well as Congress is essential as we move forward. While there is certainly the possibility that this may step on toes within HHS and/or the NIH, it is something we literally cannot afford to do if we are serious in our efforts to fight Alzheimer's disease. Indeed, developing this infrastructure at the beginning of the Plan rather than years later will likely save money and lives into the future.

Thanks for your consideration.

Sincerely,
Bruce Lamb

==========

On Mar 17, 2012, at 11:24 AM, "Michael Ellenbogen" wrote:

> I would like to commend and thank Bruce Lamb, who is an Alzheimer's researcher and Staff Scientist at Department of Neuroscience, in the Lerner Research Institute at the Cleveland Clinic. He shared his view points on January 13, 2012, under the SUBJECT: Draft Framework for the National Plan to Address Alzheimer's Disease, in the public forum.
>
> I found his view point’s very interesting and highly recommend reading if you have not already done so. He also had an attachment that was titled, Right sizing funding for Alzheimer’s disease, which was written by Todd E Golde, Bruce T Lamb, and Douglas Galasko and published May 6, 2011.
>
> http://aspe.hhs.gov/daltcp/napa/Comments/cmtach27.pdf
>
> I really like these paragraphs, which I extracted for your reading.
>
> If one assumes that funding for HIV/AIDS was right sized to enable translation of basic discoveries to successful therapies, then given the lack of effective AD therapies, one possible implication is that funding for AD has been insufficient. A quick comparison of funding levels for HIV/AIDs relative to AD in the United States suggests this may be at least one factor that has hindered the translation of AD discovery to effective therapies. Based on publicly available data, National Institute of Health funding for HIV/AIDS in the United States is currently approximately $3 billion [5]. With approximately 1 million HIV-positive subjects in the United States, this equates to $3,000 of NIH funding per person with HIV/AIDs. In contrast, current NIH funding for AD is at a level of approximately $450 million [5], with perhaps another approximately $100 million to $200 million in NIH funding that might have some relevance to the study of AD (cognitive decline in aging, related neuro degenerative conditions). With a current prevalence of approximately 5 million individuals affected with AD in the United States, this equates to a maximum of

$130 of NIH funding per person affected with the disease. So, on a per affected individual basis, NIH funding for HIV/AIDs is 23 times the level of that for AD.

Of course, there are many different ways to evaluate proportional or relative funding. Another one that is quite germane is economic impact. For AD in the United States this is estimated at more than $170 billion per year (and worldwide at $600 billion per year) [6]. Again focusing only on the United States, the yearly funding for research by the NIH represents 0.4% of the yearly costs of the disease in the United States. In other words, for every $2 the disease costs the United States, we spend less than 1 cent on research.

There are many people who believe in reinventing the wheel when undertaking a new project or endeavor. I have always been a firm believer that the people before us have laid the framework need to get started so we are not wasting a lot of time on the basics. The only approach I always followed along with that is, to delete, enhance and critique to make the plan even better. I always did that by asking the previous plan makers what they realized they did wrong and what would they do different. Ninety percent of that frame work would usually come from the best of many minds. I really believe the input and suggestion made by Bruce Lamb, be discussed when building this framework.

One thing that keeps coming to mind is the disparity issue related to AD. Am I the only one that sees this, or do we all just not want to talk about it. For example AD was first identified and named in 1906, while AIDS was identified in 1981. I see us now in the same stages as HIV was in 1988, when a focused effort was begun towards treatment or cure, with the creation of The Office of AIDS Research. It took an additional 5 years to strengthen this OAR (The NIH Revitalization Act), which really made a huge difference. Within three years of that day and by 1996 we started to finally have an impact on AIDS.

Let’s not make a similar mistake as we did with HIV. Let’s create a diseased focused agency for AD, with all the necessary strength, as of day one. Just think you can make up for the disparity that has been created and just maybe we could have a cure in less than 5 years.

Let me leave you with one last thought that I have not heard or seen anywhere. I think the government should offer a large sum of money to anyone who can come up with the cure for this disease first. While I am not sure what that amount should be it can be in cash and partial tax credits. I think that will drive many more into this arena and more efforts if the pie is big enough. Just think of all the savings insurance companies can benefit, not to mention the government. They may all be willing to help in that funding. Just a though. Sometimes you have to be creative and think outside the box.

Thanks

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

DATE: March 19, 2012
SUBJECT: Comments on NAPA agenda

I have reviewed the scientific agenda for the National Initiative on Alzheimer's Disease.

Perhaps there is another document of which I am unaware.

However if this is the gist of the national plan then I would submit with urgency that there are enormous gaps in the plan.

As a Geriatric Neurologist who specializes in diagnosing and managing patients with dementia and caring for their families I see no where in the plan for a mechanism to increase clinical providers.

There is a national urgency to recruit and keep clinicians who care for people with dementia. Currently, I am one of very few providers in my town of nearly 1million people who will see patients with dementia. I have been told that I spend too much time with them, so I would have to pay the clinic to see these patients.

I WOULD HAVE TO PAY!

I have since spoken with many other providers who have told me that they cannot afford to see these patients.

The Neurology residents at our medical school no longer rotate through our dementia clinics, since they have no intention of taking these patients.

I am constantly asked by the public where to turn for dementia providers. I am at a loss. I have asked Alzheimer's Association representatives for recommendations and they just shake their heads and say they cannot find providers either.

If we are to take important research findings and bring them to the public, we desperately need the providers to be there to deliver this care.

This will require a major shift away from current payment plans that value procedures over time spent with patients.

Please do not neglect this critical area in your plan.

If I can be of further assistance in this, don't hesitate to let me know.

Thanks

Germaine Odenheimer, MD
Geriatric Neurologist
Geriatric Medicine Clerkship Director
Donald W Reynolds Department of Geriatric Medicine
Associate Professor
University of Oklahoma College of Medicine

DATE: March 19, 2012
SUBJECT: ALZHEIMERS comments

I am the primary caregiver for my mom and this disease has shattered our family,

I had a bad experience with a Nursing Home and took my mom home (which was about about 8 months ago); took time off from work...and since she has almost returned to pre-nursing home "state".

But our family needs more help...it's been a stain physically and mentally..and financially; but I am doing all I can as my mom did for my brother and I growing up..

But this disease is like murder, and we need a cure.

Hope all avenues are being taken..
Thank You,

Rich Berte
Marlborough MA

DATE: March 19, 2012
SUBJECT: National Alzheimer's Plan Comments

I am a co-author and now facilitator for our state plan, Conquering the Specter of Alzheimer's Disease in South Carolina, which was presented to the State Legislature on March 1, 2009. Needless to say, I have a keen interest in a national strategy to fight this disease. One of the recommendations that came out of South Carolina's task force was the involvement of the work force in supporting and assisting caregivers. Following is one of the recommendations in our plan regarding employers enabling caregivers to remain in the work force. This seems to coincide with the priorities of the national plan and represents an area not specifically addressed through the draft plan.

Recommendation 20. Promote and support private and public sector businesses in addressing the needs of employees who are caregivers to persons with ADRD through the use of on-site respite, support groups, or other initiatives.

Rationale: Seventy percent of people with ADRD are living at home, most of whom receive unpaid help from family members[i]. One study of family and other unpaid caregivers of people with ADRD found that 57% were employed full time or part time. Of those who were employed, two-thirds said they had to go in late, leave early or take time off because of caregiving; 18% had to take a leave of absence; 13% had reduced their hours; and 8% had turned down promotions[ii]. Eight percent of caregivers in the study had quit work entirely because of caregiving. Another study of family and other unpaid caregivers of more than 2,000 older people found that caregivers of people who had Alzheimer's or other dementias without behavioral symptoms were 31% more likely than caregivers of other older people to have reduced their hours or quit work[iii]. Caregivers of people who had Alzheimer's or other dementias with behavioral symptoms were 68% more likely than caregivers of other older people to have reduced their hours or quit work[iv].

Responsible Party: SC Alzheimer's Association, SC Chamber of Commerce, SC Better Business Bureaus, SC Technical College System, SC Manufacturers Association

References

i. 2008 Alzheimer's Disease Facts and Figures, Alzheimer's Association, p. 24.
ii. *Families Care: Alzheimer's Caregiving in the United States*. Alzheimer's Association and National Alliance for Caregiving, 2004, Accessible at http://www.alz.org).
iii. Covinsky, KI; Eng, C; Liu, L-Y; Sands, LP; Sehgal, AR; Walter, LC; et al. Reduced Employment in Caregivers of Frail Elders: Impact of Ethnicity, Patient Clinical Characteristics, and Caregiver Characteristics. Journal of Gerontology: Medical Sciences 2001; 56A (11): M707-713.
iv. 2008 Alzheimer's Disease Facts and Figures, Alzheimer's Association, p. 18.

Thank you for your time and consideration.

Sincerely,

Anne Wolf
Assistant Deputy Director of Aging Services
Lt. Governor's Office on Aging

DATE: March 18, 2012
SUBJECT: comments on national Alzheimer’s plan

I am an Occupational Therapist and specialize in Dementia Care. I have reviewed th National Alzheimer's plan and find the outline to be refreshingly comprehensive. As you and HHS move forward on the plan, please consider the important role of occuaptional therapy and the importance of providing services within a Psychosocial model and NOT a medical model.

I suggest the following beneftis for American seniors, as paid for without raising the debt.

1. Allow for medicare to reimburse for Outpatient education and training services provided to the caregiver of someone with dementia. This training must be to meet a skilled need and can be provided within context of a small group session (2-3 caregivers). For example, as an OT, I could provide training to 3 caregivers in the bathing of patients in the moderate stages of dementia. This would be an efficient use of resources and time. Medicare must accept the fact that dementia care involves treating the dyad (patient+caregiver), not just the patient.

2. Allow for coordination of services between organizations without barriers of HIPPA (I would need to call a social worker or case manager at a hospital and freely discuss a patient's case).

3. Identify Occupational Therapy as a critically needed and stand alone provider of services to dementia patients and their caregivers.

Thank you for your attention.

Thomas R. Holmes, OTR, MA, QDCS
Tyler, TX

DATE: March 17, 2012
SUBJECT: Commend and thank Bruce Lamb

I would like to commend and thank Bruce Lamb, who is an Alzheimer's researcher and Staff Scientist at Department of Neuroscience, in the Lerner Research Institute at the Cleveland Clinic. He shared his view points on January 13, 2012, under the SUBJECT: Draft Framework for the National Plan to Address Alzheimer's Disease, in the public forum.

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http://aspe.hhs.gov/daltcp/napa/Comments/cmtach27.pdf

I really like these paragraphs, which I extracted for your reading.

If one assumes that funding for HIV/AIDS was right sized to enable translation of basic discoveries to successful therapies, then given the lack of effective AD therapies, one possible implication is that funding for AD has been insufficient. A quick comparison of funding levels for HIV/AIDs relative to AD in the United States suggests this may be at least one factor that has hindered the translation of AD discovery to effective therapies. Based on publicly available data, National Institute of Health funding for HIV/AIDS in the United States is currently approximately $3 billion [5]. With approximately 1 million HIV-positive subjects in the United States, this equates to $3,000 of NIH funding per person with HIV/AIDs. In contrast, current NIH funding for AD is at a level of approximately $450 million [5], with perhaps another approximately $100 million to $200 million in NIH funding that might have some relevance to the study of AD (cognitive decline in aging, related neuro degenerative conditions). With a current prevalence of approximately 5 million individuals affected with AD in the United States, this equates to a maximum of $130 of NIH funding per person affected with the disease. So, on a per affected individual basis, NIH funding for HIV/AIDs is 23 times the level of that for AD.

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Thanks

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

DATE: March 16, 2012
SUBJECT: Comments on Psychologists and Neuropsychologists - We need to better educate our doctors.

My name is Michael Ellenbogen and I was diagnosed with Alzheimer's at age 49, after struggling to get a diagnoses from age 39. We need to better educate our doctors.

I had the opportunity to read many of the public comments. Many referred Psychologists and Neuropsychologists that may not have been in the plan. While I think they can add a benefit to people with AD, they can also hinder diagnose, as was done to me. In my experience it delayed my diagnoses for about 10 years, not to mention the financial burden it created to our health system. Many need to be better educated on how people with AD react to the test they provide. They also need to put some merit in what their patients and caregivers may share with them. Especially if the caregiver is a RN.

In June 1999, I had my first full Neuropsychological Evaluation conducted by Dr. Lindsey Robinson. The summary and recommendations were: *Current level of overall intellectual functioning is in the average range, with verbal and nonverbal cognitive skills relatively evenly developed. Neuropsychological testing revealed moderate to severe impairments in information processing speed and sustained attention, with mild to moderate impairments in verbal learning efficiency. Short-term attention, expressive/receptive language skills, verbal and nonverbal abstract reasoning, and cognitive flexibility were within normal limits for age. There was no evidence of clinically significant depression, anxiety, or other psychological disorder which might account for the patient's cognitive deficits. The etiology of Mr. Ellenbogen's cognitive impairment is unclear as, from a neuropsychological perspective, his symptoms are nonspecific. However, the magnitude of impairment observed on objective testing, in the absence of identifiable affective disorder, does suggest the presence of some form of organic cerebral dysfunction. Further neurological evaluation recommended.*

I another appointment with Dr. Lindsey Robinson on February 2001. It was frustrating dealing with these doctors because every time I had to see a new doctor or take a test, my primary doctor needed to okay it. The other frustration was that sometimes I had to wait 5 months for appointments, which was the case with this appointment. The test that I was about to retake was questionable. I was not sure my insurance would cover the procedure, so I had to jump through hoops with the doctor and my insurance company. If the test was not covered, it would cost me about $2,500.00. When you deal with these insurance companies, document the conversation for yourself and ask them to do the same. I cannot tell you how many times they tried to get out of paying, but then they checked their records and saw I had received pre-approval. They kept putting up roadblocks and I had to be in touch with them a lot, when I should have been working. It was bad enough that I had to leave work for appointments, I did not need the added aggravation from the insurance company.

I finally met with Dr. Lindsey Robinson. She had commented on my other doctors findings in the beginning of her report: *The etiology of his cognitive symptoms was felt to be multifactorial, including normal aging, alcohol consumption, and anxiety.*

I have to tell you that when I saw those comments, I was very angry. She was making up her mind before even administering the test.

Her summary and recommendations were: *Current level of overall intellectual functioning is in the average range, with no significant discrepancy between verbal cognitive skills and nonverbal* *reasoning abilities, There is no significant change in overall intellectual ability in comparison with the evaluation in June of 1999. On neuropsychological testing, Mr. Ellenbogen displays generalized psychomotor slowing and inconsistent impairments in attention, concentration, and memory. In comparison with the previous evaluation, a variable, inconsistent pattern of change was demonstrated, with improvements on some measures and declines on others. This pattern of performance is not suggestive of focal or lateralized organic cerebral dysfunction, and is not consistent with the presence of a progressive cognitive disorder. Rather, Mr. Ellenbogen's neuropsychological test performance suggestive of fluctuating levels of attention, concentration, and performance speed. Objective psychological screening suggest the presence of mild to moderate symptoms of depression and anxiety, and an introspective, perfectionistic personality style. These psychological symptoms are most likely playing a significant role in Mr. Ellenbogen's subjective cognitive dysfunction.*

She encouraged me to seek a psychiatric consultation to determine whether a trial of antidepressant or anti-anxiety medication might be helpful in ameliorating my cognitive symptoms. She got me so aggravated, and she would not listen to anything my wife or I tried to tell her. She just did not want to hear it.

I went back to Dr. Lindsey J. Robinson, the Clinical Neuropsychologist, in January 2006. She was going to redo the neuropsychological testing. I thought it would be best to use this doctor again because she had a baseline for me and could compare my new results with the old. It would take months for the results. The other issue was that there were not many doctors, who performed this test, that were covered under my health insurance policy.

In June 2006, just a few weeks after my 48th birthday, Dr. Lindsey J. Robinson finally got back with the results of my testing. Her results for neuropsychological testing were as follows: *Background -- Previous neuropsychological evaluation in 1999 and 2001 revealed fluctuating, inconsistent impairments in attention, concentration, and performance speed, and symptoms consistent with anxiety and depression. Summary and recommendations -- Multiple aspects of Mr. Ellenbogen's behavior and test performance suggestive of inconsistent/incomplete effort during the evaluation. Thus, this test results described are not regarded as a valid representation of his optimal cognitive functioning. Mr. Ellenbogen's clinical presentation and test are unchanged in comparison with prior neuropsychological evaluation in 1999 and 2001. There is no evidence of progression of cognitive impairments, and Mr. Ellenbogen's developmental history and current test performance are not consistent with a diagnosis of attention deficit/hyperactivity disorder or any other organically-based cognitive disorder. Mr. Ellenbogen demonstrated an anxious/ obsessive personality style and some symptoms of depression. His cognitive can be most parsimoniously attributed to affective disorder and/or other motivational or psychological factors.*

Diagnostic Impression;

R/O Dementia (not in evidence)
R/O Anxiety Disorder, NOS
R/O Personality Disorder, NOS

Her recommendations -- *Mr. Ellenbogen should be reassured that thorough medical/neurological evaluation on multiple occasions has revealed no evidence of neurological cause for his cognitive symptoms. A trial of psychotropic medication could be considered to address Mr. Ellenbogen's apparent effective symptoms. He is unlikely to benefit from psychotherapy due to his reluctance to accept a non-medical explanation for his symptoms.*

I have to tell you that when I met with her and read this report, I was so upset that I had made the decision to go back to her. First of all, during my testing we were not in a quiet area. Anytime I hear noise, it just throws me off. I have difficulty processing and concentrating when that occurs. There was nothing she could do to make it better. I tried very hard to be accurate during my testing and worked as quickly as I could. I tried to inform her that she was wrong in her findings, but she did not want to hear it.

She was so confident in her failure to diagnose me properly, that when I had reach out to her to make her aware that other Psychologists and Neuropsychologists determined that I did have Alzheimer's. She insisted on writing a letter to tell my primary doctor, that the others were wrong and she felt that her diagnosis was correct. Since that day I tried to reach out to her and gave her the opportunity to see the conclusions that 3 other doctors cane up with, but her office refused. Doctors like this will only hurt people like me. There should be a specific testing they must go through before they can test YOAD patients.

Maybe someone from your office can educate her. [address removed]

As you can see, it requires special doctors with the right training to deal with YOAD. I hope you will insure that happens.

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

DATE: March 16, 2012
SUBJECT: Check out my two, new YouTube videos - Thanks

Please check out my new videos. Please make it count and spread the word. Add it to your face book, websites and twitter. Sorry if you are receiving it a second time.

http://youtu.be/viQre91DAL8

http://youtu.be/J7uL6FIyPOs

Thanks

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

DATE: March 16, 2012
SUBJECT: national plan

I am pleased more money and attention is proposed for the NAPA and that you are asking for comments.

I am a caregiver for my husband, Al Hayes (80 Yrs. old), who has had Dementia for five or more years. He has been diagnosed going int the advance stage; little language skills, completely dependent on me for his personal care and sleeps 15 hours a day. The only outside help (other than family) I get is two afternoons a week when the Santa Fe Senior Services provide Respite Care for three hours, which gives me a chance for free time. I felt very lonely until I took advantage of various Alzheimer's groups, caregivers, Alzheimer Cafe and discussion groups each meeting is only one day a month. There are no day care programs or affordable home care. I am 85 years old and have full 24+7 caretakers responsibility, I can not leave Al alone to go shopping. I have had to give up all my interest my involvement with my church and various activities.

I feel more attention should be directed towards caregivers and their needs and their family. My desire is to keep Al Home as long as possible but I need more help at home. I am 85 years old and I am concerned about how much longer I can keep up with all the demands of being a caregiver.

The caregiver is like the elephant in the room everyone knows it is there but they keep their blinders on. Caregivers need to be recognized and helped in every way possible.

Sincerely,

Yvonne Hayes
Santa Fe, NM

DATE: March 15, 2012
SUBJECT: Comments on Draft National Plan to Address Alzheimer's Disease

I believe we met a year or so ago at the CDC's fall prevention expert panel. I hope you are doing well!

I had the opportunity to read the Draft National Plan to Address Alzheimer's Disease and had some thoughts to pass along to you:

1. It seems like HHS is assigned responsibility frequently throughout. Where translational efforts are mentioned (e.g., p. 12, Action 1.E.2.), I'd suggest specifically calling out partnering with groups like the CDC's Prevention Research Centers Healthy Aging Network (CDC-HAN, http://www.prc-han.org/) and also the Geriatric Education Centers.

2. There is mention (p. 14, Action 2.A.1.) of training health care providers in how to manage Alzheimer's "in the context of other health conditions." I would assert that there is not sufficient evidence on this topic to date to direct such training, and that some of the funds earmarked for research should go to agencies like AHRQ or the CDC to support external investigators to conduct studies in this area.

3. Also mentioned in this same section are tools that are being developed to detect cognitive impairment, and (p. 16, Action 2.B.2.) HHS identifying tools for use in outpatient settings to assess cognition. Such tools are in fact already in existence, and in use in clinical practice, and should be cited here. See for example the Mini-Cog (PDF attached).

4. There is mention (p. 14, Action 2.A.3.) of HHS developing a clearinghouse. CDC-HAN has experience developing and maintaining a clearinghouse (see http://depts.washington.edu/hansite/drupal/); this clearinghouse has won an APEX Award for Excellence in Publication. HHS could consider contracting with CDC-HAN for this activity.

5. There is mention of the need for measures of quality of care (p. 17, Strategy 2.D.). There is no reference here to the ACOVE work on this topic, and that work should be cited. See Feil DG, MacLean C, Sultzer D. Quality indicators for the care of dementia in vulnerable elders. J Am Geriatr Soc. 2007 Oct;55 Suppl 2:S293-301.

6. On p. 18, I suggest adding references for the demonstrations mentioned under Action 2.E.1. and 2.E.2. if available, or at least more detail on where these demonstrations are being done, who is funding them, and who the PIs are.

7. There is emphasis (p. 19, Action 2.F.1.) on hospital safety for persons with AD. However, there is no emphasis on preventing hospitalization in the first place. This is a very realistic and important goal for persons with dementia at all stages of the disease, and I suggest it be added. See a recent publication that I authored examining potentially preventable hospitalizations in persons with dementia compared to a cohort who remained free of dementia: Phelan EA, Borson S, Grothaus L, Balch S, Larson EB. Association of incident dementia with hospitalizations. JAMA. 2012 Jan 11;307(2):165-72.

Thanks for conveying my input into the appropriate channels. As an academic geriatrician with an active clinical geriatrics practice, I applaud this undertaking and will look forward to seeing the final version of the plan!

And please let me know if any questions.

Best wishes,

Elizabeth A. Phelan, MD, MS
Associate Professor of Medicine/Gerontology and Geriatric Medicine
Adjunct Associate Professor of Health Services, School of Public Health
Affiliate Investigator, Group Health Research Institute
Co-Director, Center for Interdisciplinary Geriatric Health Care Research
Assistant Director and Director of Evaluation, Northwest Geriatric Education Center
Founding Director, Fall Prevention Clinic, Harborview Medical Center
University of Washington
Seattle, WA

DATE: March 15, 2012
SUBJECT: Draft National Plan to Address Alzheimer's Disease - time to comment

I serve on the North Carolina Healthy Aging Coalition and am excited about the proposed national plan addressing Alzheimer's Disease. I have a few comments that may already be inferred in sections of the draft, but did not specifically see the following addressed:

- On page 14 ,Action 2.A.2 talks about encouraging providers to pursue careers in geriatric specialties and I would like Allied Health professionals added to this section since many of us provide direct care to individuals and their caregivers of those with Alzheimer's Disease.
- On page 14, Action 2.A.4 talks about strengthening the direct-care workforce. I whole-heartedly agree that this is needed; but also think there needs to be a plan of action to increase the number of cost-effective sites that are designed specifically for those with Alzheimer's Disease. I know later in the Plan, there is discussion about different housing options, but feel that this could be strengthened in the Plan. From my experience, many families do not have the funds to have their loved one cared for in a "Memory Cottage." Along the same lines, perhaps some type of long term health care insurance for dementia could be provided, if it is not currently available.
- On page 21, Goal 3 indicates $10.5 million dollars will be available in 2013 to support caregivers' needs, but does not indicate how this money will be dispersed and who can apply for the monies.
- One area I did not seen mentioned in the Plan is research money for prevention strategies, such as fall prevention and home safety. Both of these preventative strategies are crucial in helping the person with Alzheimer's not only remain in their home longer, but also promote their functional performance and integrity.

Thanks for the opportunity to share my thoughts and I look forward to seeing the final Plan,

Jane Painter, EdD., OTR/L, FAOTA
Professor and Academic Fieldwork Coordinator
East Carolina University
College of Allied Health Sciences
Occupational Therapy Department
Greenville, NC
http://www.aota.org/Educate/EdRes/Fieldwork/Workshop.aspx

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The Draft National Plan to Address Alzheimer's Disease is available for comment until March 30. This is a very important plan with significant implications for older adults and their caregivers. I encourage you to review the draft and submit any comments to Helen Lamont (helen.lamont@hhs.gov). If there are elements you would like to discuss, given their relevance to North Carolina, please share them via the listserv.

Once the plan is finalized, we will want to consider what we can do to promote implementation in North Carolina. The CDC-Healthy Aging Research Network's Healthy Brain Workgroup will be very engaged, and there will be important roles for geriatric education centers, academic institutions, aging services, public health, mental health, healthcare and indeed, for all of us.

Best to you!

Rebecca H. Hunter, M.Ed.
Senior Scientist, UNC Institute on Aging
Research Associate, Center for Health Promotion and Disease Prevention

ATTACHMENT: Draft National Plan to Address Alzheimer's Disease.pdf

Available as separate links:	
Draft National Plan To Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach87.pdf

DATE: March 15, 2012
SUBJECT: National Alzheimer's Plan - Input -

As a Caregiver and Advocate for those affected by Alzheimer's Disease, I am Extremely pleased with the Draft National Plan To Address Alzheimer's Disease.

Given the fact that people are living longer, this Dreadful, Devastating disease is on the Fast track to becoming an Epidemic, which I am confident The National Plan will in deed keep in check and make much more manageable, so long as it is Fully Supported and Enforced. Below, I wish to offer my input, which comes from Real Life Experience as a Caregiver and Advocate

I sincerely hope that you will find this input most helpful.

With Respect To Diagnosis:

One of the Keys to Success in Keeping Alzheimer's Disease In Check Is Early, Timely Diagnosis.

I have found in my work as a Caregiver and Advocate that Alzheimer's enters the lives of those affected in ways we may classify as minor or may overlook such as; having to write things down more often, patterns of not being able to locate items or patterns of memory lapses, all of which we may joke off as ' Pre- Senior or Senior Moments '.

It is up to All Of Us to Keep An Eye On Each Other and Those Around Us, Should we see these behaviors, we Must Take Them Seriously and Track Them As Such.

Cognitive Testing / Evaluations Must Become Part Of Routine Exams For Everyone ,As We Never Know Where or When This Dreadful Disease May Strike.

With Respect To Testing / Evaluation, It Must Be More than asking a person their name, what day it is, what year it is and who the President is. I Propose we include questioning about work, family, driving skills, life skills, household management, personal care. In addition to Monitoring Personality / Behavioral Status and Changes.

The Key here is Proper Evaluation, Monitoring, Detection of Changes and Knowing When To Red Flag.

Education / Training:

Education and Training are Critically Important and Mandatory in the Diagnosis, Treatment and Care of Those Affected By Alzheimer's Disease, and Must Be An Ongoing Process As The Disease Evolves Over Time.

Through my Exposure and Experience I have seen the Blood Boiling Impact that Those With Poor / Little To No Knowledge, Education and Training can have when it comes to Alzheimer's, from Arguing with Patients , Poor / In-Effective Communication Skills to Leaving Patients Un-Attended. All of which are 100 Percent Un-Acceptable and In-Excusable.

People who are working in Any Capacity With Those Affected By Alzheimer's Must Be The Best Of The Best, The Cream Of The Crop as There Is No Room To Settle For Second Best.

Ill Willed or Under Qualified People Pose A Grave Danger and Threat To Those With Alzheimer's and We Must Ensure, The Best Of The Best Are Ready, Willing and Able To Step Up and Provide The Necessary Care.

Caregivers and Support:

Formal, Thorough, Ongoing Education, Training and Support Are Essential at All levels of the Caregiving Process, and It Must Be Seamless.

There Must Also Be Flexibility Within Medical Coverage Of All Types To Allow For Flexibility and Out of Network / Program Services If These Out Of Network / Program Services Provide A Level of Care / Support Which Standards and Quality Exceed In Network / Program. Why Should Those With Alzheimer's and Their Caregivers Be Backed Into A Corner Which Forces Acceptance Of Sub-Standard Services?

Caregivers at All levels also Need Adequate and Timely Relief To Prevent ' Burnout ' and To Tend To Their Own Personal Health and Affairs.

Caregivers Must Be Educated and Informed Of All Available Support Services, which as a Caregiver , Myself Can Be Overwhelming , In and Of Itself, As Most Are Unsure Of How To Begin The Process Of Locating Services or Lack the Time and Energy To Do So.

Given This, I wish to offer my services, as an official community resource, with respect to assisting Caregivers research, locate, apply for and coordinate support services. I have Professionally and Successfully Linked Caregivers with a myriad of support services ranging from In Home Personal Care Services to Financial and Prescription Support Services.

Closing Thoughts:

In Closing, I Agree That Alzheimer's Is Quickly Approaching Epidemic Levels and If We Fail To Act Now, This Failure Will Prove To Be Devastating To Say The Least.

The National Plan, When Combined With Input, Such As Contained In This Document, Ensure That A Proactive Approach Will Lessen The Burden and Devastation Of Alzheimer's At All Levels.

We Must Also Unite and Advocate Tirelessly To Ensure Every Aspect Of This Plan Does Not Fall Prey To The " Politics ' Of Our Government ,As That Too Will Prove To Be Devastating.

Thank You For The Opportunity To Provide Input On The National Plan, It Has Been An Extreme Honor To Say The Least and I Look Forward To This Being Fully Enacted and Enforced.

Sincerely

Brian C Hornak
Advocate / Caregiver
Kearny, NJ

DATE: March 15, 2012
SUBJECT: Advisory Council on Alzheimer's - Expanded talking points for Michael Ellenbogen

This is a follow-up to my speech yesterday with an expanded version. I was concerned in keeping my 3 minute limit, which made me a bit nervous.

First of all, I would like to thank you, the federal and non federal committee members, and all others involved, for what have already been accomplished, but we still have a long way to go. Money is going to be the biggest issue, even though the president recently committed more.

I am a 53 year old, living with Alzheimer's. I was diagnosed at age 49 after struggling for 10 years to get a diagnosis from age 39.

I have a few issues to address. The first one is related to 2025 date which was originally thought of, I have heard many on this committee and others with the dissatisfaction of that date. I strongly recommend that we show urgency and use the 2020 date that everyone seems to support. I know it will take some courage on many of you to rethink this date but do it for all of us who have been waiting so long already. Just look back at the momentum and target dates they were trying to shot for HIV and Cancer. They were much more aggressive.

Second issues is the disparity around this disease. While I would like to see more funding dedicated to Alzheimer's, that may not always be possible. Today 18.7 percent of the NIH research budget goes to cancer, 9.9% to HIV, and just 1.4% to Alzheimer's. We need to be more fairly with the designation of those dollar amounts. There are many more people living with Alzheimer's than HIV, yet it receives much less funding. More funding is desperately for Alzheimer. They are all important causes and should be treated fairly. Keep in mind 98 percent of breast cancer patients continue to have a normal life when it its diagnosed early. Yet Alzheimer's patients do not have any chance what so ever. In fact 40% of their last years are so horrific that you would not wish it on your worst enemy, but all of our families have to endure it and become ill in the process..

And last, a subject that no one wants to talk about, but can save millions. The right to die with the help of a doctors. Many of us who have this disease do not want to ride it out to the end. We want to be remembered in a more positive view. We also do not want our families to suffer or have the added financial burden. Please consider the right to die for devastating diseases like this. While I do not like to talk about this, it is important to know how so many of us feel. I have had the opportunity to speak with other like me and they feel the same way. My biggest concern is that I may take my life much earlier than I need to or I may even screw up in the process and great a bigger medical condition because I did it to late and failed. That would not have been an issue a few years ago, when I had guns in the house. I gave the up for the concern for my own family. I did not want to wake up one day and think that they were intruders and shoot them. I would love to opportunity to let someone know what my wishes are based on a number of question answered so they know at what point and time they should acct on my wishes. It can be as simples as a score on the mini mental exam done at two different times. Please don't make me and my family suffer more than I need to. Have some passion. And of course this is based on being able to make these decision when one was still capable to make those decisions with a sound mind, which I still have.

I would also like to volunteer my services to be on your committees to represents others like myself who has this debilitating disease.

I would also like to see an open public input conference line, for all future meetings. I think it's very important for people like me to voice their opinions. What I did not like about the meeting is where many companies are trying to self advertise their special interest for their companies. There is a time for that and it should not take away from the people who are living with the pain. One example was the person representing GE and the petscan. We all know this is great product and all know it's needed, but they should have more brains then that.

Thanks again for hearing my shorten version yesterday and reading my extended version now.

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

DATE: March 14, 2012
SUBJECT: Public Comments

Please submit my attached testimony to the public comment section of the NAPA website.

Thank you,

Mary Hogan

ATTACHMENT: ACT March 14.pdf

Available as separate links:	
Public Testimony for NAPA Advisory Council Teleconference Meeting	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach86.pdf

DATE: March 14, 2012
SUBJECT: A voice for AD patients

My name is Joan Uronis. I am 62 and have recently been diagnosed with AD. Long before my diagnosis, I have been a passionate advocate for those with the diagnosis of Alzheimer's. Since I am no longer able to work, my new full-time career is one of advocacy. I have held executive positions in the healthcare field for over 15 years. My last position was as General Manager of a Hospice where I met with caregivers of persons with AD as well as those with the disease. For some reason I found myself devoted to this population. I also worked as Executive Director of an Assisted Living where I had contact with this special group as well.

My mother had Alzheimer's and died in 2010 at age 92 of the disease. I was her part-time caregiver. I have worked the disease and now am living it. I am a support group facilitator for the Alzheimer's Association and volunteer at an Assisted Living in their Alzheimer's/Dementia care center.

Having worked and experienced the lack of care for those of us with the disease, I am a voice for the voiceless, a voice for those ashamed to speak out and a voice for the issues and concerns that face all of us. Our main concern is one of adequate quality care. Alzheimer's patients require a unique type of care. My observations of the care that is provided to patients in Assisted Livings, Nursing Homes, Hospitals and by some physicians leaves my heart hurting. It leaves me with little hope of what may be in store for me.

My recommendations to give hope to those of us with the disease and to ease the minds of their caregivers are the following:

- Care given by state certified persons trained in working with those with AD. They need to be required to be recertified to continue to work with this population
- Physicians trained in Alzheimer's as most have patients with the disease
- All Medical students should to be trained in Alzheimer's and how to give the respect and dignity that we deserve. We are still human.
- Nursing schools should also train nurses in the same regard. Being cold and hurried does not ease anxiety and frustration and leads to dehumanization
- Hospitals need to be particularly aware of those with Alzheimer's and ensure their safety and check on them regularly
- Emergency Room staff need to be aware of patients admitted with Alzheimer's. This was brought to light by my mother who was taken to the ER from her AL, she was in the late stage of the disease. When I arrived, she was at the edge of the bed with no one in attendance. Being confused I could only image what may have happened if I had not arrived.
- A place where we can go that is specifically for us, not a part of another facility. This place would have staff that is certified in Alzheimer's care. The ratio of caregivers to patients would be small enough to ensure quality care. This would also ease the minds of caregivers.

These same concerns have been expressed to me by caregivers who have found the same to be true. We all need to be treated with dignity, respect, concern for our safety and given the unique quality of care that we deserve. Alzheimer's care is unique and requires a much better understanding. On behalf of myself and those with the most dreaded disease, I thank you for listening. Our future is in your hands. God bless.

Joan Uronis

DATE: March 14, 2012
SUBJECT: National Alzheimer's Plan - Need C4A Member Input

can you please make sure these comments get added to the public input.
thanks.

Laura Trejo, MSG, MPA
General Manager
Los Angeles Department of Aging
Los Angeles, CA

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Here are CSS' comments:

We have no additional comments; however we have identified a few points of interests:

Unless the disease can be effectively treated or prevented, the number of Americans with Alzheimer's disease will increase significantly in the next two decades. Therefore, HHS has included the following five foundational goals:

1. Prevent and Effectively Treat Alzheimer's Disease by 2025
2. Optimize Care Quality and Efficiency
3. Expand Supports for People with Alzheimer's Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Track Progress and Drive Improvement

Also, Goals 3 &4 have the most implications to our AAA programs as follows:

Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families
Supporting people with Alzheimer's disease and their families and caregivers requires giving them the tools that they need, helping to plan for future needs, and ensuring that safety and dignity are maintained. To help respond to the challenges faced by families and other caregivers, the Obama Administration's Alzheimer's disease announcement makes a new investment of $10.5 million in fiscal year 2013 to support the needs of caregivers of people with Alzheimer's disease.

Goal 4: Enhance Public Awareness and Engagement
There are widespread and significant public misperceptions about diagnosis and treatment that lead to delayed diagnosis and to people with the disease and their caregivers feeling isolated and stigmatized. Enhancing public awareness and engagement is an essential goal of this project.

Please let us know if you need any additional information.

Lorenza C. Sanchez
Assistant Director
Los Angeles County Community & Senior Services Department
Aging & Adult Services Branch
Los Angeles, CA
Web-Site: http://css.lacounty.gov

DATE: March 13, 2012
SUBJECT: Alzheimer's Research

It is with great hope that I am writing this letter. My mother suffered from this disease for eight years. Not only did she suffer consequences to her health, but the whole family suffered with her. And, other family members in her family had Alzheimers in later years. Our generation is waiting for the disease to strike one of the adult children, with hope that we will not have to deal with this monster. Please, continue the research and give our family and other families hope to live long disease free lives.

Liz Harwood
Pueblo, CO

DATE: March 13, 2012
SUBJECT: Commonwealth of Virginia Alzheimer’s Disease and Related Disorders Commission

Attached please find public comment from the Commonwealth of Virginia Alzheimer's Disease and Related Disorders Commission on the draft National Plan to Address Alzheimer’s Disease.

Amy Marschean, J.D.
Senior Policy Analyst
Virginia Department for the Aging

ATTACHMENT: DOC020810-004.pdf

Available as separate links:	
Virginia Alzheimer’s Disease and Related Disorders Commission Comments on Draft National Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach85.pdf

DATE: March 13, 2012
SUBJECT: Congresswoman McMorris Rodgers would like to submit a letter

I understand that the advisory committee for NAPA will be meeting tomorrow. My boss would like to have the attached letter submitted as part of the record. Is that possible?

Thanks,

Karen L. Summar, MD, MS
Joseph P. Kennedy Foundation Public Policy Fellow
Office of Congresswoman Cathy McMorris Rodgers
Washington, DC

ATTACHMENT: 2012FEB08_CMR_toFrancisCollins_$50Mill_Alz.pdf

Available as separate links:	
Comments on Down Syndrome and Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach84.pdf

DATE: March 13, 2012
SUBJECT: Comments on NAPA

Per a Twitter Chat on **#NAPA** (#talkalz) today, please consider the following questions for the upcoming revision of the Act:

1. **What incentives exist for direct care staff to increase education and raise standards of care proposed under NAPA**? (As a reminder, their current pay rate is roughly that of a worker at McDonald's while their responsibilities for human health and welfare are exponentially greater.)

2. **Will there be a dedicated funding stream for mandates in the NAPA Act**? Without appropriate funding, legislation will force UNFUNDED MANDATES upon the plates of service providers and effectively establish a DIS-incentive to provide Elder Care Services for people with acquired cognitive disabilities like Alzheimer's.

3. What working models from 10 countries with existing Alzheimer's Planning are being reviewed for successful implementation? If possible, can you **please provide a link to those resources**?

Thank you very much for your consideration.

Respectfully,

Kimberley Thompson
Director of Social Media & Community Management
SUNRISE COMMUNITY, INC.
Miami, FL

DATE: March 12, 2012
SUBJECT: Introducing EmFinders

I am the president of EmFinders, the leading national recovery solution for cognitively-impaired individuals who wander off and end up missing. I wanted to reach out to you personally to discuss the benefits of EmFinders for seniors with Alzheimers', their caregivers, and assisted living communities. We at EmFinders are dedicated to helping recover residents who elope as quickly, safely, and affordably as possible.

Our new EmFinders Elopement Risk Program (EERP) features the EmFinders EmSeeQ bracelet worn by residents who have been assessed via the program to be 'at risk'. The unique and patented cellular technology of our device features the smallest personal locator available for nationwide coverage. If a resident leaves their home or community unsupervised for example, the device is activated and notifies the nearest local law enforcement agency via the Emergency 9-1-1 system, and the individual is quickly located by first responders. We have enabled 106 rescues to date, with 100% success rate, and with a median recovery time of 30 minutes..

The EERP and the EmSeeQ device provide the first comprehensive program for caregivers and communities to pro-actively identify and manage elopement risk both for memory care residents as well as the assisted living population at large. By design, this new program should significantly reduce assisted living communities' exposure, while also bringing peace of mind to staff and family members in the event an actual elopement were to occur.

I would be pleased to discuss our solution and your requirements. We have been working with a number of larger Assisted Living providers and we have developed considerable expertise in rolling out and managing our solutions for national caregivers and communities.

I will be attending the upcoming Aging in America event in Washington, D.C. from 26 Mar - 1 April -- we have a booth there and I would be delighted to meet your representatives locally at this event or of course in your office.

Please let me know what would be a good day and time to meet the week of the 26th and I'll be happy to schedule.

I look forward to talking with HHS soon.

Best regards,

Patrice McAree
EmFinders, President

ATTACHMENT: EERPImplementationFinal Rev 5 PM-01712x.pdf

Available as separate links:	
EmFinders Elopement Risk Program for Senior Care Communities: Bringing Peace of Mind to Families, Caregivers and Senior Communities	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach83.pdf

DATE: March 12, 2012
SUBJECT: Comments on the draft National Plan for Alzheimer's and Related Disorders

Please accept the following comments on the draft National Plan for Alzheimer's and Related Disorders from the State Unit on Aging in Connecticut:

1. While evidence based research can be a reliable tool, more flexibility should be granted to community providers and researchers to explore innovative and creative non-pharmacological approaches to living with and treating Alzheimer's disease. Our CONNECTIONS grant from AoA and our work in CT with NECC and cognitive training has afforded us with many examples of the positive impacts of this intervention on the quality of life for the caregiver as well as the individual with dementia. Excluding such projects from funding opportunities, further exploration or dismissing them as models because they do not have the full complement of expansive research behind them is short-sighted and limiting to families. Often the most innovative approaches are the ones that afford families a sense of empowerment in combating the disease process.

2. The strategy area of "maintaining the dignity, safety and rights of people with Alzheimer's Disease" is critical. The perception of this disease and the assumed burden that families incur upon diagnosis often negatively impacts the delivery of care received by those with the diagnosis. Training medical and legal personnel as well as other individuals in the field is an excellent way to begin addressing the stigma associated with the disease and some of the misperceptions and assumptions that are prevalent. Monitoring and reporting the use of anti-psychotics in nursing homes is an excellent proposed action, as is providing awareness training and education for professional caregivers.

3. It would be beneficial to incorporate hospice options into any training module offered to families as well as facilities working with this population.

4. The design and implementation of a national education initiative is enthusiastically supported. We are still struggling with the same level of stigma 14 years after implementing our Statewide Respite Care Program (for individuals with Alzheimer's disease) in Connecticut, and many conversations with our local Chapter of the Alzheimer's Association underscore this sentiment.

5. I strongly encourage the Plan team to conduct a comprehensive needs assessment before new activities are initiated. Since many states and individual organizations may already be implementing aspects of the plan, best practices should be observed to obviate unnecessary and costly duplication or delays.

Please contact me or Cynthia Grant our Alzheimer's contract specialist at the above email address should you need more information.

Pam A. Giannini, MSW, Director
Bureau of Aging (SUA)
Community & Social Work Services
Department of Social Services
Hartford, CT

DATE: March 12, 2012
SUBJECT: NCMHA Comments on Draft Plan to Address AD

On behalf of the National Coalition on Mental Health and Aging, I am pleased to submit the attached comments on the Draft National Plan to Address Alzheimer's Disease.

Sincerely,

Deborah DiGilio, MPH
NCMHA Executive Committee Member

ATTACHMENT: NCMHA Comments on the Draft National Plan to Address AD.pdf

Available as separate links:	
National Coalition on Mental Health and Aging Comments on the Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach82.pdf

DATE: March 9, 2012
SUBJECT: mental health issues with people with Dementia

It is essential that when talking about cures for Alzheimers that the mental health problems associated with this disease be addressed as well.

Otherwise, the job is only being half heartedly.

Hope Reiner
Senior Life Enhancement Specialist
HOPE CARES

DATE: March 9, 2012
SUBJECT: Request to orally present this written comment for the Alzheimer's Research, Care, and Services, 3-14-12 Teleconference Advisory Council Meeting

I wish to make this statement on Wednesday, orally, during the Teleconference, and to have these words below and the names of the co-signers, part of the transcript:

For patients who will someday suffer from Alzheimer's and related dementias, Advance Care Planning is most urgent, most important, and most challenging. The process of expressing one's end-of-life wishes in advance warrants both 1) the development of innovative planning tools that are easy, effective, and acceptable to both patients and physicians, and 2) sufficient effort to encourage people to complete them.

Why is Advance Care Planning most urgent? Unlike most diseases, patients who have dementia typically lose mental capacity to make end-of-life medical decisions early in the course of the disease. Once their window of opportunity to make decisions closes, they will not be able to participate in their own end-of-life planning. The huge epidemic predicted for Alzheimer's makes promoting Advance Care Planning urgent on a societal level.

Why is Advance Care Planning most important? Unlike most diseases, patients can linger in the terminal stage of Advanced Dementia for several years. They may frustrate clinicians, caregivers and loved ones as their disease ravages on. The multiple burdens on others are well known. More than one-third of caregivers are depressed. Yet the suffering patients themselves experience is under-appreciated. For too many, pain and suffering may go unrecognized and therefore under-treated for months, or even years.

Why is Advance Care Planning most challenging? Unlike most diseases, there are often no life-sustaining treatments that physicians can withhold or withdraw. Typically, a strong body houses a feeble brain. Many who feel the pang of the "Dementia Fear" consider "premature dying." This kind of thinking is typical: "If I don't kill myself now, I won't be able to kill myself later. I'll be trapped in a condition I hate so much that I'd rather be dead." Those who act on this fear only increase the tragedy of their disease. We must offer patients an effective advance care plan so they can feel confident they can avoid a prolonged dying of months to years with suffering and burdens. Then they will choose to live as long, and as well as possible—as they benefit from improvements in medical and non-medical management of their disease.

Advance Care Planning that specifically includes Advanced Dementia needs funding to develop and implement, even if researchers discover new drugs that delay the onset of symptoms or slow down their progression. Here's why: Changes in the brains of afflicted people start one or more decades before clinical symptoms emerge. Meanwhile, it will at best take many years to prove the safety and efficacy of new drugs and adopt a policy for widespread treatment. Realistically, most of the 76 million baby boomers who are now destined to get dementia will probably still become demented. Even if new drugs were available today, Alzheimer's-afflicted with who do not die of another cause will eventually reach the stage of Advanced Dementia… and, wWhen they do, they will be able to rely only on their Advance Directives, to control how long, and how much, they must suffer before they die.

To reduce end-of-life suffering of millions of victims of Alzheimer's disease and their loved ones, we thus must: 1) develop new Advance Directives that are easy, effective, and acceptable; and, 2) implement programs to encourage people to complete them.

Sincerely,

Stanley A. Terman, PhD, MD
Medical Director and CEO
Caring Advocates
Carlsbad, CA

Ladislav Volicer, MD, PhD
University of South Florida
School of Aging Studies
Tampa, FL

Ronald Baker Miller, MD
Clinical Professor of Medicine, Emeritus
Founding Director of the Program in Medical Ethics
University of California Irvine
Irvine, CA

Karl E. Steinberg, MD, CMD
Scripps Coastal Medical Center
Associate Medical Director for Skilled Nursing Care
Vista, CA

Thaddeus Mason Pope, JD, PhD
Director, Health Law Institute
Hamline University School of Law
Saint Paul, MN

Ferdinando L. Mirarchi, D.O., FAAEM, FACEP
Medical Director, Department of Emergency Medicine
Chairman, Hamot Physician Network Governance Council
Principal Investigator, Realistic Interpretation of Advance Directive
University of Pittsburgh Medical Center at Hamot
Erie, PA

Guy Micco, MD
Clinical Professor
Joint Medical Program Div. of Health & Medical Sciences
Director, Resource Center on Aging
University of California Berkeley
Berkeley, CA

Robert M. Gibson, PhD, JD
Psychologist and Attorney
San Diego, CA

DATE: March 9, 2012
SUBJECT: Draft National Plan

I would like to comment on the Draft National Plan released by HHS on February 22, 2012. My name is Bruce Lamb and I am a Staff Scientist at the Lerner Research Institute at the Cleveland Clinic, where my laboratory works to understand basic disease mechanisms underlying Alzheimer's disease.

I would first like to congratulate HHS for developing an ambitious plan with admirable overall goals. The five goals identified as building blocks for transformation as well laid out and conceived and most of the details within each sub aim for the goals are well articulated. However, in order to achieve these goals, the plan must be supported by equally ambitious and transformative changes in the funding, organization and monitoring of progress in the fight against Alzheimer's disease as outlined below.

1. **Continued Research Investments**
   The recent announcement that an additional $50 million will be invested in Alzheimer's research this year and that President Obama has requested an additional $80 million in the FY13 budget is certainly a great start in adding resources in an attempt to meet the Goal 1 to "Prevent and Effectively Treat Alzheimer's Disease by 2025." However, this can only be the first step, towards a larger goal of making strategic investments in Alzheimer's research over the next several years. In coming years, it will be critical to add to these investments, with the ultimate goals of supporting $2 billion of Alzheimer's research per year. If we are truly serious about the ambitious goal of having a prevention/treatment by 2025, this level of investment is required to get us there (as supported by a recent panel of experts assembled by the Alzheimer's Association). These details should be spelled out more clearly in the National Plan. The current draft plan suggests that the initial $130 million in investments in Alzheimer's research proposed in this year and next are "key to advancing this goal (goal 1)." However, in reality, this must represent only the initial investment in a series of increased investments over the next several years.

2. **Research Infrastructure/Organization**
   It remains unclear how the sub aims under goal 1 will be coordinated and organized. To achieve goal 1 of the draft plan, it will be absolutely critical to have an infrastructure and organization that can coordinate federal research efforts across all funding agencies, interact with non-profits and industry, promote awareness of the disease and the role that research will play in combating the disease as well as reporting to the Advisory Council directly as outlined in the plan. In order for this organization/infrastructure to be truly successful and transformative, it will be essential that its efforts are entirely focused on combating Alzheimer's disease. This will provide a uniquely focused organization that will have the most chance of success. A similar "disease-focused" agency was created in 1988 for HIV/AIDS entitled the "Office of AIDS Research" (OAR) within the Office of the NIH Director, that played a key role in successfully coordinating the federal response to AIDS. If we are truly serious about transforming Alzheimer's research and achieving the goals laid out in the plan, a similar type of organizational structure (perhaps an Office of Alzheimer's Research?) is required either within HHS or NIH.

3. **Monitoring Progress**
   The conference in May of 2012 will certainly help identify the key research areas that need to be addressed to achieve goal 1 of the plan. However, as part of the plan, there

should also be regularly scheduled conferences to assess progress in meeting the goals identified in May. This will not only provide an opportunity to assess whether particular milestones have been met, but also regularly and quickly reassess research priorities. This level of assessment and monitoring is best carried out by an office/infrastructure exclusively focused on meeting goal 1 of the plan (see #2 above).

Thank you for the opportunity to provide input into the Draft National Plan to Address Alzheimer's Disease! Please contact me directly if you have any questions regarding the issues I have addressed here.

Sincerely,

Bruce Lamb, Ph.D.
Staff Scientist
Department of Neurosciences
The Lerner Research Institute
The Cleveland Clinic Foundation
Cleveland, OH

DATE: March 9, 2012
SUBJECT: Draft HHS National Plan to Address Alzheimer's Disease - Comments from Cambridge Cognition

Thank you for the opportunity to comment on the draft HHS National Plan to Address Alzheimer's Disease.

Cambridge Cognition offers the attached document for consideration.

Sincerely

Ruth Keir
Chief Executive Officer
Cambridge Cognition Ltd
web: http://www.cambridgecognition.com

ATTACHMENT: submission to napa.pdf

Available as separate links:	
Comments from Cambridge Cognition	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach81.pdf

DATE: March 9, 2012
SUBJECT: National Alzheimer's Plan QUESTION - diagnosis prevents eligibility for long term care insurance

How does the National Alzheimer's Plan address long term care insurance with Alzheimer's diagnosis.

In MD, perhaps nationally, if a person is diagnosed with Alzheimer's, they are NOT eligible for long term care insurance policy -- the very thing they need!

The National Alzheimer's Plan is promoting diagnosis; however this will PREVENT those individuals from getting the type of helpful insurance they need.

What is the plan doing to address this?

Susan Howe Crowson
Alzheimer's Memory Care Specialist
Alzheimer's Education and Advocacy
Alzheimer's Association Ambassador
http://www.FamilyCareCoach.com

DATE: March 8, 2012
SUBJECT: Alzheimer's

Is this disorder reversible? PBS TV indicates this may be the case.   Please address-

THX.

Sandy Colhard

DATE: March 8, 2012
SUBJECT: Comments on the draft National Alzheimer's Plan

Attached, please find the National Council for Community Behavioral Healthcare's comments on the draft National Alzheimer's Plan.

Kirsten Reed
Policy Associate
National Council for Community Behavioral Healthcare
Washington, DC 20006

ATTACHMENT: NAP Letter 2nd draft.doc

Available as separate links:	
Comments on the Draft National Alzheimer's Plan	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach80.pdf

DATE: March 7, 2012
SUBJECT: Draft National Plan

I would like to thank this committee for their efforts on this project. I am writing a very long letter and hope someone takes the time to read it and forward to all involved.

As this plan moves forward I can applaud the parts of the plan that involve research and drug development. I am sure it will make the researchers and drug companies very happy!! I have no problem researching early on set Alzhemers, but really the brain is an organ just like the heart and lungs. There is no cure for old, period! When a person shows signs of this disease at 75 years of age it is just that, the brain is getting old. The government can dump millions into drugs that they them selves will be paying for. Do you know how much Nemenda costs? Most people that take it could never afford it, so the government pays for a drug that has very little effect on the person that takes it. Financial aid and support to the families trying to care for a loved one at home is where this country will benefit.

I am a 52 year old daughter taking care of an 87 year old father with severe Alzheimers. We have a unique situation where I as well as 2 brothers live next door to my dad on land given to us by him. For the last 10 years I have taken care of him as well as worked and raised a family. I have 2 children who are in the health field, 1 a nurse and 1 in a Doctor Pharmacy program, that I struggle to keep in school since I have had to stop working. In the beginning my dad just required monitoring, meals delivered and laundry done, as the disease progressed we alarmed the house so he could not wander off at night. He tripped and broke his right hip in April 2010, surgery made the disease go crazy and I have been a full time caregiver since that day! My data never took a dime of government assistance, he lived and worked as a construction worker and farmed through some very difficult times. He had maybe $35,000 in an IRA when this began. My brothers help where they can and I private pay caregivers (35 hours per week) with the money he has remaining to the tune of $1400 a month. He collects $1267 social security. So after utilities, insurance, drugs and food the remainder comes from the IRA. You can see that when we pre-pay a funeral he will almost be broke. I stopped working, stay 5 nights a week with my dad. Moving someone to a skilled care only worsens this disease or any dementia. April 2011 dad broke his left hip, Hospital 5 days Nov 2011 for and infection. After every surgery or hospital stay he was sent to skilled care (I use that term very loosely) the very basics are not being met in these homes, my dad was left unattended wet and soiled on a daily basis. He developed pineal yeast infections that went unchecked until I discovered it. This is caused by neglect and poor hygiene The workers are miserable, patients are ignored, no one smiles or even pretends to hear them. Don't believe me, take off your suit and go undercover for a visit. I saw this care across the board in 3 different skilled care facilities. My dad is no longer verbal enough to get a point across, but after every trip to a skilled home I would insist on bringing him home when he looked like death. Home is where it is at!!! Love and proper care, I have him walking with a walker, I have him on a bathroom schedule (he is never wet). At night I taught myself how to use an external catheter (something I had to fight to have Medicare approve). This is an aid that is simple to use and eliminates wetness at night and helps to prevent bedsores.

My dad now receives some help from the area on aging, that provides 3 half days of daycare. This is income based and I am controlled if I want to remain in the program to keep his withdraws from his IRA to a minimum. I do this so he dosen't run out of money therefore forcing him onto Medicaid and forcing us to put him in a home. Where is the burden of care? on me!!! Now we are hearing budgets cut to the access public transportation he rides to and from day care. I will be forced to enroll my dad onto Medicaid this will cost the government more than $9,000 monthly.

We were not rich enough to hire an Elder Attorney to transfer my dads assets out of his name, nor do we feel it was our right. How many rich people are on Medicaid because they were taught to spend down their assets? Not one person in this country should be able to give their undeserving children an inheritance before they die, period! Not one person is more in need of skilled care than my dad 24/7 and I could qualify him in a heart beat if I pre-pay a funeral. However I know without a doubt that I am giving him better care than he would get in a home. He is happy in his home and everyday that he smiles and says thank you is a gift to me!

My recommendations give the families financial help to keep their loved ones at home. Give the care giver that quit her job a tax break, so they can continue to help send their own children to college. Allow people to hire quality private care givers, don't force an agency that charges double the hourly rate on us. Respite care that is now covered only under Medicaid, so that we can a least get a weeks break to refresh our minds would be nice! Stop taxing the elderly when they can prove every dime of there money is going to care for themselves. Adult Day care should be a medical expense.

I also see both sides of this story my in-laws were forced by 2 of their children to move to assisted living. They pay $4300 a month and my father-in-law takes care of his wife their and the home is very happy to have them. They should be, he does their job for them and they collect the pay check!!! They hate where they live!

There was a song written over 50 years ago the title is “The House of Shame” by Smiley Bates. My dad would call a local radio station almost every Saturday and request it, he then would call each of his children to tell them listen to it. I challenge you to listen to it, I did! Nothing has really changed in 50 years.

I am sorry this is so long, but unless you know the entire problem you can not fix it.

Sincerely,

Abby Kessner
Oakdale, PA

DATE: March 5, 2012
SUBJECT: Follow up on Informed Consent for Human Research and Testing Question

I request that you please refer the Advisory Council to the following http://ohsr.od.nih.gov/guidelines/nuremberg.html that discusses informed consent requirements for human research testing. Can you please forward this information to the Advisory Committee that is studying human research testing for citizens with Alzheimer's disease who may not be able to give informed consent.

NUREMBERG CODE

1. The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonable to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment.

   The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.
2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.
3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.
4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
5. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except, perhaps, in those experiments where the experimental physicians also serve as subjects.
6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.
9. During the course of the experiment the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.

10. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill and careful judgment required of him that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

Latifa Ring

DATE: March 5, 2012
SUBJECT: Draft National Plan to Address Alzheimer's Disease - Comments

Our company, Constant Care Family Management provides compassionate memory care in a home-like environment to individuals living with Alzheimer's and other forms of dementia.

We are very pleased knowing the Advisory Council is reaching out to the healthcare industry for ideas and input to better develop a well-rounded strategy that takes into account the many facets associated with Alzheimer's and dementia from educating people, broadcasting national awareness, helping the caregivers, to tackling the wandering problem.

Attached, please find our recommendations.

Once again, thank you for bringing this terrible epidemic to the forefront and making it a priority.

Warmest regards,

Dave Millheiser
Vice President, Marketing and Sales
Constant Care Family Management
The LaSalle Group
Irving, TX

ATTACHMENT: National.Plan.to.Address.Alzheimers.Disease.2012.Ver.II.DOCX

Available as separate links:	
Comments of Constant Care Family Management Submitted to HSS on the Draft Framework for the National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach79.pdf

DATE: March 5, 2012
SUBJECT: National Alzheimer's Project Act...Questions?

I was reading through your plan this weekend. CNS Vital Signs http://www.cnsvs.com is a small yet highly successful computerized neurocognitive assessment platform used by over 6500 clinicians in 52 countries. It is regularly used to assess neurocognitive impairment (see attached PDF). It significantly supports the new MCI Guidelines… I noticed Action 2.B.2 (see below) and was wondering if we can get more detailed information as to…

HOW & WHO WILL BE DOING THE ASSESSMENT OF THE NEUROCOGNITIVE ASSESSMENT TOOLS?
Will CNS Vital Signs be included in the mix of recommended tools?
Is there other contacts I should be making within this endeavor?
CNS Vital Signs has been used by most of the major pharmaceutical companies (2000 investigator sites worldwide) in clinical trials and we are working with some academic based neuropsychologists on a new tests. Is it possible for either the academic institutions or our small business to receive some funding to research - enhance the assessment of neurocognition using our assessment platform? How can we as a small business get help?

If you, your staff, or any interested parties would like a FREE TRIAL of our assessment platform… simply register at our website http://www.cnsvs.com; download the LOCAL software app… and begin testing… we also have a WEB app demo at https://www.cnsvs.com/index.php/demo-learn just follow the instructions.

I know this issue is of great importance to our country and we stand ready to help in any way possible.

Action 2.B.2: Identify and disseminate appropriate assessment tools
The Affordable Care Act created the Medicare Annual Wellness Visit. "Detection of any cognitive impairment" must be included as part of the wellness visit. HHS is using research findings to identify the most appropriate assessment tools that can be used in a variety of outpatient clinical settings to assess cognition. The recommended tools will be distributed to practitioners to aid in identification and evaluation of cognitive impairment and risk for dementia.

Regards,

Craig Fitzgerald
Vice President
CNS Vital Signs
Concussion Vital Signs
http://www.cnsvs.com
http://www.concussionvitalsigns.com

ATTACHMENT: VSX CNS Vital Signs Memory Healthy Aging White Paper.pdf

Available as separate links:	
CNS Vital Signs Memory and Health Aging	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach78.pdf

DATE: March 4, 2012
SUBJECT: The NAPA Project

I have worked in the healthcare industry for 20 plus years, specifically with the geriatric population. I am currently the Director of Therapeutic Recreation and Volunteer Services at a long term care facility in New York.

My comments, or rather hopes with this project are really very simple. I deal with individuals who have been diagnosed with Alzheimer's Disease and other types of Dementia and have lived with it for years, by the time they come to our facility they may have lived in the community for 1 to 5 years before a loved knew that taking care of them at home was no longer a safe option.

My hope is that this project builds in funds for caregivers who provide treatment modalities such as therapeutic recreation, music therapy, art therapy etc., treatments that do not include psychopharmacological components only, treatments that treat the individual as a person with a personality, with nuances to their personality,or rather their new personality that has manifested itself via the disease. Things like painting, singing, reminiscing, cooking, gardening etc are in fact very important parts of treatment for the person living with Alzheimer's Disease, and are sometimes the most important aspect related to the quality of life for the person and their families.

Please know that those who provide this type of treatment are people like me, A Certified Dementia Practioner, with a Master's Degree in Community Health, a quality of life specialist, who treat the person as a person and not just a symptom. I do know that this is cliche, but please know how important it is for the day to day activities of these individuals to have meaningful activity with a sense of purpose and focus and most important...dignity.

Please build in funds for these disciplines in this industry, I know how utterly important it is to provide funding for research towards a cure, but these patients, these people, these grandmothers and grandfathers etc. Must have activity and must have some meaningful quality to their lives until the day we find a cure.

Thank you so very much for your time and for working on this project.

Respectfully,

Carolyn Perito

DATE: March 4, 2012
SUBJECT: NAPA

I have read the draft and think it is great. I am a Gerontological Clinical Nurse Specialist and board certified though the ANCC since 1994. I am also a Certified Dementia Practitioner thru the National Council of Certified Dementia Practitioners. I think this type of certified educator would be beneficial. I would love to help in any way I can for this project.

And the final thing is that my Mom was diagnosed with AD last year -- so I am a caregiver as well. Thank you for this great initiative.

Linda J. Hassler, RN, MS, GCNS-BC
Geriatric Program Manager
Ann May Center for Nursing
Neptune, NJ

DATE: March 3, 2012
SUBJECT: Comment on Draft National Plan

I was very pleased to see the terminology **Alzheimer's Disease and related dementias (ADRD)** being used on the NAPA Web page (http://aspe.hhs.gov/daltcp/napa) I am the caregiver for my husband who has a related dementia (Primary Progressive Aphasia). My biggest concern with the draft National Plan document is the overwhelming usage of the term Alzheimer's Disease (AD) throughout the report. There are only two brief references to the other dementias in the entire report. I strongly encourage the Advisory Council to use the acronym **ADRD** in the final version of the report to replace AD. That kind of terminology would continuously keep those afflicted with "related dementias" in the forefront of the discussion. I also feel that an **expanded list of the related dementias** should be included in the report, perhaps in an appendix. Currently only four related dementias are mentioned.

Thank you for the wonderful work of the Advisory Council on this very important national concern.

Mary Beth Riedner
Schaumburg, IL

DATE: March 2, 2012
SUBJECT: Comment

I did not see anything planned for costs. Why is long term care not covered by Medicare, health insurance or Veterans Administration? Memory care is extremely expensive; it is basically round the clock care by skilled staff trained in Alzheimer care.

CDR Debra J. Hassinan, P.E.
Environmental Engineer Consultant
Indian Health Service
Office of Environmental Health and Engineering
Tempe, AZ

DATE: March 2, 2012
SUBJECT: Etiology of Neuro Degenerative Disease, Alzheimer, MS, Parkinson, ALS, Movies of Cerebro Spinal Fluid Leakage

Some Alzheimer patients show the presence of the amyloid protein. Leakage of Cerebro Spinal Fluid antigenic proteins, like the antigenic tau proteins, could be the source of the antigens generating the autoimmune reactions as the origin of Alzheimer lesions.

The tau proteins have been identified as a significant participant in Alzheimer's disease. There are indications that they are originating in the ventricular cerebro spinal fluid and leaking as a result of intercranial pressure. Alzheimer's may be the result of pathologic CSF hydrodynamics. If this condition can be corrected it could halt the progress of Alzheimer's.

Movies, detecting CSF leakage, with the Fonar, Upright MRI can be seen on the first page of our website http://www.fonar.com. This can be corrected as seen at http://www.fonar.com/news/110211.html.

These new findings are important in understanding neuro degenerative disease, not only Alzheimers. We would be available to speak speak to you in more detail.

Sincerely yours,

Art Brady
http://www.fonar.com

DATE: March 2, 2012
SUBJECT: Comment re: Draft National Alzheimer's Plan

Thanks for distributing my comments to the Advisory Board.

Dave Axelson
Redmond, OR

ATTACHMENT: ALZ DRAFT PLAN COMMENTARY.docx

Available as separate links:	
Commentary Re: "Draft National Plan to Address Alzheimer's Disease"	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach77.pdf

DATE: March 1, 2012
SUBJECT: let’s change

I am filled with wonder reading about the American historical decision in the ADRD problem: NAPA. It's not only a simple Government decision, but also a decision of the American People. The US Government and People continues to be an example and source of inspiration for all the World, because the ADRD problem involve the human, especially the human future.

In my opinion, the key of the origin of the ADRD will changed all the clasical medical science. It's inevitable to reflect about new ways, about new concepts in the medical science. For example, think only about one fact: in the fatal moment of an AD patient, frequently all the serum general data of this patient are...perfect.

Sicerely,

Cristian SOCOLOV.