

NAPA -- FACA 2012 Public Comments
(February Comments Only)
 April 6, 2012

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FEBRUARY 2012 COMMENTS

DATE: February 29, 2012

SUBJECT: Alzheimer's plan

The plan is comprehensive but fails to address a fundamental problem. The real funding decisions are made by the "peer review" process, and in Alzheimer's, at least, the peer review process is seriously flawed and excludes new researchers with new ideas, not because the reviewers consciously want to do this, but because the system makes it almost inevitable.

The reviewers, like all good scientists, are convinced their own ideas are right and worried that giving money to those with different ideas will take away funds from their own research and cost lives. Moreover, because they are working full time on their own research they clearly have no time to actually read the papers of grant applicants and just glance at the number of publications and the journals they appeared in. They tend to decide early on whether they support or oppose an idea, and go with their gut, providing details only to justify their position. This turns labs into paper mills that produce no real advances. Consequently I have been told many times that the only way to get funding for a new idea is to complete the entire study before applying for funding.

I work on the fundamental biochemistry of Alzheimer's, in the laboratory of Dr. Shaohua Xu, who was the first to image tau colloids using atomic force microscopy. We've worked months on NIH grants that were turned down by reviewers who obviously had not read the relevant papers and did not even make an effort to understand the proposal. Having research section members recuse themselves from judging their own grants obviously does not make this process objective; scientists are as susceptible to bias as any other human being. To deny this problem denies basic human psychology.

IF NIH expects to solve this problem, the NIH research section directors, who are not supported by grants, should have the authority to make the final funding decisions. They may have the help of reviewers but should have the full power to accept or reject reviewers' comments. They may not choose to fund our proposals, but at least they will be unbiased, and they have an incentive to find a cure, not to defend a theory.

Respectfully,

Dan Woodard, MD
Kennedy Space Center, FL

DATE: February 29, 2012
SUBJECT: Comment

Comment: I have had the opportunity to work with those struggling with Alzheimer's and other dementias and their caregivers for over 17 years. My main observation and suggestion is that these are very strong ,and willing individuals who have been presented with a huge challenge which last for many years and effects an entire family not just one individual. The best and most effective treatment out there is maintaining the historic emotional connection these individuals have with each other. This can be done through recognizing those caregivers and supporting them through strong educational and emotional support and respite care programs, such as Adult day programs.

Our physicians also need strong support in education and encouragement to assist those dealing with the many challenges of dementia. Recognize those who specialize in geriatric care.

Thank you for recognizing the challenge facing our nation with this disease and starting the process of dealing with it.

Ginny Berube ,BSSW
Case manager
Camano Island, WA

DATE: February 28, 2012
SUBJECT: Comments on NAPA Draft

First, thanks so very much to the committee and the US government for a comprehensive thoughtful plan. It is concrete. It is clear. And it is so encouraging to read! Please accept my comments below in context of my deep gratitude for all the work and initiative that created a plan worthy of response.

I have been a caregiver of two parents with AD/dementia over the past 4-5 years. As I tackled the problems of one, then two parents with AD/dementia, first cross country, then moving my mom to my city after losing my dad, I've been on a steep learning curve (over four years and counting) to learn and understand what's happening, what's the best thing to do, etc. I have grown as a caregiver, after having been a high-technology marketing executive for 20+ years. I am still learning, but I am also now a strong resource, having learned a great deal as I've grown with this responsibility.

Again, please know these comments are in response to a terrific draft.

Pg. 6, Guiding principle 3: Transform the way we approach Alzheimer's disease.

Completely agree. Would like to see "transformation" more aggressively articulated and delivered in Strategies for Goals 2-4.

Goal 1 & Strategies, pgs. 7-12, all reflect the three guiding principles, and demonstrate vision, initiative and innovation. Goal #1 strategies are impressively aggressive and actively embrace the acceleration in scientific and medical discoveries that is happening.

Goals 2-4 & Strategies, pgs. 13-27, are thorough but not transformative, not ambitious enough, not innovative, not visionary - they seem more safe, incremental, rote. Unlike Goal 1, Goals 2-4 are not "crossing the chasm" (per Geoffrey Moore's term for technologies that break with the past). "Breaking with the past" matters because a safe plan will not drive change fast enough to retrain the medical, legal and financial communities, support families and caregivers sufficiently, or change the cultural landscape to rally NOW. Here are a few thoughts about enhancing Goals 2-4 to make them more transformative, but innovation could be pushed even farther -

1. **Goals 2 and 3: For Caregivers, create a more transformative vision and more proactive, innovative strategies that view them not just in need of support and education, but as an active resource and collaborative partner.** In the first stages of stepping up to caregiving, I yearned for direct, straightforward information. I felt too many people hesitated to teach me how to think about Alzheimer's because a) they really didn't know and 2) every patient is different. But I've learned a lot that now could be shared, and much more quickly than I was taught. Five years later, I've stepped up, and I am now a strong resource. I realize that caregivers need a lot of support, but please leverage our expertise too. I do not want to be viewed as weak, helpless, or a victim. I want to be viewed as a collaborative partner with the ability to constructively contribute to a team and care plan. I know a lot of other caregivers have the same strength. Caregivers deserve recognition not only for their ongoing contribution, but also their varied skill levels and ability to actively participate in care planning, as well as training, with health care professionals. Develop a) a scale that measures caregiver experience and b) programs that harness and leverage experience. Create web-based training modules that track a caregiver's growing capabilities. In the Draft Plan, change language that views caregivers as "helped", "supported" and "dependent" on the system. Where

appropriate, decouple caregivers from those with AD, again to include them in a more active collaborative model, not just attached to their loved ones with AD.

Other suggestions to add a little more transformation into Goals 2 and 3 -

- Add an Action 2.A.7 that develops a way to connect experienced caregivers to the health care "workforce" - recognize an active role for caregivers.
- In Strategy 3.B, add an Action for Caregiver Financial Supports, including social security credit, tax credits, and 401k waiver of fees for those who lose income when they must support family with Alzheimer's and cannot continue to work. As an experienced business person/MBA, I felt unsupported and invisible by a lack of financial support/incentive. A few changes would not only offer a financial boost, but a moral boost. It's depressing to be financially invisible/taken for granted, even as one works to do the right thing.
- Strategy 3.C reads as though it's all about money and the pros know best. The source and the message are as much the problem as the audience. "Educating people about their potential needs" requires an honest setting of expectations that frankly I have not seen in medical professionals and certainly not financial professionals. This section needs a more transformative, "glass breaking" approach, not simply awareness building. People know a little about LTC, etc., but the costs are high and the sales pitches are muddled. (My parents had LTC insurance and it has made a tremendous difference.)
- Strategy 3.D is very important and is very clear. Action 3.D.1- please insert "Educate legal *<and financial>* professionals..." because financial professionals aren't very informed either about the impact of the disease on an elder's ability to make financial decisions.
- Action 3.D.2 is transformative. So is Strategy 3.E. Thank you.

2. **To achieve transformation, Goal 4 needs a more aggressive, ambitious articulation with trackable results that are very high impact.** The current Goal 4 does not reflect a vision or ambition for awareness building. Strategy 4.A, "Educate the public about AD" seems tame, neither aggressive nor transformative. Public awareness of AD is high, but based on bad information and stigmas. The stigma of AD prevents learning. Campaign strategy needs to aim higher than awareness building: start with the goal of erasing the stigma of AD, and replacing it with an embrace of the humanity of those with AD and the ambitions to eradicate AD.

Again, please know how grateful I am, as a caregiver to two parents with AD/dementia, that a National Plan to attack Alzheimer's exists. I send these comments from the front line, and ask that you consider them with the respect and gratitude in which they are offered.

Sincerely,

Suzanne Brisendine
San Francisco, CA

DATE: February 28, 2012

SUBJECT: Public Comments on the Draft National Alzheimer's Plan

Please find attached the public comments on the draft of the National Alzheimer's Plan by the Rosalynn Carter Institute for Caregiving. I note that in several areas of the draft are opportunities to serve on a panel or participate in a meeting. Please know that the Rosalynn Carter Institute for Caregiving would be willing to serve and work together to address the needs of caregivers caring for those with Alzheimer's disease.

Thanks,

Leisa Easom, PhD, RN
Executive Director
Rosalynn Carter Institute for Caregiving
Georgia Southwestern State University
Americus, GA

ATTACHMENT: National Alzheimer's Plan Public Comments.pdf

<i>Available as separate links:</i>	
Public Comments on Draft National Plan to Address Alzheimer's disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach76.pdf

DATE: February 27, 2012

SUBJECT: A national plan to address Alzheimer's

I strongly support Mr. Vradenberg's plan and plea to eliminate alzheimers disease by 2025, It is clearly becoming epidenic in proportion and needs strong advocacy and support. only the government with private help can produce these results so let us push for both.

Carolyn Alper

DATE: February 26, 2012

SUBJECT: Public comment on National Plan to overcome Alzheimer's disease and related dementias

1. Please support neurologists who want to specialize in behavioral neurology & neuropsychiatry. We are not mentioned in Action 2.A.2.

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

HHS will enhance three programs that encourage providers to focus on geriatric specialties. The Comprehensive Geriatric Education Program, as mandated by the Affordable Care Act, provides traineeships to support students pursuing advanced degrees in geriatric nursing, long-term services and supports, and gero-psychiatric nursing. In addition, HRSA will continue to support training projects that provide fellowships for individuals studying to be geriatricians, geriatric dentists, or geriatric psychiatrists. These programs prepare professionals to address the needs of people with Alzheimer's disease through service rotations in different care settings. HRSA will also continue to support the career development of geriatric specialists in academia through the Geriatric Academic Career Awards Program. Currently 65 percent of these awardees provide interprofessional clinical training on Alzheimer's disease.

2. Please consider the neurologists who many patients consider their primary physicians. May neurologist shy away from taking care of patients with dementia because of the time required and low reimbursement for this cognitive speciality.

Action 2.E.1: Evaluate the effectiveness of medical home models for people with AD

Medical homes utilize a team approach to provide care and to improve the quality and coordination of health care services. CMMI is currently carrying out the Multi-payer Advanced Primary Care Practice Demonstration and the Comprehensive Primary Care initiative to measure the effectiveness of medical home models. CMMI will conduct subgroup analyses to examine changes in care quality and care coordination among people with AD to explore whether these models lead to more effective and efficient care.

Mary Ellen Quiceno, M.D.

Assistant Professor of Neurology

Director, Cognitive & Memory Disorders Clinic

Leader, Education & Information Core of the Alzheimer Disease Center

University of Texas Southwestern Medical Center at Dallas

DATE: February 26, 2012
SUBJECT: New Alzheimer's Initiative

It is interesting that the NIA-AA definitions for Dementia are not used in this proposal. And yet, other causes of Dementia are included (Alzheimer's disease and related dementias) I suggest that there be some consistency and support for other groups working on this project by at least using the same terminology.

This should be an effort to decrease dementia with an emphasis on funds to treat the things we can treat, funds to research the things we can not yet treat and funds to support the families and caregivers of all those with dementia.

Michael Raab, MD

DATE: February 24, 2012
SUBJECT: PUBLIC COMMENT ON FEDERAL REGISTER this agency will vote to fill the elders with 200 vaccines to make money off their bodies

I AM WRITING TO COMPLAINT ABOUT \$130 MILLION ALL OF A SUDDEN BEING USED BY OBAMA IN AN ATTEMPT TO WIN VOTES. HE DID NOTH ING ON THIS FOR 3 YEARS. NOW WITH ELECTION COMING UP, HE STARTS SPENDING AND SPENDING AND SPENDING. I SEE A WHOLE LOT OF FAT CAT BUREAUCRATS ARE GETTING JOBS. THE PLAN WILL BE A LOT OF FAT CAT BUREUACRAT RELATIVES OF POLITICIANS WILL GET JOBS. THEY WILL HAVE MEETINGS AND SIT AROUND FOR 2 OR 3 YEARS UNTIL THE MONEY IS GONE. WHEN MONEY IS GONE, NOT ONE DARN THING WILL HAVE CHANGED IN AMERICA. THESE GOVT AGENCIES ARE THE BIGGEST WASTERS OF TIME AND MONEY ON THE GLOBE. THE BUDGET FOR THIS SHOULD BE ZERO. THIS AGENCY SHOULD HAVE BEEN GIVEN THE PROJECT WITH NO ADDITIONAL FUNDS AT ALL. THESE EMPLOYEES WASTE TIME EVERY DAY.

JEAN PUBLIC

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Date: Fri, 24 Feb 2012 10:37:25 -0500
Subject: this agency will vote to fill the elders with 200 vaccines to make money off their bodies
From: [withheld]
To: [withheld]
[Federal Register Volume 77, Number 37 (Friday, February 24, 2012)]
[Notices]
[Pages 11116-11117]
From the Federal Register Online via the Government Printing Office [<http://www.gpo.gov>]
[FR Doc No: 2012-4278]

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Draft National Plan To Address Alzheimer's Disease

AGENCY: Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services.

ACTION: Comment period.

SUMMARY: HHS is soliciting public input on the draft National Plan to Address Alzheimer's Disease, which is available at <http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml>.

DATES: Submit input by email or USPS mail before March 30, 2012.

ADDRESSES: You may submit your comments in one of two ways:

1. Electronically. You may submit electronic comments to napa@hhs.gov
2. By mail. You may mail written comments to: Helen Lamont, Ph.D., Office of the Assistant Secretary for Planning and Evaluation, Room 424E Humphrey Building, Department of Health and Human Services, 200 Independence Avenue SW., Washington, DC 20201.

Please allow sufficient time for mailed comments to be received before the close of the comment period.

FOR FURTHER INFORMATION CONTACT: Helen Lamont (202) 690-7996, helen.lamont@hhs.gov.

SUPPLEMENTARY INFORMATION: Inspection of all Public Comments: All comments received before the close of the comment period are available for viewing by the public, including any personally identifiable or confidential business information that is included in a comment. We post all comments received on the following Web site as soon as possible after they have been received: <http://aspe.hhs.gov/daltcp/napa/#comments>.

Background

On January 4, 2011, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA), requiring the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:

[[Page 11117]]

- Create and maintain an integrated national plan to overcome Alzheimer's disease.
- Coordinate Alzheimer's disease research and services across all federal agencies.
- Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease.
- Improve early diagnosis and coordination of care and treatment of Alzheimer's disease.
- Improve outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's disease.
- Coordinate with international bodies to fight Alzheimer's globally.

The law also establishes the Advisory Council on Alzheimer's Research, Care, and Services and requires the Secretary of HHS, in collaboration with the Advisory Council, to create and maintain a national plan to overcome Alzheimer's disease (AD).

On February 22, 2012, HHS released a draft National Plan to Address Alzheimer's Disease. The draft National Plan has five 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.

The draft National Plan includes strategies to achieve each goal and specific actions that HHS or its federal partners will take to drive progress towards achieving the goal.

Sherry Glied,
Assistant Secretary for Planning and Evaluation.
[FR Doc. 2012-4278 Filed 2-23-12; 8:45 am]
BILLING CODE P

DATE: February 24, 2012

SUBJECT: Informed Consent for Human Research and Testing Question

What EXACTLY is HHS and NIH doing to ensure that people who are enrolled in your Medical (Human) Research and Clinical Trials that you are desperately trying to recruit Alzheimer's patients for have the CAPACITY to give INFORMED CONSENT?

History has shown that some of the most abusive governments in History used vulnerable elderly and incapacitated patients for medical and human research. This was addressed international laws and federal laws in this country.

As an elder rights advocate, I am extremely concerned about the mad rush to do testing on individuals who have been declared incompetent or incapacitated and who do not have the capacity to give informed consent. No surrogate decision maker should be allowed to give informed consent on behalf of any other human being. The surrogate decision maker cannot feel the pain and horrific side effects and the incapacitated person with Alzheimer's may suffer immensely but not be able to even communicate the pain they are involuntarily being forced to endure.

What do you plan to do about this? An all out campaign is needed to HALT any plans to use incapacitated Alzheimer's and dementia patients for human research trials (including drug and other medical research) without informed consent being provided by the individual who will be subjected to the human research and testing!

The press needs to get involved in warning the American people about this travesty.

Please let me know what we can do to ensure that these concerns are addressed.

Latifa Ring

National Organization To Stop Elder Abuse and Guardianship Abuse

<http://www.stopelderabuse.net>

DATE: February 24, 2012
SUBJECT: COMMENTS ON NAPA ACT DRAFT PLAN

OVERALL I FIND THE DRAFT PLAN A REASONABLE AND READABLE DOCUMENT, EVEN THE HHS BOILERPLATE. I HAVE SOME COMMENTS WHICH ARE BASED ON MY OWN EXPERIENCE, WHICH I WILL STATE BRIEFLY: MY WIFE, MARTHA, WAS DIAGNOSED WITH A/D AND COPD IN THE FALL OF 2007. I CARED FOR HER AT HOME WITH SOME RESPITE ASSISTANCE UNTIL I COULD NO LONGER DO SO IN JULY OF 2009. I MOVED HER TO AN ASSISTED LIVING FACILITY FOR SIX MONTHS AFTER WHICH TWO HOSPITALIZATIONS MADE IT NECESSARY TO PUT HER IN A HOSPICE FACILITY FOR THE NEXT SIX MONTHS. IN JUNE OF 2010 I BROUGHT HER TO THE HOUSE ON HOME HOSPICE. I WILL NEVER REGRET DOING THAT. AFTER 55 DAYS, ON AUGUST 4th, 2010, SHE DIED.

PAGE TWO OF THE PLAN LISTS FOUR GOALS. TWO OF THEM ARE: "... ENHANCE HEALTHCARE PROVIDERS' KNOWLEDGE ...", AND "... SUPPORT FOR PEOPLE WITH ALZHEIMER'S DISEASE AND CAREGIVERS ...". THEY ARE IN THE MIDDLE OF THE GOALS. I THINK THAT THEY SHOULD BE GIVEN MORE PROMINENCE AND A GREATER SENSE OF URGENCY. WHY? BECAUSE DISCONTINUITIES IN AVAILABLE MEDICAL CARE ARE A SERIOUS AND GROWING PROBLEM - RIGHT NOW - AND ALZHEIMER'S SUFFERERS AND THEIR CAREGIVERS ARE PAYING THE PRICE - RIGHT NOW. WE ALL HOPE THAT EVENTUALLY A CURE WILL BE FOUND FOR ALZHEIMER'S. BUT AN IMMEDIATE AND MORE ACUTE PROBLEM IS COHERENT AND GRADUATED CARE FOR ALZHEIMER'S AS THE DISEASE PROGRESSES, AND RELIEF FOR THE BURDEN THIS PLACES ON CAREGIVERS.

THIS IS WHAT HAPPENED TO US:

1. IT WAS LIKE PULLING TEETH TO GET A DIAGNOSIS. AFTER TWO \$600 SESSIONS WITH A MEDICAL "EXPERT" IN THE SPRING AND FALL OF 2007, HE STILL WOULD NOT DIAGNOSE A/D. OUR FAMILY DOCTOR, AN INTERNIST, HAD TO MAKE THE CALL AND BEGIN TREATMENT.
2. IN JULY 2009, AFTER A HELLISH TWO WEEKS IN A BEHAVIORAL HEALTH CLINIC TO GET THE RIGHT DOSAGE OF A/D DRUGS, THE DOSAGES STILL WERE NOT RIGHT AND OUR INTERNIST HAD TO MAKE THE ADJUSTMENTS LATER.
3. BY THE FALL OF 2009 15-MINUTE APPOINTMENTS WITH OUR INTERNIST WERE NO LONGER ENOUGH BUT THERE WAS NO AVAILABLE MEDICAL "NEXT STEP". I FOUND THAT AT LEAST IN NORTHERN MISSISSIPPI, ALL THE GERIATRICIANS HAVE BEEN COOPTED AND ABSORBED BY THE HOSPITAL-HOSPICE, NURSING HOME OR HOSPICE INDUSTRIES. THESE INSTITUTIONS ARE NOT DESIGNED FOR AND DO NOT WANT ALZHEIMER'S PATIENTS. THEY PREFER PATIENTS WHO NEED MONEY-MAKING REHABILITATIVE THERAPIES.
4. MONEY IS NOT THE WHOLE ANSWER. WE HAD NURSING HOME INSURANCE, WHICH WOULD HAVE PAID UP TO \$254 A DAY. NURSING HOMES COSTING \$230

A DAY HAD NO OPENINGS, PREFERRING PATIENTS NEEDING THERAPIES. I OPTED FOR A \$90 A DAY ASSISTED LIVING FACILITY, WHICH WAS FINE UNTIL SHE WAS BED-RIDDEN AND HER NEEDS BECAME TOO GREAT FOR ASSISTED LIVING. AS IT WAS, BECAUSE OF THE 90-DAY EXCLUSION ON OUR NURSING HOME INSURANCE, WE BARELY BROKE EVEN ON THAT POLICY.

5. THE NEXT TRANSITION, AND IT WAS ABRUPT, WAS TO A HOSPICE FACILITY. THE HOSPICE BILLED MEDICARE \$1000 A DAY FOR HER CARE. HER CARE THERE WAS PERHAPS TWICE AS GOOD AS IN ASSISTED LIVING, BUT IT WAS NOT ELEVEN TIMES AS GOOD AS THE BILLING WOULD SUGGEST. THE MEDICARE HOSPICE BENEFIT IS A WONDERFUL THING, BUT THE HOSPICE INDUSTRY IS GETTING FAT ON WHAT IT CHARGES, AND IT IS COMPLETELY INADEQUATE FOR THE TREATMENT OF ALZHEIMER'S.
6. THE LAST TRANSITION WAS IN JUNE OF 2010 AND IT WAS ALSO ABRUPT. I WAS TOLD SHE HAD TIMED OUT OF IN-PATIENT HOSPICE. I FOUND THAT NURSING HOMES WERE STILL NOT INTERESTED IN HER AS A PATIENT SO I OPTED FOR HOME HOSPICE. I PERSONALLY PREFERRED THAT TO A NURSING HOME, BUT EVEN THOUGH I HIRED A CNA AND AN LPN TO SUPPLEMENT MY EFFORTS AND THE HOME HOSPICE EFFORT, WHICH WAS UNEVEN, HER CARE WAS NOT AS GOOD AS THAT IN A NURSING HOME . BUT, HOME HOSPICE STILL BILLED MEDICARE \$250 A DAY, WHICH WAS MORE THAN A NURSING HOME.

I SAY AGAIN THAT CONTINUITY OF COHERENT AND GRADUATED MEDICAL CARE FOR THE ALZHEIMER'S PATIENT AND RELIEF FOR THE CAREGIVER IS AN ACUTE AND GROWING PROBLEM THAT NEEDS GREATER EMPHASIS IN YOUR PLAN. IT IS A - RIGHT NOW - PROBLEM, NOT SOMETHING THAT CAN BE CHIPPED AWAY AT OVER TIME. BECAUSE OF MY WIFE'S COPD COMPLICATION, WHICH REQUIRED 24/7 OXYGEN, OUR ORDEAL WAS MERCIFULLY SHORTER, LESS THAN THREE YEARS, THAN IS TYPICAL FOR ALZHEIMER'S PATIENTS AND CAREGIVERS. OTHERS HAVE IT HARDER THAN WE DID.

I HAVE DETAILED RECORDS FOR EVERYTHING I HAVE SAID ABOVE. I CAN PROVIDE ANYTHING MORE THAT YOU NEED FROM ME.

THOMAS A. LOGAN
BELDEN, MS

DATE: February 24, 2012
SUBJECT: Alzheimer's Project

Adult day health services should be an important part of any plan to either slow the progress of Alzheimer's, improve quality of life, or to support caregivers.

Social interaction, rather than isolation at home, and physical and mental stimulation are keys to slowing memory loss, preventing agitation, and enhancing life.

Caregivers of people with Alzheimer's are more likely to suffer debilitating illnesses themselves so respite is important.

Adult day health services can be all of the above.

Linda Cabiness
Community Outreach Coordinator
Life Enrichment Center Adult Day Care & Health Service
Shelby, NC
<http://www.lifeenrichmentcenter.org>

DATE: February 24, 2012

SUBJECT: Comment (National Proposal for \$1B+ Healthcare cost savings annually)

Please post the attached Comment/Proposal, which could potentially save the nation \$1B+ annually in national healthcare costs through innovation and prevention relative to Dementia. I would appreciate a confirmation email. Thank you.

Ray Ashton
Founder, STAR-10R
Chairman, CEO
STAR Preventive Wellness
AFFECTS LLC
<http://www.affects.biz>

ATTACHMENT: STAR-10R Proposal.docx

Available as separate links:

Proposal: Early Stage Dementia Care (STAR-10R), a New Thinking For Dementia Care	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach75.pdf
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DATE: February 23, 2012
SUBJECT: Draft National Alzheimer's Plan

As a 66-year old woman who is conservator for a relative with Alzheimer's and who has watched several other relatives lose their mental faculties and eventually all their other faculties before they died a very long drawn out death, I cannot urge you enough to increase the amount of money spent on research into Alzheimer's and other dementia diseases. Yes, Alzheimer's is devastating to the individual and possibly even more so to the families and caregivers.

When I see that HIV/AIDS research receives about \$3 billion from our government whereas Alzheimer's, with 5 times as many affected Americans as there are American HIV patients, even with this new initiative will only get half a billion dollars, I truly don't understand why research into Alzheimer's is so underfunded. I also don't understand why HIV/AIDS patients receive much more government paid assistance than patients with most other diseases. I'm afraid the Alzheimer's lobby has not been vocal enough unlike the HIV/AIDS lobby. But I admire what has been accomplished in making HIV now a treatable chronic illness because of the resources invested in that research.

Don't waste a lot of funding looking for more expensive ways to diagnose Alzheimer's when simple questionnaires and interviews can determine that dementia is present or not. Since dementia is not contagious early diagnosis is only helpful for getting your affairs in order until a viable treatment is discovered.

Unfortunately none of the drugs currently used for Alzheimer's have any long-term benefit and even short-term benefits are questionable. Basic research into what causes or leads to Alzheimer's is where most of the funding needs to go. Hopefully this could lead to understanding how to avoid Alzheimer's altogether as prevention is always preferable and less expensive than treatment. It is important to include nutritional supplements such as curcumin and vinpocetine in the research since studies have demonstrated some success with several supplements. Just because they can't be patented by drug companies, not enough money is being spent on their research. How cost effective they would be for both patients and the health care system.

If prevention and/or treatment of Alzheimer's and other dementias is not found soon the cost to the government will be astronomical in the future, as families have less ability and inclination to care for dementia patients at home. I predict dementia patients will frequently be abandoned so they can receive medicaid-paid nursing home care.

I urge the Alzheimer's plan to be implemented quickly and research funding be increased exponentially.

Martha Dragoo
Colusa, CA

DATE: February 23, 2012
SUBJECT: NAPA

\$450 million for Alzheimer's research; \$3 billion for AIDS. In 2011, total Medicare and Medicaid spending for individuals with Alzheimer's disease was estimated at \$130 billion. \$450 million is NOT enough and 2025 is NOT soon enough. We can do better. Spend the money on the front end; alleviate the suffering and find a cure NOW!

Lynda Everman

DATE: February 23, 2012

SUBJECT: Comment on Draft National Plan to Address Alzheimer's Disease and Related Dementias

Although the draft does make mention of the use of psychologists in the treatment and care of Alzheimer's disease, I find it curious that nowhere in the draft is the role of clinical neuropsychologists and early assessment of cognitive problems mentioned (particularly under the heading Strategy 1.C: Accelerate efforts to identify early and presymptomatic stages of Alzheimer's disease).

This lack of attention to the role well qualified clinical neuropsychologists can have in early detection is unfortunate given that a thorough assessment can often differentiate between Alzheimer's disease and other cognitive concerns before anything is found on neuroimaging, leading to earlier interventions.

Liv E. Miller, Psy.D.
Clinical Neuropsychologist
Central Arkansas Veterans Healthcare System
North Little Rock, AR

DATE: February 23, 2012

SUBJECT: comments re Draft National Plan to Address Alzheimer's Disease and Related Dementias

In reference to the Draft National Plan to Address Alzheimer's Disease and Related Dementias, as a psychologist I have found that I have been able to start the process of Alzheimer's identification by simple screenings such as MMSE or RBANS. If the Alzheimer's process is far advanced the screens alone can be sufficient, if not, it's an indication for further neuropsychological testing. I have found working in an outpatient primary care clinic that physicians rely on psychologists to help them with diagnosis of memory or other cognitive disorders. Psychologists and neuropsychologists then, should be an integral part of this initiative.

Christina Stauble, Psy.D
Clinical Psychologist
Jacksonville OPC, NF/SGVAMC

DATE: February 23, 2012
SUBJECT: Meet with President Obama

By now I think most of you know who I am. I will be coming to Washington DC in April from the 23-25. I had the opportunity to meet with many members of congress and senate this past year. I even had an opportunity to speak with Melody Barnes and Jeff Crowley, but it saddens me that they moved on. I would love to have the opportunity to meet with, President Obama, so he can personally understand what people like me deal with and our needs. I hope he is willing to hear from one of his constituents, that represents so many.

I am reaching out to many of you because I am hoping one, will be able to pave the way for my visit. Please help me accomplish this goal, while my mind is still functioning. If at all possible I would like to meet on the 25th, if that is not doable, I can be there on the other days. Remember I am 53 years old and most people are not willing to take this step, but someone must for all those who can't.

Please help me with my dreams of changing this world around Alzheimer's.

Regards,

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

P.S. I will need access for my wife Shari, who is in the medical profession, and someone from the Alzheimer Association to accompany us.

DATE: February 23, 2012
SUBJECT: Public Comments

Please address the lack of funding to provide intermediate care (Assisted Living) for those with early Dementia. This group often can no longer live at home safely, due to lack of family support or resources, but are not yet debilitated enough to meet criteria for Nursing home. Few insurance policies cover Assist living, and Medicare doesn't cover this setting either. There is a state program which with a "wavier" funding is available, but this doesn't nearly cover all who could benefit from this level of care. Thank you for considering this important issue.

Leslie A. Briscoe CNP
Cleveland, OH

DATE: February 23, 2012
SUBJECT: Life an ego-friendly lifestyle

In relation to your research, published by the European College on Psychopharmacology, published by Reuters agency on 05.09.2011, from Prof. Dr. Hans-Ulrich Wittchen, I'm sending you the attached material.

SCREEN OF THE HEALTH IN THE HAIRY BACK

Today we are living in a world filled with tension, broken families, psychological whirlpool and local wars. The human self is torn apart, and it seems that prevents million of people from being together and free. We consider that the reason for this is the Syndrome of the Emotional Breakdown (SEB), that has a visible external sign. We are convinced that there is a functional virus, that penetrates the limbic system of the human brain, as a result of improper emotional impact.

Remarkably, during the course of evolution, the human had developed his brain to a level, to be able to hurt himself by means of thoughts. There exist mental viruses, or functional viruses. They cause a contamination in the emotional assessments of the humans, and as a result of this he develops a diagnosis SEB. The contaminated person generates in the course of his daily life toxic thoughts that create in egological contamination.

In a person living with SEB, in the hairy back of the head could be visualised a red patch in different shades - from light pink, through bright red, to dark purple. It could be on spots, or on well-seen red figures - different variants exist. When the patch becomes dark purple, it means that this individual is about 30-40 hours away from death.

We consider that the SEB is a reason for destruction of personality, the reason makes people live in disharmony with themselves and with society.

How could Homo Sapiens be infected with the SEB f.virus?

By receiving improper emotional value, quarrel in a bus, short negative telephone conversation, scolding a child for breaking by accident the Christmas toy, not keeping the right of way on a crossroad, watching a conflicting T.V. show - in short experiencing negative feeling. (1)

The very act of infecting is a mental action, aimed at hurting someone. In such a way an individual, or the society as a whole could be infected. Each person is in constant contact with other. Even the mere presence without talking, or seeing is a form of contact.

Long time ago the man had invented the mental weapon, but still there is no vaccine, or some kind of defence against the negative impact, that only humans are able to inflict upon each other. That is why when we are hurting others, we are hurting also ourselves.

After the f.virus gets in the limbic system it may be inactive for a period of time - sometimes it may take years before it strikes the host. An egological contamination of the planet is being created.

It has been observed, that in infants, the patch disappears after a proper drug treatment and parents care. There are adults with a well visible path, their body is fighting to reach the necessary balance.

A man is a buld in such a way, that from the day he was born till his last day he fights with the debalancing cataclysms.All the known pharmakopea exist in the human body - it is a system by itselfs. The patch is like a screen that reflects one's health status.

Unfortunately,still the drug or the vaccine to fight the SEB is not invented. There is a danger to human health when the SEB becomes host's essence. The f.virus contaminates the emotional assessment,which like a ruffled mirror reflects the incoming emotional values feelings like agression,envy,hatrear, jealousy,indifference,addictional to alcohol, drugs,gambling,lonelines and pathology like diabetes,AIDS,cancer,cirrhosis, etc - the list could be quite long.There are different medical brands,fighting to balance the existing total disbalance.

For better clarity in determing the degree of contamination the following levels of SEB are distinguished:

Level 1

Humans,trying to get into conflict at first opportunity, or that are impartial to the suffiring of the surrounding people.The most typical feelings of these people are agression, hatred,jealiusy, greediness.The patch is light pink in colour,small in siza, andvery dangerous to to the host himself and to the surrounding.Family quarrels, cold blooded and cruel murders, divorces, etc. are due to the fighting hormons in the blood and cells of the host.We observe these people not as defendants,but as victims.Of course according to the law, everybody is responsible for his own actions.The people at 1-st level are most dangerous for themselves, and for the society as a whole.Their live is subjected to this plague of 21-st century.

Level 2- This level is causing the world economic crisis!

People that are infected with Level 2 cannot make a reightful assessment of the necessity of the investments for the benefit of the society.If we appoint a Level 2 infected person at leading position at a financial structure,the collaps of the institutiuin is immienent. This condition is known as business destroyer.These are people that cannot distinguish between a friendly and enemy hand.Such people have difficulty finding a job, and cannot find their place in prosperous structures, if ultimately they get into such structures, it is for a very short time - 2 - 3 months.The patch is like drops of spray - small, red and very dangerous for the host's business.Such person is better not be an entrepreneur.

Level 3

This is the level of the addicted to drugs, alcohol, tobacco, gambling, etc.These people think that being healthy or not is out of theirmanageability. Is there an alcoholic that considers that alcohol is dangerous to his health? Is there a gambler who does not believe that with the next bid he will get back the lost money, of not today, then tomorrow? The patch is red and big.It is very difficult to get out of this level, and it will long time.Large part of the body is contaminated, and this could be overcome only with relevant therapy and will.

Level 4

This is level of chronic diseases like diabetes, cancer high blood pressure, apathy, depression, psoriasis, etc. The patch is very big and pink to purple in colour.People at this level are better strict to medecines an diets, known to the traditional medicine.

Level 5

Level 5 is little known, because there is no coming back. The patch is big purple - a warning that death is knocking on the door. Mothers had observed such patch at the back of their children that committed suicide. The patch disappears 12 hours after death.

It is possible to suffer from chronic illness, without having SEB. It is possible to live the whole life without SEB. The patch is like a screen of the health status that warns, that if body could not cope by itself, it will need appropriate intervention - medical, egological or surgical. Many people live having the patch, but SEB had not turned to be their essence.

When SEB controls the man?

When the emotional perception is constantly disturbed. In a strong way the f.virus modifies the incoming emotional values. It is known, that when the SEB f.virus settles in the limbic system of the Homo Sapiens, it transforms the impulses to the pituitary. In the limbic system are built chains of nervous limbic ways. Some of them by means of the thalamic cores end in the cortex. In such a way the impulses coming from the limbic system are integrated into the nervous system.

Other ways end in the hypothalamic cores. Through the cores the functional influence is transmitted to the cores the functional influence is transmitted to the pituitary gland and to the entire endocrine system. Through these ways an influence is effected also on the vegetative visceromotor cores. Thus the activity of the limbic system is interconnected with the endocrine organs, locomotive organs, the heart. They participate in the emotional behavior of the individual.

The endocrine glands produce one or several hormones. By means of blood flow these hormones reach all parts of the body, but effect influence only on some of them. A regulation of the function of the body is effected by means organic substances dispersed in body liquids.

The endocrine glands excrete secretion in the blood. They are in close functional connection with the nervous system. When the improper emotional value enters the individual through the way known to medicine, it is lead to the pituitary gland. The latter signals the relevant endocrine gland, and in case the individual is contaminated by SEB, a hormonal ingredient is being created, which is of no need to the body in this particular moment. This hormonal substance jams the mitochondria in the cells with parahormonal substance.

Thus the cell changes its mass. It cannot breathe and capsules itself, and cannot function properly. If this cell happens to be a neuron, pathologic change in the brain could occur, as a result of SEB. By this very mechanism excess quantities enter into mitochondria of the muscle fibres, the structure of the cells of the locomotive apparatus changes, the structure of the host organs changes.

The foundations of the science called Egology, the studies and fights the SEB for more 24 years, are laid in Bulgaria. In a center Egology, for more 24 years the influence of SEB is being ignored, more nine thousand photos are made to visualise the SEB. The cell mass of thousands of people is regenerated under a strict medical supervision. For the purpose of visualisation and indirect attack to ignore the SEB special test are created, that shows its availability in a person. Exist SEB-indirect neutralizers, Neutralizers are created that in an unexplainable way collect within themselves inorganic substances. The neutralizers like from the man the egological contamination. They change their colour without changing its structures. In the web

seite egology by you can find filmed opinions thousands of patients that recover their health status after the SEB had been removed from them. In these cases the SEB red patch fades.

The tests are personal and for single use. They discover faultlessly the contamination, thus warning the individual. Exist also products, that help to balance the emotional status- internet side <http://egologia.bg>.

best regards

Juriy Peykov
Sofia

DATE: February 22, 2012
SUBJECT: Comment on draft plan-research

The document is very well written and comprehensive, but I am concerned that it does not yet insure sufficient diversity in ideas for research funding. The majority of investigators, including most of the "top dogs" remain single mindedly focused on amyloid-centric therapeutic targets leaving little room for expansion into other areas. Rather than relying on an annual consensus meeting in which I expect the loudest and most dominant voices to prevail (again), it might instead be more effective to explicitly state that several promising areas will be encouraged for funding. Further thought might even be given up front to defining those areas (including a miscellaneous category to anticipate unexpected possibilities) and quantifying the funds allocated to each (e.g., 50% for basic science/50% for clinical research; among the basic science 50% for amyloid related work, 30% for tau related work, 15% for apoe and 5% miscellaneous; among the clinical research, 60% for clinical trials and 40% for original investigations). Something like that...and then consensus panels could be created within each subgroup. In my opinion the greatest threat to AD research is not the total dollars but how they end up being allocated. This would address the allocation concern.

Richard J. Caselli, M.D.

DATE: February 22, 2012

SUBJECT: Draft National Plan to Address Alzheimer's Disease and Related Dementias -
Public Comment

Thank you for the opportunity to comment on the Draft National Plan to Address Alzheimer's Disease and Related Dementias. I am glad to see some immediate increased funding for AD and the call for a research summit. I would hope to see increased emphasis on geriatric workforce development and caregiver support with more specific language (i.e. scholarship loan paybacks, exemption of geriatric training from residency caps, Medicare and State Medicaid caregiver support and respite programs).

Best wishes,

James S. Powers MD
Associate Professor of Medicine
Vanderbilt University Medical Center

DATE: February 22, 2012
SUBJECT: Michael Ellenbogen's comments on draft National Plan to fight Alzheimer's Disease

First of all I would like to thank you all for the progress that has been made on this important development in the war against Alzheimer's. While I cannot say I am happy, I do feel better with some of the wording in goal number 1.

I strongly recommend that you find it in your hearts and guts to make the statement even stronger. Let's change that date to **2020 and show some urgency** in the matter. Too many people are dying. The way they die is not a pretty site and no family should ever have to see this first hand. If I could only share some of the horror stories I have read, it scared me to death that my family may have to endure that with me. I do not want to become a burden on my family, society or even the healthcare system.

Something that has not been mentioned in this report and should also be considered is for the right to die sooner with the help of doctors. When I get to the point that my brain is no longer functioning, I want to be put out of my misery. I want to go out with dignity and be remembered for the good things I have done and not what I will be come soon. I also want my family to remember me that way, not in my pains and suffering along with their frustrations of dealing with me. I know this is a tough subject to speak about, but we all are adults and need to keep an open mind. This decision would benefit so many not only emotionally, but financially.

As far as the extra money being allocated to this, I would say we are still falling very short. HIV receives so much more in funding then Alzheimer's. Yet there are more people living with Alzheimer. Where is the justice in all this? Does this make any sense at all? While we have made some funding progress, do not fool yourself. We need to do a lot more now, even if it means to move some of the other funding from other diseases to this category. All because Alzheimer's patients can no longer speak, write or have died off, is no excuse to not look out for them.

Please, Please make Alzheimer's end with me.

Thank you,

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

P.S. I would love to be a part of the committee to represent Alzheimer's patients.

DATE: February 22, 2012
SUBJECT: Comments

First, let me thank you for the efforts and work toward the National Plan to Address Alzheimer's Disease. At the Rosalynn Carter Institute for Caregiving, we have worked many years to support caregivers caring for loved ones living with this disease. The first deadline for public comments on the draft has passed. Can you share with me if there will be another opportunity to submit written comments? We, at the Institute, would like the opportunity to do so.

Thanks,

Leisa Easom, PhD, RN
Executive Director
Rosalynn Carter Institute for Caregiving
Georgia Southwestern State University
Americus, GA

DATE: February 18, 2012
SUBJECT: National Plan to Address Alzheimer's Disease

I realize I am late with my comments. First, as a Fellow of the American Psychological Association, I endorse and support their comments and recommendations.

Second, caregiver needs and the excellent support available through appropriately selected technologies needs to be much more emphasized. My colleagues in psychology and rehabilitation medicine have done a good deal of research in this area.

From wheelchairs to hearing aids, assistive technology has long been a staple of caring for the elderly with disabilities. Additionally, and depending on individual needs and preferences, those with Alzheimer's disease can potentially benefit from a blend of personal assistance; strategies; everyday technologies (ie, wristwatch, SmartPhone); and specialized technologies (e-pill alarm watch). Which combination is most appropriate for an individual requires an early and comprehensive assessment. For example, an Apple iPhone has many helpful features for individuals with cognitive disability and specialized applications can be obtained, but the phone has a small screen, small keys, and the complexity may make it less useful for some with Alzheimer's disease, especially those who have poor motor control and poor eyesight. An alternative is the Jitterbug® phone (<http://www.greatcall.com>), which has a simpler interface, large keypad with yes/no action buttons (ie, no confusing icons), and a speaker with an ear pad that is also compatible with hearing aids. Many other examples of products are given in my new book, ***Assistive Technologies and Other Supports for People With Brain Impairments*** [<http://www.springerpub.com/product/9780826106452>]. I discuss an array of assistive and cognitive support technologies, advise methods of implementation using real-life situations, and provide other resources for long-term care providers, caregivers, and families of those with Alzheimer's disease. I also extensively review research in this area by me and my colleagues.

I do hope you will give the promise of cognitive support technologies much more attention in your forthcoming National Plan.

Respectfully submitted,

Marcia J. Scherer, PhD, MPH, FACRM
President
Institute for Matching Person & Technology
Webster, NY
<http://matchingpersonandtechnology.com>

Editor, *Disability and Rehabilitation: Assistive Technology*
<http://www.informahealthcare.com/idt>

Professor of Physical Medicine and Rehabilitation
University of Rochester Medical Center
Rochester, NY
http://www.urmc.rochester.edu/web/index.cfm?event=doctor.profile.show&person_id=1001471

Co-PI, Center on Effective Rehabilitation Technology (CERT)
Burton Blatt Institute, Syracuse University
<http://bbi.syr.edu/projects/cert/cert.htm>

DATE: February 18, 2012
SUBJECT: National Alzheimer's project

Hi, Is it too late for public comment for this project?

Nancy E. Richeson, Ph.D. CTRS
Professor
University of Southern Maine
Portland, ME

DATE: February 16, 2012
SUBJECT: National Task Group Document - input to NAPA process

Just wanted to check this through with you. We know we 'informally' presented our National Task Group in Intellectual Disabilities and Dementia Practices' national report and plan to the Council at its meeting on January 17th, but were concerned that perhaps it was not a formal submission and thus may not warrant distribution to the Council and our intent not recognized in official comments submitted to the Council and the NAPA DHHS team.

If that is the case, please accept this submission (with the NTG report attached) as our 'official' submission to the NAPA process. Our cover note accompanying the dissemination of the document is provided below.

Thanks for your help with our effort -- it is much appreciated.

Dr. Matthew P. Janicki
Rockport, ME

=====

National Plan on Dementia and Adults with Intellectual Disabilities

The National Task Group on Intellectual Disabilities and Dementia Practices has issued a plan for improving the community care of adults with intellectual disabilities affected by dementia. "This is an issue that will only grow in intensity and the nation needs to address this challenge head on" said Dr. Seth M. Keller, the President of the American Academy on Developmental Medicine and Dentistry and co-chair of the National Task Group. The Group's 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*", summarizes and addresses some of the challenges facing the nation due to the increasing rate of dementia found in older people with intellectual disabilities.

The report offers recommendations for the improvement of services and suggests that its findings and recommendations be considered and integrated into the reports and plans being developed by the federal Advisory Council on Alzheimer's Research, Care, and Services -- under the National Alzheimer's Project Act. The report notes 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.

Dr. Keller said that "families are often the main caregivers for adults with an intellectual disability and when Alzheimer's occurs they are profoundly impacted." Such families not only include parents, but also siblings and other relatives. The report notes that many such families have difficulties in providing extensive care at home once dementia becomes pronounced and care demands overwhelm them.

The report also notes that it is important to recognize signs of dementia-related changes early, and identified an instrument potentially applicable to adults with an intellectual disability. This instrument could also be used for the cognitive assessment provision of the annual wellness visit under the Affordable Care Act. The report recommends adoption of such an instrument by

providers and regulatory authorities to identify those adults at-risk due to early signs of mild cognitive impairment or dementia.

Dr. Matthew P. Janicki, of the University of Illinois at Chicago, the other co-chair, said that "generally there is little information on this issue and much needs to be done to make people more aware of it." He noted that the Group recommended an intensified community education effort to enhance the capabilities of staff, clinicians, community providers, and administrators. Further, education is needed to raise awareness of dementia and how it affects adults with an intellectual disability among families and other caregivers.

The report notes 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. The National Task Group wants its report to contribute to the work of the federal Advisory Council on Alzheimer's Research, Care, and Services. Plans are also in place to produce educational materials, develop guidelines for care, and hold training sessions across the country.

The report and its 'Action Plan' are available at these websites: <http://www.aadmd.org/ntg> and <http://www.rrtcadd.org>.

Co-Chairs:

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)

ATTACHMENT: NTG_Thinker_Report_FINAL.pdf

Available as separate links:

'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	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach74.pdf
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DATE: February 15, 2012

SUBJECT: Fwd: Simple Way To Stop Alzheimer's

If you care to view my YouTube video (see PEERS ALZHEIMER), you will quickly see how to end America's Alzheimer crisis. I hope to publish my completed hypothesis--implicating refined polyunsaturated vegetable oils--sometime this year.

I have been working on this disease since 1990, but could not work out a key link in the chain of causation, until helped by Wisconsin neuroscientist Dr Deng-Shun Wang, just last year.

It's Goodbye Alzheimer's at last!!

Best Wishes,

Dr Robert Peers, MBBS (Unimelb)
General, Preventive & Nutritional Medical Practitioner
North Carlton, Vic., Australia

DATE: February 13, 2012
SUBJECT: Comment

I support Assisted living!!!

Raymond Wright

DATE: February 12, 2012
SUBJECT: Holistic approach to Alzheimer's care

I received a notice that your organization will be evaluating ideas from Alzheimer's caregivers. I would be greatly honored to provide some ideas on my holistic Assisted Living Practice, which has been successful in stabilizing both, Alzheimer's and Dementia conditions in a short time frame. We work closely with the resident's MD and their prescribed medications at the beginning, then we immerse the resident in a completely holistic diet, where their medications are much more effective and over a short period (2-3 weeks), the resident's medications can be reduced, therefore, improving their alertness and ability to maintain their independence in many of their daily activities.

Feel free to contact me if you should wish to discuss our program. I am working on a book at this time and will be sharing very helpful cases and our holistic approach within a peaceful residential environment.

Best regards,

Ingrid Mendez
My Country Home, Inc.
<http://mycountryhomeinc.com>

DATE: February 11, 2012
SUBJECT: Terapie non farmacologiche: corso di formazione "Terapia della Bambola"
(Alzheimer, Autismo, ...)

<p>Il prossimo corso si terrà a</p> <p>Milano sabato 5 maggio 2012 presso la Fondazione "DON CARLO GNOCCHI ONLUS" Via Capecelatro 66 Milano</p> <p>Richiesta accreditamento ECM Figure professionali: Psicologi, Infermieri, Fisioterapisti, Educatori</p> <hr/> <p>Per informazioni: www.ivocilesi.it info@ivocilesi.it Tel. 035-760400</p>	<p>LA TERAPIA DELLA BAMBOLA <i>Corso di formazione</i></p> <p>Corso di formazione "LA TERAPIA DELLA BAMBOLA" destinato a:</p> <ul style="list-style-type: none">• Medici• Psicologi• Educatori• Operatori socio assistenziali• Infermieri• Fisioterapisti• ... e tutti i professionisti che si occupano di relazione d'aiuto. <p>Si tratta di un percorso formativo di 8 ore sulle modalità e tecniche di inserimento/applicazione della Terapia della bambola.</p> <p>Sono previsti approfondimenti riguardanti le terapie non farmacologiche e le loro modalità all'interno dei percorsi di cura.</p> <p>Il percorso formativo si propone diversi obiettivi:</p> <ul style="list-style-type: none">• Ottimizzare le sinergie tra i diversi interventi terapeutici• Gestire le problematiche comportamentali con la bambola terapia• Favorire attraverso l'utilizzo della terapia della bambola gli interventi assistenziali e terapeutici• Migliorare l'efficacia degli interventi sull'utenza. <p>Documentazione: Durante il corso verrà rilasciata ai partecipanti la documentazione riguardante i protocolli sulla metodologia e modalità applicative della terapia della bambola. Ai partecipanti verrà rilasciato un attestato di partecipazione al corso.</p> <p>Vi suggeriamo di visitare il sito www.ivocilesi.it per ulteriori dettagli sul corso. Alleghiamo la locandina del corso ed il modulo di iscrizione.</p> <p>Dr. Ivo Cilesi - Psicoterapeuta Psicopedagogista</p>
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ATTACHMENT: Locandina_corsi_2012.pdf
Modulo_iscrizione_2012.pdf

Available as separate links:	
Corso di Formazione -- La Terapia Della Bambola	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach72.pdf
Scheda di iscrizione al corso -- La Terapia Della Bambola	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach73.pdf

DATE: February 9, 2012

SUBJECT: INTRO: Author, Radio Host, Speaker: Alzheimer's

Hello, I wish to be involved in NAPA. I was a television executive, but I barely survived as a caregiver to my (once-adoring) obstinate elderly father and sweet but ailing mother, both with Alzheimer's which went undiagnosed for over a year. But after fighting through the medical system, endless tears, and depleting my parents' life savings and much of my own--I finally figured everything out medically, behaviorally, socially, legally, financially and emotionally. Passion to save others (especially from getting so frustrated they commit elder abuse) resulted in my first book, **ELDER RAGE**, a Book-of-the-Month Club selection, launching the **COPING WITH CAREGIVING** radio show, and becoming an **INTERNATIONAL SPEAKER** (CEU/CMEs) on Alzheimer's. I am compelled to educated on issues that so unnecessarily cost years of my life--and then nearly my life itself when I survived invasive Brst. Cancer. **(Please let me know you received this.)**

Jacqueline Marcell

Author, Radio Host, Speaker

"Elder Rage, or Take My Father... Please! How to Survive Caring for Aging Parents"

Coping with Caregiving Radio Show

Irvine, CA

<http://www.ElderRage.com>

DATE: February 9, 2012
SUBJECT: Comment

Attached please find letter from each of our respective department heads here at Shrewsbury Crossings (Benchmark Senior Living) pertaining to the passage of the National Alzheimer's Project Act.

Please feel free to contact me at 508-845-2100 with any additional questions.

Regards,

Jeff Kingsbury
Director of Business Administration

ATTACHMENT: DOC020912-0001.pdf
DOC020912-0002.pdf
DOC020912-0003.pdf
DOC020912-0004.pdf
DOC020912-0005.pdf
DOC020912-0006.pdf
DOC020912-0007.pdf
DOC020912-0008.pdf

<i>Available as separate links:</i>	
Draft National Plan to Address Alzheimer's Disease: Comments from Ed Win	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach64.pdf
Draft National Plan to Address Alzheimer's Disease: Comments from Jeff Kingsbury	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach65.pdf
Draft National Plan to Address Alzheimer's Disease: Comments from Karen Corcoran	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach66.pdf
Draft National Plan to Address Alzheimer's Disease: Comments from Marisa Rossetti	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach67.pdf
Draft National Plan to Address Alzheimer's Disease: Comments from Maria Sands	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach68.pdf
Draft National Plan to Address Alzheimer's Disease: Comments from Peter Donaty	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach69.pdf
Draft National Plan to Address Alzheimer's Disease: Comments from Diane Evans	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach70.pdf
Draft National Plan to Address Alzheimer's Disease: Comments from Michael Bavuso	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach71.pdf

DATE: February 8, 2012
SUBJECT: Draft Framework Input

CARIE previously submitted comments about the importance of including unbefriended elderly with Alzheimer's disease in the National Plan. Even though they do not have a voice and are often hidden in communities throughout the country, the needs of these individuals should not be overlooked. Please consider adding this population to Strategy 2.G: *Improve Care for Populations Disproportionally Affected by Alzheimer's Disease*. The unbefriended elderly are clearly disproportionately affected by Alzheimer's disease and should not be overlooked as this epidemic grows. Should you need any additional information, please contact me. Thank you in advance for your consideration to this recommendation.

Kathy Cubit
Center for Advocacy for the Rights and Interests of the Elderly (CARIE)
Director of Advocacy Initiatives
Philadelphia, PA
<http://www.carie.org>
<http://www.caregivergps.org>

DATE: February 8, 2012
SUBJECT: Elimination of the ADSSP program

I am working with a group of African American caregivers who are caring for a family member with Alzheimer's disease. The cuts to the ADSSP program are devastating now, and will be even more challenging as further cuts are proposed. At our support group we discussed the challenges ahead and also, decided to write to let you know that our lives will be negatively impacted by the decision to take funds from the ADSSP program, which provides educational and supportive services for caregivers.

=====

I am a family caregiver to a person with Alzheimer's disease. I was fortunate to receive supportive services through the ADSSP program. This help made a significant difference in my ability to care for my family member.

I understand that funds for this important service have been cut. As an African American person, I am especially concerned about the increase risk for Alzheimer's disease in the minority population. African Americans are at greater risk due to health factors such as; high blood pressure, high cholesterol and diabetes. In addition, with the aging of the baby boomers we need to add more services to support people with Alzheimer's disease and their caregivers. I urge you to encourage the federal government to restore and sustain this crucial program. It does so much to help families like ours.

Lill Guardian Angels African American Support Group	
Support group members/Caregiver	Caring for person with Alzheimer's disease
Juanita Williams	Husband
Paulette Jackson	Dad
Gertha Cochran	Mother
Latietia McLaughlin	Dad
Linda Green	Mother
Diane Anderson	Husband
Valorie Brown	Uncle
Erma Bland	Husband
Freddie Mae Owens	Husband
Henretta Carter	Husband
Anna Majors	Mother-in law
Olivia Morrison	Husband
Sandy Harp	Neighborhood

Dorothea Harris, LGSW
Family Memory Care Consultant
Volunteers of America MN
Senior Services
Mpls., MN
<http://www.voamn.org/Family-Memory-Care>

DATE: February 8, 2012

SUBJECT: Pioneer Network Comments on the Draft National Alzheimer's Plan Framework

Thank you very much for the opportunity to provide comments on the Draft National Alzheimer's Plan Framework. Comments from the Pioneer Network are attached to this email.

Best Regards,

Peter Reed, PhD, MPH
Chief Executive Officer
Pioneer Network
Chicago, IL

ATTACHMENT: Pioneer Network Comments on Draft National Alzheimer's Plan 2-8-2012.pdf

Available as separate links:

Comments on the Draft Framework for the National Plan to Address Alzheimer's Disease, submitted to the HHS Advisory Council on Alzheimer's Research, Care, and Services	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach63.pdf
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DATE: February 8, 2012

SUBJECT: DRAFT Framework for the National Plan to Address Alzheimer's disease

Thank you for the opportunity to provide comments on the DRAFT Framework for the National Plan to Address Alzheimer's Disease.

The Virginia Assisted Living Association (VALA), representing assisted living providers from throughout Virginia, as well as thousands of residents and employees served by these providers, supported the passage of the National Alzheimer's Project Act. We strongly support the goals outlined in the Draft Framework, but we are disappointed in the lack of acknowledgement of the importance of and the extensive use of assisted living services for individuals with Alzheimer's disease.

Assisted living is long-term care service provider, that offers a more affordable home and community based alternative to skilled nursing care. Assisted living providers focus on the resident and offer services that are unique to the individual needs of the residents to allow for individual choice and help residents maintain dignity and respect. Assisted living is a professionally managed, community-based option for seniors and disabled individuals to use when needing assistance with activities of daily living, including specialized care for individuals with memory loss.

Statistics will show that consumers prefer assisted living care over institutionalized care settings, which is directly contributing to the drastic increase in the population numbers of assisted living communities. As reported in the 2009 Overview of Assisted Living (research conducted and analyzed by Acclaro Growth Partners), more than 1/3 of all residents living in assisted living communities have a diagnosis of Alzheimer's or a related dementia. The US Government has evidence of this in its release of the 2010 National Survey of Residential Care Facilities as conducted by the CDC's National Center for Health Statistics, which stated that 42% of the residents living in residential care have Alzheimer's disease. This number is expected to continue or even increase as the levels of care and the options of care continue to expand within assisted living communities for memory impaired residents.

We respectfully request HHS to acknowledge and to include assisted living as a viable option when educating and caring for individuals with Alzheimer's and their families. We also request that the word "patient" be replaced with the word "individual". Below is listing of some of our recommendations of changes to the Draft Framework...

- Goal 2. Add licensed assisted living communities to the list of settings in the opening paragraph after "hospitals"
- Strategy 2.A Change patients to individuals
- Strategy 2.B Change patients to individuals
- Strategy 2.C Change patients in the title to individuals
- Strategy 2.E Add assisted living and a transition options from the home to assisted living and from hospitals to assisted living
- Strategy 2.E Change patients to individuals and add assisted living to the list of transition settings after "home"
- Goal 3: Change the title to Expand Support of Individuals with Alzheimer's and their Families, and add assisted living to the list of care settings after "hospitals"
- Strategy 3.B Add assisted living before "nursing home placement" in both references

- Strategy 3.D The use of the term “residential care facilities” in the first sentence is odd because that term has never been used throughout the document. A more consistent term could be “long term care settings”. In two places the term “assisted living facilities” is used and the term “facilities” should be replaced with “communities”. This strategy should be strengthened to support a zero tolerance for abuse of individual’s with Alzheimer’s, regardless of where they live. Criminal background checks, educating family members, residents and staff in how to recognize, respond and report suspected abuse and termination of staff when appropriate must be a top priority.

Thank you for your time and consideration of these comments, and please contact me should I be able to offer you assistance in this ongoing Plan.

Cordially,

Judy M. Hackler
Executive Director
Virginia Assisted Living Association (VALA)
Henrico, VA
<http://vala.alfa.org>

ATTACHMENT: HHS Letter Regarding Alzheimers - 2012-02.pdf

Available as separate links:

DRAFT Framework for the National Plan to Address Alzheimer’s disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach62.pdf
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DATE: February 8, 2012

SUBJECT: Feedback on the Draft Framework for the National Plan on AD

Please find attached feedback from the Lewy Body Dementia Association on the Draft Framework for the National Plan to Address Alzheimer's Disease. The letter is from the President of LBDA's Board of Directors, Angela Herron, in consultation with our Scientific Advisory Council.

I have also copied the text itself below for your convenience in including it on the NAPA website.

Please feel free to contact me with any questions.

Sincerely,

Angela Taylor
Director of Programs
Lewy Body Dementia Association
Lilburn, GA
<http://www.lbda.org>

**An Open Letter to the U.S. Department of Health and Human Services
Feedback on the Draft Framework for the
National Plan to Address Alzheimer's Disease**

The Lewy Body Dementia Association (LBDA) supports and applauds the development of a national plan to address Alzheimer's disease and related disorders.

With appreciation for the magnitude of the task at hand and the complexity of the issues, LBDA is providing limited feedback that is a) relevant for dementia in general and b) an important consideration specific to the spectrum of Lewy body dementias (LBD): dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD).

An estimated 1.3 million Americans have LBD, which features progressive dementia plus varying combinations of symptoms (especially at onset), ranging from parkinsonism, fluctuating cognition and visual hallucinations, to REM sleep behavior disorder, a severe sensitivity to antipsychotic medications, mood disorders and autonomic dysfunction. Both clinical diagnoses within the LBD spectrum feature Lewy body pathology, but the timing and severity of symptom onset differs.

Dementia with Lewy bodies represents approximately 20 percent of all dementias and is the most frequent dementia type misdiagnosed clinically, most often as Alzheimer's. Features that differentiate LBD from Alzheimer's at the early stage include visual hallucinations, REM sleep behavior disorder and results of neuropsychological assessment.

Most older adults with Parkinson's disease have some degree of cognitive impairment at the time of diagnosis. Approximately 80% of people with Parkinson's will ultimately develop dementia. The prevalence of cognitive impairment and dementia in Parkinson's disease has not yet become common knowledge among clinicians. There is no general public awareness about dementia in Parkinson's disease. Caregivers of people with PDD report to LBDA that the progression to dementia ultimately proves to be their most difficult caregiving challenge.

It's not always Alzheimer's.

We appreciate the importance of communicating the plan in a manner that is both straightforward and understandable by the general public. While Alzheimer's disease is the most common form of dementia, there are millions of Americans whose lives are deeply affected by related disorders like stroke, LBD and frontotemporal degeneration; while they receive nominal mention in the background material as being included in this plan, there is no mention of them in the draft agenda.

Public awareness and education is one of the core goals of the draft agenda. LBDA urges the names of related disorders be included in the opening statement of the draft agenda, so that educating the public about the most common forms of dementia begins now and continues throughout the advancement of the National Plan to Address Alzheimer's Disease, through public relations efforts of federal agencies, disease advocacy organizations and academia. As the plan receives coverage in the media, deliberate inclusion of related disorders will also minimize disenfranchisement of Americans affected by lesser-known, non-Alzheimer's dementias like LBD, many of whom might easily infer the omission indicates the federal government does not appreciate that their plight is as fraught with burden as those dealing with Alzheimer's disease.

Diagnosis

While improving the timeliness of diagnosis is important, the Lewy Body Dementia Association strongly recommends the inclusion of the word 'differential' when referring to diagnosis.

A general dementia diagnosis or an inaccurate diagnosis of Alzheimer's disease leaves people with LBD at risk for exposure to potentially severe or irreversible medication side effects. (Approximately 50% of people with DLB who are exposed to neuroleptics will experience a severe reaction.) Inaccurate diagnosis also prevents the opportunity to prepare families for the complexity of LBD symptoms, treatment and high toll of LBD caregiving. Accurate differential diagnosis not only leads to more appropriate therapeutic interventions but also improves the selection for study candidates in research trials.

Primary care physicians must become more familiar with the top four causes of dementia, specifically Alzheimer's, LBD, stroke and frontotemporal degeneration. Delayed or inaccurate diagnoses are further compounded by the low percentage of referrals from primary care physicians to specialists. Simple screening tools to highlight when a referral is warranted for differential diagnosis are urgently needed, especially for people with LBD.

Care Quality

When assessing the care needs of persons with dementia, it is essential to look beyond the cognitive deficits and their impact on employment, incidental activities of daily living and activities of daily living. In the case of Lewy body dementias, care quality must also address motor symptoms (such as the risk of falls), behavioral problems, sleep and autonomic issues. Other professionals who regularly provide care for people with dementia include specialists treating sleep and autonomic symptoms as well as physical, occupational and speech therapists.

Care Guidelines across Care Settings

Given the increased rate of hospitalization of people with dementia, hospitals should be included in the list of care settings for which dementia care guidelines and measures are to be developed. Many hospitals are not equipped to provide adequate care to people with dementia, especially those with behavioral problems, leading to excessive or avoidable treatment with antipsychotic medications. (This is especially dangerous to the person with LBD, who may experience modest to significant decline without a return to their baseline from as little as a single dose of haloperidol.) Additionally, consideration should be given to non-cognitive symptoms, such as motor problems, which affect activities of daily living and increase fall risk. As LBD is a multi-system disorder, routine care coordination between multiple physicians is particularly challenging with LBD. By changing medications without consulting the treating neurologist, another physician may unknowingly exacerbate any one of several LBD symptoms.

Patient and Family Support

In addressing the long term care needs of people with dementia, caregivers need more accessible resources to provide quality care for the person with dementia in their own home as long as possible, while also maintaining balance of the equally important quality of life for the family caregiver.

Patient advocacy groups should be included in the draft framework as an important source of counseling, support and information to patients and families upon a differential diagnosis.

Public Awareness

The general public needs to be educated about the difference between dementia and the disease processes that cause it, much like the education the public received about HIV and AIDS. Few people understand that dementia is sometimes treatable. Educating the public that dementia is a symptom requiring medical attention, not a disease in itself, will help de-stigmatize both dementia and the many related clinical diagnoses.

In order to improve the reporting to physicians of all dementia-related symptoms beyond memory problems alone, such as those seen in stroke and LBD, it is imperative that the general public learn that the most common causes of dementia are Alzheimer's disease, stroke and LBD, and what symptoms should be reported to their physicians.

The Lewy Body Dementia Association is encouraged at the expansive nature of this draft agenda, especially as it pertains to the impact of dementia disorders not just on the patient but on the family caregiver as well. We look forward to following the progression of your work with great anticipation.

ATTACHMENT: LBDA reply to NAPA framework 2012 0208.pdf

Available as separate links:
An Open Letter to the U.S. Department of Health and Human Services -- Feedback on the Draft Framework for the National Plan to Address Alzheimer's Disease
http://aspe.hhs.gov/daltcp/napa/Comments/cmtach61.pdf

DATE: February 8, 2012
SUBJECT: LEAD Comments on Draft Framework

Attached please find comments on the Draft Framework for the National Plan to Address Alzheimer's Disease from Leaders Engaged on Alzheimer's Disease (LEAD). Also attached are the comments collected from researchers on behalf of LEAD's Research Workgroup to be submitted for your consideration. Please contact me with any questions you may have.

Thank you,

Patrick Fritz
Project Manager
Leaders Engaged on Alzheimer's Disease (LEAD)

ATTACHMENT: LEAD Framework Comments vf.pdf
Research Workgroup Recommendations vf.pdf

<i>Available as separate links:</i>	
Draft Framework for the National Plan to Address Alzheimer's Disease Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach59.pdf
Research Workgroup Suggested Recommendations	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach60.pdf

DATE: February 8, 2012

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

On behalf of the Alzheimer's Association, the leading voluntary health organization in Alzheimer's care, support and research, thank you for the opportunity to comment on the U.S. Department of Health and Human Services "Draft Framework for the National Plan to Address Alzheimer's Disease." Please let us know if you have any additional questions. Thank you again.

Best,

Rachel M. Conant
Director, Federal Affairs
Alzheimer's Association
Washington, DC

ATTACHMENT: Alzheimer's Association - Draft Framework Comments.pdf

Available as separate links:

Alzheimer's Association comments on the
Draft Framework for the National Plan to
Address Alzheimer's Disease

<http://aspe.hhs.gov/daltcp/napa/Comments/cmtach58.pdf>

DATE: February 8, 2012
SUBJECT: Comment letter to draft Framework

Please accept the attached document as the Society for Women's Health Research's comment to the Draft Framework for a National Plan on Alzheimer's disease from the NAPA Advisory Council.

Thank you

Martha Nolan
Vice President, Public Policy
Society for Women's Health Research (SWHR)
Washington, DC
<http://www.swhr.org>

ATTACHMENT: SWHR comment letter on NAPA Draft Framework.pdf

Available as separate links:

Draft Framework for the National Plan to Address Alzheimer's Disease Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach57.pdf
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DATE: February 8, 2012
SUBJECT: HHS National Plan to Address Alzheimer's Disease

Please see the attached letter from Division 40 of the American Psychological Association.

William B. Barr Ph.D., ABPP
President of Division 40 (Clinical Neuropsychology)
American Psychological Association (APA)

ATTACHMENT: APA Div 40 - HHS National Plan Draft.pdf

<i>Available as separate links:</i>	
Draft Framework for the National Plan to Address Alzheimer's Disease Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach56.pdf

DATE: February 8, 2012
SUBJECT: Re: ADSSP

I am writing to let you know first, how much I appreciate Amy Landers, our social worker. Because of this program, it allowed her to introduce us to several areas for help that was much needed for my husband who suffers with Alzheimer's, and for me as his caregiver. I am very grateful for the funding of this special program and how it continues to help, and honestly don't know what I would have done without it. **It helps make life better, and is so needed.**

Thanks for now and the foreseeable future!

Lillian Williams

DATE: February 8, 2012

SUBJECT: Strategy 3.a

3.a would benefit by a slight expansion to this effect: encouraging the development of technology-supported, culturally- and linguistically-appropriate interventions that are translatable to family caregiving situations

Boyd H. Davis, PhD.

Bonnie E. Cone Professor of Teaching

Professor, Applied Linguistics/English

Professor, Gerontology

UNC Charlotte

Charlotte NC

<http://english.uncc.edu/faculty/80-boyd-h-davis.html>

<http://webpages.uncc.edu/~bdavis/>

DATE: February 8, 2012
SUBJECT: ADSSP Program

I am a family caregiver to a person with Alzheimer's Disease. I was fortunate to receive supportive services through the ADSSP program. This program helped make a significant difference in my ability to understand the needs of and care for my loved one.

I understand that funds for this important service have been cut. With the aging of the baby boomers we need to add more services to support people with Alzheimer's disease and their caregivers. I urge you to encourage the federal government to restore and sustain this crucial program.

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

- Evelina Paredes (submitted February 8). Added information: "I was my mother's caregiver; Goyita as we called her, she was a victim with the Alzheimer's disease. These supportive services helped and made a significant difference with my ability to care for my mother with her disease; thanks so these services I was able to take on a part time job to pay for extra costs arising from her disease. Baby Boomers have worked and already gave their contribution to fund these services. It would be regrettable, shameful and cruel that these funds were eliminated and leave out people who already worked for this country."
- Kristine Dwyer, LSW, MS, Family Memory Care Program Consultant, Carlton and Southern St. Louis Counties, MN (submitted February 8). Added information: "I am a Caregiver Consultant for the Family Memory Care Program in Minnesota and have personally served over 40 families who care for a person with Alzheimer's disease with the Family Memory Care grant. This program is funded through ADSSP grant money. It has helped make a significant difference in my ability to serve caregivers and keep their loved one at home for an extended period of time due to the support, education and resources available via this valuable program. I have been able to serve caregivers and their families in my funded position for the past four years and the referrals are mounting each month. I am the only person in my region of the state that is available under the Family Memory Care Program to assist caregivers who care for a family member with Alzheimer's disease. The need for this support program is immeasurable!"
- Linde Higton, Cioquet, MN (submitted February 8)
- Robyn Schroeder (submitted February 8)
- Carol Shapiro (submitted February 8). Added information: "I am a family caregiver to my husband with young on-set Alzheimer's Disease. Families dealing with Alzheimer's face many crisis situations as they watch their loved one progress through the disease. It does so much to help families like mine."
- Marilyn Hagen (submitted February 8)
- Ernie Strandberg, Carlton, MN (submitted February 8). Added information: "It has helped to sustain me through this difficult time. It does so much to help families like mine."
- Shirley Spearin (submitted February 8). Added information: "It does so much to help families like mine."

- Kathleen Rejeena Peterson (submitted February 9). Added information: "It does so much to help families like mine. I would be lost without this help."

DATE: February 8, 2012
SUBJECT: BIO Comments to Draft Framework for the National Plan to Address Alzheimer's Disease

Attached please find the Biotechnology Industry Organization's (BIO) feedback on the draft framework for the National Plan to Address Alzheimer's Disease. Thank you for your consideration of our comments. Please let me know if you have any questions.

Regards,

Laurel L. Todd
Managing Director, Reimbursement and Health Policy
Biotechnology Industry Organization
<http://www.bio.org>

ATTACHMENT: Final Draft BIO NAPA comments 2-7-12.pdf

<i>Available as separate links:</i>	
Draft Framework for the National Plan to Address Alzheimer's Disease Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach55.pdf

DATE: February 8, 2012

SUBJECT: The importance of Caregivers Supports and ADSSP

I am the wife of a person with early dementia, my husband and I have been very fortunate to be the beneficiary of services received through the ADSSP program. I cannot tell you what a difference they have made in my life as well as my husbands. We have been able to make many changes that we can already tell are making a difference in his cognitive function and for me it is a lifesaver. I can't do this alone, please continue to fund the ADSSP program or something similar to provide support for those of us who care for people with dementia especially in the early stages when so much can be done to make a difference. Having someone in the community that can walk with me and coach me and my children on developing and implementing a plan has been incredible. There likely will not be a cure for many years, for those of us who a cure will not save please continue to provide the important supports that you have. They mean everything to us.

Thanks and bless you for the wonderful work you are doing,

Donna Walberg

DATE: February 7, 2012
SUBJECT: NAPA Comments

I am a retired business executive whose father, and some close college friends, had Alzheimer's. This led me to become involved with Alzheimer's activities starting in 2002, and I am a newly elected Alzheimer's Association National Board Director. Please note that my comments do not represent any organization in which I participate.

I start my input by noting my appreciation for the fact that we finally have a National Alzheimer's Project Act. I believe that the work to date on NAPA has been excellent, especially considering the challenges to be addressed and the need to get significant results sooner than later.

A review of complex program histories/results, reveals that to achieve significant progress requires focus and proper funding. In looking at the draft National Plan and associated set of goals, it appears that the agenda has too much going on at the same time. I do believe that all of the identified challenges must be addressed at some point, but I suggest that a much more focused initial effort would lead to better results.

Additionally, we need to consider the probable federal funding constraints that will exist for the next several years.

With focus and funding in mind, I suggest giving priority to two of the stated goals:

1. Obtain and utilize increased funding for research; we need to get to \$2 billion/year immediately.
2. Improve the care of victims of the disease and provide better education/support for the family caregivers.

A final issue is that the number of government organizations that will potentially be involved with NAPA (see attachment which comes from initial work by the Council) is very large and could impact progress.

Again, looking at successful programs, we see that the simpler the organization/number of interfaces, the better. As such, I suggest that the implementation of NAPA be accomplished with fewer, more responsible entities. I realize this is much easier said than done, but in the long run, would lead to a more successful and less expensive result.

Finally, thanks for the opportunity to provide comments. I am looking forward to a successful NAPA.

Paul Wexler
Newport Beach, CA

ATTACHMENT: Depts and Agencies.xls

Available as separate links:	
List of Participating Departments and Agencies	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach54.pdf

DATE: February 7, 2012

SUBJECT: Re' Draft Framework for the National Plan to Address Alzheimer's Disease

Attached please find our comments to the Draft Framework for the National Plan to Address Alzheimer's Disease. Thank you for the opportunity to provide input.

Sincerely,

Laura Landwirth, CAE
President & CEO
LeadingAge Colorado
<http://www.leadingagecolorado.org>

ATTACHMENT: LeadingAge Colorado Comments 02 07 12.pdf

<i>Available as separate links:</i>	
Draft Framework for the National Plan to	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach53.pdf
Address Alzheimer's Disease Comments	

DATE: February 7, 2012
SUBJECT: National ALZ Plan

I was shocked to see that Assisted Living has been left out of the draft guidelines for the National Plan for Alz Disease with the exception of the section on elder abuse. We are filing the attached comments..

RIALA - Our Strength is in Membership

Kathleen Kelly
Executive Director
RI Assisted Living Association
East Providence, RI

ATTACHMENT: RI Assisted Living Comment National ALZ Plan.doc

Available as separate links:

Comments of the RI Assisted Living Association submitted to HHS on the Draft Framework for the National Plan to Address Alzheimer's disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach52.pdf
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DATE: February 7, 2012

SUBJECT: Two Additional Comments on the National Alzheimer's Plan

Below are two comments received from my readers regarding the draft of the National Alzheimer's Plan. Thank you for your work on this incredibly important project.

Norman Roberts says:

After reading the document I am pleased so much interest given to finding a cure. However I would like more emphasis on reasearch on finding better ways to help those expreiencing AZ problems now. We have waited a long time finding a cure and during the continued wait please spend more money, research & engergy helping us now.

My specific request is for research to help couples, both are a patient and a caregiver. Skilled people to assist us the with flustration [social & psychological] would help us continue in our home and not cost us or government to care for us in a more expensive setting. After a extensive search I find no specific help for COUPLES both having MCI. I think our medical & government should do better by us.

February 7, 2012 at 5:39 am

(11) Trevor Mumby says:

We have 80 staff who are coached in small groups to manage the daily challenges whilst they are living -in with families who are experiencing dementia. Our visiting carers undergo the same coaching.

Families are invited to attend coaching groups.

It is the DAILY 24/7 domain where NEW, simple skills need to be learned which fit the UNIQUE circumstances of the family dynamic.

Our experience is that cosmetic generalised approaches can frequently create even more erratic responses.

The results are proof that we have found a method to empower the family, including the person with dementia to live a more well being life.

We are based near Oxford UK and would be glad to share.

Esther Heerema, LMSW
Guide to Alzheimer's Disease
<http://alzheimers.about.com>

DATE: February 7, 2012
SUBJECT: comments on Alzheimer's National Framework

Please see the attached comments from the Assisted Living Federation of America on the draft Framework for the National Plan to address Alzheimer's Disease. If you have any questions do not hesitate to contact me.

Maribeth Bersani
Senior Vice President Public Policy
ALFA
Alexandria, VA

ATTACHMENT: Thank you for the opportunity to provide comments on the Draft Framework for the National Plan to Address Alzheimermb.docx

Available as separate links:

Comments of the Assisted Living Federation of America submitted to HHS on the Draft Framework for the National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach51.pdf
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DATE: February 7, 2012
SUBJECT: CEAL Comments to National Plan

The Center for Excellence in Assisted Living (CEAL) appreciates the opportunity to comment on the draft framework for the National Plan to Address Alzheimer's Disease. Our comments are attached in Microsoft Word and Adobe Acrobat formats. Feel free to contact me if you have any questions or wish to discuss the comments.

Regards,

Josh Allen, RN
Chair, Board of Directors
Center for Excellence in Assisted Living

ATTACHMENT: CEAL Comments to Draft Framework for the National Plan to Address Alzheimer's FINAL.docx
CEAL Comments to Draft Framework for the National Plan to Address Alzheimer's FINAL.pdf

Available as separate links:

Draft Framework for the National Plan to Address Alzheimer's Disease Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach50.pdf
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DATE: February 6, 2012
SUBJECT: Comments Draft Framework

Attached please find Merck's comments regarding the Draft Framework of the 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
<http://www.merck.com>

ATTACHMENT: Merck Comments NAPA Framework.pdf

Available as separate links:

Comments for Draft Framework for the National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach49.pdf
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DATE: February 6, 2012

SUBJECT: Alzheimer's Disease Supportive Services Program Slated for Elimination

Thank you for your time and commitment to the NAPA process. Your efforts are greatly appreciated. As you work diligently to prepare this landmark national plan which will help our country prepare for the coming onslaught of Alzheimer's disease, I want to urge you to address a current program that has helped thousands of families over the past twenty years but which is currently slated for dramatic cuts in 2012 and probable elimination in 2013. The Alzheimer's Disease Supportive Services Program (ADSSP), also known as the Alzheimer's Disease Demonstration Grants to States Program, was created by federal legislation in 1991 with the hope that it would increase access to quality services for people with Alzheimer's disease and their family caregivers nationwide. Since its inception, this program has created services for many under-served populations; Latinos, African Americans, Asian Pacific Islanders, and rural families have all benefited from this investment. Many of the innovative programs created with this funding have been replicated in new cities and states such as the Guidelines for Management of Alzheimer's Disease, an evidence-based, a practice guideline for primary care physicians and the El Portal Dementia Care Network model for reaching under-served populations.

There have been criticisms of the program and like all programs, it could be improved. The major criticism has been that ADSSP serves relatively few families. There are two good reasons for this. First, the program was developed to serve hard-to-reach families. The initial evaluation of the program completed by Dr. Rhonda Montgomery demonstrated that you must reach thousands through culturally appropriate outreach and education in order to bring direct services to relatively small numbers of hard-to-reach families. More recently, the program refocused on bringing evidence-based programs to the broader community. While this is a good goal, it means that fewer families can be reached as these evidence-based programs deliver more intensive services to fewer people.

I want to urge the Council to include support for the ADSSP program in our national plan. The program needs to be institutionalized rather than remain a demonstration project. This is the only national program that is Alzheimer's-specific, delivering respite, support and education to hard-to-reach Alzheimer's families in their communities. Without it, thousands of families will get no services.

I urge you to restore and preserve this important program.

Thank you for taking the time to read this input.

Sincerely,

Debra L. Cherry, Ph.D.
Executive Vice President
Alzheimer's Association, California Southland
Los Angeles, CA

DATE: February 5, 2012
SUBJECT: Article on Alzheimer's

Please share this with the non and federal committee. Thanks

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

DATE: February 5, 2012
SUBJECT: National Alzheimer's Project Act

See attached.

Mary Gnosini
Cultural Ambassador
Leominster Crossings
Leominster, MA

ATTACHMENT: Letter.docx

<i>Available as separate links:</i>	
Draft National Plan Comment	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach48.pdf

DATE: February 3, 2012
SUBJECT: Comments on the Draft Framework for the National Plan to Address Alzheimer's Disease

See attached.

Sally Michael
President
California Assisted Living Association
Sacramento, CA
<http://www.CAassistedliving.org>

ATTACHMENT: CALA Comments to HHS 2.3.12.pdf

<i>Available as separate links:</i>
Comments from the California Assisted Living Association (CALA) submitted to HHS on the Draft Framework for the National Plan to Address Alzheimer's Disease http://aspe.hhs.gov/daltcp/napa/Comments/cmtach47.pdf

DATE: February 3, 2012
SUBJECT: ALFA/ Alzheimer's crisis

As a nurse of over 20 years I was shocked to learn that the draft of recommendations on how to overcome the Alzheimer's crisis didn't include Assisted Living. As our population ages, and is living longer due to advances in detection and treatment Alzheimer's disease will only become more of a problem. Assisted Living is one of the best options for those suffering from this disease. Nursing homes are for those with skilled needs. Medicare will not pay for someone to be in a nursing home because they have Dementia and need help with ADLs they can no longer do for themselves. If a person doesn't have \$10,000.00-15,000.00/month to pay privately for a nursing home, which they really shouldn't be in, what option do they have. Children today are no longer able to care for their parents as they were many years ago. Most households have both people working, busy lifestyles, and it's just not an option. Assisted living enables people with dementia to still live independently in a safe environment where help is available when needed, or for those with severe dementia an environment where all of their ADLs, medication management, social, and nutritional needs are provided for. The cost is half the price of a nursing home in a social environment. How this could have been left out makes me wonder who the drafters of the recommendations were, and what their backgrounds are. Not only as a nurse but also as the daughter of a mother who suffered from Dementia, please include Assisted Living. Our older generation deserves the best quality of care in an environment that is enjoyable. We all will be old someday and may have Dementia, we would want this for ourselves so let's give it to our parents.

Sincerely a concerned American,

Maria Sands

DATE: February 3, 2012
SUBJECT: Comment

Hey, You are missing Assisted Living, Senior Living facilities in your proposals from ALFA. We are more and more involved in the daily living of Seniors with Dementia. So please add us to the wording on all of your proposals. Thanks.

John Gagnon
Director of Plant Operations
Orchard Valley at Wilbraham
Wilbraham, MA

DATE: February 3, 2012
SUBJECT: Comment

Please read this important email.

Clare Welch
Administrative Assistant
Waltham Crossings
Waltham, MA

ATTACHMENT: Document1.docx

<i>Available as separate links:</i>	
Comment on the Draft National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach46.pdf

DATE: February 3, 2012

SUBJECT: Assisted Living being added to the National Plan to Address Alzheimer's Disease

I am requesting that assisted living communities be part of the draft framework for the National Plan to Address Alzheimer's Disease. Assisted Living communities care for so many affected by this disease and we would be an asset to the National Plan in addressing this terrible disease.

Please include us as an industry and allow us to help in this critical plan.

Thank you

Valerie Whitman
Director of OCF Engagement
Benchmark Senior Living
<http://www.benchmarkseniorliving.com>
<http://www.onecompanyfund.com>

DATE: February 3, 2012
SUBJECT: National Alzheimer's Project Act

It is with great concern that in review of the draft of the National Alzheimer's Project Act that the entire sector of assisted living benefits was omitted from your review and recommendations. In every state in our country, assisted living venues house and care for men and women who have been affected by Alzheimer's. It is the foundation of senior living to assist with the components of memory care that not only deal with the necessities of daily living such as bathing, dressing, grooming and nutrition, but also to foster the necessary continual mind engaging programming and social camaraderie needs that every person with memory impairment deserves. If your research was thorough, I am sure you found that assisted living is a lower cost and more successful alternative to skilled nursing environments across the country. In a more homelike environment, people thrive as their bodies typically remain well through their disease progression while working to coax their brain connections each day to try to maintain as much cognition as possible.

Please re-evaluate your dismissal of assisted living as part of your recommendations in the National Alzheimer's Project Act.

Thank you for your consideration,

Tracey Hamlin-Landry
Kingston, NH

DATE: February 3, 2012
SUBJECT: NAPA

Please hear my concerns!

Doug McLaughlin
Administrative Assistant, Human Resources & Customer Experience
Benchmark Senior Living
Wellesley, MA

ATTACHMENT: NAPA.pdf

<i>Available as separate links:</i>	
NAPA Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach45.pdf

DATE: February 3, 2012
SUBJECT: National Plan for Alzheimer's Disease

I have reviewed the current proposed National Plan For Alzheimer's Disease. As a registered Nurse with over 35 years experience in geriatrics, I would strongly urge you to include licensed Assisted Living Services Agencies in the current proposal. These communities are often the first resource for family members and persons with Alzheimers Disease.

Thank you for your assistance

Lynn R. Veith, RN
Resident Care Director
River Ridge at Avon
Avon, CT

ATTACHMENT: National Plan For Alzheimer's Disease.doc

Available as separate links:

National Plan for Alzheimer's Disease Comments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach44.pdf
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DATE: February 3, 2012
SUBJECT: Assisted Living

I am writing today to express my concern regarding the draft of the National Plan to Address Alzheimer's Disease. I stand with the Assisted Living Federation of America and the Alzheimer's Association in their call to include assisted living communities in this discussion. Assisted living communities play a vital role in the lives of memory impaired residents. The omission of assisted living is completely unacceptable. Below are the changes/additions that we want to see included in the National Plan to Address Alzheimer's Disease.

- We request that the word "patient" used throughout the document be changed to "individual" or "resident". While we understand that someone under a physician's orders is called a patient, individuals residing in assisted living and other home and community based options are referred to as individuals or residents.
- Please add "licensed assisted living communities" to the list of settings throughout the document
- In Goal 3: Change the title to Expand Support of Individuals with Alzheimer's and their Families.
- In Strategy 3. D The use of the term "residential care facilities" in the first sentence is odd because that term has never been used throughout the document. A more consistent term could be "long term care settings." In two places the term "assisted living facilities" is used and the term "facilities" should be replaced with "communities". This strategy should be strengthened to support a zero tolerance for abuse of individual's with Alzheimer's, regardless of where they live. Criminal background checks, educating family members, residents and staff in how to recognize respond and report suspected abuse and termination of staff when appropriate must be a top priority.

As we all work together to fight this terrible disease, I eagerly anticipate the revised National Plan to Address Alzheimer's Disease. Please do the right thing and include assisted living communities.

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

- Jennifer Land, Director of Business Administration, Greenwich Farms at Warwick, Warwick, RI, <http://www.greenwichfarmsatwarwick.com> (submitted February 3)
- Elena Leon Fulkerson, Director of Community Relations, Orchard Valley at Wilbraham, Wilbraham, MA, <http://www.benchmarkquality.com> (submitted February 3). Added information: "...Benchmark Senior Living where we provide housing and care for residents with Alzheimer's Disease and other dementias. I see daily the wonderful impact we have on our residents and their families, providing not only high quality care, but as importantly, an engaging lifestyle in a residential atmosphere...in my opinion, a night and day difference from the traditional "old school" nursing home which still exists. I am a member of the Tri-Country Partnership for the Alzheimer's Association here in Western Mass and volunteer in other capacities with the Alzheimer's Association. I also am a family member of a loved one who has experienced memory loss through Alzheimer's Disease which eventually required placement in a care community."
- Tracey Hamlin-Landry, Senior Director of Community Relations, Greystone Farm at Salem, <http://www.greystonefarmatsalem.com> (submitted February 3)
- Debbie Yerardi, Receptionist, Benchmark Senior Living, Wellesley, MA (submitted February 3)

- Marcia Werber, RN, Regional Director of Resident Care, Benchmark Senior Living, Wellesley, MA, <http://www.benchmarkquality.com> (submitted February 3)
- Sandra DePrimio, Executive Assistant, Investment/Development/Capital Acquisitions Department, Benchmark Assisted Living, Wellesley, MA (submitted February 3). Added information: "I am a caretaker for my 86 year old mother, who is a severe diabetic, has recently developed AFIB and other age-related ailments, but thankfully still has no symptoms of Alzheimer's. It is my sincere hope that she will be able to remain at home until her passing, but if that is not possible and she begins to develop Alzheimer's or any other form of memory impairment, I will be seeking an assisted living community to accommodate her needs. We, as a nation, must care and protect our elderly and stop treating them as a "disposal" segment of our society."
- Helen Blanchard, Director of Business Administration, Crescent Point at Niantic, Niantic, CT (submitted February 3)
- Donna DiFabio, Director of Business Administration, Chelmsford Crossings, Chelmsford, MA (submitted February 3)
- Marcia Kuchuk, Receptionist, Maple Woods, Hamden, CT (submitted February 3)
- Heather Jagodowski, Harbor Program Director, The Atrium at Cardinal Drive, Agawam, MA (submitted February 3)
- Jennifer L. Porter, Director of Community Relations, Putnam Farm at Danvers, Danvers, MA (submitted February 3)
- Cathy Ballini, Executive Director, Atrium at Cardinal Drive, Agawam, MA, <http://www.benchmarkquality.com> (submitted February 3)
- Mary S. Young, RN BSN, Resident Care Director, Academy Point at Mystic, Mystic, CT, <http://www.benchmarkquality.com> (submitted February 3)
- Dale Adams, Harbor Program Director, Greenwich Farms at Warwick, Warwick, RI (submitted February 3)
- Todd Hopkins, Plant Operations Director, Benchmark Assisted Living (submitted February 3). Added information: "I have worked with people with Alzheimer's disease for six years now. To me it is one of the most insidious diseases there is. It not only robs the individual of their memories but the most painful is the family members that are lost in a fog. The saddest moment I can recall was watching a granddaughter coming down the stairs crying because her grandmother no longer knew who she was. We associates working in Assisted Living communities are trained not only to deal with the loss of memory for the person but we have a heart for the family members that are so affected by this disease. I took the time that day to sit with the young lady and explain the process that her grandmother was going through. I told her that it was a progressive disease but assured her that her grandmother may remember her once again for a short time. This convinced her to keep coming. Over the next few months she kept coming and to her delight there were times that her grandmother remembered. Because of the care we give and the training we have that young woman got to enjoy the last months of her grandmothers life, occasionally as her granddaughter but mostly (in her grandmothers words) as that wonderful young woman that was always so pleasant. This is a small part of what we in the Assisted Living field bring to the table."

- Thomas H. Grape, Chairman and CEO, Benchmark Senior Living, Wellesley, MA (submitted February 3)
- Elizabeth Skerry-Hastings, Senior Executive Director, Benchmark Senior Living, Orchard Valley at Wilbraham, Wilbraham, MA, <http://www.benchmarkquality.com> (submitted February 3)
- Susan Boudreau, Harbor Program Director, Blenheim-Newport, RI (submitted February 3)
- Gregory Batchelder, Executive Director, Greystone Farm, Salem, NH (submitted February 4)
- Tiffany Lagacy, Program Coordinator, The Atrium at Cardinal Drive, Agawam, MA (submitted February 5)
- Heather A. Seigars, Director of Business Administration, The Village at East Farms, Waterbury, CT (submitted February 5). Added information: "I am also the granddaughter of a wonderful woman who suffers with Alzheimers Disease. While my Grandma currently has ample family support in her home, I would hope that if things get worse, she would not need to be placed in a Nursing Facility to take care of her Memory Care. She does not require medical intervention, only the care and services of a caring Community such as the one that I work in. Assisted Living Communities such as ours provide QUALITY family-like settings for persons needing Memory Care."
- Sam Jackson, Executive Director, Haverhill Crossings, Haverhill, MA, <http://www.haverhilcrossings.com> (submitted February 5). Added information: "My community not only houses memory impaired residents in our secured Harbor program, but also has many residents who are experiencing early stages of Alzheimer's in our traditional environment. On a personal level, my grandmother up until recently lived in an assisted living community in Wisconsin while her own Alzheimer's progress."
- Melanie Perry, Resident Care Director, Haverhill Crossing, Haverhill, MA (submitted February 5)
- Peggy Mellen, Director of Business Administration, Ashland Farm, North Andover, MA (submitted February 5)
- David Kouloganes, Plant Operations Director, The Atrium at Rocky Hill, Rocky Hill, CT (submitted February 6). Added information: "...I am not only employed in the memory impaired industry my father has been afflicted by this disease."
- Danielle Taylor, Traditional Care Director, Haverhill Crossings, <http://www.haverhillcrossings.com> (submitted February 6)
- Melinda Fayette, Social Media Coordinator, Benchmark Senior Living (submitted February 6)
- Rachel Azer, RN, Interim Harbor Care Director, Ashland Farms, North Andover, MA, <http://www.ashlandfarmatnorthandover.com> (submitted February 6). Added information: "The Harbor unit houses those with all forms of dementia, with the largest percentage being Alzheimer's."
- Noeline Cranston, RN, Resident Care Director, Greystone Farm at Salem, NH (submitted February 6)
- Frida Bartlett, Director of Business Administration, The Atrium at Drum Hill, North Chelmsford, MA (submitted February 6)

- Barbara Upperman, The Atrium at Drum Hill, N. Chelmsford, MA (submitted February 6)
- Tracey F. Pidgeon, Director of Community Relations, Atrium at Cardinal Drive, Agawam, MA, <http://www.benchmarkseniorliving.com> (submitted February 6)
- Mary Roux, Resident Care Nurse, The Atrium at Drum Hill, North Chelmsford, MA (submitted February 6)
- Christie Tanguay-Frappier, Director of Business Administration, Orchard Valley at Wilbraham, Wilbraham, MA (submitted February 6)
- Kelly Sostre, Harbor Program Director (submitted February 6). Added information: "The Harbor program that I work in has 30 residents that have Alzheimer's or another form of dementia. We also have folks come in from the community for our day stay program and they too have Alzheimer's Disease."
- Tori Gamble, Harbor Program Director, The Atrium at Veronica Drive, Danvers, MA (submitted February 6)
- Ellen Courtemanche, RN, Resident Care Director (submitted February 6)
- Scott Weissman, Activity Director, Orchard Valley at Wilbraham (submitted February 7)
- Brenda Pelley, RN, Executive Director, The Atrium at Drum Hill, North Chelmsford, MA (submitted February 7)
- Elizabeth A. Harris, LSW, Plymouth Crossings, Plymouth MA (submitted February 7). Added information: "We have a number of very vibrant residents who are also diagnosed with Alzheimer's Disease. It is our privilege to assist these community members in their home which also happen to be an assisted living residence."
- Chris Golen, Regional Director of Operations, Benchmark Senior Living, Wellesley, MA (submitted February 7)
- Joe Tortolano, Plant Operations Director, Village @ Willow Crossings, Mansfield, MA (submitted February 7)
- Joy L. Mondeau, LPN, Care Nurse Supervisor (submitted February 7). Added information: "I have been a nurse for more than 30 years, with most of my experience being caring for the senior population. As we all work together to fight this terrible disease (while some of us that work daily with these individuals embrace time spent), I eagerly anticipate the revised National Plan to Address Alzheimer's Disease."
- Kathleen Kemp, Traditional Care Director (submitted February 7)
- Kristin Quarrell, Director of Business Administration, Haverhill Crossings, Haverhill, MA (submitted February 8)
- Tim Reilly, VP of Human Resources, Benchmark Senior Living, Wellesley, MA (submitted February 8). Added information: "During my 14 years in the assisted living industry (two employers) I have been fortunate to get to know many residents afflicted with Alzheimer's Disease, interact with their families and witness the extraordinary care that was provided until their last days in many assisted living communities."

- Jean Moran, Resident Care Director (submitted February 8)
- Theresa Waldron-Yancoskie, Director of Resident Lifestyle, Coachman Square at Woodbridge, Woodbridge, CT (submitted February 8)

DATE: February 3, 2012

SUBJECT: CCAL Comments on National Alz Plan...J. Pinkowitz, Chair

We respectfully submit the attached comments and appreciate your enabling us to do so.

Sincerely,

Jackie Pinkowitz, M.Ed.

Chair

CCAL -- Advancing Person-Centered Living

<http://www.ccal.org>

ATTACHMENT: CCAL National Alz Plan Comments 2.4.12.doc

<i>Available as separate links:</i>
Comments Submitted on the Draft Framework for the National Plan to Address Alzheimer's disease http://aspe.hhs.gov/daltcp/napa/Comments/cmtach43.pdf

DATE: February 3, 2012

SUBJECT: Draft Framework for the National Plan to Address Alzheimer's Disease

Recently The Department released The Draft Framework for the National Plan to Address Alzheimer's Disease. We thank you for developing a plan and a strategy for addressing Alzheimer's Disease. We are writing to The Department regarding the Draft and the issue that assisted living was omitted from all but one of its strategies and recommendations in the Draft.

Since assisted living communities accommodate a rapidly growing number of seniors with Alzheimer's disease and related dementia, assisted living communities have and will play a role in the future of Alzheimer's care and treatment. In fact, more than one third of current residents living in assisted living have Alzheimer's disease or dementia.

We recommend that assisted living be included in more of the strategies and recommendations in the Draft.

Below are highlighted areas for your consideration:

- Goal 2. Add licensed/certified assisted living communities to the list of settings in the opening paragraph after "hospitals"
- Strategy 2.D Add assisted living as a care setting after "physicians office"
- Strategy 2.E Add assisted living to the list of transition settings after "home"
- Goal 3: Change the title to Expand Support of Individuals with Alzheimer's and their Families, and add assisted living to the list of care settings after "hospitals"
- Strategy 3.B Add assisted living before "nursing home placement" in both references
- Strategy 3.D The use of the term "residential care facilities" in the first sentence is odd because that term has never been used throughout the document. A more consistent term could be "long term care settings". In two places the term "assisted living facilities" is used and the term "facilities" should be replaced with "communities".

Thank you for your consideration of these recommendations.

Emily Meyer
President
Massachusetts Assisted Living Facilities Association
Waltham, MA
<http://www.massalfa.org>

DATE: February 3, 2012
SUBJECT: National Plan to Address Alzheimer's Disease

As a cognitive aging researcher, it's appalling that the new draft framework on AD does not mention the influence of lifestyle and the environment in ***Strategy 1.B: Enhance Scientific Research Aimed at Preventing and Treating Alzheimer's Disease.***

Assuming that AD is entirely a biological disease and it not influenced by the environment and the stimulation that a person receives goes against basic psychological, cognitive, and neuroscience research (e.g., even rats placed in stimulating environments show more neuronal growth). In addition to this complete oversight, such a framework for prevention assumes that there is nothing a person can do (i.e., "we'll give you a drug, and hope for the best"). Providing older adults with ways they can take control of their own future, and possibly influence their own likelihood of preventing AD (e.g., not smoking, not being overweight, stressed, and staying cognitively and socially engaged) is a far more universal and economical approach and avenue to take, in addition to research on pharmacological interventions. Psychological research has been occurring on AD and MCI for years, and failing to acknowledge this contribution is ignorant and hurts the overall goal of addressing AD.

I would also like to note that relying entirely on general practitioners, not trained in detecting dementia symptoms is a poor focus as well. Personally, my aunt was recently having some memory problems, and after having a MRI that was clear, was sent to her GP for follow-up. Without even conducting a MMSE, the GP told her she had dementia, and he would prescribe Aricept. He didn't conduct a MMSE until 2 weeks later, at which point she received a score of 27/30, and the GP said, "oh, I guess she's fine". There is no way dementia can be diagnosed with such little knowledge, and not even simply relying on the MMSE is sufficient. There is a rich literature on neuropsychological testing in diagnosing AD, other dementia types, and using those tests to detect MCI and other conditions. If we can't subject every person with small memory problems to a spinal tap, neuropsychological testing that has been developed to be sensitive to small changes in cognition is a front-runner in where to focus our efforts. Relying on GPs for this type of diagnosis is not appropriate.

Sincerely,

Allison Bielak, PhD
Assistant Professor
Department of Human Development & Family Studies
Colorado State University
Fort Collins, CO

DATE: February 3, 2012
SUBJECT: NAPA Meeting follow-up

In 2008, I was diagnosed with Alzheimer's disease after struggling to get a diagnosis since my first symptoms at age 39. As one of 5.4 million people living with this debilitating disease, I currently live every day to make a difference. In fact, I am now an advocate for the education and eradication of this disease. While I only had an opportunity to watch it the second day of the NAPA meeting last month, I found it very interesting, yet my memory had already started to fade away. Some of my issues that I came up with are.

The 2020 date should be the date we shoot for as a cure date for Alzheimer's. 2025, should be the date that we eliminated it completely from all who have it, or at least stopped their progression at their given state. People react to dates and when they see date so far out they will not even give it a second thought, that is human nature. I use to see that with all the project I ever ran. While sometimes a date may be unrealistically, it is better to use one that is sooner than further away, keep the momentum going. That is what they also teach in project management.

I could see and hear the same frustration as I had from many of the committee members (both the non and federal) related to the date. Let's do what is right for those have been overlooked for so many years already. Use your heart to make the right decision. I have had the opportunity to speak to some of you, and you are not even sure why it's taken so long to get to this point. Let make this meeting count and make a statement to the World, that you do care about Alzheimer Patients and the injustice will end now.

I also feel the two days was kind of short and the original time given seemed to be cut short based on what needed to be talked about -- that's my viewpoint as an outsider.

It would be nice to have dial in conference number, so the public can also be included to make some statements.

While public can go to the meeting if arranged in advance, I would like to see a separate call in line for people who are invited in advance by phone, into the same conference call #. Just with priority over the drop in callers people.

While I think the use of metrics is great, it should not slow progress down at all. I would even recommend bringing in a master six sigma person who would be able to show how the spending of money now, can lead to the greater saving and man hours in both the health system and government from a short and long-term perspective. The long term savings numbers would blow their minds and they can relate to those expenditures.

As far as the 2 million needed, to fund this, which I still consider that amount to small and should also be raised, If no additional funding exist, then we should cut back from some of the other parts of the pie related to other high priority diseases and make it much fairer.

Everywhere you turn you see something related to Cancer and HIV. Our government contributes 18.7 percent of the NIH research budget to cancer, 9.9% to HIV, and just 1.4% to Alzheimer's. Why so little for Alzheimer's? There are many more people living with Alzheimer's than HIV, yet it receives much less funding.

We need to stop the disparity, or what I almost consider a form of discrimination.

Regards,

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

DATE: February 2, 2012
SUBJECT: Recommendations feedback

My name is Dr. Steve Hume and I am a member of the Alzheimer's Association national Board. I was also diagnosed with AD at the age of 60.

Feedback: I feel the framework and recommendations to date are on target and broadly cover the important issues.

Specifically, I would like to see a recommendation directed to Medicare that ensures it will develop and fund innovative in-home and in-community programs and services for persons with AD and their caregivers.

Many AD persons have Medicare but are ineligible for Medicaid. This precludes them from receiving in-home services, respite care and day treatment.

Many families cannot afford these services out-of-pocket. The result is either the caregiver reduces or eliminates their work hours or AD patients are forced into nursing home care prematurely.

When caregivers are unable to work the family suffers, more dollars are spent on welfare programs and the economy suffers as they leave the workforce.

Thank you.

Stephen Hume Psy.D.
Alzheimer's Association National Board Member

DATE: February 2, 2012
SUBJECT: NAHCA CareForce Program

Please see attached information. The NAHCA CareForce program has two components that educate and develop frontline caregivers. Feel free to contact me with any additional questions.

Regards,

Lee Larimore
SVP, Business Development
NAHCA CareForce
<http://nahcacareforce.org>

ATTACHMENTS: NAHCA CAREFORCE BROCHURE.pdf
NAHCA - History Programs Statistics 1 25 12.pptx

<i>Available as separate links:</i>	
Transform Your Workforce into a Proud & Professional CareForce	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach41.pdf
NAHCA CareForce Presentation	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach42.pdf

DATE: February 2, 2012
SUBJECT: NCCDP

Respite Care Funds for Care Givers:

We are writing on behalf of the thousands of members of the National Council of Certified Dementia Practitioners, Certified Dementia Practitioners CDP members, NCCDP Certified Alzheimer's and dementia Trainers, Certified Dementia Care Managers (Dementia Unit Managers) CDCM, NCCDP Associate Members, NCCDP Corporate Members and Certified First Responder Dementia Trainers CFRDT.

Respite Care funds must be made available for those people who lack private resources, funds, transportation and family support. Many caregivers provide 24 hour care in their home with no break, financial assistance or outside help. This leaves the care giver exhausted. Many of our nations care givers are elderly themselves. Caring for someone with a diagnosis of Alzheimer's disease or dementia is a full time job. Care givers provide full time supervision, medication disbursements, ADL care (bathing, toileting and dressing), housekeeping services, meal preparation, transportation to and from appointments, etc. Many are unable to work due to the time required to care for a loved one. This depletes their funds.

The respite funds should be used to either place a loved one in adult day care program, hire a private duty aide/home health aide, have a senior companion volunteer come to the home, utilize nursing home and assisted living respite services or whatever community program that works for the Care Giver.

Currently, care givers are exhausted with no relief in sight. Many are depressed and lonely. They are cut off from their friends, church members and neighbors. They are unable to enjoy a quality of life many of us who are not full time care givers take for granted. They are unable to go to church, participate in a hobby or any other social event. Just going grocery shopping is challenging.

Isolation can also lead to abuse and neglect. Most care givers have the best intentions but abuse and neglect can happens when there is stress, isolation, lack of funding and lack of support.

Where there are respite services in a state the Care giver lacks funding and transportation. I saw first hand as a facilitator of a support group the desperate needs of the care givers. Some respite services are time consuming with lengthy paper work required. There may be waiting lists making respite services unattainable when they need it the most. Many community respite services require the care giver to transport their loved one and they are unable to provide this. Or there may be no respite community services with in their community.

There must be state and federal funds available for caregivers without funding to use for respite services. Each community should be looking at ways to keep the patient in the home and provide the care giver options such as home care respite services, assisted living and nursing home respite services and volunteer senior companion programs all of which provides options for the care giver.

Sandra Stimson, CALA ADC CDP CDCM AC-BC
Executive Director
National Council of Certified Dementia Practitioners
Sparta, NJ
<http://www.nccdp.org>

NCCDP ALZHEIMER'S DEMENTIA STAFF EDUCATION WEEK FEBRUARY 14TH TO 21ST.
*Register at the top right of home page and begin downloading **Now to March 1st**. Free staff in-services includes power point, hand outs, staff pre and post tests. The tool kit includes, Proclamation, Alzheimer's Bill of Rights and Alzheimer's Pledge and so much more. Fantastic in-service on Sexuality and Intimacy and Dementia. See <http://www.nccdp.org>*

DATE: February 2, 2012

SUBJECT: From NCCDP Comment / Input for National Alzheimer's Plan

We are writing on behalf of the thousands of members of the National Council of Certified Dementia Practitioners, Certified Dementia Practitioners CDP members, NCCDP Certified Alzheimer's and dementia Trainers, Certified Dementia Care Managers (Dementia Unit Managers) CDCM, NCCDP Associate Members, NCCDP Corporate Members and Certified First Responder Dementia Trainers CFRDT.

It must be mandatory that all health care professionals who work in nursing homes, assisted living, CCRC, adult day care, hospice agencies, home care agencies, hospitals, senior living communities and any other setting that provides services to the geriatric population receive at minimum of 8 hours of "LIVE" Alzheimer's and dementia education by certified Alzheimer's and dementia trainers.

There must be continued ongoing education through out the year once they have received the initial training that deals with new advances, regulatory changes, culture change and abuse / neglect concerns. The state regulations for dementia education is different in each state and for each type of service industry. Care providers, front line staff and health care professionals must all receive a minimum of 8 hours of live Alzheimer's and dementia education and ongoing Alzheimer's and dementia education to insure competent and compassionate care. There are currently no national standards. The new federal standard being considered **should not target** one specific profession but must be all inclusive and include all health care professionals and front line staff who work with the geriatric population.

It must be mandated at the federal level so that all states are in compliance with mandatory live dementia education. Further more, all First Responders which includes Law Enforcement EMT's and Fire Fighters also receive comprehensive Alzheimer's dementia education. As they come face to face with the geriatric population in their community but are ill equipped due to lack of Alzheimer's and dementia education to deal with concerns affecting the geriatric populations such as recognizing abuse / neglect in the home, driving concerns in the elderly. aggressive behaviors and elopement.

Profit and not for profit companies and organizations should be included in a list of organizations and companies who offer live dementia education. There should be a national list of companies who can offer these services. The list should **not be regulated** nor designed for non profit training organizations but include for profit companies as well. Health Care organizations, First Responders and companies should have the option to pick and choose which organization they wish to utilize to provide live dementia education to their staff.

The initial live Alzheimer's Dementia education should be live training provided by live instructors who are certified Alzheimer's and dementia trainers vs utilizing video and online Alzheimer's and dementia training to insure that the health care professional and front line staff understands the material. It is critical that they be given the opportunity to interact with the instructor, ask questions and be provided the opportunity to discuss issues and concerns they may have. This can not happen with videos and online training. We respect this option for education for ongoing education through out the year but not in place of the initial live training. The National Council of Certified Dementia Practitioners provides live Alzheimer's and dementia education as well as dementia certification to front line staff, health care professionals, dementia unit managers and First Responders. The National Council of Certified Dementia Practitioners also provides train the trainer and certifies trainers as Certified Alzheimer's and Dementia

Trainer and Certified First Responder Dementia Trainer who in turn utilize current and most up to date NCCDP curriculum.

Sandra Stimson, CALA ADC CDP CDCM AC-BC
Executive Director
National Council of Certified Dementia Practitioners
Sparta, NJ
<http://www.nccdp.org>

NCCDP ALZHEIMER'S DEMENTIA STAFF EDUCATION WEEK FEBRUARY 14TH TO 21ST.
*Register at the top right of home page and begin downloading **Now to March 1st**. Free staff in-services includes power point, hand outs, staff pre and post tests. The tool kit includes, Proclamation, Alzheimer's Bill of Rights and Alzheimer's Pledge and so much more. Fantastic in-service on Sexuality and Intimacy and Dementia. See <http://www.nccdp.org>*

DATE: February 1, 2012

SUBJECT: Draft Framework for the National Plan to Address Alzheimer's Disease

I have read the *Draft Framework for the National Plan to Address Alzheimer's Disease*. I am very concerned that assisted living facilities (RCFEs, board and care communities, etc.) have been left out of this National Plan. I am respectfully requesting that at least two changes be made. To wit:

1. Under Goal 2: Enhance Care Quality and Efficiency, add assisted living facilities to the list of settings where high quality of care should be provided. As it is now, the draft only lists people's homes, doctors' offices, hospitals and nursing homes.
2. Under Strategy 3.B The existing statement: *Round the clock care needs of the person with Alzheimer's disease often necessitates nursing home placement* should be changed to: *Round the clock care needs of the person with Alzheimer's disease often necessitates placement in a nursing home or assisted living facility.*

Assisted living facilities (ALFs) play an important role in providing quality care to residents afflicted with Alzheimer's disease. In the past few year, ALFs have been accepting increased numbers of residents with high acuity care, including those with Alzheimer's and dementia and providing quality care at considerably lower cost than nursing homes. Leaving ALFs out of the National Plan to Address Alzheimer's Disease is a disservice not only to these institutions, but also to the thousands of Alzheimer's residents they serve or could potentially serve.

George Mozes
Owner/Administrator
Evergreen Chalet
Vista, CA

DATE: February 1, 2012
SUBJECT: Alzheimer's Strategies

In my opinion (which is based on years of working in the field of dementia with geriatric psychiatrists) your focus on Alzheimer's Disease is too limited to be useful to those elders who have other forms of dementia. Science tells us that there is more than one form of dementia. Alzheimer's is cortical related dementia, where visuospatial praxis declines, whereas vascular dementia can affect many other parts of the brain, producing executive function decline, depression, and other limiting behavioral changes such as disinhibition on one pole and apathy on the other. Some of these less well known effects of dementia underlie self-neglect, hoarding, inability to drive safely, and suicide.

We should examine the circuits in the brain, localize the likely causes of dementia through MRIs and fMRIs and address them more broadly in any National plan.

Thank you for taking the time to read this. I personally am committed to finding ways to extend autonomy in aging through physical activity interventions. Here is a link to my faculty page.

<http://profiles.uthscsa.edu/?pid=profile&id=0V800MZN8>

Kind Regards,

Mary (Kelly) Dunn, RN, PhD, PHCNS-BC
Associate Professor
Nancy Smith Hurd President's Chair in Geriatric Nursing and Aging Studies
University of Texas Health Science Center
School of Nursing
San Antonio, TX

DATE: February 1, 2012

SUBJECT: FW: National Alzheimer's Plan - an ALF member's response from Florida

Michael Barody, past FHCA president and current ALF Exec. Dir., sent the following email to HHS regarding the National Alzheimer's Plan. Michael makes an excellent point. Florida has ½ million residents with Alzheimer's and we know that a majority of nursing home residents have Alzheimer's disease and an increasing percentage of Assisted Living Facility residents. Florida, as the oldest state in the union, is a haven for retirees without family close by which puts them at more risk of needing more formal LTC support.

LuMarie Polivka-West, MSP
Senior Director of Policy
Florida Health Care Association
Tallahassee, FL

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From: Michael Barody

As an Executive Director of an assisted living community I am concerned about the lack of focus, in the plan, on the critical role we play in providing services to this vulnerable group of citizens. Of the 180 residents who reside with us 49 are on our early stage to moderate dementia unit. Others in our building also have beginning symptoms. We provide care and services to our residents as well as the families struggling with this disease. Our monthly support group assists our families and the public to meet with others and share concerns and feelings. Creating a quality of life environment for our residents and families is an ongoing challenge that must be supported by research and forward thinking public policies. Thank you for your consideration.

DATE: February 1, 2012
SUBJECT: National Alzheimers Plan

As an Executive Director of an assisted living community I am concerned about the lack of focus, in the plan, on the critical role we play in providing services to this vulnerable group of citizens. Of the 180 residents who reside with us 49 are on our early stage to moderate dementia unit. Others in our building also have beginning symptoms. We provide care and services to our residents as well as the families struggling with this disease. Our monthly support group assists our families and the public to meet with others and share concerns and feelings. Creating a quality of life environment for our residents and families is an ongoing challenge that must be supported by research and forward thinking public policies. Thank you for your consideration.

Michael Barody

DATE: February 1, 2012
SUBJECT: Comments

I am a Psychiatric Nurse Practitioner working with the Geriatric Population. I care for and diagnose Dementia on a very regular basis. After reviewing the document for a National Plan to Address Alzheimer's Disease I recommend the following amendments:

Strategy 2.A

Add Neuropsychologist to the list, they are invaluable in the accurate diagnosis of many of the other Dementia's and early identification of mild cognitive disorders, which will likely progress to Alzheimer's. There are not enough of these very specialized professionals to address the wave of dementia that will be occurring with this rapidly growing aging population.

Strategy 2.D

There is a large portion of the population with Dementia, that would be best served by an Assisted Living Setting (not safe at home alone, no family support available, no skilled nursing needs). This large group often live in unsafe conditions because there is no funding source (other than private pay) for this intermediate level of care. Those that need help with meals, transportation, ADL's r/t safety (in and out tub), perhaps medication monitoring/reminders/set-up, daily checks, built in emergency call system in case of falls. This would not have to be manned by RN's like SNF in LTcare. But perhaps monitored by an LPN or Designated Geriatric Provider of some kind with training in the care of mild to moderate Dementia. Families often struggle with putting a loved one in a "nursing home", so those with Dementia are either provided too high or too low a level of care. This would very likely decrease the cost of expenditures for long-term care, as it would substantially delay the use of LTC.

Strategy 3.B

Provisions for in-home respite care for those who choose to have loved ones live with them, is an invaluable service, which would allow for less caregiver burn-out and delay admission to a 24hr facility. Thus cutting down the expenditure of resources, before they are necessary

This Very complex issue will not be solved quickly or easily, I hope the above suggestions from a practitioners point of view are helpful in improving the quality of care and quality of life for those suffering with Dementia.

Leslie A. Briscoe, CNP
Louis Stokes Cleveland VA Medical Center
Cleveland, OH