

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

JANUARY 2012 COMMENTS

Draft HHS National Plan to Address Alzheimer’s Disease -- Comments from the National Academy of Neuropsychology	3
Opinion Input on NAPA	4
Comment on HHS Draft of National Plan to Address Alzheimer’s Disease	5
Simple Way To Stop Alzheimer’s	6
Alzheimer’s	7
APA Comments on Draft Framework for National Plan to Address Alzheimer’s Disease	8
Comments on the National Plan	9
Comment -- National Plan to Address Alzheimer’s Disease	10
Additional Comment on Draft of National Alzheimer’s Plan	11
Copy of Public Comments Input to Jan 17/18 HHS & Advisory Council on Alzheimer’s Research, Care, and Services National Alzheimer’s Plan	12
Alzheimer’s National Plan Framework, Public Awareness Campaign	13
Public Comment on Alzheimer’s Plan	14
Public Comment for Draft Frame Work National Plan to Address Alzheimer’s Disease	15
Are Dental X-rays Causing Alzheimer’s Disease?	17
Alzheimer’s NAPA Framework	18
Ideas to be Included in Draft Plan	19
Urge to Adopt the 2020 Goal of Increased Investment in Alzheimer’s Research and Faster Drug Development	20
Comments Regarding NAPA Advisory Council Meeting	21
Comments for the NAPA Advisory Board	22
Comment	23
Now Available for Public Comment Through Feb 8, 2012: Draft Framework for the National Plan to Address Alzheimer’s Disease	24
Comments on Alzheimer’s Care; Proposal for Long Term, Affordable Alzheimer’s Care	25
For Meeting Today	26
Comments on Draft of National Alzheimer’s Plan	27
Alzheimer’s Disease	30
Comments NAPA Draft Framework	31
Public Comment on Draft NAPA Plan and AoA Alzheimer’s Programming	33
Comment Re. National Alzheimer’s Plan and Mental Health	34
Alzheimer Proposal	35
Comment	36
NAPA Comment from Individual	37
Draft Framework for the National Plan to Address Alzheimer’s Disease	38
National Plan to Address Alzheimer’s Disease	40
Comments on Alzheimer’s	41

Please Allocate More Money Now -- Let's Solve This by 2020 or Sooner.....	42
Comment	43
Supporting the Concerns of Dr Wyman	44
Comments on Draft Framework for the National Plan to Address Alzheimer's Disease	45
Draft Framework for the National Plan to Address Alzheimer's Disease.....	46
Comments on National Plan for Alzheimer's	47
Comments - "Draft Framework for the National Plan to Address Alzheimer's Disease"	48
Now Available for Public Comment through Feb 8, 2012: Draft Framework for the National Plan to Address Alzheimer's Disease	49
Where Do I Fit in the Plan?	50
Comments on National Plan.....	51
Draft for Alzheimer's Forum.....	52
Identify Whole Person -- Safer Care.....	53
Alzheimer's	55

JANUARY 2012 COMMENTS

DATE: January 31, 2012

SUBJECT: Draft HHS National Plan to Address Alzheimer's Disease - Comments from the National Academy of Neuropsychology

Attached are comments from the National Academy of Neuropsychology regarding the Draft HHS National Plan to Address Alzheimer's Disease.

Please let me know if you have any questions or concerns.

Thank you for your time in advance.

Tim Wynkoop, Ph.D., ABPP
Board Certified in Clinical Neuropsychology (ABCN)
Clinical Assistant Professor, University of Toledo School of Medicine
Fellow & Past Program Chair, National Academy of Neuropsychology (NAN)
Co-chair, NAN Professional Affairs & Information Committee
Toledo, OH

ATTACHMENT: Draft HHS National Plan to Address Alzheimer Disease - NAN PAIC
Comments.pdf

Available as separate links:

Draft HHS National Plan to Address Alzheimer Disease Comments from the Professional Affairs & Information Committee National Academy of Neuropsychology	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach40.pdf
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DATE: January 31, 2012
SUBJECT: Opinion input on NAPA

I have learned the HHS is asking public input on the National Alzheimer's Project Act. As an Alzheimer researcher, I feel it is important to share my recent work with you and the members of the advisory committee.

Please find two of our recent articles and a "Press release" attached. The press release summarizes our main points in the articles which address the problems in the current perception and research directions.

Thank you very much.

Respectfully,
Ming Chen, Ph.D.
Associate Professor
Bay Pines VA Medical Center and University of South Florida
Bay Pines, FL

ATTACHMENTS: JAD Press release.pdf
Alzheimer Truth.pdf
What to look for in SD.pdf

Available as separate links:

New Study Challenges Accepted Approaches to Research in Senile Dementia	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach38.pdf
Scientific Truth or False Hope? Understanding Alzheimer's Disease from an Aging Perspective	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach4.pdf
What to Look for Beyond "Pathogenic" Factors in Senile Dementia? A Functional Deficiency of Ca ²⁺ Signaling	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach39.pdf

DATE: January 31, 2012

SUBJECT: Comment on US Department of Health and Human Services Draft of National Plan to Address Alzheimer's Disease

Thank you for allowing us the opportunity to comment on the current draft of the HHS National Plan to Address Alzheimer's Disease. I urge you to consider the thorough comments offered by the American Psychological Association (submitted to Dr. Lamont on 1/26/12) in your further review of the Plan. Psychologists are an integral part of the research, diagnosis, and treatment of Alzheimer's Disease and I believe they should be included among the key disciplines identified in the Plan Framework.

Thank you for your consideration of our input.

Alison Byrne, Ph.D.
Geropsychologist
Zablocki VA Medical Center
Milwaukee, WI

DATE: January 30, 2012
SUBJECT: 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: January 29, 2012
SUBJECT: Alzheimer's

I am currently a caregiver to my wife who is a patient of a care facility at Timbercrest Senior Living Community in North Manchester, IN. I do not question the care she is receiving as it is excellent. She has been in healthcare facilities for over two years and in home care for over two years preceding the institutional care. The one thing I have not seen in the draft framework is a way to offset the financial burden for the care of the patient. The cost of the care for my wife is costing me personally with no financial assistance is between \$60,000 and \$70,000 per year. Most long term care policies for this disease would not be reasonable to afford for most individuals. I think some provision needs to be made to include support for the patients with dementia or Alzheimer's disease through Medicare and this has not been addressed in the draft. This is one disease that after it reaches a certain stage cannot be handled in the home environment and must be taken care of in an institution.

Thank you,
Robert L. Hollenberg
North Manchester, IN

DATE: January 26, 2012
SUBJECT: RE: APA Comments on Draft Framework for National Plan to Address Alzheimer's Disease

Please find attached, the American Psychological Association's (APA) comments on the Draft Framework for the National Plan to Address Alzheimer's Disease.

Sincerely,

Papa Andoh

Papa Andoh, MBA
Executive & Policy Assistant
Executive Office
American Psychological Association
Washington, DC
<http://www.apa.org>

ATTACHMENT: APA Comments on Draft Framework for National Plan to Address Alzheimer's Disease.pdf

<i>Available as separate links:</i>
APA Comments on Draft Framework for the http://aspe.hhs.gov/daltcp/napa/Comments/cmtach37.pdf National Plan to Address Alzheimer's Disease

DATE: January 26, 2012
SUBJECT: Comments on the National Plan

Thank you for accepting comments on the draft of the National Plan to Address Alzheimer's Disease.

As a rhythm facilitator with a good deal of experience in elder care, I have often noticed that people experiencing the symptoms of Alzheimer's disease strongly gravitate toward any rhythm experience. The research indicates that Alzheimer's causes the brain to lose its sequencing function to a greater degree with time. The research also indicates that the experience of making or participating in rhythm helps the brain coherently sequence events.

This seems to be the initial draw for patients with Alzheimer's. I have heard many of them comment to the effect that participating in rhythm events helps these people "feel normal again," as they usually put it. I find that they will attend rhythm-making events even when most other activities lose their interest.

Rhythm-making in a group also provides multi-faceted wellness opportunities for people with Alzheimer's in all seven dimensions of wellness, as formally defined by the International Council on Active Aging:

- Physical exercise
- Intellectual stimulation
- Social interaction
- Emotional expression
- Spiritual connection
- Occupational satisfaction
- Environmental awareness of surroundings

Rhythm is innate to all humans, and when motor or brain functions begin to falter, normal respiration, pulse, and heart rate can be stabilized and strengthened by the artful use of rhythmic activity.

Much store has been put in the efficacy of computer programs to boost brain efficiency. While brain efficiency is important, it is not the only aspect of being human that matters. Brain efficiency directly depends on the function level of all the body systems. We must stop treating humans as simply brains supported by a superfluous body structure. To retain quality of life, and indeed the quality of humanness itself, all the dimensions of wellness must be addressed together.

I hope you will consider inserting a recommendation for social rhythm-making in your final protocol for Alzheimer's disease.

Thank you for accepting my comments.

Candy Davis

DATE: January 25, 2012
SUBJECT: Comment - National Plan to Address Alzheimer's Disease

Thank you for the opportunity to comment on the National Plan to Address Alzheimer's Disease. Attached is my comment.

Chaplain Karen A Reed, DMin, BCC
Staff Chaplain/Integrated Ethics Program Officer
South Texas Veterans Health Care System

ATTACHMENT: Comment - National Plan to Address Alzheimer's Disease (2).doc

<i>Available as separate links:</i>	
Comment on National Plan to Address Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach36.pdf

DATE: January 24, 2012
SUBJECT: Additional Comment on Draft of National Alzheimer's Plan

This is another comment left by a reader regarding the National Alzheimer's Plan.

Cindy Keith, RN, BS, CDP says:

As a dementia consultant I applaud the forward movements of our government in this "war" against Alzheimer's. As a daughter who watched her father succumb, and as a professional weeping with families I counsel, I ache at the snail's pace of any help in this war. This is a war in which sweat, tears of frustration and deprivation of a normal life often seem to be the only weapons a family caregiver has against an unseen enemy that resides in the brain of a loved one.

As an author, a speaker and a dementia trainer of staff in facilities, I know just how much many of those staff don't know about how to interact properly with elders with dementia, and it breaks my heart to see the money getting funneled into the pockets of the corporations or wealthy individuals running many of those homes instead of much-needed staff dementia training. That being said, I also know that even when staff receive training, unless the management reinforces and models the training, the staff will revert back to what they used to do. So, training of those people in management is also a critical piece of a successful move toward better care in facilities.

We all need specific tools with which to work, and in this war, tools are few and far between, especially for family caregivers. Information is a required tool and thankfully, About.com is helping on that front.

Let us hope the government will assist those of us possessing tools to help those who need it most.

Thank you for soliciting feedback on this critically important plan.

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

DATE: January 23, 2012
SUBJECT: Copy of public comments input to Jan 17/18 HHS & Advisory Council on Alzheimer's Research, Care, and Services National Alzheimer's Plan

The attached document is a summary of my public comments made on Jan 17, 2012 at the HHS and Advisory Council on Alzheimer's Research, Care, Services meetings to develop the national Alzheimer's plan. Thank you for the opportunity to publically voice my input at the meeting during the public input session. It was a great opportunity to meet many individuals from both the federal and private sectors who are dedicated, compassionate, and committed to fight against Alzheimer's disease through a national plan of action.

The attached document includes my specific public comments as well a few additional input comments.

Thank you for the opportunity to attend the meetings and I look forward to attending in the future as well. The work of HHS and the Advisory Council is to be highly commended.

Best regards,
Kathleen Srsic-Stoehr, MSN, MS, RN, NEA-BC
Family Advocate and Member of the National Task Group on Intellectual Disabilities and Dementia Practices

ATTACHMENT: K Srsic-Stoehr Public Cmts to Advisory Council Natl Alz Plan Mtg Jan 2012.docx

Available as separate links:

Comment Summary from Public Input Session

<http://aspe.hhs.gov/daltcp/napa/Comments/cmtach35.pdf>

DATE: January 21, 2012

SUBJECT: Alzheimers National Plan Framework, Public Awareness Campaign

I have read the Draft Framework document and I am encouraged that it include Strategy 3.C: Assist Families in Planning for Future Long Term Care Needs.

May I suggest this be expanded into a national comprehensive and coordinated public awareness campaign? The need for families to get together and talk about how and where they wish to be cared for if they ever need care is one essential element. Another is to put in place the legal documents such as Powers of Attorney and Advanced Medical Directives. And, most important, to consider purchasing long term care insurance BEFORE it is too late as correctly stated in this section.

Please utilize the services of insurance agents who specialize in long term care insurance. I am sure that the following organizations would be glad to assist:

The American Association of Long Term Care Insurance (<http://www.aaltci.org>)

The Center for Long Term Care Reform (<http://www.centerltc.com>)

The National Association of Health Underwriters (<http://www.nahu.org>)

Also estate attorneys, accountants and financial planners should have valuable input into such a public awareness effort.

Finally, within the membership of the Alzheimer's Association there are a number of authors (including myself) who have written books about their experiences. I wrote My Million Dollar Mom. <http://www.buybooksontheweb.com/product.aspx?ISBN=0-7414-6713-5> It chronicles my time caring for Mom with the help of a wonderful care giver named Nora. I was able to keep my Mom at home until her death two years ago because she and I planned for this years in advance and that planning, the documents we had in place for her and the insurance that I bought for her made the burden that much less.

I would suggest a national tour of speaking engagements (or regional conference) where we authors can talk about Alzheimer's and how real the problem is.

Please let me know what I can do to help.

Sincerely,
Ross Schriftman, RHU, LUTCF, ACBC, MSA
Horsham, PA

DATE: January 20, 2012
SUBJECT: public comment on Alzheimer's plan

I applaud the committee for beginning this effort to eliminate Alzheimer's Disease AND to support patients and their caregivers who are currently dealing with this devastating disease. I am a professional in the aging field with over 20 years experience in caregiver support and training as well as supervision of In-Home Aides. I also cared for my mother in my home for 4 years before she went to a nursing home for the last two months of her life, so I can speak from a professional AND a caregiver point of view.

By way of supporting the current caregivers and patients I see a big need for **training** for facility and home care staff, especially line staff in how to deal with Alzheimer's patients and the sometimes challenging behaviors they exhibit. I see a need for facilities (nursing homes or assisted living primarily, but also hospitals) to train staff in dealing with family caregivers as care partners rather than as peripheral entities. Much lack of adequate care could be avoided by clearer communication and understanding what is happening with the patient in terms of the disease.

There is also a HUGE need for **funding for such training, for hiring more line staff in facilities, and for providing respite for family caregivers** so that they can continue to do the wonderful job they do. Without adequate funding, all the "frameworks" in the world won't make a dent in the root issue. I've seen the Family Caregiver Support Program languish for 10 years now at nearly static funding levels (which is of course going backward since costs are NOT static). The Lifespan Respite program was widely applauded and has lofty goals, but has yet to see any real funding. Caregivers are tired of hearing Congress and federal/state agencies say to them, "oh, it's so wonderful what you do and we want to support you, but there's no money so here's a proclamation (or in this case a "framework") instead."

Again, what you have done thus far is admirable and a good first step. Now let's try to make a difference to real people on the front lines with funding to back it up.

Mary H. Troutman
Programs Supervisor
Stanly County (NC) Senior Services Department
Albemarle, NC

DATE: January 20, 2012

SUBJECT: Public Comment for Draft Frame Work Na't Plan to address alz Disease

Please submit our comment for Draft Frame Work National Plan to Address Alzheimer's Disease.

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

DATE: January 20, 2012

SUBJECT: Are Dental X-rays Causing Alzheimer's Disease?

Attached please find a PDF of the PowerPoint I prepared for the 1-17-2012 public comments. I am also attaching a Word file and a PDF of the text to the presentation. Both files the PowerPoint and text files contain more information than time allowed me to present in person.

Thank you in advance for posting both the PowerPoint and text file on the website.

Sincerely,
Caroline Rodgers

ATTACHMENTS: Alzheimer's Advisory Council presentation by Caroline Rodgers 1-17-2012
FINAL REVISION.pdf
Alzheimer's Advisory Council -- Caroline Rodgers -- 1-17-2012 sub FINAL.pdf

Available as separate links:

Are Dental X-rays Causing Alzheimer's Disease?	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach33.pdf
Are Dental X-rays Causing the Alzheimer's Epidemic?	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach34.pdf

DATE: January 20, 2012
SUBJECT: Alzheimer's NAPA Framework

I'm adding my families voices to those who want to see Alzheimer's disease eradicated ASAP. The NAPA framework is a great start -- a late start, but a great start none the less.

Please accelerate the 2025 goal & support the investment in Alzheimer's research & figure out ways to accelerate the drug treatment. I realize this is probably one of the worst times in history to be asking for more government funding -- but we didn't make significant progress on any of the other major illnesses until we focused on them by utilizing our national resources & making the eradication a priority!

This illness kills people, depletes their savings & takes a significant toll on families & caregivers. I know first-hand -- my mom has Alzheimer's, my aunt has Alzheimer's, looking back -- my grandma had some form of dementia too. Illness is never easy, but when the course of the disease is so long & it takes away the essence of who you are, it becomes devastating. There are no words to express the heartache & loss.

Thank you for your attention to this matter.

Sheri Supena

DATE: January 20, 2012
SUBJECT: ideas to be include in draft plan

I don't know who this letter is going to, but I hope to spread the word as often and to as many people as possible. Attached in the word doc are my suggestions.

Best regards,

Patrick M. Sullivan PhD
Associate Professor
Department Medicine
Division Geriatrics
Durham VA Medical Center
Duke University
Durham, NC

ATTACHMENT: The greatest challenge to finding new treatments to AD is.docx

<i>Available as separate links:</i>	
The Greatest Challenge to Finding New Treatments to AD	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach32.pdf

DATE: January 20, 2012

SUBJECT: Urge to adopt the 2020 goal of increased investment in Alzheimer's research and faster drug development

As a long standing researcher on what causes Alzheimer's disease, and how to prevent and cure it, I urge you to immediately sponsor the proposal to increase funding for Alzheimer's disease research; the figure of \$2 billion sounds about right. This was done for HIV/AIDs which is now a manageable disease. The same can happen for AD- The last few years have been exceedingly bad for AD research funding -- I have never before seen my research colleagues have to leave their positions, or leave science all together because they have not been able to secure NIH funding. The usual casualties are the more junior faculty, but I have seen it happen to senior faculty also, here at Columbia, one of the powerhouses of AD research. All of us spend much more time writing grant proposals than doing science which is a disaster if you really want progress.

I myself have cut way back on expensive translational research that uses mice genetically engineered to have Alzheimer's disease to identify good drug targets, so I now use much cheaper (but far less informative) cell models. This is entirely due to my inability to fund the much more costly translational research, even though I have been pretty successful competing for NIH funding.

Please, if you want to prevent and cure this disease, which is entirely possible with the right support, adopt the 2020 goal by increasing investment in Alzheimer's research and faster drug development and start by immediately injecting a realistic amount of funding into the research so we dont continue to rapidly slip backwards from the great progress we have made in the last 20 years.

Thank You,

Karen Duff, Ph.D.
Professor,
Department of Pathology and Cell Biology
Taub Institute for Alzheimer Disease Research
Columbia University Medical Center
Department of Integrative Neuroscience
New York State Psychiatric Institute
New York NY

DATE: January 20, 2012

SUBJECT: Comments Regarding NAPA Advisory Council Meeting

I am writing to encourage adoption of the early 2020 timeline and \$2 billion in annual funding to combat Alzheimer's.

As the majority of our population passes their fifties, this insidious disease has the potential to overwhelm and cripple our health care and care giver systems and our economy over the next ten years.

Urgent action is needed now to avert a disaster over the coming decade.

Thank you in advance for your strong support of these measures.

Sincerely

Les Deak
Washington, DC

DATE: January 19, 2012
SUBJECT: Comments for the NAPA Advisory Board

Attached is the a letter commenting on the efforts the Advisory Board in currently considering.

Thank you for your consideration of our comments.

Jean Wood
Director, Aging and Adult Services Division
Minnesota Department of Human Services
Executive Director
Minnesota Board on Aging
<http://www.dhs.state.mn.us>
<http://www.MinnesotaHelp.info>
<http://www.MnAging.org>

ATTACHMENT: adssp support letter01-2012.pdf

Available as separate links:	
Comments on the Draft Framework	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach31.pdf

DATE: January 19, 2012
SUBJECT: Comment

While I am grateful that you have set a deadline for the Alzheimer's Prevention or to slow down the progression of the disease, 2025 is not nearly soon enough. There will be millions of more people with the disease by then, and millions of more lives lost. We need a cure or prevention and we need it now.

I am a caregiver for a mother with Advanced Alzheimer's and while it will be way too late to save her it can save me and millions of others. Alzheimer's and Dementia run in on my mother's side of the family; my Grandmother had it when I was a teenager and she lived with us until the end and so I have lived through this before and now again with my mother, my mother's sister also had Dementia and she passed away last year. It is completely devastating to watch and to go through, I wouldn't wish it on my worst enemy, my father and I are completely exhausted, but we want to keep my mother home with us until the end. I am worried that I will have it very shortly because it seems to run in the family and it scares me to death after going through this twice I would rather be dead than to be diagnosed with this extremely horrible disease. I am a single women with no children and if I should get it next, I am worried what will happen to me, I will have no one to care for me and it terrifies me so much I can't sleep thinking about it. It robs you of everything, your memories, your thoughts, your independence, your dignity, you can't do anything at all for yourself anymore and you cry all the time, because you actually know something is happening to you and you are scared to death. That is how my mother feels every day. She cries all the time and says what is happening to me, why can't I do anything anymore, why don't I feel well, don't leave me I am scared, she thinks people are poisoning her and trying to kill her, she thinks she is lost. I could go on and on, but if you know someone personally in your family that has this horrible disease, then you know what I mean. Please try to get this done way, way sooner, at least by 2020, which is still way too late. Thank you for listening.

Sincerely,
Lisa Marotta

DATE: January 19, 2012

SUBJECT: FW: Now Available for Public Comment through Feb 8, 2012: Draft Framework for the National Plan to Address Alzheimer's Disease

Like the draftwould encourage expansion on section, 2.A: Build a Workforce with the Skills..... Has NICHE or the Hartford Foundation/Robert Wood Johnson had an opportunity to engage with this work? There may be efforts underway that they currently support or would be interesting in partnering here. Our VA is NICHE designated and we are tapping into much of that work in growing a better workforce here to care for seniors overall, but also some specific programming for the Veterans suffering with dementia.

Thanks for the chance to submit feedback!

Susan Gresser, MS, RN, GCNS-BC, APNP
Gerontological Clinical Nurse Specialist
Zablocki VA Medical Center
RECC Division
Milwaukee, WI

DATE: January 18, 2012
SUBJECT: to Dr. Helen Lamont comments on Alzheimer's care; proposals for long term, affordable Alzheimer's care

I heard about this Federal, national initiative with great interest. Like cancer care, there needs to be an emphasis on research; however, there also needs to be an emphasis on finding high-quality, low cost, exceptional long-term care with dignity for persons with Alzheimer's and their families.

I am attaching a proposal I have for such (nationwide) care. I would like it to be considered by the committee as part of the national plan. I think it addresses care-giver support, the health care and other financial expenses, and the need for persons with Alzheimer's to live the rest of their lives with dignity.

Please contact me if you have additional questions.

Bonnie E. Smith, PhD, PA, CCC-SLP
Private Practice
Port Charlotte, FL
Professor Emerita of Speech Pathology
University of Illinois at Chicago
Courtesy Research Professor
University of South Florida, Tampa
<http://www.voicespeechstudio.com>

ATTACHMENT: Alzheimer's long term care proposal.doc

Available as separate links:

Proposal for a New State (Nation)-Wide
Model for Long-Term Alzheimer's Care
Delivery

<http://aspe.hhs.gov/daltcp/napa/Comments/cmtach30.pdf>

DATE: January 17, 2012
SUBJECT: for meeting today

There are many young people living with Alzheimer's disease. Many of them are frustrated, frustrated, and more frustrated. Not because they have Alzheimer's, but because of the disparity and stigma surrounding this disease. The 2025 date is proof of the lack of interest to a cure.

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. More funding is desperately needed.

No one wants to talk about this disease. The people directly impacted by this disease do nothing because they are overwhelmed dealing with the disease. Alzheimer's disease impacts so many aspects of people's lives, careers, hobbies and the many things we take for granted each day. Most patients find it difficult to learn something new, which ends up creating many issues for the patient and family. Most patients die within 4-8 years of diagnosis. There are no survivors of Alzheimer's disease. Why are stars or famous people not proud to stand up and support this cause? There is no pretty outcome, but that is why their help is needed.

Today something can be done to change that. We can start by advocating for the cause. Let's start by speaking up for the many others who can no longer write, speak or have passed on. Please help support their cause like we do for others. We need to enlist the backing of famous people so the perception will change from what exists today. Remember, it does not only affect the older generation. Alzheimer's disease can strike way before the age of 65. This younger-onset version has an even bigger impact on those diagnosed with it. Alzheimer's disease is a crisis in America and the predicted cost of care will be \$1.1 trillion, based on today's dollars, by the year 2050. The number of people diagnosed will more than double by then without our action now. This is the 6th leading cause of death, and the only one out of the top 10 causes of death in the US that cannot be prevented, cured, or even slowed down in its progression. It is very easy to read this article, experience a moment of sympathy, and then move on without doing anything.

Keep in mind this could one day affect you, your spouse, your son or daughter, their grandchildren, or even a close friend. Please do not wait until that day. Do something today.

Please help by joining the cause to make others aware of this debilitating disease and how it also affects young people. The youngest on record is 24 years old. Please reach out to the website so we all can work together to find effective treatment for Alzheimer's disease. Someone will develop the disease every 69 seconds. That number will increase to every 33 seconds by 2050.

Don't wait, our time and lives are too valuable. <http://www.michaelellenbogenmovement.com/>

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

DATE: January 17, 2012
SUBJECT: Comments on Draft of National Alzheimer's Plan

The following are comments left by my readers regarding the draft of the National Alzheimer's Plan. Thank you for developing this plan and soliciting feedback!

(1) Jim says:

Back in 1961 president John F. Kennedy made a commitment of going to the moon. Then in 1969 NASA accomplish that goal, so if you do the math it only took about 8 years. Why does the government feel it would take only 13 years to find a cure for Alzheimers? The drug industry have tried for years in finding a cure. Meanwhile, the skilled nursing homes are being filled with dementia/Alzheimers victims in different stages that either end up dying of malnutrition or pneumonia. The disease is rapidly growing out of control as we are living longer. I fear the time to address this problem has already passed.

January 16, 2012 at 7:17 am

(2) carla danesi says:

Its up to us as the americans who are caregivers for those afflicted to get involved with the council and help drive their progress so that it wont take 13 more years. I arranged care for my mom who has severe alzheimers and traveled to Washington to be involved with the councils first meeting. I'm on a limited budget. We can make this happen-We must! Thank you carla danesi glorias daughter "remember gloria, gloria lives"

January 16, 2012 at 5:10 pm

(3) Terri Litz says:

In an effort to help people with Alzheimer's and their families the government should help financially by adding to medicare a provision to help pay for care givers, The cost of care is outrageous. In the beginning some care and then 24/7. Nursing home options are just as expensive and take the quality of life away from individuals with dementia. When there is no money left and medicaid is the only option left the government intervenes. Then the Alzheimer's person has to have all their caregiver's changed to an approved medicaid agency. This change alone is frightening for the family and changes the relationships built up over years with private caregivers. My mother has had Alzheimer's for 9 years so far. Benefits from the VA have not been forthcoming for almost a year and seem almost unreachable. More documentation, more waiting and never an answer as to when her aide and attendance benefits will start or if she will ever even receive it. My father was a VET from World War II. I call the VA every 2 weeks and get no where. More documentation -the application was filed last Febuary and now almost a year later they are asking for more information/ medical information faxed 3 weeks ago and now they want financial documentation. It seems that they are waiting for my mom to die. Advocate all the time and get no where.

January 16, 2012 at 6:45 pm

(4) kathy lockhart says:

Besides the research that needs more money for this disease, medicare and other insurance companies need to support care in the home 24/7. My 83 year old mother can

not do it for my dad who is 84. We have needed in home care for that past 2.5 years. We have been fortunate to afford the care so far but it isn't going to last. I do NOT want to put my father in a nursing home that still does not know how to care for Alzheimer or any other dementia patient.

Changes in the healthcae system to prepare and regulate whether or not they are in fact providing best practices for these patients is important. Without government interventions, families struggle inordinately financially, emotionally, and physically. The caregiving will kill my mom before anything else. Unless I quit my job to help, I can only do the weekends. Isn't it cheaper to keep him at home than place him?? Looks that way to me. Thanks, Kathy

January 16, 2012 at 11:16 pm
(5) Michael Brennan says:

To prevent Alzheimer's disease, let's consider how people in countries with little Alzheimer's disease live (differences in diet? stress? sleep? environment? other differeces from us?)

Let's assure funding for any reasonable research proposal that could help prevent or delay Alzheimer's. The federal deficit is no excuse for skimping on this urgent need. The deficit will be far greater if we don't prevent or delay Alzheimer's disease.

January 17, 2012 at 12:38 am
(6) Miriam Monfredo says:

I will echo what others have said in regard to the need to fund home caregiving through a medicare provision. The cost of hiring someone from outside for even one day a week is prohibitively expensive for many families. It's far less expensive to society overall for Alzheimer's patients to remain in their homes and this fact should be reflected in financial relief to their primary caregivers. Until a cure is found, this financial need will become even more acute in our aging population.

January 17, 2012 at 6:29 am
(7) Trevor Mumby says:

I know it fantastically difficult for all of us to STOP, turn around, see the person with dementia as OUR teacher and learn what changes we have to make in ourselves to promote well-being in our lives.

Seeing our loved one as a SICK PATIENT compounds the agony.

How many more trillions of dollars will poured into the monster money eating pharmaceutical industry? (Are you watching our financial decline?)

The variety of behavioural challenges is the MAJOR problem.

Doctors, nurses and the medical model is for SICK people, not people who are challenging us and our own mental strength 24/7.

It is not really surprising to explain the difficult behaviour around people where dementia is being experienced.

Acute fear, panic, confusion, irrational actions are telling us to LEARN the art of conducting situations in a light creative style. When the lessons are mastered, the progression of dementia is about how well YOU are developing into a wise and kindly person through using your new skills.

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

DATE: January 16, 2012
SUBJECT: Alzheimer's disease

To prevent Alzheimer's disease, let's consider how people in countries with little Alzheimer's disease live (differences in diet? life style? stress? sleep? environment? other differences from us?)

Let's assure funding for any reasonable research proposal that could help prevent or delay Alzheimer's. The federal deficit is no excuse for skimping on this urgent need. The deficit will be far greater if we don't prevent or delay Alzheimer's disease.

Michael Brennan

DATE: January 16, 2012
SUBJECT: Comments NAPA Draft Framework

Thank you for this opportunity to provide comments on the Draft Framework for the National Plan to Address Alzheimer's Disease. The Prepare Minnesota for Alzheimer's Disease 2020 (PMA 2020) collaboration congratulates NAPA on this first important step in the development of a national plan to overcome Alzheimer's disease. The Draft Framework presents a comprehensive set of strategies to address this devastating disease that places an enormous emotional and financial burden on individuals with Alzheimer's disease and their families and also on the health and community care systems committed to supporting them. These strategies will spur research needed to cure the disease, early detection to permit individuals and families to delay premature decline and engage in planning that can have a tremendous impact on quality of life and provide the support needed for informal caregivers to maintain their own health while providing care.

As NAPA moves forward in the development of the plan, we recommend that it look to the accomplishments of the Alzheimer's Disease Support Services Program (ADSSP) for inspiration and guidance. The ADSSP program is funded by the Federal Government and administered by the U.S. Administration on Aging. Nationally ADSSP has provided grants to states to build dementia capacity within public and private agencies, building a core of expertise that has led to the development of services and systems that have changed the way in which community and health care services identify and support people with dementia and their families. Over the last twelve years, Minnesota has gratefully used this resource to embed dementia capability within county long term care assessment systems, to engage with local clinics and hospitals to identify people with dementia early and connect them to education and support services and to translate evidence based interventions into practice such as the New York University Caregiver Intervention that has been demonstrated to delay nursing home placement by up to 18 months compared to the control group.

We encourage you to build on this strong base by calling for restored funding for ADSSP which was reduced by 65% for 2012. It makes no sense to so severely reduce a program that embodies so many of the objectives of NAPA and the Council at least until a better program that can more effectively achieve these objectives is ready to go. We encourage you to call for an analysis of the strengths and weaknesses and lessons learned from ADSSP to inform the design of a new program that builds upon its achievements. And then call for adequate federal funding to meet the new program objectives. NAPA provides an incredible opportunity to take the best of what we've learned and grow it into community and health care systems that provide the support and education needed anywhere people with dementia and their informal caregivers reside while it is also working towards the cure we all hope for.

PMA 2020 is a voluntary, state-wide collaboration of medical, academic, community, government, business and nonprofit stakeholders across Minnesota seeking to implement needed system change, using the Minnesota legislatively mandated Alzheimer's Disease Working Group recommendations as a springboard for action.

Robert Karrick
Chair
Prepare Minnesota for Alzheimer's 2020

ATTACHMENT: 2012 Napa framework comments.pdf

<i>Available as separate links:</i>	
Comments on the Draft Framework	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach29.pdf

DATE: January 16, 2012

SUBJECT: Public comment on draft NAPA plan and AoA Alzheimer's programming

I am a retired aging services professional of thirty years who also is a member of an extended family strongly affected by Alzheimer's disease. I support the draft NAPA plan for its comprehensiveness, common sense and accountability. Minnesota has recently developed a legislatively-mandated report regarding how the state needs to prepare for Alzheimer's that is in essential alignment with the NAPA plan. In my experience it bodes well when federal and state efforts are in alignment; especially when supported by community advocates--which I fully expect to be the case with NAPA.

Now there is an opportunity to see whether the plan is just another document and whether the advisory council can be effective in guiding federal resource allocation regarding Alzheimer's to be in alignment with the plan.

The Alzheimer's Disease Support Services Program (ADSSP) of the Administration on Aging has seen its funding reduced by more than half. ADSSP has provided grants to Minnesota to build dementia capacity within public and private agencies, building a core of expertise that has led to the development of services and systems that have changed the way community and health care services identify and support people with Alzheimer's and their families. Over the last twelve years, Minnesota has used this resource to build dementia capability within ongoing and separately funded programs and services making them Alzheimer's capable. That capability is now being embedded into evolving state and federal health reform activities within Minnesota.

For the last decade, the ADSSP-funded planning and innovative programming was our state's most significant public sector activity advancing the Alzheimer's goals and strategies aligned with those contained in the NAPA plan. Please review and consider the strong advisability of maintaining ADSSP capability as a key component to realize the vision of the NAPA plan. Work with AoA to build the alignment and accountability to the national plan even stronger.

Respectfully submitted,

John Selstad
Minneapolis, MN

DATE: January 13, 2012
SUBJECT: Comment Re. National Alzheimer's Plan and Mental Health

Many of us believe that it is very important that the National Alzheimer's Plan address mental health issues in the lives of people with dementia and their family caregivers. That was the gist of the discussion that took place at SAMHSA on December 16 when a group of experts were brought together to provide recommendations for SAMHSA regarding NAPA. This past week I published a short piece in the *Huffington Post* that elaborated on this position a bit. I would be glad to provide more extensive ideas if that would be useful.

Here is the link to my piece. http://www.huffingtonpost.com/michael-friedman-lmsw/dementia_b_1189082.html

I have also attached a PDF.

Sincerely,

Michael B. Friedman, LMSW
Columbia University School of Social Work
Mailman School of Public Health
Founder and Honorary Chair,
The Geriatric Mental Health Alliance of New York

ATTACHMENT: Meet_MH_Needs_of_People_With_Dementia.pdf

Available as separate links:
Meet the Mental Health Needs of People With Dementia http://aspe.hhs.gov/daltcp/napa/Comments/cmtach28.pdf

DATE: January 13, 2012
SUBJECT: Alzheimer proposal

I was reading about the upcoming legislation regarding Alzheimer's. I am very happy our Government is taking steps to address this upcoming tsunami called Alzheimer's that is going to hit our country. I am not sure where to start? so i will start at the beginning my Mother was diagnosed 11 years ago with Alzheimer's.

That was the beginning of the journey I am on with her and this disease. She is now in the late stage of the disease she does not know me very much but that's OK. What I learned from my experience was that there was not enough help out there for caregivers and family members of Loved ones with the disease!! The statistics are that 64% of caregivers of Alzheimer's are hospitalized or Die before their loved ones!! That has to change we need to be giving some tools to these people so they can survive the caregiving process. I took three years to go and investigate and learn everything I could so I could take care of my Mom the best I could. In that process i saw the need to educate the people dealing with their loved ones on how to take care of their loved ones while keeping their stress levels down!. I can't state the importance of this. If we could help everyone understand how to do this we would save Money those same people would be healthier staying out of hospitals and keeping the Health Care costs down. I am not sure if this interests you but if it does I have alot more to say about my experiences talking to thousands of people dealing with this disease. I Lead 5 support groups a month for my Church and the Alzheimer's Association locally. I am providing a link to a local article written about me for some background. I would be happy to help in any way I can.

<http://www.ocreger.com/articles/care-333943-says-home.html>

Thank You and God Bless,

Vic Mazmanian
Mind, Heart & Soul Ministry
Saddleback Church & Silverado Senior Living
Director of Faith Outreach

DATE: January 13, 2012
SUBJECT: Comment

My name is Cristian SOCOLOV, and I am a romanian physician working in France in the Alzheimer's disease care field.

I built my medical career studying and promoting the Alzheimer's disease special care field, in Romania, and in France also.

I have some special results in the scientific research of the thyroid function in the Alzheimer's disease.

I followed, with great interest, the special US Government effort, the direct implications of the White House, in the Alzheimer's disease problem.

My question is related to the scientific research in Alzheimer's disease: are they specialised organisations in the USA, interested by news research idea in this field?

Gratefully, and a Happy New Year!

Dr.Cristian SOCOLOV M.D.,Ph.D.

DATE: January 13, 2012
SUBJECT: NAPA comment from individual

I shared the following comments with the Alzheimer's Association about the draft of the National Plan (NAPA), and wish to share them directly, also, with your office.

My father was diagnosed from autopsy with Alzheimers and other related disorders. I am not a medical professional.

Comments:

I believe the document should mention related disorders as a group, or specific examples of related disorders such as Lewy Body Disease and Parkinson's Disease. It seems to me that research is headed in the direction of finding that the large group of people that we formerly referred to as Alzheimer's Disease patients are now being determined, by exam or autopsy, to have various related disorders, sometimes instead of or in addition to Alzheimer's Disease. The way the draft was written, I foresee that some patients/clients/test subjects could, at some point, be excluded if they are found to have a related disease. They could be excluded from participation or services. If the related disorders are not accounted for in this document, it may be possible that some research or projects become derailed, if the test subjects are found to primarily have one of the related disorders.

Sincerely,
Amy E. Freeman
Hilliard, OH

DATE: January 13, 2012

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

My name is Bruce Lamb and I am an Alzheimer's researcher and Staff Scientist in the Department of Neuroscience in the Lerner Research Institute at the Cleveland Clinic. I would like to provide comments and suggestions regarding the Draft Framework for the National Plan to Address Alzheimer's Disease that was released on January 9, 2012.

I think this is a very welcome and important first step in devising a National Plan for combating Alzheimer's, and the goal laid out for developing a treatment/prevention for Alzheimer's disease by the year 2025 is admirable and likely achievable, provided the plan is sufficiently bold and transformative. While I appreciate that the current document is only a Framework for the National Plan, there are several significant issues that I hope you will consider as the details of the plan are developed, in particular as it relates to research investments, strategies, goals and infrastructure (Goal 1).

1) Committing Additional Resources to Research

The planned NIA sponsored conference in May 2012 will provide invaluable insight into the goals and strategies required to achieve the goal of a treatment/prevention by the year 2025.

However, while a reorganization and coordination across all research domains will increase research productivity, without additional research funds, the goals of having a treatment/prevention by 2025 is likely unattainable. There is currently no effective treatment for AD and thus additional funds are necessary to promote basic research, translational research, drug development and clinical research. Currently, funding rates at NIH and most non-profits is in the single digits (5-10% of all grant being funded), thus leaving a very large number of meritorious applications (the top 20-25%) unfunded. If we are truly serious about achieving the goals set forth in the Draft Framework, additional federal, non-profit and industrial investments in Alzheimer's research have to be part of the answer. While there will likely a considerable debate about the exact amount of investment required to achieve this goal, a starting point would likely be \$2 billion/year as put forward in the Alzheimer's Breakthrough Act of 2010. As clearly laid out in the attached paper by myself, Dr. Todd Golde and Dr. Doug Galasko, similar types of investments in other diseases (i.e., HIV/AIDS) have proven transformative and lead to effective therapies. While I appreciate that the current funding climate is very tight and highly political, it is only with these types of investments are we likely to transform the Alzheimer's research endeavor and achieve Goal 1 of the Framework.

2) Strategies/Goals

The conference in May of 2012 will certainly help identify the key research areas that need to be addressed to achieve Goal 1 of the Framework. As part of the detailed National Plan, it will be important to both identify these targets as well as commit funding commensurate to achieve the goals identified. Funding one research domain at the expense of another will not enable us to achieve the ultimate goal laid out in the Framework. For each target, clear goals must be identified and an infrastructure/organization (see below) put in place to regularly assess progress within these areas.

3) Infrastructure/Organization

To achieve Goal 1 of the Framework, it will be absolutely critical to have an infrastructure and organization that can coordinate federal research efforts across all funding agencies, interact with non-profits and industry, promote awareness of the disease and the role that research will play in combating the disease as well as reporting to the Advisory Council directly as outlined in the Framework. In order for this organization/infrastructure to be truly successful and

transformative, it will be essential that its efforts are entirely focused on combating Alzheimer's disease. This will provide a uniquely focused organization that will have the most chance of success. A similar "disease-focused" agency was created in 1988 for HIV/AIDS entitled the "Office of AIDS Research" (OAR) within the Office of the NIH Director, that played a key role in successfully coordinating the federal response to AIDS. The NIH Revitalization Act of 1993 strengthened the OAR, providing it with increased authority in the planning, coordination and evaluation of AIDS research. If we are truly serious about transforming Alzheimer's research and achieving the goals laid out in the Framework, a similar type of organizational structure (perhaps an Office of Alzheimer's Research?) is required.

Thank you for the opportunity to provide input into the Draft Plan to Address Alzheimer's Disease! Please contact me directly if you have any questions regarding the issues I have addressed here.

Sincerely,

Bruce Lamb, Ph.D.
Staff Scientist
Department of Neurosciences
The Lerner Research Institute
The Cleveland Clinic Foundation
Cleveland, OH

ATTACHMENT: Golde et al 2011.pdf

<i>Available as separate links:</i>
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Right Sizing Funding for Alzheimer's Disease http://aspe.hhs.gov/daltcp/napa/Comments/cmtach27.pdf
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DATE: January 13, 2012

SUBJECT: National Plan to Address Alzheimer's Disease

As a geriatrician for many years, my only comment is that unless this education, training, etc. with a focus on such a prevalent disease, is started early on in medical school, PA, Nursing school, etc. and fully integrated into post graduate training for internal medicine, family medicine, internships, practicums, etc. not much will change. Unless academic medicine has a reason to buy in, we will continue to have medical providers lacking knowledge and skills in these areas. We may need more a focus on this for mid level providers since general internal medicine and family medicine are slowly declining in our health care system.

Nannette Hoffman

DATE: January 13, 2012
SUBJECT: Comments on Alzheimer's

There is an ongoing focus on curing AD, However, with the continued emphasis on "cure" the immediate need is often overlooked or minimized. The actual beneficial need is for relief early on so as to increase the probability of quality of life for the individual AND the designated caregiver.

Even with the great promise shown in early trials J-147 will take years to come to market in approved use. There are several genuine advances that hold much promise yet they do not address the needs of the moment. Consideration must be given to those individuals and their loved ones suffering with this debilitating malady right now. As a civilized society we cannot stand idly by as we wait for a "cure" we must act with what will be of benefit today and improve the quality of life for those unfortunates. How can one not justify this morally and ethical position?

Florida currently has more than 10 percent of the reported AD population in our Nation. The impact on caregivers is staggering. There are more qualified AD facilities than any other state. The fact that this huge increase in AD confirmations is real and factual.

What is of great need is the early screening and detection of AD at the earliest possible stage. For many reasons this is not being emphasized, due to stigma or denial or other reasons. By placing an emphasis on early detection through education and PSA's (all media has a provision for such) highlighting local community screening facilities there will be an early means of detection and increased quality of life for all concerned.

We must take advantage of currently available meds for relief TODAY as the cure is remote and in the future. The acknowledged treatment of Aricept in conjunction with Namenda offers relief at present time. At least this will furnish an improved condition for the individual so diagnosed.

It is projected that the number of diagnosed AD patients could increase by 50% through the widespread availability of early screening that would lead to official diagnosis. With the advent of the "boomer" generation becoming into the known range it is felt that this is mandatory in order to provide relief for the coming wave of incidents.

Elder Care Advocacy of Florida has been long involved in this battle and participated in numerous seminars and panels over the years. As an effort with much experience it is felt that we must consider the needs of the "here and now" while we await further advancements in research and medical trials. We have had all too many friends and associates pass from this mind=robbing and life destroying disease that steals the very soul of our fellow loved ones.

The opportunity to be of service is always appreciated.

Austin R. Curry,
Executive Director
Elder Care Advocacy of Florida

DATE: January 12, 2012

SUBJECT: Please allocate more money now...let's solve this by 2020 or sooner

This is an important step in the fight to cure Alzheimer's. More money allocated for research and the development of drugs to cure the disease will lessen the huge toll on our health system if nothing is done. Sometimes you have to pay up front to avoid even more cost in the future. My dad is currently at mild stage and it is doubtful anything new will help him. But there are millions of other people that will benefit. Let's fight to keep another family from going through this atrocious disease.

Sincerely,
Marianna L. Kersey

DATE: January 12, 2012
SUBJECT: Comment

Thank you for your work on Alzheimer's Disease and related dementias. Please note that I support a more ambitious date than 2025 to prevent and effectively treat Alzheimer's Disease. This date affords no hope for those who are recently diagnosed and their loved ones. Alzheimer's was first identified in 1906; I believe we have the capacity to END Alzheimer's by 2020; we cannot afford to wait more than a decade to achieve this goal. Please revise your target date and give hope to the millions of Americans suffering from mild cognitive impairment, early onset Alzheimer's, and other devastating dementias.

Lynda Everman

DATE: January 12, 2012
SUBJECT: Supporting the Concerns of Dr Wyman

Why no psychology? See below

"I learned about this call for feedback earlier today via a different listserv. Comments on that listserv made me curious enough to read through the draft. I was surprised when I realized that the words "psychologist" or "psychology" do not appear once in the Draft of the National Plan. Psychologists are not listed as one of the essential disciplines under "Goal 2," though many of the services that we provide are noted as vitally important to focus on in the coming years. I see this as a serious error -- not because of my desire to protect the "turf" of psychology, but because it simply does not reflect the reality of healthcare today for persons with Alzheimer's Disease. HBPC is but one healthcare setting in which psychologists play an important role in the care of these patients -- not to mention the many, many psychologists conducting research in this important area. Thanks,

Mary F. Wyman, Ph.D.
Clinical Psychologist, Home Based Primary Care"

Jan Stephen Cavanaugh, Ph.D.
HBPC Psychologist
Geriatric and Extended Care Service/HBPC
Chair, VISN 6 Dementia Committee
Fayetteville, NC

DATE: January 11, 2012

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

I would like to provide comments on the Draft Framework for the National Plan to Address Alzheimer's Disease (AD). I appreciate the efforts to develop a national plan for most effectively addressing AD. The overall goals of the Plan are important, but they seem to focus more on medical aspects of dementia and focus little on psychological, behavioral, and functional aspects of dementia. In particular, a greater focus on promoting each of the following is critical for more fully addressing AD and its impact: (1) research and practice related to psychological interventions for managing behavioral sequelae of dementia; (2) research on approaches designed to maximize independence of individuals with dementia, including residing at home (which I think is increasingly going to be the trend in the future); (3) research on and demonstration of innovative care settings for individuals with dementia and severe behavioral or mental health issues. In addition, psychologists are conspicuously absent in the section on building a workforce to provide high quality care to individuals with dementia, though psychiatrists, social workers, neurologists, and others are specified. Psychologists are essential to the assessment and management of AD and many co-occurring conditions and work as core members of interdisciplinary teams in a wide variety of clinical settings that provide care to individuals with AD. Furthermore, in the Veterans Health Administration (VHA), psychologists work as integral, full-time members of each (130+) Home Based Primary Care team that provides care to Veterans in their homes, some of which have AD or other forms of dementia. Accordingly, the specification of psychologists in the Plan as an important part of the workforce for effectively treating AD and for focused recruitment efforts is strongly recommended.

Thank you for your consideration of these comments.

Sincerely,

Bradley E. Karlin, Ph.D.
National Mental Health Director,
Psychotherapy and Psychogeriatrics
Office of Mental Health Services
VA Central Office
Washington, DC

DATE: January 11, 2012

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

First of all, I would like to commend HHS for proactively working towards a comprehensive plan to address the personal and public impact of Alzheimer's disease. This plan is needed to ensure that there is proper allocation of resources to address dementias both empirically and clinically.

I was surprised to find that the plan did not mention the field of Psychology. Psychological researchers have played an integral role in the knowledge base on dementias and have developed diagnostic tools which are highly specific, yet cost effective. Furthermore, Psychologists and Neuropsychologists are often called upon to make formal diagnosis of dementia, relay this diagnostic information to patients and families, provide psychoeducation and support, assist with advanced care planning, assist teams/families in identifying and using non-pharmacological strategies for managing difficult behaviors, and provide services at the end-of-life.

As a Psychologist within the VA healthcare system, I provide such services within our Community Living Centers (i.e., nursing homes). Psychologists are specially trained to understand the psychosocial factors impacting older adults, as well as cultural/diversity impacts. As such, Psychologists are poised to deliver high quality assessment and intervention services to persons with dementia and their families. Furthermore, Psychologists have unique skills in assessment and program evaluation which allows us to monitor and measure our work in a way that can be directly linked to cost savings. I have seen how Psychology's presence on the CLCs has led to more positive outcomes, such as the significant reduction of use of antipsychotic medications, reduced caregiver burden, improved mood functioning for patients, and reduced strain on staff.

The exclusion of Psychologists in this framework could have detrimental financial impacts on our ability to provide these services in the future. I strongly believe that the elimination of Psychology from the interdisciplinary teams serving dementia patients would have dire effects on the provision of quality care.

I appreciate your strong consideration of including Psychologists in this framework.

Sincerely,
Erin L. Patel, Psy.D.
Clinical Psychologist
Psychology ADPAC- York Campus
Tennessee Valley Healthcare System
Alvin C. York VAMC
Murfreesboro, TN

DATE: January 11, 2012

SUBJECT: Comments on National Plan for Alzheimer's

I am encouraged by the effort. However is several off the goals a key player to support for early to middle stages of the disease is Assisted Living and Assisted Living special care units. There is no mention within the plan about specially designed units that provide support to the people with this disease. They are often less restrictive and provide programming to enhance quality of life. It would be helpful to have guideline regarding quality of life issues for the resident in Assisted Living (residential care), Special care units and nursing homes

Thanks for your work. This coordination will benefit many over the next 10 years

Sharon Risser

Owner

Assisted Living with a Special Care unit

DATE: January 11, 2012
SUBJECT: Comments - "Draft Framework for the National Plan to Address Alzheimer's Disease"

Thank-you for the opportunity to suggest several minor enhancements to the "National Plan to Address Alzheimer's Disease."

The third sentence of Goal 2 to "Enhance Care Quality and Efficiency" should be edited as follows, to be inclusive of the 114,000 secured Assisted Living settings in the US that provide specialized programming and care for those with various forms of Dementia and Alzheimer's (data source, National Investment Center, <http://www.nic.org/research/fags1.aspx>):

High-quality care should be provided from the point of diagnosis through the end-of-life and in settings including people's homes, doctor's offices, hospitals, licensed assisted living communities and nursing homes.

Including this reference will balance the fact that the only other current reference in this document to the Assisted Living industry is within the context of abuse in Strategy 3.D.

The wording in Strategy 3.D provides information, but is not proposing any changes or enhancements to minimize the abusers or to properly recognize that the vast majority of those providing care for individuals with Alzheimer's and related dementias do "maintain the dignity, safety, and rights of peoples with Alzheimer's Disease." I propose the following wording enhancements:

People with Alzheimer's disease are particularly vulnerable to financial exploitation, physical or emotional abuse, and neglect both at home and in institutional care settings ~~residential care facilities~~.¹⁸ Reports of elder abuse are handled by state Adult Protective Services, which is charged with responding to and resolving alleged abuse. State survey and certification agencies investigate abuse in licensed facilities, which may include nursing homes, assisted living facilities and board and care homes. AoA's National Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities and can help address issues related to potential abuse or neglect. National trend reporting of substantiated cases of abuse or neglect for those with Alzheimer's by care setting type, as a percentage of total residents cared for, should be enhanced to better inform the public of those settings most likely to provide the type of care and support expected and the low incidence of this type of abuse.

Please let me know if you have questions that I may be of assistance with or need a clarification related to my suggestions for improving your plan documents.

Roger Thiele
VP Marketing and Product Line Management
Brookdale Senior Living
Brentwood, TN

DATE: January 10, 2012

SUBJECT: FW: Now Available for Public Comment through Feb 8, 2012: Draft Framework for the National Plan to Address Alzheimer's Disease

Hello, I received the draft framework for the National Plan to Address Alzheimer's Disease, and when I read through the draft, I was surprised to find that the words "psychologist" or "psychology" don't appear even once in the Draft. Even though many of the services psychologists provide are noted as vitally important to focus on in the coming years, psychologists are not listed as one of the essential disciplines under "Goal 2." My work in Home Based Primary Care is but one healthcare setting in which psychologists play an important role in the care of these patients. I see this as a serious error because it simply doesn't reflect the reality of healthcare today for persons with Alzheimer's Disease.

Kalyn Diamond, Ph.D.

Home Based Primary Care and Palliative Care Psychologist
VA Eastern Kansas Health Care System

DATE: January 10, 2012
SUBJECT: Where Do I Fit in the Plan?

Have just read the draft of the National Plan for Alzheimer's Disease and it is true. A colleague pointed out that our discipline is not included anywhere in the document. If psychologists are frontline in providing guidance to caregivers of people with Alzheimer's Disease (not to mention the patients themselves), why are psychologists or psychology as a discipline not even mentioned? Oversight? Psychologists are also doing a lot of collaborative work with other disciplines on the research end of this issue. Not even being mentioned in a national document that ultimately impacts our work does not seem right to me. We are also stakeholders in this project. Just sayin'...

Sheryl A. Ebert, Ph.D., MSPH
HBPC Psychologist
Memphis VA Medical Center
Memphis, TN

DATE: January 10, 2012
SUBJECT: comments on National Plan

I am a clinical psychologist with training in gerontology, working within the VA healthcare system as part of the Home Based Primary Care (HBPC) program. HBPC serves a population of chronically ill and disabled Veterans and their families, including many with Alzheimer's Disease, providing services within their home or assisted living facility. This program is a relatively new national initiative within the VA system and has already been shown to meet many of the initial goals for improving care and reducing costs. It is considered cutting-edge health care for this most vulnerable and complex group of patients. In recognition of the value of addressing mental health as well as physical health for these patients, HBPC interdisciplinary teams are mandated to include a full-time mental health provider, which is almost always a PSYCHOLOGIST.

The wide range of expert services that a psychologist can offer to persons dealing with Alzheimer's Disease -- including but not limited to cognitive testing, diagnosis and treatment of psychiatric symptoms, caregiver support, and training of families and facility staff -- cannot be duplicated by any other professional discipline. Indeed, psychologists are integral to the clinical care of persons with Alzheimer's Disease, not only in my work setting within the VA, but across the nation in clinic, home, and nursing facility settings. In addition, it goes without saying that much of the most important research in the area of Alzheimer's Disease is conducted by psychologists.

I was shocked when I realized that the words "psychologist" or "psychology" do not appear once in the Draft of the National Plan. Psychologists are not listed as one of the essential disciplines under "Goal 2," though many of the services that we provide are noted as vitally important to focus on in the coming years. I see this as a serious error – not because of my desire to protect the "turf" of psychology, but because it simply does not reflect the reality of healthcare today for persons with Alzheimer's Disease.

I urge you to correct this omission and formally recognize the significant role Psychology already plays in the diagnosis and treatment of persons with Alzheimer's Disease. For example, the National Plan should include language to note the importance of supporting training for geropsychologists and funding for psychological services for these persons and their families.

Thank you for your attention.

Regards,
Mary F. Wyman, Ph.D.
Clinical Psychologist, Home Based Primary Care
W.S. Middleton Memorial Veterans Hospital
Madison, WI

DATE: January 10, 2012
SUBJECT: Draft for Alzheimer's Forum

The Greatest need I have seen in Connecticut, is affordable care in regards to housing for our loved ones with dementia. Many adult children are taking on the enormous task of taking care of their family member while balancing work with caring for their loved one! As this disease progresses, care is needed 24/7, leaving the caretaker stressed and exhausted. Solutions exist, but only for those who can afford it. Assisted living with memory impaired care is a solution but only a small segment of the senior population can afford this option. Also, another option, long term care in an institution is costly to states / government. We need more affordable living options for our senior population suffering from dementia---yesterday!!

Suzanne Burbage
Elderly Services Coordinator and Municipal Agent
Hamden, CT

DATE: January 10, 2012
SUBJECT: BBrock- Identify Whole Person- Safer Care

I would like to make you aware of the resource described below.

**Resource
Patient Safety
Reduce Care Transitions
through the use of a
Standardized Cognitive Assessment.**

In past years the focus of health care professionals was on patient's physical/medical problems primarily because little was known about dementia and its ravaging effects. Oftentimes dementia patients tend to communicate the state of their health care situation incorrectly to health care professionals because their cognitive abilities have been affected. Simply put, they don't understand questions being asked of them. Other dementia patients have limited vocabularies due to their dementia.

Dementia patients often give incorrect yes or no responses to medical questions. Sometimes costly health related decisions are repeatedly made due to the fact that health care professionals assume *because a resident may speak well, therefore they must think well or worse yet, because a resident doesn't speak, therefore they assume the patient has lost their ability to think.* **This costly miss-match communication approach** to identify appropriate health needs of memory impaired patients may lead to **expensive health care mistakes**. Plus it usually ignites a downward spiral of the wrong type of health care services and development of inappropriate care plans that leads to **repeated re-admissions**.

Currently health care professionals are challenged to reduce re-admissions. Most often, level of health care services is determined by health care professionals without regard to patient's current level of cognitive understanding. These miss-leading assumptions may drive the re-admission process higher and higher.

Today soaring numbers of elderly dementia patients requiring healthcare has brought forth a vital missing piece of health information regarding this vulnerable population. The missing piece of information is the **identification of each patient's cognitive factor**. Health care professionals have enormous amounts of information about the patients' physical state but **lack valid and reliable information regarding their cognitive condition**. We even develop care plans primarily based on patients' physical condition but fail to include or identify their cognitive state. This hap hazard approach of treating memory impaired patients is very costly to say the least.

The need for a tool that can identify each patient's cognitive factor is paramount if health care professional's goal is to treat the "**Whole Person**", **keep patients safer, reduce fall risk and diminish expensive care transitions**.

The Reality Comprehension Clock Test (1999 RCCT Brock,B., et al) is a standardized cognitive assessment that has a valid and reliable scoring process that identifies patients':

- functional age,
- stage of dementia
- risk of fall

- reveals memory deficits.

The RCCT unlike other clock drawing tests provides data that leads to the development of appropriate care plans.

The RCCT data also helps patients, their families and the health care professionals who care for them answer difficult questions such as:

How much does the patient understand? Are they capable of taking care of themselves?

The RCCT's powerful information can:

- **reduce care transitions**
- **drive identification of appropriate levels of care at the right time**
- **assist in developing appropriate care plans**
- **keep dementia patients safe**
- **reduce costly re- admissions**

Incorporating the cognitive factor, transfers into care of the whole person not just patient's physical needs. The valuable **RCCT sets the precedent for a Dramatic Change in healthcare.**

The RCCT is in the National Alzheimer's Association's Greenfield Library

Published: Sept 2005 "Visual Spatial Abilities and Fall Risk" An Assessment Tool for Individuals with Dementia"

Gerontological Journal of Nursing

Published: May 2005 "Application of Reality Comprehension Clock Test as a screening of patient with vascular cognitive impairment- no dementia."

Chinese Journal of Rehabilitation Medicine

April 2009 Reality Comprehension Clock Test on CMS MedQIC Resource list under Patient Safety

Education and Certification:

RCCT workshops are offered to health care professionals so they can become educated and certified to administer the RCCT.

I am one of the research authors of the RCCT.

Barbara Brock

Published Research Author, President

Communication Art, Inc.

Safer Care with Health Care's Most Valuable Cognitive Assessment

<http://www.clocktestcct.com>

DATE: January 9, 2012
SUBJECT: Alzheimer's

WHY CAN'T THE STATE OF TENNESSE SEE HOW MUCH CHEAPER IT WOULD BE TO KEEP YOUR FAMILY MEMBER AT HOME, INSTEAD OF HAVING TO PUT THEM IN THE NURSING HOME. YOU COULD PAY HALF THE MONEY IT TAKES FOR A NURSING HOME VERSES THEM STAYING AT HOME. IF THE FAMILY COULD JUST GET HALF THE MONEY AND THEY COULD HIRE SOMEONE TO STAY AT HOME WITH THERE FAMILY MEMBER WHILE THEY STILL HAVE TO WORK. IT WAS THE HARDEST THING I EVER HAD TO DO WHEN I HAD TO PUT MY MOM IN THE NURSING HOME DUE TO THE EXPENSE OF PAYING SOMEONE TO STAY WITH HER WHILE I HAD TO WORK. THE PRICE THE NURSING HOME CHARGES I COULD HAVE HIRED SOMEONE FOR HALF THE PRICE BUT THERE WAS NO FUNDS OUT THERE TO HELP FAMILIES KEEP THEM AT HOME. BUT WHEN SHE WENT INTO THE HOME THEY PAID EVERYTHING EXCEPT FOR TAKING HER CHECK AND ALLOW HER 40.00 DOLLARS A MONTH, I DON'T UNDERSTAND WHY TENNESEE COULDN'T DO LIKE SOME OF THE OTHER STATES, THEY HAVE PROVED THAT IT WAS A LOT CHEAPER AND THE PEOPLE DONE BETTER AT STAYING AT HOME. PLEASE LOOK INTO THIS . THANKS

Rita Conger