RETIREMENT RESEARCH FOUNDATION REPORT

Coalesce and Connect: Building a National Network of Dementia Care Voices

Abstract

Approximately 5 million people in the USA are living with dementia. Many more people including family members and friends, service providers and caregivers are actively involved in supporting them to live well. The importance of living well with dementia cannot be understated but currently policy governing health and social care infrastructures does not support this goal. We currently have, from both an policy and practice perspective, a very biomedical approach to dementia and as a result we have a society that is not only frightened of this disease but also associate with it loss of dignity and control and indeed loss of their personhood. There is a different way.

This project aimed to support the process of coalescing and connecting a new network of people passionate about living well with dementia. To do that we engaged people living with dementia, their care partners, policymakers, health professionals, providers, advocates, researchers and educators in a series of activities firstly to develop the Dementia Action Alliance and secondly to listen to those people and set forth their vision for the direction and priorities of Government policy. The significance of this being that direction and priority drives funding and other resources. These resources need to be aimed where the need is greatest.

The Dementia Action Alliance coalesces and connects the people most affected by dementia and their supporters so that they can speak out and be heard. The project helped to deliver the infrastructure for this new person-centered, inclusive advocacy group for people living with all types of dementia. The findings of our national Delphi survey revealed their priorities to be: caregiver support, long-term care support, research for care as well as cure, education and training, and advocacy and awareness raising. These findings were disseminated to the NAPA Advisory Council in July 2014 and will be continue to be disseminated over the coming months. Work continues to grow the Dementia Action Alliance and influence public policy through community engagement and a positive stance to protect the civil rights of those people living with dementia.

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Executive Summary

There is a timely need for a national grassroots advocacy initiative (network) to connect and coalesce the voices of people living with dementia and their care partners and other advocates. The purpose of such a network would be to inform the National Alzheimer's Project Act (NAPA) Advisory Council members, policymakers, and other strategic stakeholders about the priorities and preferences of people living with dementia.

The project was structured as a 7-month effort, aimed at informing the development of an advocacy network to give voice to people living with dementia, and their care partners and other advocates. The project also identified and prioritized the preferences and issues faced by people living with dementia and their care partners, in order to influence the progress of the NAPA Plan and consequently balance the distribution of resources to reflect the need for PERSON-CENTERED CARE in a comprehensive National Plan. The four aims of this project built on each other, as follows:

1. Increase awareness and invite engagement of people living with dementia, their care partners and other advocates, and strategic stakeholder organizations about the imbalance of "cure" and "treatment" components over "care" in the National Plan.
2. Gather feedback through online surveys of people living with dementia, their care partners and other advocates, and key stakeholders to collect recommendations on their dementia needs, preferences, and priorities.
3. Disseminate the written results of the project to DHHS Secretary, the NAPA Advisory Council members, and other key policymakers.
4. Develop an infrastructure to connect and coalesce people with dementia, their care partners, and other advocates in a national Dementia Action Alliance.

Methods:
Each aim has its own method or strategies which built on each other to achieve the ultimate goal of developing a national Dementia Action Alliance to promote the voice of people with dementia and the care partners. Aim 1 –used the strength of current national networks (for example existing support groups, professional associations and dementia coalitions) and the team's contacts to develop a mechanism for raising awareness about the NAPA national plan. Aim 2 – used the Delphi method to gain consensus from a wide range of stakeholders about the preferences and priorities for dementia care resources and research. Aim 3 – disseminated the findings of aim 2 at the federal level. Aim 4 – focused on developing a corporate funding base to support developing and sustaining the Dementia Action Alliance.

Findings:
Aim 1 – Of the 23 interviews with leaders of prominent aging-related organizations 5 had not heard of NAPA, 10 had heard of it but didn't know enough to comment on NAPA's efforts, and 8 were familiar and had some comments to make. Only 2 of those 8 comments had positive elements.

Aim 2 – The Delphi study revealed 5 main priorities for policy caregiver support, long-term care support, research for care as well as cure, education and training, and advocacy and awareness raising. Although these are not dissimilar to the goals of NAPA the balance of resources and

allocation of funding does not reflect the vision of people living with dementia or their supporters.

Aim 3 – Dissemination of the Delphi study to policy makers was achieved at the Quarterly Meeting of the NAPA Council in July 2014. Efforts to continue a broad dissemination will continue in the coming months.

Aim 4 – The infrastructure of the newly formed Dementia Action Alliance was developed and the outreach to policymakers, industry, advocates and other supporters continues as the group grows and develops its influence.

Background

In 2011, President Obama signed the National Alzheimer's Project Act (NAPA) into law. Part of the law called for the creation of an Advisory Council comprised of representatives of federal agencies involved in aging issues and a dozen individuals appointed by the Secretary of the U.S. Department of Health and Human Services (DHHS). The Advisory Council members were tasked with developing recommendations for priorities and actions needed to prepare the U.S. to meet the needs surrounding Alzheimer's disease and related dementias (dementia). The first National Plan to Address Alzheimer's Disease that contained the national priorities and recommendations was released in May 2012. As mandated, annual plan updates, released in June 2013 and April 2014, "reflect the nation's progress toward accomplishing goals set in 2012 and current action steps to achieving them."

Although NAPA is applauded as an important initiative to develop a national framework for dementia, it is currently unbalanced in its focus on the "cure" and "treatment" aspects of Alzheimer's disease, with insufficient focus on the "care" needs of persons living with the condition. Three of the five goals that form the foundation of the National Plan are oriented on aspects of care [e.g., enhance care quality and efficiency, expand supports for people with Alzheimer's disease and their families, and enhance public awareness and engagement]. However, the majority of the Plan's focus and resources are directed to cure and treatment. While it is critically important to find a cure and treatment for Alzheimer's and related dementias, the importance of care needs of people living with dementia cannot be diminished.

The U.S is the only country in the world whose National Plan focuses on Alzheimer's disease, rather than the broader category of dementia. The plan notes that the term "Alzheimer's" refers to the broader category of dementia. However, when the term "Alzheimer's" is used in this way, the broader focus on 'dementia' is effectively negated. As a result, people living with other types of dementias (for example vascular dementia, Lewy Body dementia, or dementias relating to other neurological conditions such as Parkinson's Disease or Traumatic Brain Injury) feel that their needs are not being adequately addressed by the National Plan.

While, person-centered care forms the foundation for the context of care; it is mentioned only once in the Plan and in reference to the "Hand in Hand" training program developed by the Centers for Medicare and Medicaid. The Affordable Care Act mandates a person- centered system of long-term services and supports. The lack of person-centered context in the National Plan not only suggests limited input from persons living with dementia and their care partners, but it also reflects the omission of the gold standard of care in the recommendations being developed.

More than five million Americans (Alzheimer's Association, 2013) are living with dementia, and these numbers continue to increase at alarming rates. It is imperative, therefore, that we identify ways to best support these individuals outside the realm of biomedicine. Traditional dementia care has been grounded in a medical orientation, focusing primarily on the physical needs of an individual and the pharmacological treatment of the disease. This orientation reflects a more clinician and organization-centered approach, rather than a person-centered one. Biomedicine is an important component of dementia care, but person-centered practices broaden the lens of dementia care by addressing the varied (e.g. psychosocial, spiritual) needs of the person who has dementia. Person-centered dementia care, based on the seminal work of Tom Kitwood and Carl Rogers (Kitwood, 1997; Rogers, 1961), places persons living with dementia at the center of their care, focuses on their whole personhood rather than just their medical condition, and includes their subjective experience (Edvardsson et al., 2010).

The Alzheimer's Association has formally changed its mission and purpose to focus mostly on the cure and biomedical treatment of Alzheimer's disease. This mission change has led to a void of representation for care needs and the voices of persons living with dementia (PLWD) in NAPA's efforts. There currently are no national consumer advocate groups focused on ensuring that the voices of PLWDs are heard and that their needs are meaningfully addressed in the National Plan. Accordingly, this project addresses the need for a national grassroots advocacy initiative by connecting and coalescing the voices of people living with dementia, their care partners, and other advocates. The purpose of such a network is to inform the NAPA Advisory Council members, policymakers, and other strategic stakeholders about the priorities and preferences of people living with dementia.

Purpose of the Project

The purpose of this project was to develop a national advocacy network to give voice to people living with dementia, as well as their care partners and other advocates. Furthermore, this network would base its advocacy on the priorities and preferences of people living with dementia along with their care partners and advocates. A major advocacy objective throughout the project was to bring their priorities to the attention of the NAPA council, national policymakers and other key stakeholders. The four aims of the project were:

1. Increase awareness and invite engagement of people living with dementia, their care partners and other advocates, and strategic stakeholder organizations about the imbalance of "cure" and "treatment" components over "care" in the National Plan.
2. Gather feedback through online surveys of people living with dementia, their care partners and other advocates, and key stakeholders to collect recommendations on

their dementia needs, preferences, and priorities.

3. Disseminate the written results of the project to DHHS Secretary, the NAPA Advisory Council members, and other key policymakers.
4. Develop an infrastructure to connect and coalesce people with dementia, their care partners, and other advocates in a national Dementia Action Alliance.

The remainder of the report details the strategies used and the outcomes achieved for each aim, as well as the comments provided to the NAPA Advisory Council Members by Karen Love at their July 21, 2014 Quarterly Meeting.

Aim 1

To increase awareness and invite engagement of people who are living with dementia, care partners, and strategic stakeholder organizations about the imbalance of "cure," "treatment," and "care" components of the National Plan.

Strategies

For Aim 1 we focused on engaging with two distinct groups of stakeholders that have important perspectives and knowledge about person-centered dementia care: (1) two loosely formed grassroots dementia advocacy groups (Purple Angels/USA, Memory Cafés/USA); and (2) national organizations that are invested in advocating for people who are living with dementia and their care partners. Three team members, Karen Love, Jackie Pinkowitz and Sonya Barsness contacted leaders of 27 organizations by phone and completed a structured interview to discuss: (1) their awareness and understanding about NAPA's goals and priorities; (2) concerns that NAPA's focus on cure and treatment is imbalanced and needs to better include care; (3) their thoughts and suggestions about rebalancing the National Plan and the creation of a national

Dementia Action Alliance; and (4) invite their participation in the Delphi survey process to gather feedback qualitatively and identify others in their organizations to participate in these surveys. Notes from each of the discussions were taken and recorded on the data collection form.

Respondents. Of the 34 organizations contacted, 23 telephone interviews were completed. A data collection sheet was completed for each interview (see Appendix A). Interviews were conducted with a wide range of organizations. Generally the interviews were conducted with an executive or senior leader in the organization. To show the breadth of our inquiry, interviews were completed with the following organizations. All these organizations agreed to distribute the Delphi survey to their members or networks and all signed on to the Dementia Action Alliance listserv to receive information.

- American Association of Retired Persons (AARP)
- Advancing Excellence
- Agency for Health Care Administration (AHCA)
- American Medical Directors Assoc. (AMDA)
- Caregiver Action Network (CAN)
- Coalition of Geriatric Nursing Organizations
- Consumer Coalition for Quality Health Care
- Consumer Voice
- The Council on Quality (CQL)
- Family Care Alliance
- Green House Project
- LeadingAge Georgia

- Metropolitan Area Agency on Aging – MN
- National Association of States United for Aging and Disabilities (NASUAD)
- National Assoc. for Professional Geriatric Care Managers
- National Assoc. of State Ombudsman Programs
- National Assoc. of Social Workers
- National Center for Assisted Living (NCAL)
- New Jersey Alliance for Culture Change
- Pioneer Network
- Planetree

The following six organizations, Gerontological Society of America, LeadingAge NJ, National Active & Retired Federal Employees Association, Compassion & Choices, the National Council on Aging, and NAHC National Assoc. for Home Care & Hospice, were contacted but either did not respond or were not able to schedule a telephone call. Most of these organizations did agree to distribute the Delphi survey to their members or networks and all but GSA signed up for the DAA listserv. The following advocacy and support groups were also contacted and all agreed to participate in the Delphi survey: Purple Angels, Alzheimer's Speaks, Shepherd Centers, Alzheimer's Café, and Alzheimer's Playbook.

Findings. The first section of the interview focused on NAPA. Of the 23 interviews with leaders of prominent aging-related organizations 5 had not heard of NAPA, 10 had heard of it but didn't know enough to comment on NAPA's efforts, and 8 were familiar and had some comments to make.

Two of the 8 comments had positive elements. One respondent said "*There are lots of good things in the plan. 1. The call to action for cure, 2. Co-ordination of care is highlighted, and 3. Bringing best practices together*". The other respondent said "*It was a monumental achievement to get the law passed*". This respondent was also very impressed at the open process in gathering data for the Plan. However both of these comments were tempered with concern about implementation. As one said "*But, it is a broad plan and this begs the question of real-world implementation – or will it just remain on the shelf?*"

The remaining 6 comments were consistent in their criticism of NAPA's focus and efforts. All commented on the biomedical focus including the emphasis on funding for research into cure, treatment and prevention. Although there was recognition of the importance of this work, respondents felt the emphasis should be more on issues of support services for the person living with dementia and caregiving. For example:

> *"The general constructs are just the same as the Alzheimer's Association plan – it's more about research and not a lot of direct support services for families"*

> *"Day-to-day living with dementia is not being addressed"*

> *"Too biomedical – needs to include care"*

> *"Well intentioned but too focused on medical treatment and prevention and not supporting those with dementia and their caregivers… Lacks caregiving from a social aspect, lacks help on how we can have people with dementia actually live in their community. I know prevention and treatment are important but the NAPA plan lacks what people need."*

> *"There is good attention to cure and money for research but the plan is not good about addressing the needs of people living with dementia"*

For those respondents who were not familiar with NAPA a brief summary was provided. The remainder of the interview then focused on what they would hope to see NAPA focus on as it considers its goals and priorities and any recommendations they could make. Several areas of concern were identified from respondents' unprompted comments.

1. Focus on Care

The most frequently stated recommendation for NAPA was to increase its focus on care issues. Specifically, respondents mentioned the need for care for the whole family and holistic care, not just medical care for the person living with dementia. Concern was expressed on the over medicalization of dementia and the need to promote person-centered care. The need for research on these issues was also noted.

2. Support and training for caregivers

The need to increase attention on family caregivers in the NAPA plan, citing issues such as the need for respite care, employment leave, and financial aid due to lost employment and expenses. Support for training and education for all types of caregivers was the next most frequently stated priority. Training was also recommended for law enforcement, volunteers, care assistants working in people's homes, as well as health professionals.

3. Coordination and standardization

The next frequently cited issue was coordination and standardization of all facets of dementia care. Access to services, dissemination and access to resources including information, portals for research and treatment protocols were suggestions for achieving improvements. In order to promote standardization and effectiveness, resources to scale up tested models of effective care was identified as a priority. In this theme the problem of fragmentation of care also was identified with a recommendation that NAPA focus on creating minimum standards for States to follow on dementia care.

4. Environment and communities

The final set of recommendations centered on improving environments where there are people living with dementia whether at home, in health care or long term care facilities, or in the community at large. Strengthening community infrastructure including developing dementia-friendly communities was put forth as a priority. This recommendation clearly overlaps with the need to educate and train anyone who might come in contact with a person living with dementia.

5. Cure versus care

The respondents were very concerned about the lack of attention and resources allocated to care and services for people living with dementia and their caregivers. The need for both research on prevention, cure, and treatment was evidently supported. The problem identified was the focus of resources and the desperate need to support those people who have dementia now and in the foreseeable future until or if there are indeed viable treatments. Even then, as we know with other chronic conditions such as heart or lung disease, pharmacological treatments are predominantly palliative although with life-prolonging attributes; there are very few cures. Care, on the other hand, will always be required.

The response to whether NAPA should decrease or increase funding for cure and treatment-related research was mixed. The argument for increasing federal funding in this area was the obvious need for this research. The argument for decreasing federal was that cure and treatment could be the responsibility of the pharmaceutical companies. One respondent argued that no one except the Federal and State governments would fund care, so all the resources from NAPA should flow to care. To sum up the majority view the following quote is taken from the verbatim interview notes.

> *Finding cures, treatments and prevention is important and I'm not talking about giving them up. But I would love to see NAPA looking at all other aspects of care; better approaches to supporting people living with dementia: the psycho social aspects, also complementary care; and using person-centered approaches to behavioral responses. To support family caregivers, care partners and workforce at all levels across the continuum of services.*

Aim 2

Conduct online surveys of people living with dementia, their care partners, and other advocates to collect recommendations on dementia needs, preferences, and priorities to substantiate and validate NAPA's current unbalanced priorities.

Method

In order to collect feedback and comments from the project's identified stakeholders, University at Buffalo research team conducted online surveys using the Delphi method and process (Jones & Hunter 1995). The purpose of the survey was to find consensus on important issues related to dementia from the perspective of the people most affected, that is, people living with dementia and their care partners. The Delphi method was selected because it offers a number of advantages including:

- Anonymity of response – this avoids dominance of any one voice or group.
- Iteration – process involves “rounds,” allowing individuals to change their opinions as the issues and options evolve
- Statistical group response – expressing judgment using summary measures of the full group response, thus giving more information than just a consensus statement

This method has been used successfully to develop consensus around priorities and information, research, education and training, and clinical practice in a number of settings. The Delphi method predominately generates qualitative data in the form of single words, phrases, and short sentences indicating respondents’ ideas, thoughts, and suggestions on the topic.

Data was collected in two rounds. The first round asked open questions about dementia: the needs of people living with dementia; the needs of the family; priorities for dementia research; and priorities for the federal government. In addition we provided space for respondents to add anything that they felt was important related to dementia.

A simple content analysis was conducted and ideas, concepts and suggestions were grouped into thematic areas. These identified areas formed the basis for developing items for the second round. In the second round, respondents were asked to rank the identified categories and topics in terms of importance. This round resulted in a more complex task of responding to 11 topic areas in two major groupings: priorities for government and priorities for research. Each grouping began by ranking the categories followed by ranking of topics within categories. The 11 categories are listed below; each category contained between 4 to 6 topics identified in round 1. The Government priority categories included: Education and training; Caregiver support; Long-term care; Advocacy and awareness. The Research Priorities were: Caregiving; Care settings; Complementary and alternative therapies; Education; Quality of life.

Recruitment of Participants. The organizations listed in Aim 1 were primary contacts for disseminating the online survey. In addition email networks from the project team's (CCAL Advancing Person-Centered Living and the University at Buffalo (UB) Institute for Person-Centered Care (IPCC)) listservs, and personal contacts were used to distribute the SurveyMonkey® link to as many people living with dementia and their care partners as possible. No identifying information was asked for in round 1. The same organizations, contacts and networks were used for round 2. Demographic details of respondents in each round are presented in the results section.

For respondents who were not comfortable with technology, questionnaires were mailed along with pre-addressed, postage-paid return envelopes. These responses were entered into SurveyMonkey® by the research assistant so that all responses were analyzed together.

Ethical approval to conduct the study was obtained from the University at Buffalo (UB) Institutional Review Board for Social and Behavioral Sciences. Consent to participate was included at the first screen on accessing the SurveyMonkey® link. No identifying information was gathered.

Analysis

A simple content analysis was performed on the data in round 1 as described above. For round 2 calculation of consensus ranking was performed using a voting system referred to as a Borda count. The Borda count is a single-winner election method in which voters rank options or candidates in order of preference. Because the process selects broadly acceptable options, rather than those preferred by a majority, the Borda count is often described as a consensus-based voting system. The Borda count determines the outcome of a debate or the winner of an election by giving each candidate, for each ballot, a number of points corresponding to the number of candidates ranked lower. Once all votes have been counted the option or candidate with the least points is the winner. This may seem counter intuitive but ranking the top option as 1 (or first) and the least favored option as 5 (or fifth) results in the lower numbers representing the highest preference.

Results

Participants came from 31 states and DC as illustrated in figure 1.

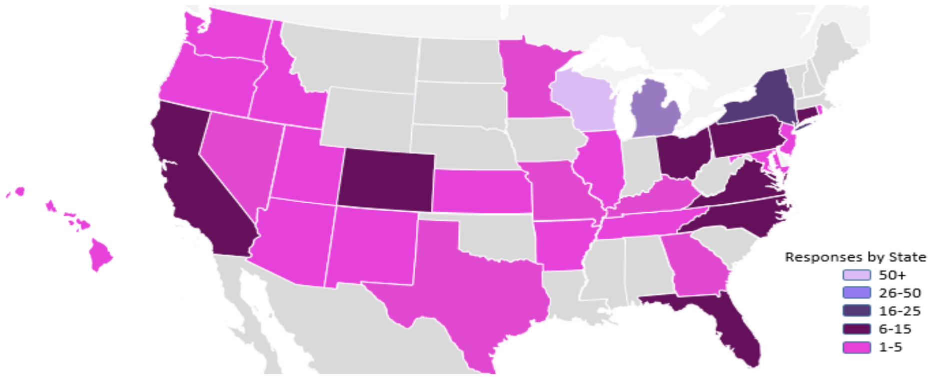

Figure 1. Geographic Spread of Responses

Demographics from each round are shown in Table 1. Table 2 reports what relationships the respondent had/has with a person living with dementia. To overcome some of the response problems from SurveyMonkey® we used the following rules for reporting. First, we used "responses" rather than "respondents" as the denominator.

Table 1 *Participant Demographics*

Characteristic	Round 1	Round 2
Gender	(n=233)	(n=250)
Female	202 (86.70%)	212 (84.80%)
Male	31 (13.30%)	38 (15.20%)
Age	(n=229)	(n=246)
18-29	10 (4.35%)	14 (5.69%)
30-39	15 (6.52%)	18 (7.32%)
40-49	36 (15.65%)	36 (14.63%)
50-59	76 (33.04%)	78 (31.71%)
60-69	65 (28.26%)	76 (30.89%)
70-79	25 (10.87%)	19 (7.72%)
80-89	2 (0.87%)	4 (1.63%)
Race/Ethnicity	(n=232)	(n=249)
Caucasian	212 (91.38%)	226 (90.76%)
African American	8 (3.45%)	4 (1.61%)
Hispanic	5 (2.16%)	5 (2.01%)
Asian	2 (0.86%)	5 (2.01%)
Other/Declined	7 (3.02%)	9 (3.61%)

Table 2. *Key Relationships with People Living With Dementia*

Relationship	Round 1	Round 2
Current	(n=166)	(n=162)
Parent	52 (31.33%)	59 (36.42%)
Spouse/Partner	22 (13.25%)	28 (17.28%)
Friend	38 (22.89%)	33 (20.37%)
Brother/Sister	12 (7.23%)	8 (4.94%)
Grandparent	8 (4.82%)	7 (4.32%)
In-Law	9 (5.42%)	7 (4.32%)
Aunt/Uncle	5 (3.01%)	3 (1.85%)
Self	12 (7.23%)	8 (4.94%)
Other	8 (4.82%)	9 (5.56%)
Past	(n=212)	(n=190)
Parent	64 (30.19%)	62 (32.63%)
Spouse/Partner	5 (2.36%)	6 (3.16%)
Friend	38 (17.92%)	29 (15.26%)
Brother/Sister	7 (3.30%)	2 (1.05%)
Grandparent	53 (25%)	51 (26.84%)
In-Law	21 (9.91%)	13 (6.84%)
Aunt/Uncle	11 (5.19%)	13 (6.84%)
Other	13 (6.13%)	14 (7.37%)

*Denominator: # responses

Some respondents had more than one person they were caring or had cared for; using responses clarifies the number of relationships. Secondly, each participant was limited to the closest blood relative, for example, if they said in-law and grandparent we chose grandparent. Thirdly, we added "self" to the key relationships section and modified the total number count accordingly. We had originally asked that question separately.

The analysis of round 1 responses revealed a wealth of ideas and suggestions. The responses were heartfelt and at times had a sense of desperation due to the difficulties and burdens, both emotional and financial, which beset caregivers. We focused the analysis on two questions specifically asking respondents for Federal Government priorities and Research priorities in order to create the items for ranking in round 2. The results of this analysis provided 11 sets of statements for ranking. Each set had between three and six statements; most had five.

After calculating the Borda count for each of the sets, we were able to produce a ranked order of preference for prioritizing each topic area based on the consensus views of participants. The following tables detail the Borda count and the final ranking. After each set of rankings, participants were given the opportunity to comment on the statements. A sample of quotes from these open comments are included after each set. Common to all of the open comments was the difficulty experienced by participants in choosing between the statements.

The results appear in the order they were presented in SurveyMonkey®. The first table indicates the ranking of each priority area including research providing the overall importance of each issue. This is followed by the detailed rankings within each issue with the government priorities first then the research priorities.

Government Priorities

Table 3.

Overall Priorities for the Federal Government

General Priority Topics for the Federal Government	Borda Count	Ranking
Prioritize caregiver support – financial compensation for caregivers, respite, case management, counseling	644	1
Prioritize long-term care needs – care provided in-home, community, and institutional settings, workforce issues, regulations long-term care facilities	648	2
Prioritize research involving medical factors, social factors, technological approaches to care, alternative approaches to care	722	3
Prioritize education and training for formal and informal caregivers, families, community, staff, workforce	744	4
Prioritize advocacy and awareness about dementia – public education campaigns, aging in place, adequate funding	1057	5

> *This was a very difficult question. ALL of these topics are of great need. I had a very difficult time ranking them. As this population increases we are going to need more and more to help support them and their families/caregivers long term*

Table 4. *Education and Training Priorities*

Priority topics for the Federal Government concerning education and training	Borda Count	Ranking
Skills training for care partners / caregivers / families – e.g. communication, care, utilizing a person-centered approach	588	1
Skills training for workforce – healthcare workers including nursing home and hospital staff, public agency workers, home care workers	643	2
Provide training incentives to increase the number of individuals skilled in working with persons with dementia – e.g. physicians, nurses, social workers, occupational and physical therapists, counselors	766	3
Long-term care planning and assistance – understanding, planning and paying for long-term care	881	4
Education on alternative, non-drug approaches for caring for persons with dementia – music therapy, art therapy, massage, touch	973	5

"Need $$ for supporting more diverse ethnic and racial physicians and nurses - *not just Care Assistants"*

"Investing in training family caregivers and healthcare/social workers will prevent premature institutionalization of people w/ dementia"

"Facilities need to know now *as they currently are doing the crises intervention because the*

other supports aren't in place yet....”

“It would be good to look at what is working in other countries and ask them to share what they have learned. The US needs a culture change, and become a more compassionate people toward all elderly.”

Table 5. *Caregiver Support Priorities*

Priority topics for the Federal Government concerning caregiver support	Borda Count	Ranking
Financial assistance or funding for in-home and out of home respite	620	1
Financial assistance or funding for in-home support – case management, medical supplies, home care	676	2
Counseling and emotional assistance for individuals caring for the person with dementia – e.g. stress management, how to prevent caregiver burnout, consultation	809	3
Financial assistance or funding for adult day care	854	4
Compensation for individuals caring for persons with dementia	865	5

“If I had a dollar to allocate, I might divide it equally among these priorities”

“Very difficult! All are important. However, caregivers wouldn't have as much stress and need emotional assistance if they had the supports they needed for their loved one in the home”

“HARDEST job that I have ever done. If you haven't done it, you don't have any idea how hard it is. Not much support for the caregiver!!”

Many family caregivers, male and female, give up working outside the home to become a fulltime *caregiver because they can't afford outside help. Caregiving can last years, and the resulting loss in income and lack of employability (who's going to hire someone who spent the last 5 years caring for his mom?) afterwards can devastate a family caregiver.*

Table 6. *Long-Term Care Priorities*

Priority topics for the Federal Government concerning long-term care needs	Borda Count	Ranking
Home and community based services – transportation, affordable assisted living, home delivered meals, care management, resources to support aging in place	525	1
Building an experienced workforce skilled in provided in-home and nursing home care	702	2
Increasing standards for assisted living facilities, skilled nursing facilities, and hospitals – e.g. oversight of care, avoiding the use of anti-psychotic medications to deal with difficult behaviors, tracking progress and change	741	3
Increasing the number of long-term care facilities skilled in providing care to persons with dementia	858	4
Increasing the number of staff within long-term care facilities – nursing, social work, health care aids	917	5

"First we need home and community based services so those with dementia can remain in their homes as long as possible. Then, we need a competent workforce and nursing homes that provide quality person centered care. We need it all!"

“Regulations are inconsistent at best... Would like to see some broader rules from the federal level that are enforced at…a much higher standard.”

“The standards for AL and Adult Day need to include cultural competence… What do they know about the cultures they/hope to serve?”

There is a big need for long-term care that supports people in the early to mid-stages of the disease. Too much of the long-term care system in place now is for people whose disease has advanced to critical stages, but there is still a great deal of need for less intensive, intermediate-term care for people with dementia.

Table 7. *Advocacy and Awareness Priorities*

Priority topics for the Federal Government concerning advocacy and awareness	Borda Count	Ranking
Public education to help understand dementia – de-stigmatize and facilitate understanding of the disease	865	5
Public awareness of resources and supportive services to assist persons living with dementia and individuals caring for persons with dementia	725	3
Make dementia the number one priority for public health policy	835	4
Support policies that promote aging in place for the person living with dementia	712	2
Support policies that provide adequate funding to support persons living with dementia and their care providers	574	1

“*Dementia should be #1 health care policy priority precisely because it will lead the way toward greater compassion and services for people with other disabling diseases”*

“I would make support for family caregiving the number one priority for public health policy, independent of diagnosis or condition. Aging in place when it is desired and appropriate but also support for positive transitions to new settings that may promote thriving.”

“The general public has to become aware of the difficult behaviors of people with dementia and support the caregiver, be patient with the patient. The number one priority for the nation now is the mentally ill and gun control. Dementia isn't necessarily violence oriented”

Research Priorities

Table 8. *Overall Research Priorities*

General Research topics	Borda Count	Ranking
Research about cure and treatment (drug treatment)	689	1
Research about care giving – person-centered care, family caregivers and workforce	737	2
Research about education and training – for the person with dementia, families, workforce and the public	848	3
Research about quality of life – the impact of dementia on the whole family	866	4
Research about complementary therapies – supplements, remedies, alternative treatments	936	5
Research about care settings – home, long-term care, day care, hospital	963	6

“Based on research, early diagnosis and caregiver support provide the greatest impact. Early diagnosis allows for medications that slow the progression of the disease; time to plan while the individual has the capacity...make end of life decisions and care decisions. Care giver education and support decreases or delays future placement in nursing homes…Medical research on the causes of irreversible dementia will have the greatest long term impact decreasing the incidence.”

“Aging in place and homelike environments are so important to the patient and the caregiver's desires for the loved one. Support furniture, for bath, and living spaces, is so expensive! Please look at that as you plan for technology, which may not be useful or accessible for the average home.”

“Research isn't what we need - an immediate action plan is what we need!”

“We cannot prevent people from growing old - and dementia comes in too many forms to make it a prevention priority. Focus on caregivers and quality of life for those with dementia.”

“Research on cause and cure is all that matters. We who care for family members already know what the impact of dementia is.”

Table 9. *Caregiving Research Priorities*

Caregiving research topics	Borda Count	Ranking
How to reduce stress, fear and distress for the person with dementia, the family and all caregivers	732	1
Effective approaches to delivering care and providing support	774	2
Interacting and communicating with the person with dementia	809	3
Managing difficult behaviors without drugs	809	3
Care planning for families – including end of life and financial issues	911	5
Involving the person with dementia in decision making	1046	6

"Life care planning education for financial planners and company supported retirement plans to enable more individuals to be educated about this topic. It will be a concern of everyone at some time in life."

"I believe we have many effective non-pharmacological strategies to manage individual behaviors; what we lack is a consistent approach to using what we know about social and physical environments to prevent behavioral expressions/symptoms."

Table 10. *Care Setting Research Priorities*

Care setting research topics	Borda Count	Ranking
Providing and supporting care in the home – what services are needed e.g. day care, respite, home help, nursing and medical care	544	1
Creating a helpful environment for the person with dementia – e.g. routines, space, signage, homelike	703	2
Workforce issues in long-term care and hospital	784	3
Impact of facilities like Green Houses, dementia villages, households compared with traditional nursing homes	809	4
Technology to maintain safety and independence	826	5

"Creating a helpful environment for the person with dementia is very important but much is already known about this. Doesn't need research so much as dissemination."

"The number one priority should be "how do we get families to plan ahead for care needs?"

"The current traditional care home model is incredibly profit and staff-centered; alternatives should be funded and tested."

"Aging in place and homelike environments are so important to the patient and the caregiver's desires for the loved one. Support furniture, for bath and living spaces, is so expensive! Please look at that as you plan for technology, which may not be useful or accessible for the average home."

Table 11. *Complementary and Alternative Therapies Research Priorities*

Complementary and alternative therapies research topics	Borda Count	Ranking
Impact of sensory therapies such as music, art, aromatherapy on the person with dementia	517	1
Role of nutrition, supplements in the prevention and treatment of dementia	540	2
Developing methods to measure the impact of complementary and alternative therapies	558	3
Impact of touch therapies such as Reiki, massage, acupuncture on the person with dementia	798	4

"All above are important. We need to focus on a variety of tools, in addition to traditional medical model (medications)."

"All of these can be wonderful additions to helping the patient have a quality of life. Not all patients may understand or desire touch/sensory therapies, but offering these would be worthwhile."

"All of the above are needed. Unless the research leads to funding to enable access to these therapies it is a waste of time and money. Funding is needed to ensure access by all not just the financially secure to these options for care and treatment."

Table 12.

Educational Research Priorities

Educational research topics	Borda Count	Ranking
Best practices for educating/training the workforce – doctors, nurses, social workers, lawyers, aids, students etc.	453	1
Culture change and person-centered approaches to care	486	2
Best practices for educating the person with dementia, family and friends – content, method (classroom, web-based)	529	3

"I would put aides in an entirely different category than other professionals. Best practices for educating/training aides would be Number One for me."

"Education for family should be home based. Persons caring for someone with dementia are usually afraid to leave that person. They may not have access to web-based training or know how to use it."

"Culture change will flow from best practices education."

"The most important thing the medical workforce needs to learn is to stop referring people to assisted living before they have exhausted the options to remain in their own home."

Table 13. *Quality of Life Research Priorities*

Quality of life research topics	Borda Count	Ranking
How to help the person with dementia remain engaged with life	509	1
How to maintain abilities – physical, cognitive, personal skills and strengths (work issues)	551	2
How to help friends, family, caregivers engage with the person with dementia	716	3
How to measure quality of life and the impact of dementia for the person with dementia and family	753	4

"Quality of life is the goal - I believe we have the right ideas already, so made QoL measurement my lowest priority. However, we need to turn the right ideas into measure of QoL that really matter."

"We have to work on putting out the fire rather than identifying it. People dealing with people that have dementia need help NOW."

"If we teach people how to engage the person with dementia, then we are helping the person with dementia remain engaged with life and more likely to maintain abilities. Most persons with dementia I have worked with don't seem to want to remain engaged with life; it appears too depressing to stay engaged when you are still in touch with what is happening to you."

Limitations

Ideally the study would have taken place over a longer period of time allowing for a third round to achieve greater clarity of priorities and to give more time to reach more potential participants. We would have liked to engage more people living with dementia in the process of data collection. The electronic communication and online form may have limited their participation. Other ways of engaging these primary stakeholders must be considered for future research. However, adhering to this tight timeframe and mode of communication made it possible for us to present the findings at the NAPA council meeting where the agenda was to determine whether or not to increase the focus on caregiving issues. Despite the limitations we were able to engage with people living with dementia, care partners and direct caregivers from more than half of the states. We were able to attract over 300 people in each round of the Delphi to click the link to SurveyMonkey® and more than 90% of those completed some if not all of the survey.

Discussion and Conclusions

The purpose of the survey was to find consensus on important issues related to dementia from the perspective of the people most affected, that is, people living with dementia and their care partners. Dementia, including Alzheimer's, is a complex, long lasting condition which impacts every aspect of life. The biomedical approach, which has been used to see dementia as neurodegenerative pathology alone, has been rejected by all dementia supporters and advocates. The need to recognize the whole person impact for the individual and the impact of caregiving for family caregivers, professional caregivers and the communities in which they live has been highlighted in many contexts worldwide (Wortmann, 2013) has yet to make a significant impact on policy and strategy here in the USA. The current NAPA strategies focuses $100M on biomedical research and less than $10M on all other issues including services, education and training and advocacy (NAPA, 2014).

The findings of this survey indicate that research is important to people living with dementia and their care partners. However, research is ranked third and after the need for support for caregivers and resources of providing care over the long term. If the national plan followed the order of priorities identified in this survey, funding would be allocated as:

1. Financial and other resources to support caregiving
2. Financial and other resources to support long-term care and aging in place.
3. Research for cure and care
4. Education and Training for families as well as health professionals, nursing aides, and volunteers
5. Advocacy and awareness to reduce the stigma of dementia

For the research agenda, priorities would be more diverse including research to understand the multitude of care issues that were raised. Most people want a cure to be found or ways to prevent development of dementia. The reality of this happening by the 2025 deadline was not supported. As one participant wrote:

"I have known for a long time that there will be no cures in my lifetime. Maybe in my children's, not sure now, not even sure if in my grandchildren's. So there has to be some more emphasis/support/help for caregivers, and some way has to be found to pay for care- in home. Facilities in my area are costing $10,000 per month. No way is this affordable."

The specific areas of priority for research were as follows:

1. Cure, prevention and treatment.
2. Caregiving including person-centered care, family caregivers, and workforce issues
3. Education and training including for the person with dementia, families, workforce, and the public
4. Quality of life including the impact of dementia on the whole family
5. Complementary therapies including supplements, remedies, and alternative treatments
6. Care settings and environments including the home, long-term care facilities, day care, and hospitals.

Participants were clear that not all research funding should be focused on cure. The fact that so many research ideas could be generated indicates the scope of work needed to produce a strong evidence base for practice/services. Without rigorous research the ability to scale up effective interventions to meet needs on community, regional, state or even national levels will be near impossible.

The needs of people living with dementia and their care partners is great. In addition to all the information and ideas provided in this survey was the very clear call for ACTION. To have an advocacy organization focused on all people living with dementia and not just those with Alzheimer’s, could not be more imperative.

Aim 3

Disseminate the written results from Aim 2 to DHHS Secretary, the NAPA Advisory Council members, and other targeted audiences.

Strategies

Dissemination strategies are aimed at reaching a broad spectrum of stakeholders. This on-going, multi-faceted process will continue over the coming year, using diverse channels of communication to expand our reach and impact. (e.g., in-person meetings; forums and conferences; on-line webinars; email distribution; as well as dissemination throughout the ever-expanding Alliance network focused on state, regional, and community levels across the country.)

<u>Policymakers</u> – Our most time-sensitive strategy was achieved with Dr. Porock presenting the Delphi survey results to the NAPA Advisory Council Members at the July 21, 2014 Quarterly Meeting during the public comments session. An accompanying handout was distributed to the Council and audience attendees. (See Appendix B). The transcript of Dr. Porock's comments follows:

> *Council members, ladies and gentlemen. Thank you for the opportunity to speak today at this important meeting. My name is Dr. Davina Porock and I represent researchers from the University at Buffalo's Institute for Person-Centered Care and our colleagues from CCAL Advancing Person-Centered Living.*
>
> *We conducted research funded by the Retirement Research Foundation in response to our concern that the focus of dementia policy in the USA is lacking the voice of people living with dementia and their care partners. Our aim was to capture their opinions and contribute them here and in other forums.*

First we interviewed leaders of very prominent organizations focused on aging services and advocacy. It was sobering to find how few leaders were familiar or knowledgeable with NAPA's purpose and strategies. Of the leaders who were familiar, all stated the need to refocus NAPA on person-centered practices, support for caregivers and aging in place. Today's meeting focus is a step in the right direction.

Next we ran a two-round consensus building Delphi survey to determine priorities for policy and research. We targeted participation from people living with dementia including Alzheimer's and those caring for them – families as well as direct care givers in facilities. The handout you have been given presents a brief overview of the findings. A full report will be available in September. You will see the participants came from across the country and the majority had person experience with dementia. Our findings are consistent with the RAND report discussed earlier today but our study recruited over 300 participants in each round.

The dementia priorities identified from out participants were as follows. The top two areas were Caregiver Support and Long-Term Care Support. It is important to note that research took a secondary place to these two topics. Education and Training, Advocacy and Awareness also made the list of top priorities. The handouts provide more detail along with examples of what our participants meant by these priority areas. I'll just touch on highlights now.

It makes sense that Caregiver Support and Long-Term Care Support were the highest priorities. Dementia may be diagnosed in the individual but the *condition is experienced by the whole family and support system over a long period of time. The findings also parallel the report we heard today from Brenda Spillman with the findings of the National Caregiver Survey. Furthermore, as council member Laura Trejo asked in her opening statement, "What is the plan actually doing to provide services and financial support?" Our findings prioritize these issues.*

Research on cure and treatment of dementia, including Alzheimer's, was ranked highest in the research priority section. But equally and in considerable detail, participants identified care issues, quality of life and alternatives to pharmacological management as important research topics.

The need for support is very great. We need to diversify NAPA strategies to increase research opportunities in care. As Harry Johns already noted in his comments this morning, engagement – a key component of person-centered care – contributes to prevention of deterioration in cognition. This point emphasizes the need for more research in person-centered approaches to care.

In that vein, a leaf can be taken from the disabilities policy, policy and research approach where the promotion of the individual's strengths and their inclusion in all aspects of life is held paramount over what they cannot do. People living with dementia deserve the same rights and focus.

To close, I wish to remind the council that The Affordable Care Act mandates the delivery of person-centered care practices by service providers receiving payment from CMS. Person-centered practices have not yet been a focus of NAPA's efforts and we recommend that they now be addressed.

People living with dementia and their care partners – The summarized findings which formed the handout distributed at the NAPA council meeting will be sent to our participating organizations, networks and personal contacts. In addition, any individual who requested a copy and left an email address at the end of the round 2 survey will be sent a copy to that address.

Dementia care advocates and academic audiences – Articles and presentations aimed at advocates and providers (such as *Provider* and *McKnight's* magazines) are being prepared. A session was conducted in August 2014 at the national Pioneer Network Conference; and proposals are being prepared for 2015 national conference submissions. For health professionals and researchers, a manuscript will be prepared for publication in a peer-reviewed journal and the findings will be presented at scholarly meetings and conferences. For example the work was presented at the Pioneer Network meeting in August 2014.

NAPA/Federal Agencies – Outreach will be conducted to NAPA agencies, in particular the National Institute for Aging (NIA) and the Alzheimer's Association. The following represents some of the NAPA-related and Aging-related policy outreach meetings and conference calls conducted during the project period (see tables 14 and 15).

Table 14. *Outreach contacts to Federal Agencies*

Federal/State/Congressional Policy	Affiliation
Linda Elam (ex officio)	Deputy Asst Sec'y, Office of Disability, Aging and LTC Policy, ASPE
Ruth Katz (ex officio)	Assoc. Deputy Assist. Secretary, Office of Disability, Aging & LTC Policy, ASPE
Rohini Khillan (ex officio)	Office of Disability, Aging & LTC Policy, ASPE
Michele Laughman (ex officio)	Division of Nursing Homes, CMS
Ralph Lollar (ex officio)	Director, Division of Long-Term Services and Supports, CMS
Erin Long (ex officio)	Administration for Community Living
Louise Ryan (ex officio)	Office of LTC Ombudsman Programs, AoA
Jane Tilly (ex officio)	Office of Supportive & Caregiver Services, Admin for Community Living/Admin on Aging
Dan Timmel (ex officio)	Senior Analyst, CMS/HCBS
Joan Weiss (ex officio)	Chief, Geriatrics & Allied Health Branch, Health Resources and Services Administration

Table 15. *Outreach to Aging-Related Policymakers*

Aging Policy	Affiliation
Walter Coffey	President/CEO, LeadingAge Georgia
Lynn Feinberg	Sr. Strat. Policy Advisor, AARP Public Policy Institute
Val J. Halamandaris	President, Nat'l Assoc of Home Care
Teresa D. Johnson	Managing Director, Nat'l Adult Day Services Assoc
Ruta Kadonoff	VP, Quality & Reg. Affairs, Am Health Care Assoc
Ian Kremer	Executive Director, LEAD
Sarah Lock	SVP, Policy Strategy & International Affairs, AARP
Katie Maslow	Scholar in Residence, Institute of Medicine
Anne Montgomery	Sr. Policy Analyst, Altarum Institute
Cheryl Phillips	Sr. VP, Public Policy & Advocacy, LeadingAge
Don Redfoot	Senior Policy Analyst, Public Policy Institute, AARP
Martha Roherty	Exec. Dr., Nat'l Assoc of State Units on Aging and Disability
Lindsay Schwartz	Director, Workforce & Quality Improvement, Nat'l Center for Assisted Living

Aim 4

Develop the infrastructure for a national Dementia Action Alliance to connect people who are living with dementia and their care partners and other advocates across the country, so there is a means to collectively gather their perspectives and interests for representation in state and federal policy making and planning efforts.

Strategies

Karen Love and Jackie Pinkowitz from the CCAL in partnership with the Eden Alternative, Planetree, and the American Medical Directors Association (AMDA) have put together the ground work for the national advocacy group Dementia Action Alliance. To summarize the extensive work that has been achieved thus far, including the organization and implementation of a Dementia Thought Leaders' summit in early July, we include here the transcript written by Karen Love and presented by her at the NAPA council meeting on the development of this new organization. The PowerPoint slides are included in Appendix C.

> *The United States, like many nations, is facing an unprecedented growth in the number of people living with dementia. Dementia care in this country is fragmented at best and neglectful at worst. While there are many entities focused on advocacy for the CURE of Alzheimer's, there are none devoted to DEMENTIA CARE. To address this gap and work to improve dementia care, CCAL-Advancing Person-Centered Living, Planetree, The Eden Alternative, and AMDA-the Society for Post-Acute & Long-Term Care Medicine launched the Dementia Action Alliance in 2012. The Alliance is an open initiative that includes any stakeholder interested in helping to improve dementia care in this country.*
>
> *Since dementia is a societal challenge, the Alliance began by connecting and*

coalescing a broad spectrum of Americans across the country including individuals and families living with dementia, healthcare practitioners, aging and long-term service and support professionals and organizations, policymakers, researchers, and educators among others to help inform and address what is needed to improve our nation's dementia care.

Besides having to cope and manage living with a chronic, progressive neurodegenerative condition, people who have dementia suffer the indignity of being stigmatized. Because most Americans don't understand dementia, they consciously or unconsciously treat those who have the condition as "less" human. Even in the early stages of dementia doctors often talk directly to a family member who accompanies the person instead of to the person; neighbors blanch if they see someone operating a lawn mower or driving, and even long-time friends begin to exclude the person from social activities. The stigmatization increases as a person's abilities decline to the point where their frustrations, anxiety, pain, and boredom are called behavioral problems.

In order to find out what Americans identify as the needed priorities for dementia, the Dementia Action Alliance, working with the University of Buffalo's Institute for Person-Centered Care, conducted a national survey this Spring. Dr. Davina Porock will describe the findings from this survey during the Public Comment period. In another project, funded by the Commonwealth of Virginia, the Alliance worked with a former National Geographic filmmaker to develop a video on person-centered dementia care and to test its effectiveness to educate people about using better practices, person-centered ones. This video will be available *online next month along with a discussion guide that can be used as a training tool.*

The Alliance convened a one-day Dementia Thought Leaders' Summit on June 30th in Washington, DC to form consensus agreement on what is needed to improve dementia care in this country. Seventy-two leaders representing the diverse spectrum of dementia stakeholders were invited to participate including three people living with early stages of dementia – one of whom is here today, Michael Ellenbogen. Jane Tilly, Linda Elam, Rohini Khillan, and Joan Weiss from NAPA's FACA participated as well as a number of others in today's audience. This slide shows the diversity of dementia stakeholders. ***SHOW STAKEHOLDER SLIDE***

The Summit consisted of three parts: pre-Summit online discussions; the Summit; and a post-Summit meeting the following day of a smaller group of Summit participants to identify and plan next action steps.

The online discussions formed consensus agreement on some key items. Specific words used can be emotionally important as noted by Rosa's Law signed into federal legislation in 2010. Rosa's Law mandates replacing the term "mental retardation" with "intellectual disability". A number of terms are widely used in dementia that are considered by many to be problematic. The Summit participants decided:

- *That the term "dementia, including Alzheimer's" is preferred over other terms such as "Alzheimer's and related dementias". "Dementia, including*

Alzheimer's" is a more inclusive term and recognizes the prevalence of Alzheimer's.

- *That the term "person living with dementia" is preferred over "patient" or other terms. The term "patient' stigmatizes the individual. Including the word "living" underscores that people continue to live with the condition.*
- *On a definition – "Person-centered dementia care is based on the fundamental premise that every individual has a unique background, human experience, and the right to determine how to live his/her own life. Person-centered dementia care is relationship-based and focused on supporting the individual's emotional, social, physical, and spiritual well-being (e.g., belonging, experiencing a continuation of self and normality, purpose, meaning, enjoyment, comfort, and opportunities for growth)."*

Val Halamandaris, head of the National Association of Home Care and Hospice who served as counsel for over 20 years to the Senate and House Committees on Aging, made a significant point that resonated with the participants. While the U.S. Constitution provides certain inalienable rights to its citizens, this doesn't include specific rights for those who are ill, old, or disabled – but perhaps should. The treatment, stigmatization, and lack of will to provide the complement of resources needed for people living with dementia and those who care for them is a civil and human rights issue.

The Summit participants identified a single, overarching goal that could improve dementia care in our country. – ***help people live fully with dementia - SHOW SLIDE****. In order to achieve this goal, five specific strategies were identified.*

SHOW SLIDE of five strategies.

To determine whether progress is being made to achieve the goal of people living well with dementia in America, the following short-, mid-, and long-term objectives were identified: ***SHOW SLIDES***

Short-Term

- *Establish Planning Team and four Workgroups;*
- *Have agreed- upon consistent standards and expectations for dementia care and supports across all settings;*
- *Have agreed -upon an optimal education and skills curriculum for each stakeholder group;*
- *Have a national Clearinghouse that aggregates national and international information about dementia care including curated resources, dementia-friendly communities/stores/neighborhood efforts, social and behavioral science research, etc.*

Mid-Term

- *Dementia is included as a priority for the White House Conference on Aging;*
- *Criteria established for person- and family-centered assessments, resources, and settings that meet individual needs and choices;*
- *There are national initiatives that coordinate the implementation of person-centered planning for everyone and make person-centered care the norm;*

Long-Term

- *Have a national policy that fosters systems change including incentives;*
- *Have a system to ensure dementia-capable care by all those providing services and support;*
- *Have a system to incentivize, empower, and retain quality workforce needed for dementia care;*
- *Have a system to ensure there is care coordination and management;*
- *Ensure infrastructure to provide care management and coordination;*
- *Scale practice models that offer best solutions;*
- *Have a system to ensure people are getting and using the resources they need in a timely manner*
- *Have a system to ensure people are as fully integrated and included in the community as they want.*

The post-Summit meeting discussed how to prioritize and organize achieving the objectives formed during the Summit. The group decided to establish a Planning Team and four Workgroups, one for each of the main strategy areas:

- *Resources and Capacity Building*
- *Awareness and Education*
- *Optimize Health and Well-Being*
- *Access and Utilization of Resources and Services*

Specific next steps for the Dementia Action Alliance following the Dementia Summit will be to let people know about the formation of a Planning Team and four Workgroups and encourage their participation. We'll have follow-up *discussions with stakeholders across research, policy and practice, publish the national survey findings, publish the "Person-Centered Matters" video online, and continue to coalesce and connect Americans to improve dementia care in our country.*

There are many good NAPA recommendations about dementia care, but they are not as broadly informed as they could be with more involvement and coordination with entities outside of those currently participating on the NAPA Advisory Council. Dementia is a societal challenge – not just a federal government challenge. NAPA has the historic opportunity to connect with and link its efforts with the other key dementia stakeholders such as states, long-term service and support providers and organizations, healthcare practitioners, and social and behavioral science researchers among others. Without this linkage, NAPA's legacy will mostly be as a body of work contained within the federal government, rather than as a cohesive, integrated effort that benefits our whole country.

While the Alliance does not yet include representatives from every dementia care stakeholder group, it currently includes representatives from a majority of them. We would welcome the opportunity to work with NAPA to create the needed link and connection.

I would like to end with a quote from one of the Summit participants, Jack York. "We don't always agree on the ideal solution, but passion on all sides will get us to a different place as we try to deal with the realities of dementia care."

The development of the Dementia Action Alliance continues with the work groups assembling and working on strategies to accomplish goals of the organization. Part of the work from this grant was to build the DAA with financial support through efforts with development. The strategies proposed were modified by the opportunities that arose during the course of the grant and refined as more was learned about how to proceed. The following is a summary of the work that has been accomplished thus far and which will continue as the DAA develops and extends its influence.

Ms. Pinkowitz and Ms. Love worked with dozens of aging professionals including Jen Martchek, the executive director of the Southwestern PA Partnership for Aging (SWPPA) and a CCAL board member, Lori LaBey, President of Alzheimer's Speaks, and Candace Baldwin, director of the Village-to-Village Network to identify existing grassroots dementia advocates (including the Purple Angels and Memory Café leaders) to invite their participation in the Dementia Action Alliance. An extensive network of over 300 individuals and organizations has been coalesced and continues to grow as outreach efforts continue. Besides emails, bi-monthly conference calls were initiated in April 2014 so there is a mechanism to connect the network of advocates and to have discussions. A separate email and conference call mechanism was created for gerontological researchers, so they could have a means to connect with other researchers interested in person-centered dementia care and advocacy.

Fund development efforts were multi-pronged. Discussions were held with Laura Hunt, a fund development specialist, to discuss the merit and feasibility of grants from foundations that support capacity building. Meetings were held with two business professors from the McDonough School of Business at Georgetown University (Bill Novelli, director of the Center for Social Entrepreneurship at Georgetown University's McDonough School of Business; and

Betsy Page Sigman) about recommended approaches to corporate partners for supporting cause marketing/social good relationships. Ms. Love met with an angel investor, Jim Hunt, to learn about approaching angel investors interested in supporting social causes. Finally, in an effort to enlist the help and support of major corporations, the first of several planned meetings was held with Sarah Lock, Senior Vice President for Policy Strategy & International Affairs at AARP, about the DAA. Sarah signed on AARP as an Alliance Collaborator. The possibility was discussed of jointly approaching CVS Caremark about being a corporate sponsor, since CVS has taken a bold step to focus on Health by stopping the sale of tobacco products.

The six organizations that comprise the Alliance Leadership Team have each committed to contribute $2,500 to provide seed money to continue efforts beyond the funding support provided by The Retirement Research Foundation. The Leadership Team decided to pursue a social media-based challenge to raise additional funds to support the Alliance's work rather than focus on grant funding, angel investors, or corporate sponsors. A social media-based challenge provides the ability to not only raise money but to help people think differently about dementia. Plans are underway to launch in late October a CAREGIVER'S CHALLENGE using YouTube to show short video clips of ways that care partners of people living with dementia are helping lift their spirts. An example is a daughter's video clip of her mother joyfully singing an Irish song and tap dancing. The daughter knows singing and dancing take her mother to a mental and emotional place of joy. They both end up enjoying the experience. Besides serving as a means to raise awareness and funds for important work, the CAREGIVER's CHALLENGE is intended to get people thinking differently about dementia and focusing on ways to support their strengths and interests.

Financial Report

	Budget	Spent	Difference
Salary And Fringe	13053	16976.11	-3923.11
Travel	1501	1939.16	-438.16
Postage	100	36.4	63.6
Pacific Market Research	5000	0	5000
Subaward-CCAL	25800	25800	0
Software	0	1206	-1206
IDC and Fees	4545	3993.95	551.05
Total	49999	49951.62	47.38

The biggest change on the financial report was that Dr. Porock took on the task of the pacific market research by increasing her time devoted on this project and purchasing NVivo to increase efficiency on the pacific market research.

Travel was purchased to allow for UB team to present the results of this project at the NAPA conference in Washington D.C. in July 2014. Dr. Porock attended a team meeting in Washington D.C. in June 2014 as well. Funds were spent on the subaward to CCAL as planned. Only $36.40 was needed for postage. The largest category was salary and fringe benefits to support Dr. Davina Porock, Dr. Louanne Bakk and Suzanne Sullivan for the duration of the project.

Tuition was provided for Suzanne Sullivan by the University at Buffalo.

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Appendix A

RRF Dementia Action Alliance Project

Interviews with Organizations

Meetings/phone calls

Setting the Stage/Introduction

- A number of recent national initiatives [CMS Initiative to Improve Dementia; reduction of the use of antipsychotics, ASA's journal on Person-Centered Dementia Care] and the National Alzheimer's Project Act (NAPA), a federal law, have brought greater focus and attention to dementia. Much of the focus and attention is on the CURE and TREATMENT aspects for Alzheimer's disease specifically. We are interested in CARE aspects and the broader context of dementia.
- We received a grant from the Retirement Research Foundation to gather feedback from people who are living with early stage dementia, care partners and other advocates, and leaders in aging about dementia CARE needs in this country. This information, in collective format, will be used to inform policymakers on the needs and priorities of people living with dementia, their care partners, and service providers.
- As a representative of ____________________, you have knowledge and expertise that are valuable. May I ask you some questions? Your comments will be kept confidential and only used to help inform and include a broad perspective in our work.

Overview of NAPA and goals

- Are you familiar with NAPA?
  - Here is a brief overview if not familiar-

The law requires the creation of an Advisory Council through 2015. A couple key provisions are for them to - (1) create and maintain an integrated national plan for AD. (2) coordinate AD research and services across all federal agencies.

  - If familiar, what are your thoughts about NAPA's efforts?
  - What would you hope to see NAPA focus on as it considers its goal and priorities
  - Do you have any recommendations or suggestions concerning national dementia care priorities?

- We are working with the UB's Institute on Person-Centered Care. They will be conducting a short online survey next month to gather feedback about dementia care.
  - Would you be willing to complete the online survey?

    If yes, thank you very much.
- There is a need for a national grassroots advocacy network to bring together people living with dementia, their care partners, and other advocates so their voices can be heard and can inform the basis for policies, practices and services that impact them. NOTHING FOR ME WITHOUT ME.
  - The Dementia Action Alliance was formed to connect the voices to have collective impact.
  - The Dementia Action Alliance is also working to move person-centered dementia care practices from an ideal to standard practice.
  - What do you think about this effort?
  - Do you have any suggestions or recommendations for us as we develop the DAA?
  - Would your organization be interested in being on the Alliance listserv to receive update about the efforts and progress?

Thank you very much for your thoughts and insights. They are helpful. Could I share my perspective about NAPA's efforts?

- While NAPA is an important initiative in developing a national framework, it has some shortcomings from the perspective of dementia CARE advocates:
    - It is unbalanced in terms of a focus on treatment and cure, with much less focus on care-related needs.
    - NAPA does not reflect a person-centered paradigm – of concern because this is considered by IOM among others as what should be the standard.
        - ✓ [NAPA reflects a medical model of dementia care i.e. a deficit based approach to persons with dementia that primarily views them as patients with medical illnesses and focuses on their weaknesses, disabilities, and symptoms. A person-centered approach to dementia sees people with dementia as more than their diagnosis - as persons first- whole individuals who continue to have multifaceted needs beyond medical care that seeks to treat their symptoms.]

Appendix B

Dementia Priorities Identified from a National Survey

Handout

Presented at NAPA Quarterly Council Meeting, July 21, 2014

Washington D.C.

CCAL Advancing Person-Centered Living

The Institute for Person-Centered Care

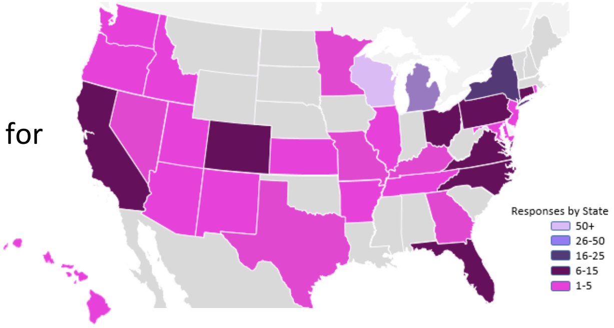
University at Buffalo The State University of New York

Dementia Priorities Identified from a National Survey

Following the 2011 National Alzheimer's Project Act (NAPA) law, the federal government published the first National Alzheimer's Plan in 2012 with annual updates and recommendations thereafter. The federal government's plans and efforts for dementia follow the National Plan and its recommendations. With funding from The Retirement Research Foundation, a collaborative team from CCAL: Advancing Person-Centered Living and the UB's Institute for Person-Centered Care conducted a national online survey with a broad spectrum of Americans with personal or professional experience with dementia, including Alzheimer's. The study used a two-round Delphi Approach to gain consensus about what people see as the important priorities for dementia and how these priorities compare with NAPA's priorities and recommendations.

Potential survey participants needed to have access to and use email, however paper versions were made available via mail. In order to reach people who at least had some personal or professional experience with dementia or with individual(s) living with dementia, email invitations were disseminated through a wide network including: grassroots dementia groups, the Pioneer Network's state coalitions, national aging service and provider organizations, and consumer advocacy organizations such as Consumer Voice among others. People who responded to the email invitation were made aware that participation would include responding to at least two rounds of survey questions and were offered the option to take the survey online or to be sent a paper copy of the survey. While the Delphi methodology is more time intensive, this methodology was selected because it provided the best means of gathering and combining opinions and developing a broad consensus.

Respondents to the survey included a broad array of people including: individuals living with dementia (3%), those who care for them at home and in long-term care settings, other family members and advocates, aging service professionals, health practitioners, and others. Most participants were women (85%) In Round One 388 people participated and in Round Two, 301 people participated. Responses were received from residents of 31 states and DC.



Demographics

Ethnicity	%	Age	%
(n=249)		(n=246)	
White	91	18-29	6
Hispanic	2	30-39	7
Afr. Amer.	2	40-49	15
Asian	2	50-59	32
Decline	2	60-69	31
Other	1	70-79	8
		80-89	1

Key Relationships with People Living with Dementia

Current Relationship (n=140)	%*	Previous Relationship (n=179)	%*
Parent	42	Parent	34
Spouse/Partner	20	Spouse/Partner	3
Friend	23	Friend	16
Brother/Sister	6	Brother/Sister	1
Grandparent	5	Grandparent	29
In-law	5	In-law	9
Uncle/Aunt	2	Uncle/Aunt	8
Other	0	Other	8

* Total exceeds 100% because some respondents indicated more than one relationship

Round One (April 8-25, 2014): Participants were asked to describe the needs of people living with dementia and their care partners and to identify priorities for federal policy and publicly funded research. Responses from Round One were analyzed and themed groups of potential priorities were identified.

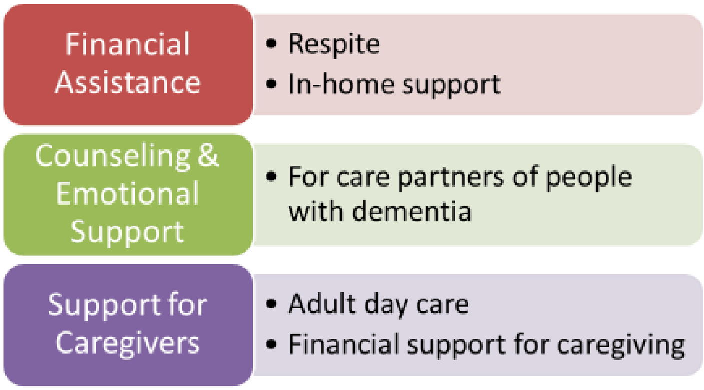
Round Two (May 24-June 6, 2014): Participants were asked to rank the themes by priority. The following are the ranked findings from the survey. Details in the meaning of each priority for people living with dementia and their care partners are provided along with quotes from participants commenting on the each set of priorities supporting or extending the themes.

Dementia Priorities Identified by National Survey

Participants found it very difficult to choose between topics. Several comments were recorded stating that the need is so great that everything needs to be ranked #1!

> *"This was a very difficult question. ALL of these topics are of great need. I had a very difficult time ranking them. As this population increases we are going to need more and more to help support them and their families/caregivers long term."*

Tied # 1 - Priorities for Caregiver Support



"If I had a dollar to allocate, I might divide it equally among these priorities"

"Very difficult! All are important. However, caregivers wouldn't have as much stress and need emotional assistance if they had the supports they needed for their loved one in the home"

"HARDEST job that I have ever done. If you haven't done it, you don't have any idea how hard it is. Not much support for the caregiver!!

"Many family caregivers, male and female, give up working outside the home to become a fulltime caregiver because they can't afford outside help. Caregiving can last years, and the resulting loss in income and lack of employability (who's going to hire someone who spent the last 5 years caring for his mom?) afterwards can devastate a family caregiver"

Tied #1 - Priorities for Long-Term Care

Provide Home & Community-Based Services	Resources to support aging in place (transportation, affordable assisted living, home delivered meals, care management, adult day services
Skilled Workforce	Build and develop dementia care knowledge and skills for LTC workforce
Increase Standards & Oversight	In assisted living, nursing homes & hospitals Avoid use of antipsychotics to manage behavioral expressions

"First we need home and community based services so those with dementia can remain in their homes as long as possible. Then, we need a competent workforce and nursing homes that provide quality person centered care. We need it all!"

"Regulations are inconsistent at best... Would like to see some broader rules from the federal level that are enforced at…a much higher standard.

"The standards for AL and Adult Day need to include cultural competence… What do they know about the cultures they/hope to serve?

"There is a big need for long-term care that supports people in the early to mid-stages of the disease. Too much of the long-term care system in place now is for people whose disease has advanced to critical stages, but there is still a great deal of need for less intensive, intermediate-term care for people with dementia.

2 - Priorities for Research

Cure	Prevention, cure and treatment-related research highly supported No specific topics suggested
Care	How to reduce stress, fear, & distress for people with dementia and care partners Person-centered care and practices Complementary therapies and non-drug approaches
Quality of Life	Educational research to inform all professionals (health, law) Impact of dementia on individuals, family and society

"Based on research, early diagnosis and caregiver support provide the greatest impact. Early diagnosis allows for medications that slow the progression of the disease; time to plan while the individual has the capacity...make end of life decisions and care decisions. Care giver education and support decreases or delays future placement in nursing homes…Medical research on the causes of irreversible dementia will have the greatest long term impact decreasing the incidence"

"Aging in place and homelike environments are so important to the patient and the caregiver's desires for the loved one. Support furniture, for bath and living spaces, is so expensive! Please look at that as you plan for technology, which may not be useful or accessible for the average home"

3 - Priorities for Education & Training

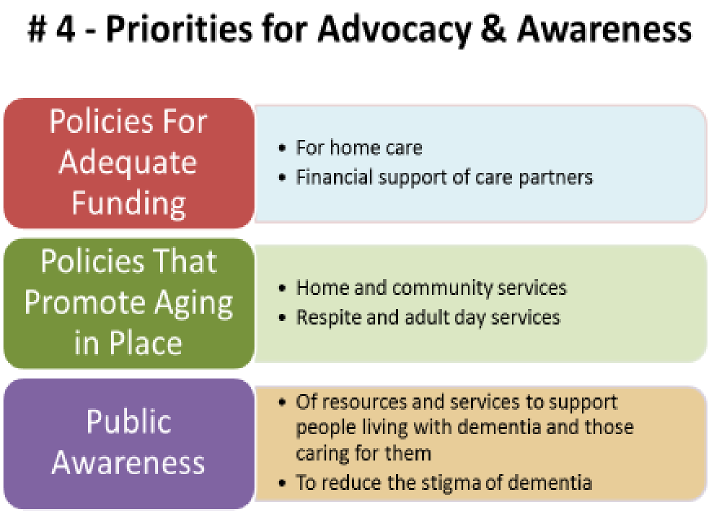
Develop Knowledge & Skills	For all caregivers: at home and in long-term care; hospitals; primary care; public agencies
Person-Centered Care and Non-Drug Approaches	Communicate with and including the person living with dementia Complementary therapies (e.g. music, massage, aromatherapy)
Incentivize Dementia as a Specialty	To increase the number of health professionals with person-centered dementia care skills

"Need $$ for supporting more diverse ethnic and racial physicians and nurses - not just Care Assistants"

"Investing in training family caregivers and healthcare/social workers will prevent premature institutionalization of people w/ dementia"

"Facilities need to know <u>now</u> as they currently are doing the crises intervention because the other supports aren't in place yet…."

"It would be good to look at what is working in other countries and ask them to share what they have learned. The US needs a culture change, and become a more compassionate people toward all elderly"



4 - Priorities for Advocacy & Awareness

Policies For Adequate Funding	For home care Financial support of care partners
Policies That Promote Aging in Place	Home and community services Respite and adult day services
Public Awareness	Of resources and services to support people living with dementia and those caring for them To reduce the stigma of dementia

"Dementia should be #1 health care policy priority precisely because it will lead the way toward greater compassion and services for people with other disabling diseases"

"I would make support for family caregiving the number one priority for public health policy, independent of diagnosis or condition. Aging in place when it is desired and appropriate but also support for positive transitions to new settings that may promote thriving"

"The general public has to become aware of the difficult behaviors of people with dementia and support the caregiver, be patient with the patient. The number one priority for the nation now is the mentally ill and gun control. Dementia isn't necessarily violence oriented"

Interviews

In addition to the online survey, confidential interviews were conducted with 27 leaders in the field of aging. Of these leaders only 16 stated they are 'familiar' or 'somewhat familiar' with NAPA's purposes and strategies. The remainder did not know about NAPA and were not able to comment further. Given the prominent organizations that these leaders were from, their responses suggest that NAPA's strategies and work is not being disseminated sufficiently.

Of the leaders who were familiar with NAPA, the following are some of their key suggestions what NAPA should focus its goals and priorities on:

- "Would like to see NAPA focus on person-centered care, use current knowledge rather than traditional medical/clinical orientation, and want them to focus more broadly across all settings."
- "We need to build a really strong community infrastructure. I'm not talking just about home care. I mean a true community-wide effort to support people with dementia to live in the community. The National Plan should reach out more broadly about community aspects – care, housing, transportation, community development, and economic development."
- "Focus on family and the informal supports. With billions of dollars in unpaid care, more can be done to help family caregivers. You have to help the people and the caregivers who are dealing with dementia now."
- "As new health care delivery models are being developed there is flexibility with how money is being spent on services. These new models can address how to pay for these services. We need to think outside the box."

Discussion

The lion's share of federal resources and dollars are invested in finding a cure and treatments for Alzheimer's. These are critically important objectives and ranked high in the survey. The priorities that ranked highest from the universe of possibilities, however, are focused on dementia CARE. This finding is in tandem with a recently released RAND Corporation report titled, “Improving Dementia Long-Term Care: A Policy Blueprint”. The RAND report identified five areas for immediate policy attention of which the survey’s top two identified priorities (caregiver support and long-term care) are two of its five priorities. NAPA’s meeting focus to date has been mostly on the CURE and CLINICAL aspects. The survey findings and RAND report suggest that NAPA should consider as high a priority and focus on dementia CARE.

The specific items identified within the top priority categories - financial assistance for respite and adult day care, counseling and emotional caregiver support programs, home and community-based services, research for the cure and care, training and education for the wide array of care partners and professionals involved in dementia care, public awareness, and increasing LTC standards and oversight – all come with financial implications. Financial implications are a key topic for NAPA’s consideration because it underpins significant aspects of dementia care. We suggest “addressing” this key topic as a necessary first step towards a viable national solution.

There were two items identified in the survey that especially stood out because conventional wisdom holds them as important. First, while survey respondents did identify “advocacy and awareness about dementia” as a need, the item ranked as not very important. We postulate that this is because people, in general, perceive advocacy and public education as helpful but not immediately beneficial to care or to their personal caregiving needs. Second, respondents ranked “involving the person with dementia in decision-making” as not very important. This is likely a result of the widespread lack of understanding of the dementia condition itself as well as needing to be educated about person-centered care practices. The Affordable Care Act mandates the delivery of person-centered care practices by service providers receiving payment by CMS. Person-centered care practices have not yet been a focus of NAPA’s efforts and we recommended they be addressed.

It is significant that so few leaders in aging services know about NAPA. If NAPA’s efforts are to be effective and successful, there needs to be active integration with the private sector as well as the agencies within the federal government. Currently there is no system in place to actively coordinate and link federal and private sector efforts to maximize beneficial outcomes. For the U.S. to make significant progress in dementia, this too will need to be addressed.

Respectfully submitted

UB IPCC team
Davina Porock, PhD
Louanne Bakk, PhD, MSW
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For a copy of this document or for more information on the study please email Davina Porock at dporock@buffalo.edu.

The study was funded by The Retirement Research Foundation, RRF Grant #2013-241

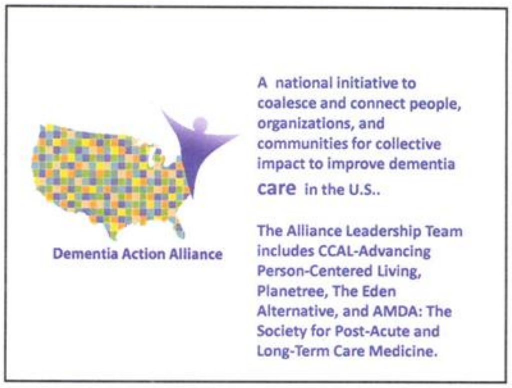
Appendix C

RRF Dementia Action Alliance Presentation Slides

NAPA 7/21/2014

Karen Love
DEMENTIA ACTION ALLIANCE
July 21, 2014 NAPA Advisory Council Meeting

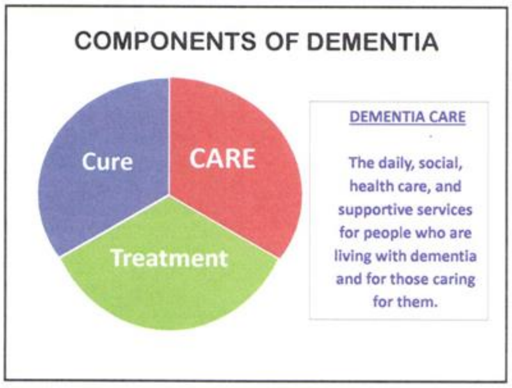
karenlove4@verizon.net



Dementia Action Alliance

A national initiative to coalesce and connect people, organizations, and communities for collective impact to improve dementia **care** in the U.S..

The Alliance Leadership Team includes CCAL-Advancing Person-Centered Living, Planetree, The Eden Alternative, and AMDA: The Society for Post-Acute and Long-Term Care Medicine.



COMPONENTS OF DEMENTIA

Cure
CARE
Treatment

DEMENTIA CARE

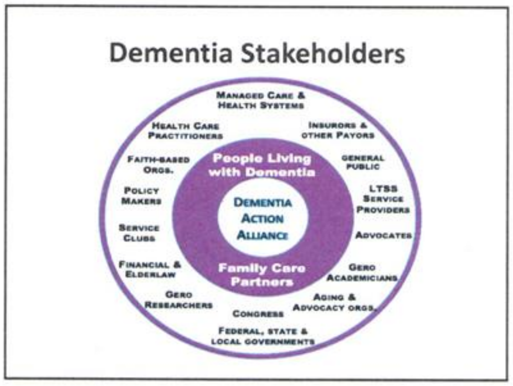
The daily, social, health care, and supportive services for people who are living with dementia and for those caring for them.

Dementia Thought Leaders Summit

June 30, 2014 ~ Washington, DC

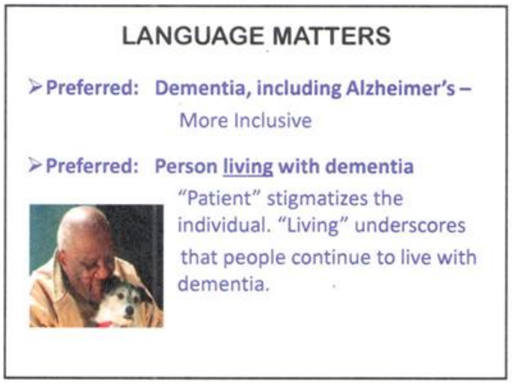
Objective –

Form consensus agreement on what is needed to improve dementia care in this country.



Dementia Stakeholders

DEMENTIA ACTION ALLIANCE
People Living with Dementia
Family Care Partners
MANAGED CARE & HEALTH SYSTEMS
INSURORS & OTHER PAYORS
GENERAL PUBLIC
LTSS SERVICE PROVIDERS
ADVOCATES
GERO ACADEMICIANS
AGING & ADVOCACY ORGS.
FEDERAL, STATE & LOCAL GOVERNMENTS
CONGRESS
GERO RESEARCHERS
FINANCIAL & ELDERLAW
SERVICE CLUBS
POLICY MAKERS
FAITH-BASED ORGS.
HEALTH CARE PRACTITIONERS



LANGUAGE MATTERS

- **Preferred: Dementia, including Alzheimer's –**
  More Inclusive
- **Preferred: Person living with dementia**
  "Patient" stigmatizes the individual. "Living" underscores that people continue to live with dementia.

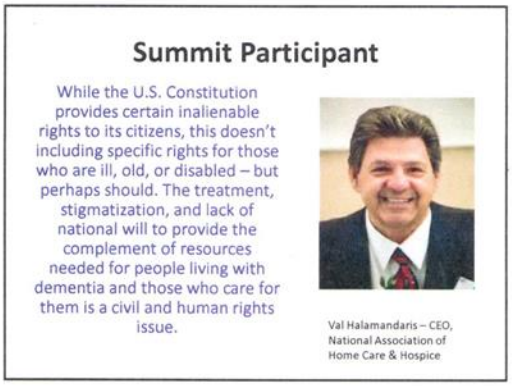
Definition of Person-Centered Care

Person-centered dementia care is based on the fundamental premise that every individual has a unique background, human experience, and the right to determine how to live his/her own life.

Person-centered dementia care is relationship-based and focused on supporting the individual's emotional, social, physical, and spiritual well-being (e.g., belonging, experiencing a continuation of self and normality, purpose, meaning, enjoyment, comfort, and opportunities for growth).

DEMENTIA SUMMIT - GOAL TO IMPROVE
DEMENTIA CARE IN THE U.S.

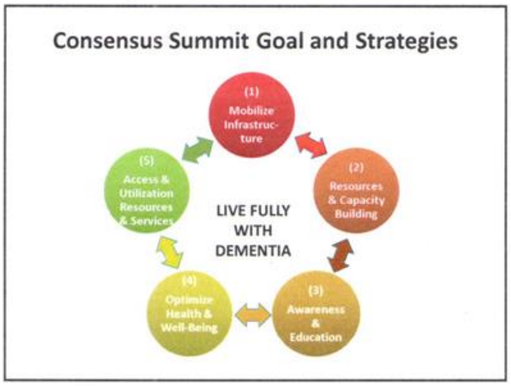
HELP PEOPLE WITH DEMENTIA
LIVE FULLY



Summit Participant

While the U.S. Constitution provides certain inalienable rights to its citizens, this doesn't including specific rights for those who are ill, old, or disabled – but perhaps should. The treatment, stigmatization, and lack of national will to provide the complement of resources needed for people living with dementia and those who care for them is a civil and human rights issue.

Val Halamandaris – CEO,
National Association of
Home Care & Hospice



Consensus Summit Goal and Strategies

(1) Mobilize Infrastructure

(2) Resources & Capacity Building

(3) Awareness & Education

(4) Optimize Health & Well-Being

(5) Access & Utilization Resources & Services

LIVE FULLY WITH DEMENTIA

Short-Term Objectives To Achieve "Helping people live well with dementia"

- Establish a Planning Team and four Workgroups;
- Have agreed-upon consistent standards and expectations for dementia services and supports across all settings;
- Have agreed-upon an optimal education and skills curriculum for each stakeholder group; and
- Have a national Clearinghouse that aggregates national and international information about dementia care including curated resources, dementia-friendly communities/stores/neighborhood efforts, social and behavioral science research, etc.

Mid-Term Objectives To Achieve "Helping people live well with dementia"

- Dementia is included as a priority for the White House Conference on Aging;
- Criteria established for person- and family-centered assessments, resources, and settings that meet individual needs and choices; and
- There are national initiatives that coordinate the implementation of person-centered planning for everyone and ensure person-centered care is the standard of care.

Long-Term Objectives To Achieve "Helping people live well with dementia"

- Have national policy that fosters system change;
- Have system to ensure dementia-capable care by all those providing services and support;
- Have system to ensure there is care coordination and management;
- Have a system to incentivize, empower, and retain quality workforce needed for dementia care;
- Scale practice models that offer best solutions;
- Have system to ensure people are getting and using the resources they need in a timely manner; and
- Have system to ensure people are as fully integrated and included in the community as they want.

Proposed Organizational & Operating Infrastructure

Summit Participant

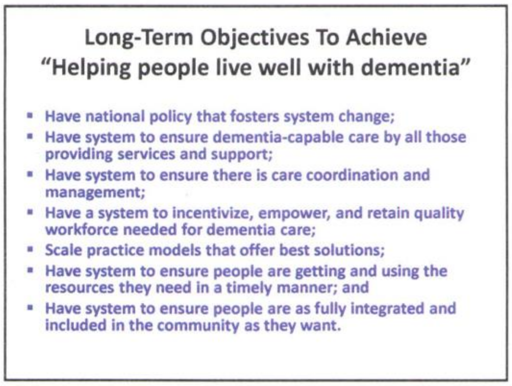
"We don't always agree on the ideal solution, but passion on all sides will get us to a different place as we try to deal with the realities of dementia care."

Jack York - CEO, It's Never 2 Late

http://vimeo.com/pasternakmedia/personcenteredmatters

Password: ARDRAF

Public service video announcement ~ Funded by the Commonwealth of Virginia's Alzheimer's and Related Diseases Research Award Fund ~ 2014



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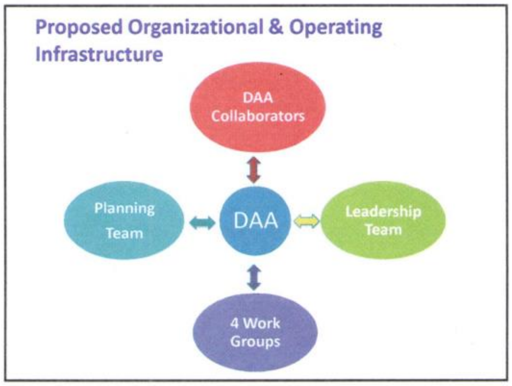

Proposed Organizational & Operating Infrastructure

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“We don’t always agree on the ideal solution, but passion on all sides will get us to a different place as we try to deal with the realities of dementia care.”

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