ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

Washington, DC

October 27, 2017

WELCOME AND INTRODUCTIONS

Laura Gitlin, Ph.D., Johns Hopkins University, Chair
Dr. Gitlin opened the meeting at 9:08 AM and introduced herself as the new chair of the Advisory Council. She welcomed Council members and invited them to introduce themselves.

OVERVIEW OF THE NAPA LEGISLATION AND THE CHARGE TO THE COUNCIL

Laura Gitlin, Ph.D.
The National Alzheimer's Project Act (NAPA) was enacted to deal with the major challenges of Alzheimer's disease and related dementias (ADRD), namely that there is currently no way to prevent, treat, or cure these dementias. Meanwhile, since we have biomarker identification and early diagnosis, we know that people with dementia are living longer.

Dementia is complex and the needs for care, services, and support of people living with dementia change as the disease advances. Better quality of care measures and staff training are imperative because care, services, and support may help reduce disability and address symptoms. Meanwhile, family members (who are the usual caregivers) and other caregivers need support. Stigma and misconceptions are widespread and impact quality of life. Medical-social/social-medical comprehensive dementia care is needed. To achieve this, we need to coordinate and track public and private progress.

The goal of NAPA, signed January 4, 2011, is to create and maintain an integrated National Plan to overcome Alzheimer's disease by coordinating research and services across all federal agencies. For the National Plan, the term Alzheimer's disease includes related dementias such as dementia with Lewy bodies, fronto-temporal lobar degeneration, vascular cognitive impairment/dementia, and Down syndrome. (The term Alzheimer's disease must be retained to comply with the legislation.) The Secretary of the U.S. Department of Health and Human Services (HHS) oversees the creation and updating of the plan and evaluates all federal programs, including budgets and approvals, as well as carrying out an annual assessment of progress.

Objectives of the National Plan are as follows:
- Balance work on biomedical approaches with care, services, and support approaches needed by people living with the disease and their care partners/caregivers.
- Engage public and private sector stakeholders.
- Outline five goals, strategies to achieve them, and long-term and immediate actions.
- Report on progress in a transparent way, giving an implementation timeline and providing an annual report to the Advisory Council, to Congress, and to the Secretary.

The Advisory Council consists of 24 federal and non-federal members who join one or more of the three working groups--Research, Clinical Care, and Long-Term Services and Supports. Federal members represent the Office of the Assistant Secretary for Planning and Evaluation (ASPE), Centers for Disease Control and Prevention (CDC), Administration on Community Living (ACL), Centers for Medicare & Medicaid Services (CMS), Indian Health Service (IHS), National Institutes of Health (NIH), Health Resources and Services Administration (HRSA), Food and Drug Administration, Agency for Healthcare Research and Quality (AHRQ), National Science Foundation, Department of Veterans Affairs (VA), and the Department of Defense. Non-federal members (two each) are patient advocates, one of whom is currently living with the disease; caregivers; health care providers; state and local health department representatives; researchers; and volunteer health association representatives.

The NAPA Advisory Council role is to consider the annual revision of the National Plan, focusing on new and current activities (such as policies, initiatives, and programs) and track their progress. The Council is unconstrained and is advisory to the Secretary and to Congress. Recommendations and revisions of the plan are informed by research summits--Alzheimer's Disease (2012, 2015), Alzheimer's Disease-Related Dementias (2013, 2016), Down Syndrome (2014), Care and Services (2017).

Comments and Questions

- In response to **Debra Cherry**, **Rohini Khillan** said the Advisory Council members' biographical sketches are posted on the Council's website. **Dr. Gitlin** encouraged members to use the website (https://aspe.hhs.gov/national-alzheimers-project-act) to disseminate and find information.

- **Bradley Hyman** observed that it is difficult to effect the charge to evaluate work because of the need to improve tracking and evaluation. **Dr. Gitlin** agreed that there is no simple answer. We may want to return to this topic toward the end of the day. Perhaps the Council could form a small working group to suggest ways to enable the Council to track and evaluate information. **Ms. Khillan** noted the added difficulty of federal members being confined by various regulations.

- **Becky Kurtz** asked whether past summits had focused on things other than research and care, specifically the breadth of input Council members should consider. **Ms. Khillan** will return to that issue in her presentation.

OVERVIEW OF THE NATIONAL PLAN AND THE PROCESS FOR RECOMMENDATIONS

Rohini Khillan, Office of the Assistant Secretary for Planning and Evaluation
The National Plan, updated annually, is designed to address the major challenges presented by ADRD--research, quality of care and caregiver training, care and support for family members and other unpaid caregivers, and coordinating and tracking public and private sector progress.

The five goals of the National Plan are as follows:

1. Prevent and effectively treat Alzheimer's disease by 2025.
2. Enhance quality and efficiency of care.
3. Expand supports for people with Alzheimer's disease and their families.
4. Enhance public awareness and engagement.
5. Improve data to track progress.

NAPA requires that the plan be updated annually through 2025. For the 2013 revision a set of milestones to assess progress was recommended: short-term, intermediate, and long-term. ASPE compiles the National Plan based on input received from several agencies' federal workgroups. The plan is then returned to those agencies for their review and then sent through HHS clearance. When the Secretary signs off on it, it is sent to Congress with the Secretary's letter of introduction.

The format on the plan is organized by goals and strategies with links to completed reports, but reads more like a progress report than a list of activities. Ms. Khillan clarified that recommendations are the issues and gaps the non-federal Council members identify, whereas the National Plan is the government's yearly progress report on what federal agencies have accomplished in their work on dementia. Recommendations from the Council that the federal agencies can address become action items in the National Plan.

Comments and Questions

- Goals and strategies are set because the National Plan fits under the overall HHS plan (the 2017 plan was released September 1).

- **Gary Epstein-Lubow**: There is a compendium of federal activities, but is there a compendium of non-federal activities? **Ms. Khillan**: The 2017 recommendations resulted entirely from non-federal members in the three subcommittees. But, these are recommendations, rather than the plan. Because

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it is a recommendation, it can be aspirational, whereas the plan must be composed of things that are actually happening.

- *Bradley Hyman*: For federal report-outs, is it true that activities rather than priorities are important? *Ms. Khillan* admitted to general uncertainty around this point, but the agency is working on it. We don't know what members are capable of doing. Nevertheless, it is important that recommendations be prioritized.

- *Gary Epstein-Lubow* asked about the document that preceded the 2017 recommendations. *Ms. Khillan* said the 2017 recommendations combine all previous recommendations.

SUBCOMMITTEES AND FEDERAL WORKGROUPS

Research Subcommittee

Angela Taylor, Lewy Body Dementia Association
Angela Taylor is the new chair of the Research Subcommittee. She strongly supports the work of the summits and thinks that the path forward is not delving into research on any single disease, but looking across diseases to recommend how to fill the gaps among them. Funding will affect how quickly goals can be achieved. Ms. Taylor wants the subcommittee's meetings to be structured so as to allow more in-depth talk on various topics raised at the summits, e.g., care and services; patient- and family-centered outcomes; assessment tools; and translating research gains into community actions. The gains in care practice reflect an adequate focus on our recommendations. Gaps can be found where issues raised in the summits are not being addressed. Lastly, nomenclature in dementia is important for all the subcommittees.

Richard Hodes, M.D., National Institute on Aging
The way the summit recommendations fall into the National Plan recommendations reflects their different granularity, e.g., broad areas of priority appear in the National Plan. Strategic planning and milestones at NIH name some 80 milestones, which have links in the National Institute on Aging (NIA) live and transparent database to relevant grants, programs, etc. For example, behavioral and social approaches to Alzheimer's disease/ADRD research include dementia care, caregiver research and interventions, epidemiology, behavioral and social pathways to ADRD, and early psychological changes in Alzheimer's disease, prevention, and disparities. The 2017 research investment has increased to $647 million from $141 million in 2014, while in the same period the number of clinical trials has increased to 69 from 12. NIA supports ADRD-specific research opportunities for small businesses ($68.1 million in 2017). The National Institute of Neurological Disorders and Stroke and VA have also announced funding opportunities.

The Alzheimer's Disease Research Summit (III) will be held March 1-2, 2018, in Bethesda, MD; and the ADRD Summit (III) will be held March 14-15, 2019 in Bethesda, MD.

Clinical Care Subcommittee

Gary Epstein-Lubow, M.D., Brown University
There is clear hope in treating dementia, and the infrastructure of clinical care must foster these treatments rather than add more stress. The National Plan continues to support early diagnosis. We also need to follow-up on the research recommendations that came from the Dementia Care Summit including defining best practices for comprehensive dementia care, which would include consideration of payment models regarding cognitive assessments. The federal opportunity recently released for early detection could advance this. Recommendation 8 concerns the new Medicare assessment. We need to devote time to advancing work on best practices for dementia care as well as the elements of high-quality care. Another recommendation is to establish codes for risk-based payment, for which CMS describes opportunities for states.

Potential areas of emphasis for 2018 are examples of solutions by state, region, and payer or system. We need to pay attention to heterogeneity of illness and differential needs by illness phase, i.e., the need for individualized care. Themes to consider are how to incorporate additional stakeholder input, emphasis on practicality, and how recommendations can be acted on. Christopher Callahan, M.D., Indiana University School of Medicine, submitted public testimony that defines an opportunity for the Senate's Special Committee on Aging. It is no longer acceptable to say that these studies are limited to impractical exercises--the question is how to take these programs to scale so they are available for all people suffering from dementia and their families.

Shari Ling, M.D., Centers for Medicare & Medicaid Services
CMS is in the process of synthesizing all their work into one system. Section 324 aligns well with the charge to the Advisory Council and the National Plan. We are transitioning toward a health care system that seeks value and quality. However, our system is designed to focus on acute elements. Now we need to build in continuity and to align with Dr. Callahan's challenge for us. We must use agency assistance to support the work for seamless and equitable care. However, federal agencies work under specific authorities, so we will focus on what is actionable sooner, rather than what would require a change in authority. At the same time, work must be iterative within and across workgroups. We see gaps as opportunities for future research.

Comments and Questions

- ***Erin Long***: CMS offers clinical and long-term care. In fact, the lines between the subcommittees are somewhat blurred.

- ***Rohini Khillan***: The iterativeness of recommendations is very important.

- ***Gary Epstein-Lubow*** asked about requesting information from the Center for Medicare and Medicaid Innovation (CMMI). ***Dr. Ling*** noted that that had been mentioned at the research summit and CMMI has a request form. CMS is setting new directions for the innovation center to promote person-centered care around what care needs to look like and what it can look like. Behavioral health models, preventive care models, and payment models are all of intense interest to CMMI.

- ***Ellen Blackwell***: There has been a sustained response with public policy on a development model, and there is strength in numbers. HHS strategy is also related. Federal agencies have been charged with a strategy and have responded by forming a new Serious Mental Illness committee, which is also doing this work. ***Ms. Khillan***: Discussion is underway at HHS.

Long-Term Services and Support Subcommittee

Donna Walberg, Minnesota Board on Aging

In Ms. Walberg's 35 years of developing and delivering services, she has seen innovation occurring everywhere. Research and health care inform service delivery, but recommendations have to be actionable. Recommendations on how person-centered care should be developed offer incredible opportunities. We want a community-support system that effectively connects clinical care and best evidence from research to the community to whom services are delivered. The summit offered an opportunity to hear from leaders in the field. An impressive take-away is that some community members are at higher risk for Alzheimer's disease--notably African Americans, Hispanics, and people with Down syndrome--and we need to be sure services are available to them. Alzheimer's disease can be compared to cancer in that it used to be a disease that no one talked about, but now, with effective treatments, it is not as dreaded as it used to be. It is important that nobody be ashamed that they have ADRD, and that they not feel hopeless. Ms. Walberg found her experience of living with a person with dementia (her husband) to be an incredible opportunity and she wants to devise a shared vision and a clear message. Moreover, we need to identify milestones that work.

Erin Long, Administration for Community Living

The 2017 Alzheimer's Disease Supportive Service Programs have added new programs in the District of Columbia, Hawaii, Idaho, and Montana and expanded programs in Illinois and Ohio. In 2017, 11 Alzheimer's Disease Initiative-Specialized Supportive Services Programs were funded. ACL published a special electronic supplement (Fall 2017) of the *Journal of the American Society on Aging*, which has 18 articles on supporting people with dementia and their caregivers (https://nadrc.acl.gov/node/110). ACL has formed partnerships with the Alaska Center for Human Development, Arizona Sonoran Center, University of Montana Rural Institute, and Arizona Developmental Disability Council. Throughout the programs being developed throughout the country, ACL is trying to infuse the human element, such as how to converse with the person cared for. To do this, they want to pull together all the voices.

Comments and Questions

- *Laura Gitlin*: These concerns reflect what we on the Advisory Council want to do, which will benefit by better integration of ideas. Therefore, each subcommittee chair will take a bigger role in shaping Council meetings and deciding what topics should be covered and what areas discussed. To move the process forward, we will convene meetings of the three non-federal chairs--e.g., each subcommittee chair has mentioned tracking as a concern. Now, Dr. Gitlin asks each non-federal member to consider what is happening in the non-federal world--i.e., research outside the NIH arena--that can be adapted to ADRD purposes.

- *Richard Hodes*: We need a more extensive presentation of Dr. Gitlin's thoughts and concerns and what exactly we are tracking. The International Alzheimer's Disease Research Portfolio (IADRP) began as a research association with NIA and then expanded to include all U.S. federal agencies, a number of nonprofits, and some international agencies related to Alzheimer's disease interventions.

- *Rohini Khillan*: Dissemination is another important issue.

- *Allan Levey* asked if a member could choose two subcommittees. Both *Ms. Khillan* and *Dr. Gitlin* said it is an issue of the time the member has to give, although membership in more than one subcommittee would be helpful for integrating ideas. *Ms. Kurtz* asked whether some subcommittees need more people. *Ms. Khillan*: Sometimes people naturally fit into one category or another because of what they do professionally, but there is much overlap. The three subcommittees have about the same number of openings for new members.

WELCOME TO NEW MEMBERS AND OATH OF OFFICE

Charles McEnerney, U.S. Department of Health and Human Services
Mr. McEnerney asked new members to stand, raise their right hand, and repeat the oath after him. He told them a member of his team would give them the appropriate document to sign.

DISCUSSION OF FUTURE MEETINGS

Laura Gitlin, Ph.D.
Council members need to decide how to organize the next set of meetings (January, April, and July 2018) and what their themes will be. We need a discussion of critical issues that can inform future recommendations, and we need an ongoing discussion of how to disseminate and bring attention to the recommendations. Dissemination is

complex, bridging medical and social systems of care. Dr. Gitlin asked members to give their initial thoughts on potential themes to cover.

Comments and Questions

- *Gary Epstein-Lubow*: Define core elements of care and services, metrics for how well they have done, and research across all areas within, e.g., IADRP. This is a "bandwidth" question. *Ms. Khillan*: NAPA is a budget-neutral program, and limitations around that may prevent some of these activities, but they could collaborate with other agencies. *Dr. Gitlin*: The reports from RTI, available on the ASPE website, will be helpful. Nonpharmacological approaches include programs, components, and principles. These could be addressed in post-summit activities, but all of it must be tied to the evidence. The question is how to integrate it with what we know works. One goal of the recent summit was to help us understand what we know. We will have post-summit activities to implement these things. *Ms. Khillan*: The summit is a great vehicle to push things forward.

- *Sowande Tichawonna*: All this should also be directed to people with intellectual disabilities.

- *Bruce Finke*: The Driver diagram is a logic model that postulates aim, a set of key drivers, secondary drivers, and key concepts. It takes where you want to go to procedures you need to get there. It addresses prioritization--not all the things we want to do, but what we think is really necessary. *Ms. Khillan*: The Council has been focusing on themes, but that has been a bit haphazard. Maybe we could start with that discussion for the next meeting.

- *Katie Brandt*: We need to define the ways in which persons with intellectual disabilities experience barriers to Alzheimer's disease services.

- *Cynthia Huling-Hummel*: We need to consider services for persons living alone without a caregiver.

- *Anthony Pacifico*: We need to develop a strategy for portfolio analysis like IADRP's.

- *Robert Egge*: Interaction among people is critical. How do we put into practice the positive results of research and move things of primary importance along?

- *Debra Cherry*: We need to know where and how ethnicity, different dementias, and different socioeconomic groups fit in.

- *Becky Kurtz*: A logic model makes a lot of sense. In addition, we need to consider the challenges of stigma. The stigma of age-ism is also part of this. How should experts be talking about aging? This relates to how they do outreach to

the general public. There is also a piece about elder justice. ***Ms. Khillan***: A lot of what we're talking about fits under the framing issue.

- ***Donna Walberg***: How does the framework work with tracking?

- ***Rohini Khillan***: Also important is impact, i.e., understanding how well the programs we come up with work.

- ***Laura Gitlin***: Actions before the next meeting include considering the Driver model and having themes that fit within it. Tracking and nomenclature could be the topics.

CARE SUMMIT OVERVIEW AND PRESENTATION OF RECOMMENDATIONS

Laura Gitlin, Ph.D.

The most recent summit was the first National Research Summit on Care, Services, and Supports for Individuals Living with Dementia and their Caregivers. Whereas NIH sponsored previous summits, the Advisory Council sponsored this summit. Steering Committee members represented various federal agencies, the Advisory Council, and others including persons living with dementia; and six stakeholder groups participated. Research recommendations were relevant to NIH as well as other federal agencies, foundations, and industry. Because research on care, services, and support is complex and multi-faceted, multiple agencies must be involved.

More than 1,000 people registered for the summit, 500 for in-person attendance and 787 for Webcast Day 1 and 591 for Webcast Day 2. The plenary sessions covered demographic profiles, diversity, and implications for care and services; the interdependence of biomedical and care and services research; and nomenclature. The six sessions were Research on Care Needs and Supportive Approaches for Persons with Dementia, Research on Supportive Approaches for Family and Other Caregivers, Involving Persons with Dementia and Caregivers as Members of the Research Team, Involving Persons with Dementia as Study Participants, Research on Models of Care for Persons Living with Dementia and Their Families across the Disease Trajectory, and Thinking Outside the Box.

Recommendations were submitted from eight pre-summit conferences and other activities; stakeholder groups; plenary summit speakers; session chairs, speakers, and panelists; cross-cutting chairs; and the audience, via in-person and online submission. The recommendations generated are available on the ASPE website (https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-recommendations). This Advisory Council has a key role in disseminating recommendations and then monitoring and coordinating efforts to move them forward. Now the Advisory Council must discuss how to proceed.

Comments and Questions

- ***Richard Hodes*** noted that care and services have been a theme from the beginning. Although not new, this is an important expansion.

- ***Lisa McGuire***:   All 464 recommendations are important, valuable, and powerful and touch particular populations, but it will be a challenge to make them actionable. Moreover, CDC wants their recommendations to be consistent with these. ***Dr. Gitlin***: Consistency is needed and evident in the recommendations.

Dr. Gitlin and Katie Maslow are in the process of categorizing the recommendations into 11 "buckets." What has clearly emerged is that we need to do research differently. Other considerations include getting the right amount of detail.

Katie Maslow, Gerontological Society of America
The research subcategories (not prioritized) are as follows (for more detail, see the website):

1. Research methodology
2. Heterogeneity
3. The lived experience and psychosocial processes of persons living with dementia
4. Caregivers, relationships, networks, and roles
5. Comprehensive models of dementia care and clinical approaches that are person- and family-centered, combine social-medical models, and span disease continuum and etiologies
6. Strategies for scaling and disseminating existing evidence, drawing upon implementation science
7. Financial burdens across disease trajectory including loss of income, health insurance, and costs of care and services
8. Living arrangements, housing, care settings, and environmental design
9. Technology Nomenclature
10. Workforce

The big gaps in knowledge include how to involve people living with dementia as members of the research team; the lived experience of dementia including psychosocial processes, adaptive mechanisms, and stigma and impact by gender, race, and disease stage; financial burdens across the disease trajectory for individuals and caregivers; disparities and impact on access to and delivery of care and services; and perceived and structural stigma throughout the disease trajectory.

Ways to begin include developing a set of core outcomes to use consistently in research in care and services; linking evidence-based interventions, strategies, and approaches to disease stage and etiology; and using the core outcomes to guide what can be used now and what is ready for scaling up; however, we need consensus as to what interventions and programs are ready for scaling up. The Stage Model is useful when still building evidence for a program.

Next steps:

- Eliminate redundancies within categories.
- For each category, finalize and list specific research recommendations.
- Identify the process to generate milestones.
- By the end of January, generate a final report of categories, recommendations, and milestones.
- Generate a process for accountability and tracking of progress.

Comments and Questions

- ***Bruce Finke***: We need to think of technology as assisting in a solution rather than as a research question in and of itself. This is the spillover of research into implementation. It is the identification point at which research is ready to be implemented. ***Ms. Maslow***: This is a complicated system that involves long-term care and acute care. How are we receiving the caregiver? We need a model for evaluating at various stages and figuring out where we are. ***Dr. Gitlin***: We are seeing an important emerging science--implementation research.

- ***Allan Levey***: Biomedical research is happening in parallel with social and clinical research and the two will have to be integrated. The question is how this will be done. ***Ms. Khillan*** agreed that we need to figure out where that synergy is and how to make them work together.

- ***Robert Egge***: Biomarker data will involve measurement people. ***Dr. Gitlin***: What emerged throughout recommendations generated at the summit was the need to do research differently and interventions must be integrated with that.

- ***Cynthia Huling-Hummel***: It is so important to have people with dementia at the table.

- ***Debra Cherry***: First we want to develop research questions. The second challenge is dissemination. How can we develop best practices for the community? ***Ms. Maslow***: The all-in approach can also serve as a vehicle for getting messages out. The big next step is getting the message out to the people who will use it. Industry groups might be interested in funding some recommendations. ***Dr. Gitlin***: How we put it together will be critical. ***Dr. Epstein-Lubow***: We should tie the Driver model to the recommendations.

- ***Laura Gitlin***: We were trying to do the summit differently with the all-in approach. We have to work differently in the space and must look much more at interdisciplinary connections. There have been 30 years of excellent caregiver interventions and we are ready to move forward. We need to put out a request for applications announcement. We have to characterize the population we are targeting, including the caregivers. We have specific research recommendations,

but they are broad and may be appropriated for various areas. Different infrastructures are needed for different areas. Some are ready for research, but require a network to effect, which requires rethinking how to do this. We need a strategy for rapid deployment. We need to know how to do intervention research in the future to deal with systematology, co-morbidity, etc. It is not one system, one intervention, one trial with a follow-up trial of several years each.

- The issue is complex, but there is not much controversy. There are similarities in the recommendations, but also important differences. There are relevancies to all the stakeholders. The Peer-Based Coordination Model is important. We have strategies for addressing some, but not all, symptoms. A lot more work is needed, but we have a place to begin. Furthermore, some of that evidence is stronger than pharmacologic evidence.

- **Richard Hodes**: An important consideration is that studies are ready for translation in a complicated situation with a new population.

- **Cynthia Huling-Hummel**: The importance of translating consistently emerges. We should consider the broadest audience when we consider translation.

- **Bruce Finke**: What looks like the right evidence depends on your perspective, e.g., that of the private payer. Can the user determine the effectiveness of the intervention? **Ms. Maslow**: The real task is to understand how the top payers are considering this. What is it we need to show? Are we producing the outcomes they are interested in? **Dr. Gitlin**: In thinking about the evidence, we need to alter our approach. This is part of the consideration for intervention research. It is also important to understand who did not benefit.

- **Bradley Hyman**: We should add the dimension robustness. Can the treatment be exported to a broad population?

- **Richard Hodes**: Another dimension is the multiple roles we all serve. At any given state of knowledge, things will happen, and they will not be put on hold until we are certain of all the elements. We need to know the quality of evidence for any intervention that was successful. Foremost, we should not make recommendations on the basis of incomplete knowledge.

- **Rohini Khillan**: An added variable is that among the innovative care providers, none were doing the same things.

- **Anthony Pacifico**: If we treat nonpharmacological interventions like pharmacological interventions, it breaks down to risk and resiliency factors. **Dr. Gitlin**: All these issues deserve focus and can be post-summit discussions.

- **Angela Taylor**: Are we not getting the right evidence because we are not asking the right person the right question? .**Dr. Gitlin**: This complex problem is caused

by more than one thing. We are seeing the limitations of not looking at why something works, of not knowing who benefits and who does not, etc.

- *Laura Gitlin*: In an effort to eliminate redundancy, we want a summary of evidence from each session. We need to brainstorm a process, which we will bring to the Council in January for discussion. Considerations will include accountability, dissemination, publication, research recommendations, and stakeholder reports.

ETHICS TRAINING FOR NON-FEDERAL FACA MEMBERS

This was a closed session for new members.

PUBLIC INPUT

Ashley Helsing, National Down Syndrome Society [for David Egan]
The National Down Syndrome Society announces the release in the first week in November of its booklet "Down Syndrome and Alzheimer's Disease," a practical guide for family and caregivers of persons with Down syndrome. It explains the connection between Down syndrome and Alzheimer's disease and how to adapt and thrive when these diagnoses have been made.

Mary Hogan, National Task Group on Intellectual Disabilities and Dementia Practices
Ms. Hogan has come to this meeting since 2011 because of her brother who had Down syndrome, and died of Alzheimer's disease. She wants to facilitate increased attention to people with Down syndrome. There are issues around diagnoses such that a differential diagnosis is difficult to obtain. Most people with intellectual disabilities live with their families who need support services as the person with Down syndrome and the family members age. Ms. Hogan represents a volunteer program that addresses these issues. To illustrate, she told about the experience of a couple and their son, who died of complications of Down syndrome when he was in his 40s.

Matt Janicki, National Task Group on Intellectual Disabilities and Dementia Practices
Mr. Janicki is co-chair of the volunteer National Task Force on Intellectual Disabilities and Dementia. The organization looks at the broader dimension, not just rehabilitation pathology. Their educational workforce developed a national curriculum on dementia, which is now being used in training workshops. They have provided some 30 training workshops in 17 states. An international summit held in 2016 generated several papers that are at various stages of publication. Mr. Jenson hopes these papers will contribute to broader understanding of this field.

Ian Kremer, Leaders Engaged on Alzheimer's Disease

This Advisory Council was responsible for convening the summit on caregiving. Decades of lived experience informs all this research--person by person, moment by moment. But, we have to make sure that what comes of the National Plan and this summit is informed by quality of life, not by productivity, i.e., outcomes should be framed in terms of quality of life. We need a research summit to inform how to change quality of life. Researchers could choose to measure factors such as role model example (reducing antipsychotics), depression (caregivers and persons living with dementia), impoverishment, isolation, falls, wandering, abuse (in its many forms), unnecessary hospitalizations, or rates of diagnosis (diagnosis should be accurate, timely, specific, compassionate, and actionable, e.g., referrals to clinical trials).

Jadene Ransdell

Ms. Ransdell has a 43-year-old son with Down syndrome, autism, and now Alzheimer's disease. The National Task Group (co-chaired by Mary Hogan) has helped her immensely. The task group started a bi-monthly newsletter for people affected by Down syndrome and Alzheimer's disease. Far too few doctors and service providers are aware of the connection between Down syndrome and Alzheimer's dementia. There are some unique differences as well. We need readily available information on this. In April the National Alliance for Caregiving will host a summit on Down syndrome and Alzheimer's disease. Meanwhile, we need to continue to advocate for people with Down syndrome, recognizing the changes that occur, and we need to continue the dialogue with volunteers.

Matt Sharp, Association for Frontotemporal Degeneration

We should keep heterogeneity at the forefront of the life span of care and services and not revert to the once-size-fits-all paradigm.

DEVELOPING, SUSTAINING, AND TAKING INNOVATIONS TO SCALE

Marie Schall, Institute for Healthcare Improvement

The Institute for Healthcare Improvement is a nonprofit, international organization, headquartered in Boston, whose mission is to improve health and health care worldwide. They work in areas of patient safety, healthy populations, and health care provision that provides best value. They focus on how to get results at scale, i.e., improvement science. You have to have an aim, know whether you are making progress, have ideas about how you would make that progress, and use plan-do-study-act cycles. The health care improvement objectives are to apply key concepts and strategies for taking innovations to full scale; to consider a sequence of activities to plan and guide scale-up initiatives; and to learn about, and apply lessons to, the context gleaned from specific case examples.

Key concepts start with sowing seeds, but in order to be successful, this needs to be done in a planned way. As Don Berwick said, "Some is not a number, soon is not a time…." We are really talking about creating a new system to improve and design for

scale while holding gains, and then getting results at scale. To do this, we need to think about scale from the beginning, not as an outcome of a linear process. We begin by anticipating the needs of the bigger system and develop a model accordingly. The Scale-Up Framework begins with existing best practices and new scale-up ideas, which then go into set-up and progress, to building a scalable unit, testing scale-up, and going to full scale, all phases feeding back and forth into each other. For success, we need alignment among leaders and people in the community while we slowly expand testing to larger and larger groups. We must get people to the point where they think something is a good idea and then take the leap to do it.

Adoption mechanisms involve leadership, communication, social networks, a culture of urgency, and persistence. The change must be relatively advantageous, simple, trial-able, compatible, and observable, all of which is related to how you package and market the change. These mechanisms enable people to want to change and to do it. Throughout, we need to make sure that the systems in which these people work will support them to make the desired change.

5X scale-up reduces cost and improves care for socially complex situations. The issues increase and change with the increase in the number of people: For five people, system issues address forming a team of volunteers and finding people through referrals. For 25 people, issues become the full-time team, redesigning the practice, cooperation of hospitals for data, and assessing outcomes. For 125 people, issues will include grant funding for operations, and consistent population outcomes.

Methods for getting to full scale include the following:

- Breakthrough series collaboratives. This is a way to bring people together and spread ideas among multiple sites. It addresses the challenge of how you sustain connections among people.
- Campaigns, e.g., the100,000 Lives Campaign. This requires immediacy, a compelling aim, straightforward steps, alignment with other national initiatives, and connections with the public.
- Learning networks, e.g., 100 Million Healthier Lives by 2020. They require a compelling aim, a specific time frame and numerical goals, distributed leadership, and a structure that supports dynamic and organic growth. It builds relationships.

Other methods are as follows:

- Executive mandate/policy
- Extension agents
- Hybrid approaches

Comments and Questions

- *Marie Schall* replied to *Ms. Huling-Hummel* that not only does the Institute for Healthcare Improvement include those with lived experience, but they are putting them in leadership roles.

- *Robert Egge*: Council members need advice about the role this Advisory Council can play. *Ms. Schall* is helping to set the agenda. The Council has an incredibly strong role in terms of policy. First, we need to determine what policies hinder or could help, e.g., there are big issues around infrastructure.

- *Debra Olster*: How much is predicated on similar situations in all these places, but seem to be real differences? *Ms. Schall*: When we find the commonalities or maybe how different members deal with the same situation, we can use similar systems to deal with them.

- *Anthony Pacifico*: How would the framework differ between a descriptive study and a clinical study? *Ms. Schall*: This applies mainly to interventional studies. We want to change the way people interact with the system. The framework is meant to enhance interventional studies.

- *Laura Gitlin*: What about evidence? *Ms. Schall*: As you move up the scale, you want to increase your level of confidence. Care system changes are often done in controlled settings, and translating a process for a controlled setting to a less restrictive setting is a challenge.

2017 NATIONAL PLAN DISCUSSION

Rohini Khillan
This year's National Plan was released September 1, 2017. Implementation milestones have been updated. Officially the National Plan is updated with items from members of the Advisory Council and other national groups over the year. This year, five states provided new items and ongoing work. At this stage, an issue for the Council is how we open to more organizations to make the plan truly national.

Comments and Questions

- *Ellen Blackwell*: The separation of non-federal from federal is hard to follow. It relates to format. *Mr. Egge*: Who does what? How will we know when we have done it? What is it? We need specificity. The Alzheimer's Association could be responsible for what? *Ms. Khillan*: We will receive large quantities of information, which must all be sorted. At the state level, lots of work is ongoing, and, we are missing a lot of that. *Ms. Brandt*: Non-federal nonprofits are also doing national work, and setting clear boundaries could make it more fair.

- *Laura Gitlin*: We should establish criteria.

- *Bruce Finke*: What are the changes we are asking for? We should align them with the strategic plan, rather than thinking about planning and developing within NAPA. Meanwhile, the National Plan is detailed, but inaccessible.

- *Katie Brandt*: Have organizations been asked for endorsements rather than additions? *Ms. Khillan*: We are limited in asking for endorsements because this is a federal document.

- *Bradley Hyman*: What questions do you want them to answer? *Ms. Khillan*: We have no good "elevator pitch" right now.

- *Donna Walberg*: First we should figure out what to do and then how to do it. *Dr. Gitlin*: We need to know who is doing what to advance what, and we need to link those things.

- *Angela Taylor*: It might be helpful to prioritize and put the previous year's recommendations in the appendix. *Ms. Khillan*: Because this is a federal document, we cannot be aspirational. We must report what has actually happened.

- *Debra Cherry*: We need a communications expert.

- *Becky Kurtz*: We could use the Drivers model and maybe have an online appendix or compendium geared to a particular state that supports the goals. This would appeal to members of Congress.

- *Ellen Blackwell* is a member of another group that updates its strategy every year. She suggested separating the strategy from the body of the report.

- *Rohini Khillan*: How do we open the plan to more organizations? *Dr. Levey*: Could we disseminate information at a town hall meeting? *Dr. Cherry*: An executive summary at the front could suffice if it included links to information in the plan. We could highlight information on a particular state for members of Congress.

- *Rohini Khillan*: How do we better disseminate the National Plan, a document of some 100 pages? *Dr. Gitlin*: We should think about all this and revisit it at the January meeting.

FEDERAL WORKGROUP UPDATES

Erin Long, Administration for Community Living
ACL includes the Administration on Aging, which has a state and a community grant-giving program. In August, six new grants, totaling $3.8 million, were awarded, and last month 11 new grants were awarded for research on evidence-based interventions for Alzheimer's disease. Additionally, ACL is getting good response to its electronic book, which is online and free.

William Spector, Ph.D., Agency for Healthcare Research and Quality
AHRQ has no particular focus on Alzheimer's disease. An NIH-funded initiative on dementia has begun, but is not yet ready for an education campaign on key interventions. However, they could research physical activity or nutrition, but first they need to understand what the question is we're trying to ask. We must be careful about separating what we learn from what points in any particular direction.

Bruce Finke, M.D., Indian Health Service
REACH into Indian Country is an award-winning, evidence-based program that supports caregivers of patients with Alzheimer's disease or dementia. To advance the workforce, they have been using HRSA-funded Geriatrics Workforce Enhancement Programs. Furthermore, IHS has begun work on use of the Extension for Community Healthcare Outcomes model for workforce and caregiver support. This model links expert specialist teams at an academic center with primary care clinicians in local communities who participate in weekly teleconferencing clinics, supported by basic, widely available teleconferencing technology.

Marianne Shaughnessy, Ph.D., CRNP, Department of Veterans Affairs
The VA has two major training and caregiving programs that include dementia caregiving: the Caregiver Support Program offers training, educational resources, and multiple tools; the Caregiver Support Line offers advice on being a caregiver.

Ellen Blackwell, Centers for Medicare & Medicaid Services [for Shari Ling, M.D.]
Dementia must be considered in the context of other chronic conditions and is included in numerous CMS programs. For example, Medicare programs include Chronic Care Management, Cognitive Impairment Assessment, Advance Care Planning, Home Health, Hospital, Short-Term Nursing Home Care, and Telehealth. Medicaid programs include Home and County-Based Services, Health Homes, Home Health, Rehabilitative Services, and Telehealth. The National Partnership to Improve Dementia in Nursing Homes is one example of success. Meanwhile, State Dementia Care Coalitions have identified best practice strategies, such as direct facility outreach, workshops and conferences, training opportunities, and use of the Civil Money Penalty fund. The Initiative to Reduce Avoidable Hospitalizations among Nursing Facility Residents resulted in significant improvement at all seven sites. Other initiatives include Integrated Care Resource Center, Health Care Innovation Awards; Healthcare Innovation Awards, 2nd annual report; CMS Behavioral Health Payment and Care Delivery Innovation

Summit; and a CMS Innovation Center (CMMI) Request for Information. Meanwhile, HRSA is sponsoring dementia-specific training.

Joan Weiss, Ph.D., Health Resources and Services Administration
When HRSA offered training for caregivers who deal with Alzheimer's disease and dementia, 9,500 health care providers took the training. In addition, HRSA offers 402 continuing education programs. One of their innovations is to integrate geriatrics into primary care. In another, NAPA charged HRSA with developing a curriculum for dementia training for health care professionals, and that 16-module curriculum has now gone live; 12 of the modules address specific topics. In these modules, caregivers learn how to interact with persons living with dementia; the Office on Women's Health asked for the caregiver modules. HRSA will now work with CMS to present the modules on YouTube. CMS wants training modules for workers to take to their desks and complete in 15 minutes. HRSA is now working to convert these modules to 15-minute sessions.

Richard Hodes, M.D., National Institute on Aging
NIA launched the IADRP database in collaboration with the Alzheimer's Association in 2010, before NAPA was enacted. The Alzheimer's disease research ontology was coded and linked to abstracts. With this database, Alzheimer's disease and ADRD research implementation milestones can be tied to priorities and activities.

Bypass Budget. In 2015, legislation was enacted that required NIH to submit, directly to Congress, a report indicating the resources needed to proceed at the optimal pace. It is an important vehicle to translate milestone priorities into what it would take to accomplish them.

Comments and Questions

- ***Laura Gitlin*** clarified that the Bypass Budget refers only to NIH.

CONCLUDING REMARKS

Dr. Gitlin adjourned the Council meeting at 5:00 PM.

The next meeting will be held January 26, 2018.

Minutes submitted by Rohini Khillan (ASPE).
All presentation handouts are available at http://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings.

PARTICIPANTS

ADVISORY COUNCIL MEMBERS

Present

Ellen Blackwell, Centers for Medicare and Medicaid Services

Katie Brandt, Massachusetts General Hospital

Debra Cherry, Ph.D., Alzheimer's Greater Los Angeles

Susan Cooley, Department of Veterans Affairs [via telephone]

Gary Epstein-Lubow, M.D., Brown University

Robert Egge, Alzheimer's Association

Bruce Finke, M.D., Indian Health Service

Laura Gitlin, Ph.D., Johns Hopkins University, Chair

Richard Hodes, M.D., National Institute on Aging

Cynthia Huling-Hummel, a person living with Alzheimer's disease, Elmira, NY

Bradley Hyman, M.D., Alzheimer's Disease Research Center

Rohini Khillan, Office of the Assistant Secretary for Planning and Evaluation, HHS

Becky Kurtz, Atlanta Regional Commission, Area Agency on Aging

Allan Levey, M.D., Emory University

Shari Ling, M.D., Centers for Medicare and Medicaid Services [via telephone]

Erin Long, Administration for Community Living/Administration on Aging

Lisa McGuire, Ph.D., Centers for Disease Control and Prevention

Debra Olster, Ph.D., National Science Foundation

Anthony Pacifico, Ph.D., Department of Defense

Marianne Shaughnessy, Department of Veterans Affairs

William Spector, Ph.D., Agency for Healthcare Research and Quality

Angela Taylor, Lewy Body Dementia Association

Kara Townsend, Office of the Assistant Secretary for Planning and Evaluation, HHS

Sowande Tichawonna, caregiver, Washington, DC

Donna Walberg, Minnesota Board on Aging

Joan Weiss, Ph.D., Health Resources and Services Administration

Absent

Billy Dunn, Food and Drug Administration

Richard Allman, Veterans Affairs

October 27, 2017 -- Advisory Council Meeting #26

The meeting was held on Friday, October 27, 2017, in Washington, DC. The Advisory Council welcomed its new members and invited them to share their experiences and where they see the Council going over the length of their terms. The Advisory Council also spent some time discussing the process of developing recommendations and how those recommendations relate to the National Plan. The Council then spent much of the meeting discussing the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers, held on October 16-17. Material available from this meeting is listed below and is also available at https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Oct2017.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Handouts

National Plan to Address Alzheimer's Disease: 2017 Update	[HTML Version] [PDF Version]
Public Members of the Advisory Council on Alzheimer's Research, Care and Services: 2017 Recommendations	[HTML Version] [PDF Version]

Presentation Slides

2017 National Plan	[HTML Version] [PDF Version]
Before NAPA: IADRP	[HTML Version] [PDF Version]
Clinical Care Subcommittee Update	[HTML Version] [PDF Version]
Clinical Subcommittee Update	[HTML Version] [PDF Version]
Developing, Sustaining and Taking Innovations to Scale	[HTML Version] [PDF Version]
Discussion of Future Meetings	[HTML Version] [PDF Version]

Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Overview of the NAPA Legislation and the Charge to the Council	[HTML Version] [PDF Version]
Overview of the National Plan and the Process for Recommendations	[HTML Version] [PDF Version]
Research Progress for Alzheimer's Disease and Related Dementias	[HTML Version] [PDF Version]
Research Summit on Dementia Care Overview and Recommendations	[HTML Version] [PDF Version]

Videos

Welcome through Overviews	[Video]
Subcommittees and Fed Workgroups and Future Meeting Discussion	[Video]
Care Summit Overview and Presentation of Recommendations	[Video]
Discussion through lunch	[Video]
Public Comments	[Video]
Marie Schall Presentation and 2017 National Plan Discussion	[Video]
Federal Workgroup Updates through adjourn	[Video]

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