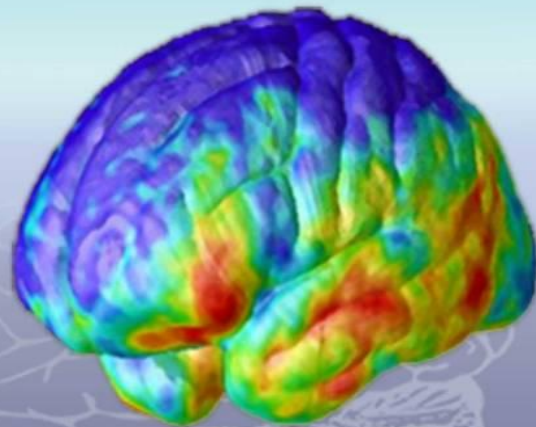


Alzheimer's Disease Research

- 1) Alzheimer's Research Summit May 14-15, 2012
- 2) Common Alzheimer's Disease Research Ontology (CADRO) and data base of supported research
- 3) FY2012 initiatives funded by President's \$50M allocation from within NIH budget
- 4) FY2013 planning for initiatives supported by President's designated \$80M additional NIH funding
- 5) Public-private-international partnerships

Alzheimer's Disease Research Summit 2012: Path to Treatment and Prevention

May 14-15, 2012
National Institutes of Health
U.S. Department of Health & Human Services
Bethesda, MD



NIH Alzheimer's Disease Research Summit 2012

- Approximately 500 attended both days
- Almost 500 watched nationally and internationally by webcast
- Representatives from 38 states and 8 countries attended
- HHS Secretary Kathleen Sebelius presented the National Plan and NIH Director, Dr. Francis Collins announced two AD Clinical Trials
- Summit webcast is archived at:
<http://videocast.nih.gov>

Alzheimer's Disease Research Summit Recommendations

- **Session 1:** Interdisciplinary Approach to Discovering and Validating the Next Generation of Therapeutic Targets for AD
- **Session 2:** Challenges in Preclinical Therapy Development
- **Session 3:** Whom to Treat, When to Treat, and What Outcomes to Measure
- **Session 4:** Drug Repurposing and Combination Therapy
- **Session 5:** Nonpharmacological Interventions
- **Session 6:** New Models of Public Private Partnerships
- <http://www.nia.nih.gov/newsroom/announcements/2012/05/alzheimers-disease-research-summit-offers-research-recommendations>

Common Alzheimer's Disease Research Ontology (CADRO)

- The CADRO is a *three-tiered classification system* jointly created by National Institute on Aging and the Alzheimer's Association to capture the complete range of AD research and AD research-related resources.
- The first level of classification consists of seven categories: five research and two research resources-related:
 - Category A – Molecular Pathogenesis and Physiology of Alzheimer's Disease
 - Category B – Diagnosis, Assessment and Disease Monitoring
 - Category C – Translational Research and Clinical Interventions
 - Category D – Epidemiology
 - Category E – Care, Support and Health Economics of Alzheimer's Disease
 - Category F – Resources for the research community
 - Category G – Consortia and Public Private Partnerships
- Each category is divided into research "topics"; many of the topics are further divided into "themes".
- Over 2000 unique AD research projects were coded using the CADRO (for 2008 to 2011) across multiple funding organizations including the National Institutes of Health, Department of Veterans Affairs, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality and the Alzheimer's Association.

Alzheimer's Disease Research Portfolio Analysis

- **Purpose** – Use the CADRO to quantify and analyze the collective investment in AD research funding over time across multiple funding organizations (beginning 2008)
- **Examples of how of portfolio can be analyzed:**
 - **Baseline to measure future performance and progress including implementation of initiatives in response to NAPA and AD Summit recommendations**
 - Targeted trend analyses of awarded research by CADRO categories, topics and themes
 - Areas of overlap, duplication, and potential opportunities for collaboration among funding organizations
 - Emerging areas of science and opportunities for translation
 - Potential research gaps and areas that may be underfunded
- **Next Steps:** make projects available to the public through a web-based searchable database – End of July 2012.

Alzheimer's Disease Projects Funded by FY 2012 NIH Additional \$50 million

On February 7, 2012, Secretary of Health and Human Services Kathleen Sebelius announced that \$50 million would be directed immediately to boost Alzheimer's research in FY2012 in response to President Obama signing the National Alzheimer's Project Act.

The following research projects will be funded:

- AD genome sequencing by NHGRI Genome Centers
- Use of new induced pluripotent stem cell methods to obtain insights into the cellular processes of Alzheimer's
- Small Business Alzheimer's Disease Research (STTR)R41/R42 -Phase I, Phase II, and Fast-Track /Small Business Innovation Research (SBIR) R43/R44 Grant - Phase I, Phase II, and Fast-Track
- Two AD Clinical Trials - one treatment and one prevention

Pilot Trial of Intranasal Insulin for Alzheimer's and MCI

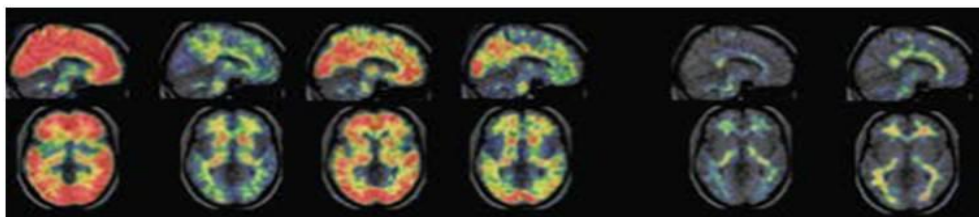
- **Pilot:** 104 adults with MCI and mild to moderate Alzheimer's; placebo, 20 IU insulin, 40 IU insulin for 4 months, administered with nasal drug delivery device
- **Results:**
 - improved delayed memory in 20 IU group compared with placebo
 - preserved general cognition, activities of daily living for younger participants in both insulin groups
 - caregivers for both insulin groups rated participant functional status higher
 - changes in some biomarkers (A β 42 and tau to A β 42 ratio) associated with changes in memory and function

Suzanne Craft et al, Arch Neurol 2012 January; 69(1): 29-38

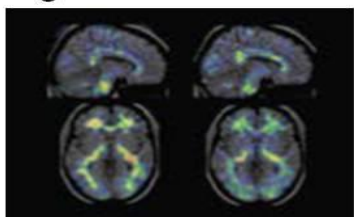
Amyloid PET Scans in *Presymptomatic* Early-Onset Alzheimer's Disease

Gene Carriers

Non-Carriers



Age 35-39 Years



Age 25-29 Years

Colombian Kindred

- N = 5000 living individuals from ~ 25 families
- 1000 with the *E280A (Glu280Ala) Presenilin1* mutation
- Autosomal dominant, 100% penetrance
- Median age of MCI = 44 years, dementia = 49 years

Reiman, Fleisher and colleagues

Alzheimer's Disease Research Planning for FY 2013 NIH Additional \$80 million

May 2012 – Alzheimer's Research Summit

June 2012 – NIH Planning process to identify FY13 initiatives

August 2012 – Preparation of Funding Opportunity Announcements (FOAs)

September 2012 – Review of proposed initiatives by

National Advisory Council on Aging

October 2012 – Announcement of FOAs and schedule for applications, review,
and funding in FY13, contingent on availability of funds

Public-Private-International Partnerships

Examples:

- 1) **Meeting of international Alzheimer's research funders:
Alzheimer's Association/National Institute on Aging
July 15, 2012, Vancouver**
- 2) **Alzheimer's disease genetics - July 14, 2012, Vancouver**
- 3) **Biomarkers
World-wide ADNI – July 13, 2012, Vancouver
International CSF biomarkers cooperation**
- 4) **Recruitment of clinical research participants
Alzheimer's Association/National Institute on Aging
July 10, 2012**
- 5) **Common Alzheimer's Disease Research Ontology (CADRO)**

CMS Activities for the National Alzheimer's Plan



CLINICAL SERVICES PROGRESS REPORT

SHARI M. LING M.D.
DEPUTY CHIEF MEDICAL OFFICER
CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)
CENTER FOR CLINICAL STANDARDS & QUALITY (CCSQ)

For completion by June 2012

2.B.2: Identify and disseminate appropriate assessment tools that can be used in a variety of outpatient settings including the Medicare Annual Wellness Visit, to assess cognition.

For completion by June 2012

2.F.2: Implement and evaluate new care models to support effective care transitions for people with AD

- \$3.2 million for UCLA's Alzheimer's and Dementia Care program, which provides comprehensive care, as well as resources and support, to patients and their caregivers to help families navigate a complex health care system.
- The program has three main components: a dementia registry, a needs-assessment of patients listed in the registry, and individualized dementia-care plans based on those assessments.

For completion by June 2012 con't

- These care plans could include family and peer support groups, consultations with neurology, psychiatry and geriatrics staff, in-home visits which include changes to the physical home environment to better serve patient's every day needs, and intensive dementia-care monitoring and care coordination by advanced practice nurses and other health professionals.
- The Alzheimer's Association describes this model, "as a paradigm example of how to promote collaboration between health care systems and community-based organizations to best manage this incurable disorder."

For completion by July 2012

2.A.4: Strengthen the direct-care workforce – release training materials for nursing home direct care workforce

- Training is available for providers, clinicians, and surveyors on Advancing Excellence website and several association, university websites
- *Hand in Hand*: (distributed to all nursing homes end of August)
 - × emphasizes person-centered care, prevention of abuse, and non-pharmacological interventions
- Comprehensive surveyor trainings in production and available by September

2.D.1: Explore programmatically relevant dementia care guidelines and measures

- TEP held to review evidence to support the development of QMs to improve the behavioral health of NH residents
- In September, the measure development contractor will convene a Technical Expert Panel (TEP) to solicit input regarding the two AP QMs as the measures move toward NQF endorsement.

For completion by July, 2012 con't



- Dementia care quality measures
 - Physician Quality Reporting Program implemented in 2012 and is reportable via registry
 - Meaningful Use -staging, cognitive, functional status assessment, counseling regarding safety, counseling regarding risks of driving and caregiver education and support.

For completion by December 2012



- 3.D.2: Monitor, report and reduce inappropriate use of anti-psychotics in nursing homes
- CMS Partnership to Improve Dementia Care

CMS Partnership to Improve Dementia Care

A MISSION TO IMPROVE BEHAVIORAL HEALTH AMONG NURSING HOME RESIDENTS WITH DEMENTIA AND TO PROTECT THEM FROM UNNECESSARY DRUG USE

Partnership Overview

Multidimensional approach includes:

- **Public Reporting**
 - × First year goal: reduce prevalence rate of antipsychotic drug use in long-stay nursing home residents by 15% by end of 2012
 - Rates of nursing homes' antipsychotic drug use available on Nursing Home Compare July 19th (long-stay prevalence; short-stay incidence)
 - ❖ clear information about nursing home performance to consumers
 - ❖ accessibility to residents and families
- **Partnerships and State-based Coalitions**
 - State Implementation Calls; 28 Calls Completed as of 7/17
 - ❖ Engage the ongoing commitment and partnership of stakeholders including state survey agency and Medicaid agencies, provider groups, resident advocates, professional associations, QIOs, LANES, consumer groups, ombudsman and others
 - ❖ Create or support existing individual state coalitions that will identify and spread best practices to individual facilities
 - ❖ Follow-up with Coalition leads to determine the progress of states' facilities



- **Research**

- Conduct research to better understand how the team makes decisions to use antipsychotic drugs in residents with dementia
 - Study factors that influence prescribing practices
 - Case studies of about 175 residents in 20-25 nursing homes in 5 States
- Implement treatments to improve overall management of residents with dementia based on results of study

- **Training**

- Available for providers, clinicians, and surveyors on Advancing Excellence website and several association, university websites
- *Hand in Hand*: series that provides direct care workers with training that emphasizes person-centered care, prevention of abuse, and non-pharmacological interventions (distributed to all nursing homes end of August)
- Two hour-long, comprehensive surveyor trainings in production and available by September
 - Will be mandatory



- **Stakeholders Involvement**

- AMDA letter distributed in June
- AHCA letter sent out in March and July
- SHM letter – going out this fall
- Ongoing work with AAGP, AMA, Advocates and others

- **Accomplishments April-July 2012**

- Newsletter articles, dissemination of partnership goals by various organizations
- CMS Presentations/Outreach



The Health Resources and Services Administration's Activities in The National Plan to Address Alzheimer's Disease

Joan Weiss, PhD, RN, CRNP
Chief, Geriatrics and Allied Health Branch
Bureau of Health Professions
Department of Health and Human Services
Health Resources and Services Administration



Geriatric Education Centers (GEC) Program Activities

Purpose:

- Provide training to healthcare providers' on Alzheimer's disease (AD) and related dementias

Goal:

- Improve detection and early intervention of AD and ultimately improve care for patients and their families



GEC Program Activities

- Revise and update existing evidence based practice curricula related to AD and related dementias and use the curricula to train interprofessional teams of health care practitioners. One of the discipline team members must be medicine
- Provide trainings free-of-charge as continuing education to providers



GEC Program Activities

- Partner with the Quality Improvement Organizations (QIOs), professional organizations and accreditation bodies to distribute these trainings more broadly
- Provide the trainings for distribution on a centralized website (site to be determined by HRSA) and
- Report on the number of trainings provided, number of disciplines, number of participants, and practice improvement of participants.



GEC Program Activities

- Provide training on the latest clinical guidelines and on how to work with patients with the disease and their families
- Learn how to assess patients for AD
- Recognize the signs and symptoms of AD
- Manage the disease in the context of other health conditions



GEC Program Activities

- Refer patients to appropriate clinical trials
- Be knowledgeable of long-term services and supports in the community
- Recognize and treat signs of caregiver burden and depression
- Train participants on the tools available to detect cognitive impairment and appropriate assessment processes for the diagnosis of AD



GEC Program Activities

- Address the unique needs of medically underserved and special populations including racial and ethnic minorities and individuals with intellectual disabilities.
- Provide information on the Health Information Portability and Accountability Act (HIPAA)
- Translate educational materials to other languages to meet the needs of their communities



West Virginia Geriatric Education Center

- Develop and provide interprofessional health professionals education and training on AD targeted at primary care, outpatient care, and long-term care
- Develop and provide interprofessional health professionals education and training on AD targeted at subspecialty and in-patient hospital based care



Geriatric Education Center of Greater Philadelphia

- Interprofessional training in the care of elders at the end of life
- Development of a maintenance of certification module for physicians caring for patients with dementia and their families
- Partnership with Quality Improvement Organization and the University of the Sciences in Philadelphia on issues of restraint reduction and pressure ulcer prevention in long-term care facilities



New Jersey Geriatric Education Center

- Build on existing partnerships with the Central Plains GEC and the Gateway GEC
- Train teams to work in long term care facilities including those engaged in Care Transitions projects with the Quality Improvement Organization
- Build dementia-capable staff in the aging services network by tailoring curricula for Aging and Disability Resource Centers staff



Contact Information

Joan Weiss, PhD, RN, CRNP
Chief, Geriatrics and Allied Health Branch
Bureau of Health Professions
Phone Number: 301-443-0403
E-mail Address: jweiss@hrsa.gov

HHS Alzheimer's Disease Awareness Campaign Update

Advisory Council on Alzheimer's Research,
Care, and Services

July 23, 2012

Hunter McKay

Ann Mosher

Administration for Community Living

National Alzheimer's Project Act Awareness Goals

- Design and conduct a national education and outreach initiative (Strategy 4.A.1)
- Expand long-term care awareness efforts (Strategy 3.C.2)

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Development Considerations

- **Significant resources about Alzheimer's disease already exist**
- Awareness of Alzheimer's is already quite high
- Accompanied by significant fear

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Strategic Goals

1. **Purpose:** *Connect caregivers with existing resources*
2. **Approach:** Use plain language coaching messages
3. **Key Message Points:**
 1. Acknowledge caregivers
 2. You don't have to go it alone

Administration for Community Living

Campaign Parameters

- **Target audience:**
 - Caregivers , especially spouses
 - Ages 60 – 75
 - Spanish-speaking
- **Estimated Funding Level:**
 - FY 2012 - \$4 million
 - FY 2013 - \$4.2 million included as a part of Secretary's FY '13 budget
- **Funds appropriated on a one-year basis**

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Step One

Develop a New Consumer Resource

Alzheimer's DOT GOV

- Consumer-oriented resource
 - Organized by topic and disease stage
 - Plain language
 - Full Spanish-language site
- Testimonials by Real People
 - Authenticity, perspectives of people who have been there
 - Real world examples of benefits of finding resources

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National Plan Launch

- Media Coverage
 - May 15th Secretary Sebelius announces National Plan and alzheimers.gov campaign
 - Very large volume of stories
- Web Site Visits
 - 15,000 unique visitors the first 24 hours
 - “Alzheimer’s is...” was the most visited section
 - Prominently featured on NBC Nightly News with Brian Williams

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The Washington Post

 The Atlanta Journal-Constitution

Detroit Free Press
www.freep.com

HOUSTON  CHRONICLE

 FINANCIAL TIMES

THE WALL STREET JOURNAL

TIME


Los Angeles Times

 Associated Press

alzheimers.gov | For the people helping people with Alzheimer's


Alzheimer's is... | Treatment Options | How to Pay & Plan | Caring for Someone | Help with Alzheimer's | Fighting Alzheimer's

The Answers Start Here [More info](#)



[Read the transcripts](#) 1 2 3 4

Answers Start Here
 Welcome to alzheimers.gov, the government's free information resource about Alzheimer's disease and related dementias. Here you can find links to authoritative, up-to-date information from agencies and organizations with expertise in these areas.



What is Alzheimer's disease? How do you know if someone has it?
 ▶ Alzheimer's disease is more than just forgetfulness. Learn the symptoms...

What are the treatment options?
 Understand how to seek medical help and the medicines that may be prescribed to help with symptoms and related...

How do I plan ahead? What does insurance pay for? What does Medicare pay for?
 Paying for Alzheimer's-related care and services is one of the...

Testimonials

- **Goals:**
 - **Use language that is authentic and speaks to target audience**
 - Provide sense of help available in each section
- **Current testimonials:**
 - Alan: calling the hotline , paying for services
 - Charles: clinical trials, finding out about the disease
 - Maggie: what can be done to know more
- **Other testimonials planned**

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Website Evolution

- **Working group of subject matter experts**
- Periodic updates
- New topics in development
- Coordination among governmental and non-governmental organizations
- Development of content based on consumer preference

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Step Two

Make Consumers Aware of the Resource

Integrated Marketing Plan

- Marketing approach to use many forms of media
- Each media format uses similar theme
- Selection of media designed for target segments
- Response to initial media buy will provide data to improve future media efforts
- **Most of all: Make It Sticky**

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Television Spot

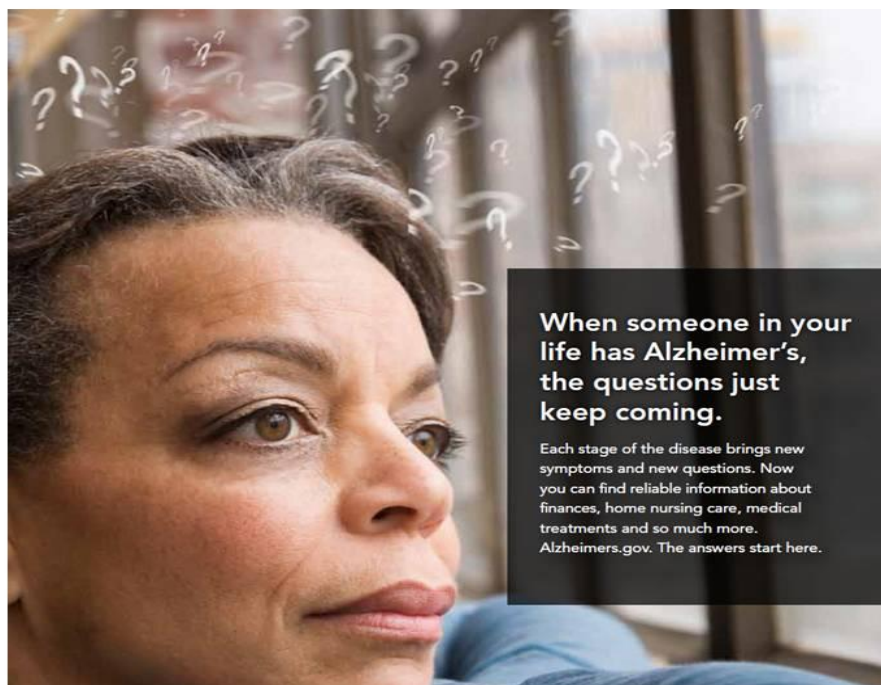
- Television Spot:
 - Features caregivers (not persons with Alzheimer's disease)
 - The context is a private moment in a public place
 - The theme focuses on the difficulty of caregiving through the many questions that caregivers have

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Other Media

- **Radio Spot:**
 - English and Spanish versions
 - Restates the theme using many voices
- **Banner Ads**
 - Question marks float and are clickable to create interactive experience
- **Print /Outdoor Ads**
 - Major publications (Parade) and outdoor spaces (bus stops)

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Media Buy

- Four Components:
 - Television
 - Radio
 - Digital
 - Print/Outdoor
- Timetable:
 - Television and print to begin August 6
 - Print/Outdoor shortly thereafter

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Campaign Co-Sponsors

- ACL not permitted to solicit contributions
- Several private interests expressed interest
 - Associations & Foundations
 - Private corporations
- No Explicit Co-branding in Campaign Materials
 - HHS may offer a press release-type acknowledgement of contribution of co-sponsors

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Step Three

Evaluate - Evaluate - Evaluate:

Content: What information do consumers want?

Outreach: What approach best reaches the target?

Evaluate

- Goal:
 - Allow consumer preference and behavior to dictate website design – **what information do consumers really want?**
 - Use marketing analytics to improve effectiveness of outreach particularly digital
- Data Sources:
 - Google Analytics
 - YouTube Analytics
 - Web Site Based Survey

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Next Steps

- Expand into Social Media
 - Effort to use FaceBook and Twitter to ignite organic conversation
 - Outreach to bloggers, FaceBook advertising ect.
- Make better use of earned media:
 - Reaction to initial press conference suggests potential for use of earned media
 - Identification of journalists with interests in this area
- Cooperate – Coordinate - Partner
 - Identify networks/partners with an existing interest in this information



Community-Based Programs Meeting

**Presentation for the Advisory Council on Alzheimer's
Research, Care, and Services -- July 23, 2012**

Laura Lawrence

**Director, Office of Nutrition and Health Promotion Programs
Administration on Aging, Administration for Community Living
U.S. Department of Health and Human Services**



While we all wish we could
fast-forward to a time when
no one has Alzheimer's disease.....



We're not quite there.....

Part of the National Plan to Address Alzheimer's Disease

“Action 3.B.3:

Review the state of the art of evidence-based interventions [for individuals with AD and their caregivers] that can be delivered by community-based organizations.”



“HHS will partner with private organizations to convene a meeting..”



TRANSLATING INNOVATION TO IMPACT:
*Evidence-Based Interventions to Support People with
Alzheimer's Disease and their Caregivers
at Home and in the Community*
June 28, 2012

In partnership:



Sponsored by:
MetLife Foundation



Meeting Objectives

- Highlight programs that have been brought to scale
- Discuss programs that did not translate well into the community
- Identify gaps in the research



Panel 1

Assisting Individuals with Dementia

Susan McCurry, PhD

University of Washington, Alzheimer's Disease Research Center
(RDAD – Reducing Disability in Alzheimer's Disease)

Michelle Barclay, MA

Alzheimer's Association -- Minnesota-North Dakota
(Memory Club and MeetUp & Mentor)

Sandra Burgener, PhD, APRN-BC, FAAN

University of Illinois, Urbana
(Multi-Modal Community Based Program for Persons with MCI
or Early-Stage Dementia)



Panel 2

Assisting the Family Caregiver

Laura Gitlin, PhD

Johns Hopkins Center for Innovative Care in Aging
(Skills₂Care)

Mary Mittelman, DrPH

New York University Comprehensive Center on Brain Aging
(NYU Caregiver Intervention)

Leisa Easom, PhD, RN

Rosalynn Carter Institute for Caregiving
(REACH II and GA translation of Cleveland Managed Care)



Panel 3 Care Coordination & Care Transitions

David Bass, PhD

Margaret Blenkner Research Institute of Benjamin Rose
(Partners in Dementia Care and Care Consultation)

Karen Hirschman, PhD, MSW

University of Pennsylvania School of Nursing
(Transitional Care Model for Cognitively Impaired Elders)

Christopher Callahan, MD, FACP

Indiana University Center for Aging Research
(Collaborative Care Model for Alzheimer's Disease and Related Dementias)



40 Attendees Inside & Outside Federal Government



BROWN



NATIONAL INSTITUTE OF NURSING RESEARCH



Administration on Aging
Administration for Community Living

A Few Initial Thoughts from the Meeting

- There are a number of evidence-based non-pharmacological programs for individuals with ADRD and their caregivers, some shown to be effective a decade or more ago



- **NONE** are widely available across the country



A Few Initial Thoughts (cont'd)

- Some evidence-based non-pharmacological programs are likely more effective than others for certain people, perhaps due to stage of the disease, race, ethnicity, relationship with caregiver



- We **NEED** more information to make right program available to the right people at the right time



A Few Initial Thoughts (cont'd)

- Although programs are available to help with some of the most difficult symptoms/situations, widely available programs for other difficult symptoms/situations have not been developed and evaluated for ADRD.



- We **MUST** make developing and testing other programs in the ADRD realm a high priority



A Few Initial Thoughts (cont'd)

- There are many opportunities in the ACA and within existing federal programs to expand research, conduct demos and pilots, and broadly implement effective programs



- We **NEED** to match opportunities with programs to expand availability in communities across the country



There are New Opportunities for Research & Broader Availability

We anticipate releasing a white paper, with recommendations, this September



Video of meeting will be available on DVD and online



Administration on Aging
Administration for Community Living

THE NATIONAL ALZHEIMER'S PLAN

AND THE NEW RESOURCE TO ALIGN STRATEGIC PLANNING, IMPLEMENTATION TRACKING, AND PROGRESS REPORTING AT HHS



July 2012

Goals

- Review the approach to align strategic planning, implementation tracking, and progress reporting across the Department
- Learn how the development of a new web-based strategic planning tool will support the National Alzheimer's Plan

Approach

- Strengthen agencies' capacity to develop interconnected logic models, strategic plans, and implementation plans, and regularly report on progress;
- Connect strategic plans with performance measures, including those tracked by ASFR through its Program Performance Tracking System to fulfill Government Performance and Results Modernization Act requirements;
- Facilitate connections of plans to each other, to reduce duplication of effort and ensure coordination where appropriate; and
- Enable HHS leadership to track achievement of goals and objectives across plans.

ASPE is leading the development of a web-based resource for strategic planning that will help to realize this approach.

National Alzheimer's Plan



- ASPE will load the National Alzheimer's Plan into the new web-based tool this summer.
- HHS agencies will be able to enter their progress on action steps for which they are responsible. The tool will facilitate reporting by HHS agencies.
- ASPE will be able to create and share reports on progress across action steps for all partners – as well as identify any action steps that are outstanding.
- Indicators of progress can be linked to a broader set of HHS measures, to connect our effort to those of others across the Department.

National Alzheimer's Plan



- Crosswalking the Alzheimer's Plan to related plans will be far easier and will facilitate identifying other plans and other efforts that may offer the potential to leverage other resources.