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

Inventories of Federal Efforts

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Background

- Interagency Group on ADRD formed in April
- Tasked with NAPA requirement to examine all efforts to address ADRD
- First step: Inventory of activities
- Divided into three subgroups: Research, Clinical Care, Long-Term Services and Supports

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Subgroup Composition

- Research
- NIH*
- VA
- CDC
- FDA
- AoA
- ASPE
- NSF
- AHRQ

- Clinical Care
- CMS*
- HRSA
- ASPE
- VA
- IHS
- SAMHSA
- NIH

- LTSS
- AoA*
- CMS*
- ASPE
- VA
- NIH
- NSF
- SAMHSA

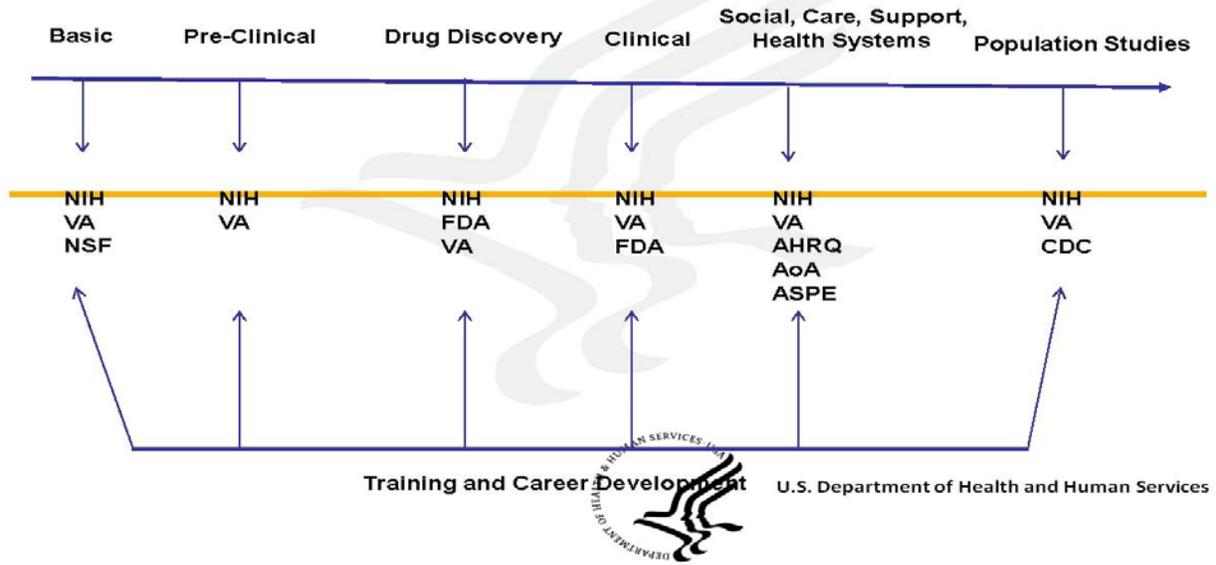U.S. Department of Health and Human Services

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ADRD Research Inventory

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NIH Lead ADRD Research Subgroup

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Alzheimer's Disease and Related Dementias Federal Research Continuum

Basic	Pre-Clinical	Drug Discovery	Clinical	Social, Care, Support, Health Systems	Population Studies
NIH	NIH	NIH	NIH	NIH	NIH
VA	VA	FDA	VA	VA	VA
NSF		VA	FDA	AHRQ	CDC
				AoA	
				ASPE	

Training and Career Development

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Development of FY 2010 ADRD Federal Research Inventory

1. Agreement on search terms: "Alzheimer's Disease," "Dementia," "Frontotemporal Dementia", "Mild Cognitive Impairment"

2. Used information from Centralized Databases: NIH Project RePORTER

3. ADRD Ontology Selected and Populated

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Alzheimer's Disease and Related Dementias Research Ontology

⮑ Biology and pathophysiology

⮑ Diagnosis, assessment and disease monitoring

⮑ Drug discovery, preclinical drug development, clinical interventions

⮑ Epidemiology

⮑ Social-behavioral, care, support, health systems

⮑ Research resources (training, infrastructure, technology)

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FY2011 ADRD Federal Research Funding by Category For NIH, VA, CDC, AHRQ

Research Category	Funding Amount
A. Biology and Pathophysiology	$187,054,063
B. Disease Diagnosis and Assessment	$82,954,009
C. Drug Development, Pre-Clinical Development, and Clinical Research	$67,259,878
D. Epidemiological and Longitudinal Studies	$52,745,309
E. Socio-behavioral ,Care, Support, and Health Systems	$29,249,374
F. Research Resources	$83,260,797
Total	$502,523,430

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FY2011 ADRD Federal Research Funding by Category and Agency

	Biology & Patho-physiology	Diagnosis & Assessment	Drug Dev., Pre-Clinical Dev. & Clinical Research	Epidemiological & Longitudinal Studies	Socio-behavioral, Care, Support & Health Systems	Research Resources
NIH	578	233	120	75	23	228
	176,827,511	76,788,041	61,738,806	49,357,507	10,129,460	82,769,638
CDC	0	0	0	5	0	0
	$0	$0	$0	$1,175,437	$0	$0
VA	44	22	16	10	19	0
	$10,227,172	$6,128,168	$5,021,863	$1,771,057	$4,809,867	$0
AHRQ	0	1	1	2	10	1
	$0	$37,800	$499,209	$441,308	$14,310,047	$491,159
Total	622	256	137	92	52	229
	$187,054,683	$82,954,009	$67,259,878	$52,745,309	$29,249,374	$83,260,797

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ADRD Clinical Care Inventory

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Centers for Medicare and Medicaid Services/
Lead ADRD Clinical Care Subgroup

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Scope and Assumptions

- Dementia
  - Alzheimer's disease, dementia of other etiologies
- Focus
  - Patients rather than the disease itself
    - Dual eligible 22% with dementia includes 11% with 5+ chronic conditions
  - Caregivers
- All services and all settings
  - "all of places where people with Alzheimer's disease (and caregivers) interact with the service system"
  - Relevant but not necessarily specific to dementia?
  - Across the disease continuum

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Process

- Broad environmental scan of existing services and programs
- Clinical services provided in long-term care settings were excluded to avoid duplication with Long-Term Care workgroup
- Services and programs reviewed and discussed over telephone conferences
- Inventory created across the care settings by disease stage
- Identified gaps in services

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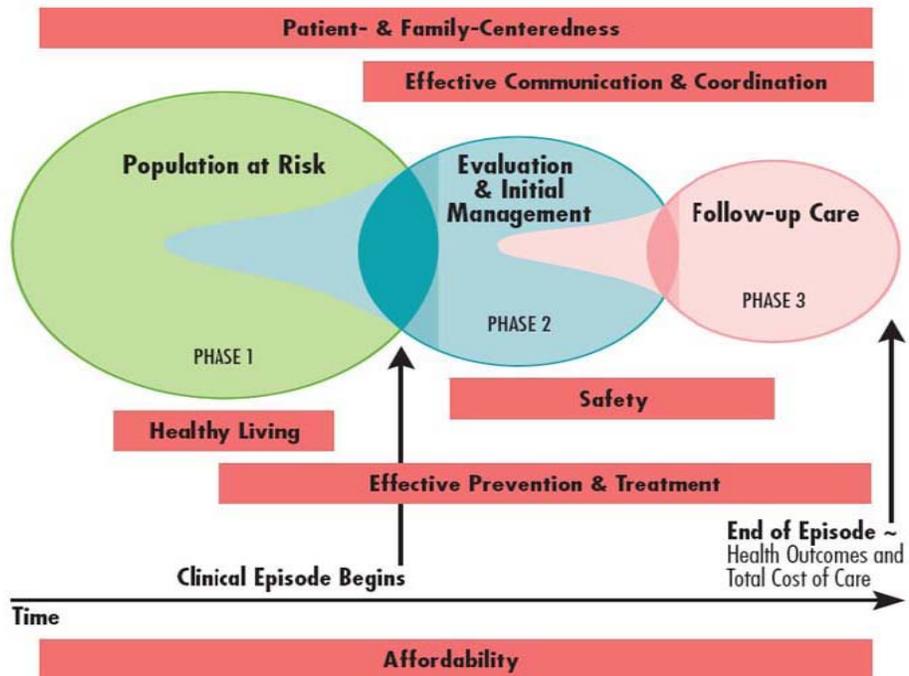
Relevant Clinical Care Topics

Clinical Focus	System Focus

• Prevention (primarily of vascular dementia- related to cardiovascular disease)
• Detection
• Diagnosis
• Treatments (Pharmacological, behavioral)
• Care Coordination
  – Transitions between providers/settings
  – Coordination with LTSS
• Advanced Care Planning
	• Professional Workforce:
	  – Physician (primary care, geriatricians, etc)
	  – Nurses
	  – Social Work/Care Managers and Home Health Aides/Home Care Providers
	  – Training
	• Social/Legal Issues
	  – Competency/independence/auto nomy/driving
	  – Financial management
	  – Elder abuse (coordinate with LTSS group)

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Health System Functions

	Prevention	Diagnosis	Management	Acute Events	Care Transitions
Patient	Effective CVD management	Detection & Assessment of Cognitive Impairment	Medicinal Behavioral	Safety Abuse	Care Coordination & Planning
Caregivers	Burden management	Stress	Behavioral Social	Driving Abuse	
System	Workforce training	Case management			

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Existing Clinical Programs and Services for Persons with Dementia

- Ambulatory Care
- Hospital Care
- Geriatric Evaluation and Management (GEM)
- Geriatric Primary Care
- Home Hospice Care
- Hospice and Palliative Care Consultation Team
- Geriatric Research, Education, and Clinical Centers (GRECCs)
- Mental Illness Research, Education, and Clinical Centers (MIRECCs)
- Older Adult Targeted Capacity Expansion (TCE)
- KIT on Evidence Based Practices to Address Depression in Older Adults
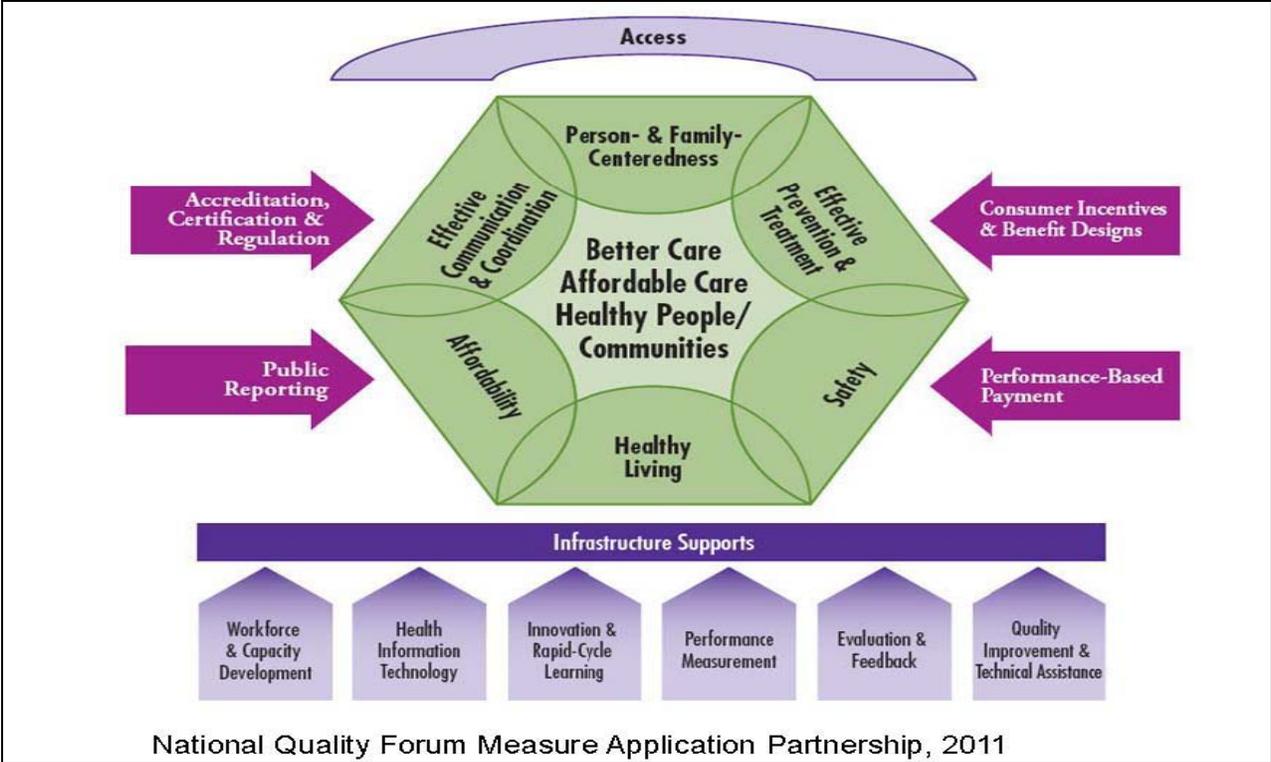- Reducing Adverse Drug Events: Patient Safety and Clinical Pharmacy Services Collaborative (PSPC)

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Affordable Care Act Programs

ACA Provision	Provision Name	Provision Description
3021	Establishment of Center for Medicare and Medicaid Innovation within CMS	Utilizing geriatric assessments and comprehensive care plans to coordinate the care (including through interdisciplinary teams) of applicable individuals with multiple chronic conditions and at least one of the following: "(I) An inability to perform 2 or more activities of daily living. "(II) Cognitive impairment, including dementia
3024	Independence at home demonstration program	Creates a new demonstration program for chronically ill Medicare beneficiaries to test a payment incentive program
3026	Community-based care transitions program	Requires the Secretary establish a community-based transitions program that provides funding to hospitals and community-based entities that furnish evidence-based care transition services to Medicare beneficiaries at high risk for readmission.
4103	Medicare coverage of annual wellness visit providing a personalized prevention plan	Provides coverage under Medicare, with no co-payment or deductible, for an annual wellness visit and personalized prevention plan services. Such services would include a comprehensive health risk assessment. The personalized prevention plan would take into account the findings of the health risk assessment and include elements such as: a five- to ten-year screening schedule; a list of identified risk factors and conditions and a strategy to address them; health advice and referral to education and preventive counseling community-based interventions to address modifiable risk factors such as physical activity, smoking, and nutrition.

Affordable Care Act Programs (continued)

ACA Provision	Provision Name	Provision Description
5305	Geriatric education and training; career awards; comprehensive geriatric education -	All family caregiver and direct care provider training programs shall include instruction on the management of psychological and behavioral aspects of dementia, communication techniques for working with individuals who have dementia, and the appropriate, safe, and effective use of medications for older adults.
5507	Demonstration project to address health professions workforce needs; extension of family-to-family health information centers	Training specific to an individual consumer's needs (including older individuals, younger individuals with disabilities, individuals with developmental disabilities, individuals with dementia, and individuals with mental and behavioral health needs)
6114	National demonstration projects on culture change and use of information technology in nursing homes	Each demonstration project conducted under this section shall take into consideration the special needs of residents of skilled nursing facilities and nursing facilities who have cognitive impairment, including dementia.
6121	Dementia and abuse prevention training	Requires facilities to include dementia management and abuse prevention training as part of pre-employment initial training for permanent and contract or agency staff, and if the Secretary determines appropriate, as part of ongoing in-service training.

National Quality Forum Measure Application Partnership, 2011

ADRD Long-Term Services and Supports Inventory

Cindy Padilla
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Co-Lead ADRD LTSS Subgroup

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Workgroup Primary Tasks

• Develop an inventory of programs serving persons with Alzheimer's disease and their caregivers.

• Begin an analysis of gaps/opportunities within and among these programs.

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LTSS Inventory Categories

Category	Subsections
Planning for Long Term Care	LTC Financing (CLASS, LTC insurance) [global and individual]; LTC Planning (Hospice, End of Life); Care Coordination (Care Transitions, Consumer Direction)
Long Term Services and Supports	Home Care/Personal Care; Caregiver Support (Formal, Informal); Health, Function and Social Issues (Mental Health, Daily Tasks, Driving, Independence); Special Populations (Intellectual Disabilities, Mental Health, Younger Onset)

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LTSS Inventory Categories

Category	Subsections
Residential Care Settings	Nursing Home; Assisted Living
Work Force	Staff Education/Training; Dementia-Capability
Quality and Safety	Elder Abuse; LTC Ombudsmen; Guardianship; Advocacy for Individuals

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LTSS Inventory

- Using these five categories, each participating agency (AoA, CMS, NIH and VA) supplied basic descriptive information about their programs, including participants, funding, and a brief description.

- Analysis of the Inventory by AoA and CMS is underway.

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LTSS Inventory: Examples

Program	Profile
Alzheimer's Disease Supportive Services Program	• Administered by AoA • Services for persons w/dementia or their caregivers • Awarded to entities of state government (e.g. State Unit on Aging, University)
National Alzheimer's Call Center	• Administered by AoA • Information and counseling service for persons with Alzheimer's, family members and unpaid caregivers • Available to people in 56 states and territories, 24 hours a day, 7 days a week, 365 days a year

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LTSS Inventory: Examples

Program	Profile
Medicaid Nursing Home Benefit	• Administered by CMS • 55.8 % of nursing home residents have mild to very severe cognitive impairments • Federal reimbursement for eligible services provided to Medicaid beneficiaries
Medicaid Home and Community Based Services	• Administered by CMS • States have several opportunities, including new ones under the Affordable Care Act to offer home and community based services to persons with Alzheimer's disease.

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LTSS Inventory: Examples

Program	Profile
VA Employee Education System	• Education and training for VA staff (e.g. physicians, nurses, social workers, pharmacists, occupational and physical therapists, dieticians) • Dementia recognition and diagnosis, challenging behaviors, safety, communication strategies, emergency preparedness
VA Interdisciplinary Planning Committee	• Continuous quality improvement effort • Veterans Health Administration Dementia Steering Committee, Veterans Integrated Service Network Dementia Committees, and Veterans Affairs Medical Center Dementia Committees.

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