T1: RESOURCES TO ADDRESS THE NEEDS OF PERSONS WITH DEMENTIA AND THEIR CAREGIVERS
2014 GOVERNOR’S CONFERENCE ON AGING AND DISABILITY

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Why should you care about AD?

Because it’s the biggest public health issue you’ve never heard of.
Facts about Alzheimer’s

- 1 in 9 Americans over the age of 65 has Alzheimer’s disease – over 5 million people.
- 210,000 Illinoisans have Alzheimer’s.
- In 2010, nearly 3,000 Illinoisans died of Alzheimer’s, according to their death certificates.
- Alzheimer’s is the sixth leading cause of death in the U.S.
- Each year over 500,000 seniors die of Alzheimer’s.
- Deaths from Alzheimer’s increased 68% from 2000 – 2010 while deaths from other major diseases decreased.

Source: Alzheimer’s Association 2014 Facts and Figures Report
Alzheimer’s disease statistics

- Over 70% of people live at home
- Almost 75% of home care provided by family and friends
- Nationwide, about 70% of all nursing home residents have cognitive impairment, 50% of assisted living residents have AD or another dementia, over 50% of adult day service participants have AD or another dementia, as well as about 25% of all elderly hospital patients.

Source: Alzheimer’s Association 2014 Facts and Figures Report
Cost to Society

- In 2013 15.5 million caregivers provided an estimated 17.7 billion hours of unpaid care valued at $220 billion.
- In 2013, Illinois caregivers provided 668 million hours of unpaid care valued at $8.3 million.
- Alzheimer’s is the most expensive condition in the nation.
  - In 2014 the direct costs to American society to care for those with Alzheimer’s is estimated to be $214 billion, including $150 billion in costs to Medicare and Medicaid.

Source: Alzheimer’s Association 2014 Facts and Figures Report
Women and Alzheimer’s

- More than 3 in 5 unpaid caregivers are women.
- 19% of women caregivers have had to quit work due to caregiving responsibilities.
- A women’s estimated lifetime risk of developing Alzheimer’s after age 65 is 1 in 6, compared with 1 in 11 for men.
- Women in their 60s are twice as likely to develop Alzheimer’s during the rest of their lives as they are to develop breast cancer.

Source: Alzheimer’s Association 2014 Facts and Figures Report
What is Dementia?

- Dementia is a category, not a diagnosis
- Decrease in mental ability from a prior level of intellectual function
- Many causes
  - Metabolic imbalances
  - Head trauma
  - Cerebrovascular events
  - Depression
  - Neurodegenerative diseases
What is Alzheimer’s disease?

- Progressive, degenerative disease
- Affects brain
- Impairs memory, thinking, behavior
- Most common form of dementia
Living with the symptoms of Alzheimer’s: Quotes from diagnosed individuals
“It’s a confusing world. I often isolate myself. I’m afraid to go outside. I pretty much stay in the house 24 hours a day.”
“There’s a financial side to AD. Being diagnosed, I knew I had to step down from my job.”

(Young onset, age 57)
“At home, putting laundry away, I forget what I’m doing. Don’t know what I was trying to do. Can’t remember where I put something.”
“I take offense too often. I get defensive. I’m having a lot of trouble in talking with my spouse. I get upset when I get too many details.”
“I have backed off from some of the things I’ve been doing and I don’t think I’ve explained why. I need to tell them. I want them to know, but I also don’t want them to know.”
“I’m doing the best I can.”
What Happens to the Brain? - Frontal
What Happens to the Brain? - Frontal

**Normal** – Personality; Reason; Movement; Speech; Attention Span; Alertness; Safety

**AD** – Change in Personality; Cannot Plan/Poor Judgment; Short Attention Span/Can’t Concentrate; Easily Distracted; Can’t Initiate Activity; Not Alert

**What to Do** – Give Step by Step Directions; Use Cues or Prompts to Start an Activity; Reduce Hazards in the Environments; Reduce Distractions
What Happens to the Brain? - Parietal
What Happens to the Brain? - Parietal

- **Normal** – Perceptions; Senses (Temperature, Touch, Pain, Space); Language

- **AD** – Can’t Understand Input from Senses; Can’t Follow Auditory or Visual Cues; Can’t Recognize Familiar Objects by Touch; Doesn’t Understand Purpose of Objects

- **What to Do** – Assist with Cueing; Use Gestures, Body Language, Demonstrate; Use “Hand-in-Hand” Technique; Use Prompt to Show Purpose of Object
What Happens to the Brain? - Occipital
What Happens to the Brain? - Occipital

• **Normal** – Vision; Interprets Information from the Eyes for Orientation, Position, Movement

• **AD** – Loss of Depth Perception; Loss of Peripheral Vision; Difficulty Processing Rapid Movements

• **What to Do** – Approach from the Front; Eye Contact; Use Slow Movements; Avoid Floor and Wall Designs that Could be Misinterpreted (for example, A Black Floor Tile Could Appear to be a Hole)
What Happens to the Brain? - Temporal
What Happens to the Brain? - Temporal

- **Normal** – Hearing; Memory; Language; Ability to Draw

- **AD** – Aphasic (Impaired Language) – Expressive (Inability to Speak); Receptive (Inability to Understand)

- **What to Do** – Fill in Missing Words
What Happens to the Brain? - Amygdala
What Happens to the Brain? - Amygdala

**Normal** – Emotions; Anger, Sex, Fear

**AD** – Angry Outbursts; Inappropriate Sexual Behaviors; Afraid

**What to Do** – Distract; Reassure; Redirect with Activities, Music, etc.
What Happens to the Brain? - Hippocampus
What Happens to the Brain? - Hippocampus

- **Normal** — Memory: Processes Short Term Memory, Stores New Memory; Learning

- **AD** — Loss of Short Term Memory; Asks Repetitive Questions; Gets Lost Easily; No Sense of Time; Easily Confused; Loses Things

- **What to Do** — Reassure; Validate; Answer Questions, Even if Repeated; Redirect; Move Slowly Between Tasks; Allow Time for Adjustment
Caregiver Issues
Stress
Financial Concerns
Isolation
Role changes
Lack of support
Sleep deprivation

Do you know that awesome feeling when you get into bed, fall right to sleep, stay asleep all night, and wake up feeling refreshed?

Me neither
Guilt

' A feeling of having committed a wrong or failed in an obligation.'
Health issues
Service Challenges

- Social isolation
- Transportation issues
- Most services are focused either at cognitively intact people or at people who are quite impaired; little available for those who are mildly impaired
- Few services for younger onset
What Services are Available for the Diagnosed Person?

- Support groups (in-person, telephone, virtual)
- Education programs
- Exercise/mindfulness programs
- Cognitive stimulation
- Online forums, chat rooms
- Social/arts programming
- Volunteer opportunities
- Memory Cafes

BUT: There are not enough programs, and they are not available throughout Illinois.
Opportunities for Service Provision

- Utilizing technology to connect people who are geographically isolated
- Creating partnerships to provide community-based services
- Using early stage services as a way to connect and establish trust with potential clients/families down the road
Resolutions and Initiatives in Illinois

Framing the Issue
Proportion of People with Alzheimer’s Disease

- 85+ years: 38%
- 75-84 years: 44%
- 65-74 years: 15%
- Under 65 years: 4%
Proportion of Alzheimer's Disease and Dementia Caregivers versus Caregivers of Other Older People by Duration of Caregiving

- Caregivers of people with Alzheimer's Disease & Other Dementias
- Caregivers of other older people

Occasionally: 2% vs. 4%
Less than 1 year: 23% vs. 34%
1-4 years: 43% vs. 33%
5+ years: 32% vs. 28%
Emotional & Physical Stress

Emotional Stress of Caregiving:
- High to very high: 59%
- Not high to somewhat high: 41%

Physical Stress of Caregiving:
- High to very high: 38%
- Not high to somewhat high: 62%
The Illinois Department on Aging received a three-year grant from the Administration for Community Living (ACL).
The **goal** is to develop and implement a sustainable Aging and Disability Resource Center (ADRC) and community-based service delivery system that is dementia-capable and meets the needs of individuals with dementia and their caregivers in Illinois.
The Illinois Department on Aging, in partnership with other state agencies, Alzheimer’s Association Chapters, Coalition for Limited English Speaking Elderly (CLESE), Area Agencies on Aging, and other key stakeholders will expand a statewide coordinated system that builds on the service infrastructure currently in place.
Grant Partners

- Alzheimer’s Association, Greater Illinois Chapter
- Alzheimer’s Association, Central Illinois Chapter
- 8 Area Agencies on Aging
- Coalition for Limited English Speaking Elderly (CLESE)
- Northwestern University’s Buehler Center on Aging, Health and Society
Grant Objectives

1. Develop and maintain dementia-capable ADRC/NWD access and referral services for individuals with dementia and caregivers.

2. Train Aging Network and Adult Protective Services personnel, SHIP sites, Supportive Living Program facilities, and Managed Care agencies on the components of dementia-capable service delivery systems.
Grant Objectives (continued)

3. Implement ADRC Options Counseling services on a statewide basis

4. Work with Alzheimer’s Association Chapters to conduct Savvy Caregiver in selected Planning and Service Areas

5. Link individuals with dementia and their caregivers to a comprehensive set of dementia-capable services including care transition services
Grant Objectives (continued)

6. Work with the Illinois Department of Healthcare and Family Services and other state agencies on a stream-lined dementia capable eligibility determination process for public programs and assistance applying for these programs.

7. Develop a data collection and quality assurance system and conduct an evaluation of the activities of the grant.

8. Ensure sustainability of the dementia-capable home and community-based service system.
Provision of Person-Centered Services

- Like others, people with dementia and their family caregivers need information about services, programs, and financing so they can make informed choices and manage their services.
- Family caregivers are likely to have a major role in decision-making and management.
- Local access agencies, such as AAAs and ADRCs, are key to providing information and entry to LTSS.
Provision of Person-Centered Services: Identifying the Person with Dementia

Problems

- Impossible to provide good person-centered care unless you recognize people with dementia and their caregivers.
- If the person with dementia rather than caregiver is seeking information, this may affect their ability to use information.
Provision of Person-Centered Services: Identifying the Person with Dementia

Solutions

- Add dementia-specific questions to intake and assessment protocols and online self-assessment forms.
- Train telephone operators and other staff at AAAs, ADRCs, and other local agencies to recognize possible cognitive impairment.
- Establish policies and procedures for referral of persons with possible cognitive impairment for professional assessment.
Solutions

- Be sensitive to different cultural traditions about dementia.
- Partner effectively: Alzheimer’s Association staff will provide training for ADRC staff.
Provision of Person-Centered Services: Additional Issues

- Assess agency (e.g., AAAs, ADRCs) capability to provide general information about dementia and refer to more specialized organizations.

- Refer to organizations and providers with dementia expertise (although all should be dementia capable).
Service Use: Use of Home and Community-Based Services

- Most programs focus on providing services to the eligible beneficiary (i.e., person with dementia).
- Some resistance to covering services to caregivers, such as caregiver counseling or caregiver training.
- Caregiver training and support can be covered through Medicaid home and community-based services waivers and rehabilitation services.
VISION: The Illinois Cognitive Resources Network (ICRN) will make Illinois a national leader in the development and implementation of effective community-based models for adults to access research, education, training, and support services to promote cognitive health and quality of life.

MISSION: The Collaboration will leverage strengths of Alzheimer’s Association chapters, Alzheimer’s Disease Assistance Centers, and organizations in the Aging, Disability, and Public Health Networks to optimize the cognitive and functional well-being of Illinois residents and their families.

CONTACT US: Web: ILBrainHealth.org or email: info@ILBrainHealth.org
Healthy Brain Initiative (next session)
Thank you

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