

A CONVERSATION WITH PERSONS WITH DEMENTIA AND THEIR FAMILIES NAVIGATING THE MAZE OF SERVICES

GREG KYROUAC, MSED, SOUTHERN ILLINOIS UNIVERSITY SCHOOL OF MEDICINE

DARBY MORHARDT, PHD, NORTHWESTERN UNIVERSITY FEINBERG SCHOOL OF MEDICINE

RAJ C. SHAH, MD, RUSH UNIVERSITY MEDICAL CENTER



APHA Chicago, IL (November 4, 2015)

Objectives

- Understand the principles of person-centered care and services in dementia
- Describe current state-wide models of multi-stakeholder collaborations to advance person-centered dementia care and services
- Identify key elements needed to nurture the growth and development of state collaborations such as the Illinois Cognitive Resources Network

Illinois Cognitive Resources Network (ICRN)



The Ideal – Dementia Friendly Communities



Source: www.actonalz.org

Illinois Cognitive Resources Network (ICRN)



The Disconnect

- **Families including Persons with Memory Loss**
 - “We are all alone. There is no one to help us.”
- **Memory Loss Service Providers**
 - “We want to help. Our doors are open. Where are our prospective clients.”

Patient-Centered Principles

Helps people and their caregivers to:

- Have their voices heard
- Communicate desired health outcomes,
- Make informed health care decisions,
- Assess the value of health care options

Illinois Cognitive Resources Network (ICRN)



Person-Centered Questions

- Given my personal characteristics, conditions and preferences, what should I expect will happen to me?
- What are my options and what are the potential benefits and harms of those options?
- What can I do to improve the outcomes that are most important to me?
- How can providers and the care delivery systems they work in help me make the best decisions about my health and healthcare?

Illinois Cognitive Resources Network (ICRN)



State-Wide Collaborative Efforts



Illinois Cognitive Resources Network (ICRN)



ACT on Alzheimer's®

PREPARING MINNESOTA COMMUNITIES

ACT on Alzheimer's is a statewide, volunteer-driven collaboration preparing Minnesota for the personal, social, and budgetary impacts of Alzheimer's disease. Passionate and committed partners, supporters, action communities, and Minnesotans are taking part in the work and making a difference.



Our communities must ACT to be ready. Here's why:

89,000 Minnesotans age 65+ live with Alzheimer's disease and the number is growing.



A Sampling of Key Partners...

AARP Minnesota	Essence Health	Minnesota Department of Human Services
Accredited Investors, Inc.	Fairview	Minnesota Hospital Association
Aging Services of Minnesota	Greater Twin Cities United Way	Minnesota Medical Association
Alina Health	HealthPartners	Minnesota's Area Agencies on Aging
Alzheimer's Association Minnesota-North Dakota	Medigo Clinic	Stress Health
Armand H. Winder Foundation	Medica	U of MN Center on Aging
Blue Cross Blue Shield of Minnesota	Minnesota Board on Aging	UCare
Care Providers of Minnesota	Minnesota Department of Health	Volunteers of America - Minnesota

Illinois Cognitive Resources Network (ICRN)



Source: www.actonalz.org

Illinois Cognitive Resources Network

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.

Illinois Cognitive Resources Network (ICRN)



Overview

- Why the Illinois Cognitive Resources Network (ICRN) came together
- What has kept the ICRN together
- Progress to date in helping individuals, families and professionals access research, education, training and support services

Illinois Cognitive Resources Network (ICRN)



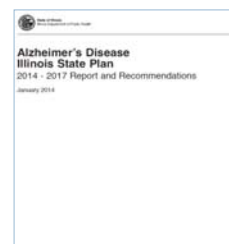
□ Why the Illinois Cognitive Resources Network (ICRN) came together

Illinois Cognitive Resources Network (ICRN)



Alzheimer's Disease Assistance Act (410 ILCS 405)

- 1985 – Mandated
 - ✓ Develop and maintain the Alzheimer's Disease Advisory Committee (ADAC)
 - ✓ Collaborate with 3 Regional Alzheimer's Disease Assistance Centers
 - ✓ Coordinate Alzheimer's Disease Research Fund grants
 - ✓ Develop a state plan every 3 years
- 2003 – Amended to require recommendations from the Committee to improve state services based on reports provided by state agencies serving persons with Alzheimer's disease and related dementias.
- 2012 – Amended changing composition of the ADAC and enhanced state plan contents.



Illinois Cognitive Resources Network (ICRN)



Illinois Cognitive Resources Network -- Why

- Many residents in Illinois feel disconnected when obtaining services regarding cognitive health.
- Also, many service providers feel disconnected from other service providers. They feel that their services are not being fully utilized.
- It is not clear how best to translate national agendas and efforts into statewide and local community efforts.

Illinois Cognitive Resources Network (ICRN)



National Agendas for Cognition



- Healthy People 2020
- National Alzheimer's Project Act and National Plan to Address Alzheimer's Disease
- Healthy Brain Initiative



Illinois Cognitive Resources Network (ICRN)

Healthy People 2020

A society in which all people live long, healthy lives

Illinois Cognitive Resources Network (ICRN)

ICRN
Illinois Cognitive Resources Network

Overarching Goals:

- Attain high quality, longer lives free of preventable disease, disability, injury, and premature death.
- Achieve health equity, eliminate disparities, and improve the health of all groups
- Create social and physical environments that promote good health for all.
- Promote quality of life, healthy development and healthy behaviors across all life stages.

National Alzheimer's Project Act

National Alzheimer's Project Act

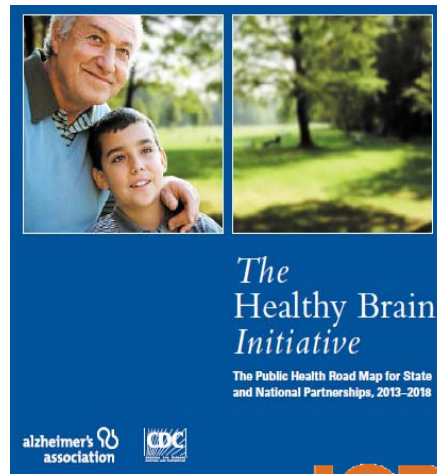
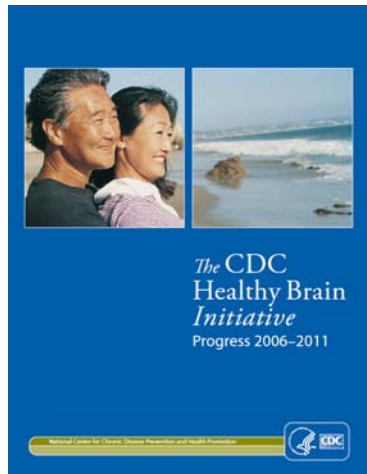
On January 4, 2011, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA), requiring the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:

- Create and maintain an integrated national plan to overcome Alzheimer's disease.
- Coordinate Alzheimer's disease research and services across all federal agencies.
- Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease.
- Improve early diagnosis and coordination of care and treatment of Alzheimer's disease.
- Improve outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's disease.
- Coordinate with international bodies to fight Alzheimer's globally.

Illinois Cognitive Resources Network (ICRN)

ICRN
Illinois Cognitive Resources Network

The Healthy Brain Initiative



Illinois Cognitive Resources Network (ICRN)



- What has kept the ICRN together

Illinois Cognitive Resources Network (ICRN)



Illinois Cognitive Resources Network -- How

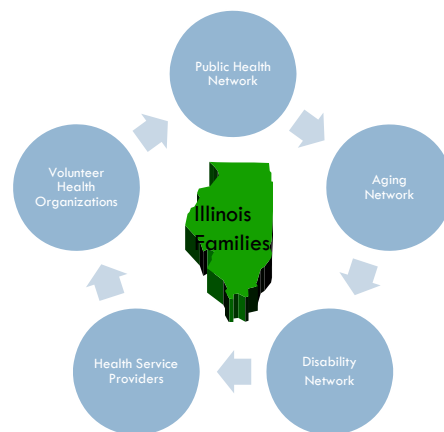
- Regular monthly meeting forum for exchange of ideas and opportunities to collaborate
- Significant collaborative effort to develop an acceptable name, vision, and mission statement.
- Constant feedback from state agencies and stakeholder leadership groups.
- Short-term steps to build momentum along with long-term goals.

Illinois Cognitive Resources Network (ICRN)



Organization

Each group will give something of value to help other collaboration members and the Illinois residents they serve and each group will receive something back to meet its individual goals.



Illinois Cognitive Resources Network (ICRN)



Progress in Activities

- Support of Public Surveys on Aging and Cognition
- Education and Training
- Input on State Programs
- Dissemination at Meetings
- Obtaining Innovation Funds

Illinois Cognitive Resources Network (ICRN)



Education and Training

- Illinois Care Coordination Units Training Committee
- Identified need for updating dementia training materials for Care Coordinators (assessors of services for State Area Agencies on Aging)
- Reached out to ICRN
- Needs Assessment

Illinois Cognitive Resources Network (ICRN)



Care Coordinator Unit Survey Results

What do staff and supervisors struggle with most when completing a home visit/assessment with an individual with cognitive impairment?

- Feel a general lack of education regarding cognitive disorders.
- More training on how to interview the cognitively impaired clients.
 - ▣ How to respond when the client's impairment obstructs communication?
 - ▣ How to respond to family who may not recognize issues?
 - ▣ Determining level of cognitive impairment at initial visit.
- How to determine capacity to make decisions?
 - ▣ Recognition that the assessment does not always reflect the person's capacity.
- The lack of family or other support system to provide information
- Lack accurate information from referral source especially regarding cognitive impairment.



Creating the ICCCU Dementia training Video: A Model of Collaboration

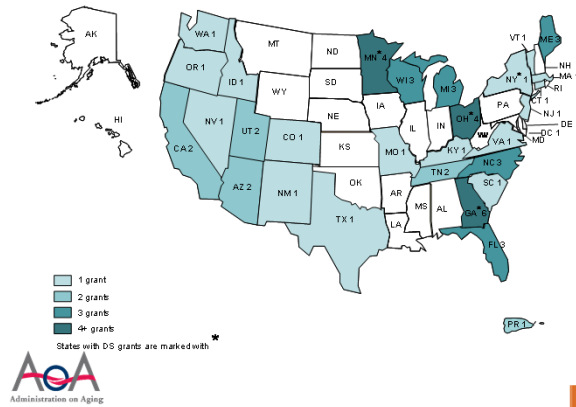
- Video clips of care coordinators describing cases of two individuals exhibiting challenging behaviors
- Told through the eyes of a new and an experienced care coordinator
- Tips and resources are then provided by a “panel of consultants” from the IL Alzheimer’s Disease Assistance Centers.
- Highlighted issues of self-neglect, capacity, wandering, how to respond to combative behaviors

Illinois Cognitive Resources Network (ICRN)



Obtaining Federal Funds

Total Active ADSSP Grants



Illinois Cognitive Resources Network (ICRN)



Illinois Dementia-Capable Grant

The Illinois Department on Aging, in **partnership** with other state agencies, Alzheimer’s Association Chapters, Area Agencies on Aging, and other key stakeholders will expand a statewide coordinated system that builds on the service infrastructure currently in place.

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.

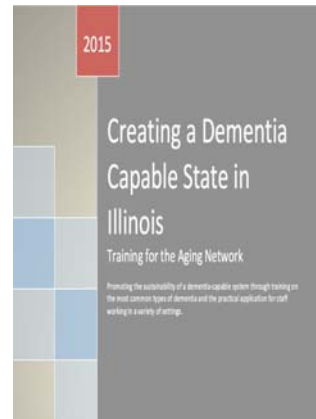
Three-year grant from the Administration on Community Living (2013-2016)

Illinois Cognitive Resources Network (ICRN)



Dementia-Capable State Grant Objectives

- Dementia-capable access and referral services;
- State-wide dementia-capable training
 - ▣ Aging Network, Adult Protective Services, SHIP, Supportive Living, Managed Implement Options Counseling services on a statewide basis
- Savvy Caregiver in selected Planning and Service Areas;
- Link individuals with dementia and their caregivers to a comprehensive set of dementia-capable services including care transition services;
- Streamline the dementia capable public program eligibility determination process;
- Develop a data collection and quality assurance system; and,
- Ensure sustainability of the dementia-capable home and community-based service system.



Illinois Cognitive Resources Network (ICRN)



Healthy Brain Initiative Roadmap

- **Illinois Awarded Roadmap Funds**
 - ▣ IDPH placed importance on applying for funds
 - ▣ One of six entities to receive grant –
 - Arizona, Hawaii, Illinois, Minnesota, Wisconsin and Puerto Rico
 - ▣ April 1, 2014 to March 31, 2015; April 1-September 30, 2015
 - ▣ Intended outcomes:
 - 1) Apply public health expertise to cognitive health issues,
 - 2) Build the momentum in states,
 - 3) Enhance surveillance and epidemiological work related to cognitive impairment, and
 - 4) Improve capacity for states to address cognitive health as a *growing public health problem*.
- All funds awarded to partner grantees.

Illinois Cognitive Resources Network (ICRN)



Geriatric Workforce Enhancement Program

The Geriatrics Workforce Enhancement Program aims to improve the quality of healthcare for older Americans by:

- Changing clinical training environments into integrated geriatrics and primary care delivery systems.
- Training providers who can assess and address the needs of older adults and their families or caregivers at the individual, community, and population levels.
- Delivering community-based programs that will provide patients, families, and caregivers with the knowledge and skills to improve health outcomes and the quality of care for older adults.

Illinois Cognitive Resources Network (ICRN)



Healthy Brain Research Network

- Network activities will build on the mission of CDC's Healthy Brain Research Network to
- Better understand attitudes and perceived changes in cognitive functioning over time through public health surveillance.
- Build a strong evidence base for communication (e.g., messaging) and programmatic interventions to improve or maintain cognitive function.
- Translate that evidence base into effective public health programs and practices in states and communities.

University of Illinois at Chicago added as network member in 2015

Illinois Cognitive Resources Network (ICRN)



Conclusion

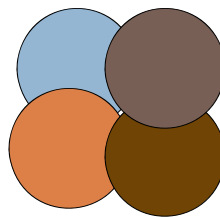
State-wide, diverse and inclusive, “community of care” groups are needed to best meet the needs of persons living with or at risk for cognitive loss and their support systems.

Early trust-building and open-communication efforts can lead to a significant process of improvement.

We hope Illinois Cognitive Resources Network can serve as a continuing example of a model that can be translated to other States/communities.

Communities

Health Care Providers



Illinois Cognitive Resources Network (ICRN)

Persons & Families

Researchers



Acknowledgements

□ The Illinois Cognitive Resources Network – Acknowledgements

- **Aging Network:** Area Agencies on Aging – Age Options/Suburban Cook, City of Chicago, Lincolnland, & Northwestern Illinois; Illinois Association of Area Agencies on Aging (I4A); Illinois Department on Aging; Rush Health and Aging
- **Alzheimer’s Association:** Central Illinois; Greater Illinois; Greater Iowa; St. Louis Chapters
- **Alzheimer’s Disease Assistance Centers:** Northwestern University Feinberg School of Medicine - Cognitive Neurology and Alzheimer’s Disease Center; Rush University Medical Center - Rush Alzheimer’s Disease Center; Southern Illinois University School of Medicine - Center for Alzheimer’s Disease and Related Disorders
- **Disability Network:** Department of Human Services, Division of Rehabilitation Services, Bureau of Home Services
- **Illinois Department of Public Health; National Institutes on Health**

Illinois Cognitive Resources Network (ICRN)



Illinois Cognitive Resources Network – Contact Information

Raj C. Shah, MD
Associate Professor, Family Medicine and Rush
Alzheimer's Disease Center
Rush University Medical Center
600 South Paulina, Suite 1022
Chicago, Illinois 60612
Raj_C_Shah@rush.edu

www.ilbrainhealth.org

Illinois Cognitive Resources Network (ICRN)



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 5.3 million people.
- 210,000 Illinoisans have Alzheimer's.
- Alzheimer's - 6th leading cause of death in the US
- One-third of all seniors who die in a given year have been diagnosed with Alzheimer's or another dementia.
- Between 2000-2013, % of deaths from heart disease, stroke, prostate cancer and HIV ↓14%, 23%, 11% and 52%, respectively, while % from AD ↑71%.

Alzheimer's Association, 2015 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia 11 (2015) 332-384



Cost to Society

- In 2013 15.5 million caregivers provided an estimated 17.7 billion hours of unpaid care valued at \$220 billion.
- 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.

Alzheimer's Association, 2015 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia 11 (2015) 332-384



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.

Alzheimer's Association, 2015 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia 11 (2015) 332-384



A Poll of County Health Departments in Rural Illinois Regarding the Evaluation of Alzheimer's Disease and the Availability of Related Educational Information

Tom Ala, MD & Greg Kyrouac, MEd
 Center for Alzheimer Disease & Related Disorders
 Southern Illinois University School of Medicine
 Springfield, Illinois

(originally presented at 136th American Public Health Association Annual Meeting, San Diego, CA; October 2008)

gkyrouac@siumed.edu

www.siumed.edu/alz



Objectives

- Determine the level of awareness of Alzheimer disease (AD) care in out-state Illinois.
- Determine the level of awareness of rural health care providers for the SIU Primary Provider Program.

Out-state Illinois means outside of the nine county region encompassing Chicago and its suburbs.



Methods

- Telephone calls to every county health department to determine:
 - if they know where people may be evaluated for AD.
 - if they know where information about AD may be obtained.
 - if they know how an in-home evaluation of a suspected AD patient could be arranged (if the person refuses to travel to a physician's office).
 - if they are aware of the SIU Primary Provider (PP) program.



Primary Provider program

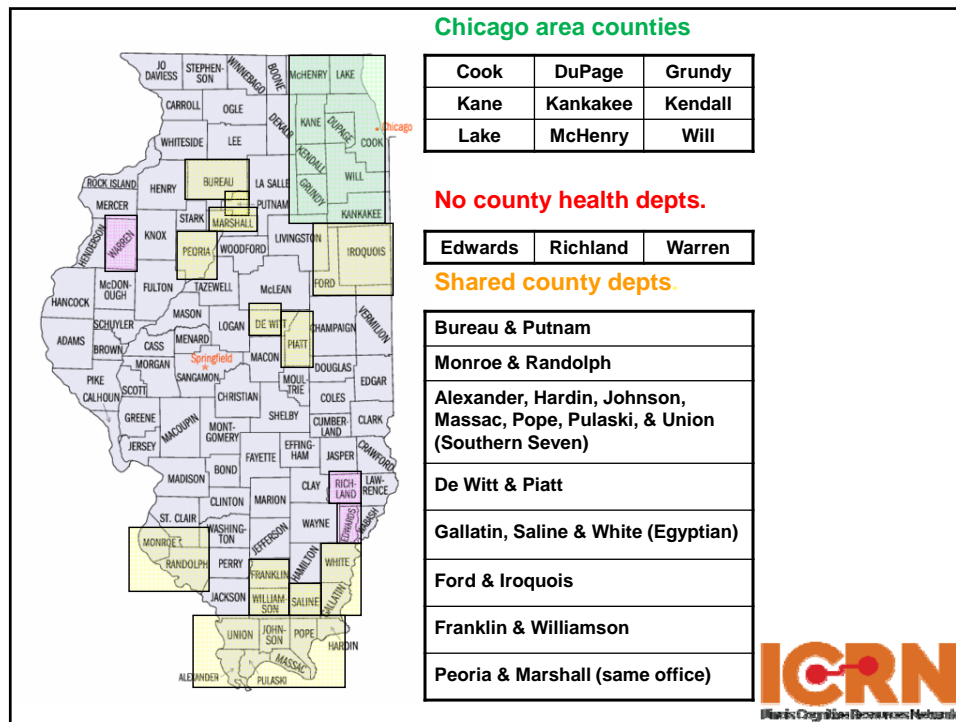
29 members



County Health Departments

- Name and phone number were obtained from the Illinois Department of Public Health website.
- 93 rural Illinois counties
 - ▣ 102 total minus 9 Chicago-area counties.
- 3 counties had no office.
- 20 counties combined into 7 offices.
- 2 counties shared same office.
- n=77 county offices called





Specific questions asked of the county health departments

- “I am calling to find out where in this area someone could be evaluated for symptoms of AD.” *If asked, this person would not have a primary care doctor.*
- “Do you know where I can get educational information about AD in this area?”
- “If the person refuses to come in for an evaluation, do you know how I might be able to have someone visit her in her home to see if she needs professional help?”

Results of calling the county health departments

- Regarding where can one be evaluated for AD:
 - 29 Excellent (provided name & number of specific clinic or PP site) (*mentioned 17 different sites*)
 - 36 Good (provided name & number of indirect resource)
 - 6 Fair (provided general information without number)
 - 2 Fair (name but incorrect number of an indirect resource)
 - 2 Fair (directed the caller to a nursing home)
 - 2 Poor (provided no information)



Results of calling the county health departments

- Regarding where can one be evaluated for AD:
 - 65 (84%) Good-Excellent
 - 10 (13%) Fair
 - 2 (3%) Poor



Results of calling the county health departments

- Regarding where one could obtain educational material:
 - 47 provided a specific phone number, website, organization, or offered to send information.
 - 25 provided nonspecific information, such as searching the internet, using the phone book, going to a library, or calling a doctor's office.
 - 6 did not provide any help.
 - 13 of the above recommended calling the Alzheimer's Association (9 providing the phone number).



Results of calling the county health departments

- Regarding where one could obtain educational material:
 - 47 (61%) Good-Excellent
 - 25 (32%) Fair
 - 6 (8%) Poor
 - 13 (17%) recommended the Alzheimer's Association



Results of calling the county health departments

- Regarding how one could have an uncooperative patient evaluated in his/her home:
 - 3 a nurse can make a visit.
 - 53 referred the caller to another resource.
 - 12 didn't know with no information provided.
 - 1 hung up the phone.
 - 5 a doctor's order was needed for a nurse visit.
 - 2 a legal order would be necessary.
 - 1 recommended nursing home placement.



Results of calling the county health departments

- Regarding how one could have an uncooperative patient evaluated in his/her home:
 - 3 (4%) Good-excellent
 - 53 (69%) Fair
 - 13 (17%) Poor
 - 8 (10%) Misleading/Wrong



Conclusions of this exercise

- The county health departments are helpful but could be better informed.
- The Alzheimer's Association is not well-known.
- The SIU Primary Provider Program is not well-known.
 - ▣ Subsequently renamed Memory & Aging Network, currently with 31 sites.



Has the situation changed in the last seven years regarding Alzheimer's Awareness and Access?

2014 State of Illinois Alzheimer's Disease Annual Survey
conducted by the
Alzheimer's Association, Greater Illinois Chapter,
released July 8, 2014



When it comes to getting information about Alzheimer's disease, which of the following do YOU trust the most?

- ▣ **58.7%** - The Alzheimer's Association
- ▣ **21.3%** - My doctor
- ▣ **14.6%** - Leading scientists/researchers
- ▣ **3.9%** - Online sources like WebMD
- ▣ **1.0%** - The Media
- ▣ **0.3%** - My county health department
- ▣ **0.1%** - The State of Illinois

From the 2014 State of Illinois Alzheimer's Disease Annual Survey conducted by Alzheimer's Association, Greater Illinois Chapter, released July 8, 2014



How did you learn about community services that are available in your area?

- ▣ **43.1%** - The Alzheimer's Association
- ▣ **35.1%** - Word of mouth/family & friends
- ▣ **34.0%** - Online Internet searches
- ▣ **24.6%** - My doctor or my doctor's staff
- ▣ **16.5%** - Alzheimer's support group
- ▣ **16.5%** - The Area Agency on Aging
- ▣ **8.1%** - The Media
- ▣ **7.4%** - My senior center
- ▣ **4.7%** - My employer (HR/EAP)
- ▣ **2.9%** - My religious organization
- ▣ **2.4%** - My county's health department

From the 2014 State of Illinois Alzheimer's Disease Annual Survey conducted by Alzheimer's Association, Greater Illinois Chapter, released July 8, 2014



UPDATE: Has the situation changed in the last seven years regarding Alzheimer's Awareness and Access?

2015 State of Illinois Alzheimer's Disease Annual Survey
conducted by the
Alzheimer's Association, Greater Illinois Chapter,
released **Monday, November 2, 2015**



When it comes to getting information about Alzheimer's disease, which of the following do YOU trust the most?

- ▣ **58.7%** - The Alzheimer's Association (0.0)
- ▣ **12.6%** - My doctor (↓8.7)
- ▣ **17.6%** - Leading scientists/researchers (↑ 3.0)
- ▣ **1.0%** - The Media (0.0)
- ▣ **0.7%** - My county health department (↑ 0.4)

From the 2015 State of Illinois Alzheimer's Disease Annual Survey
conducted by Alzheimer's Association, Greater Illinois Chapter, released
November 2, 2015



Comments

- Should a case be made for better training of those on the front lines?
 - Availability of resources?
 - Willingness or insight to refer the caller to someone who might have a better answer?
 - Are the responses of those on the front lines true reflections of their clinic philosophy?



Conversations with persons with dementia and their families