Integrated delivery of early detection, diagnosis and support for Alzheimer's disease and other dementias in rural populations: *challenges and opportunities*

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Session Objectives

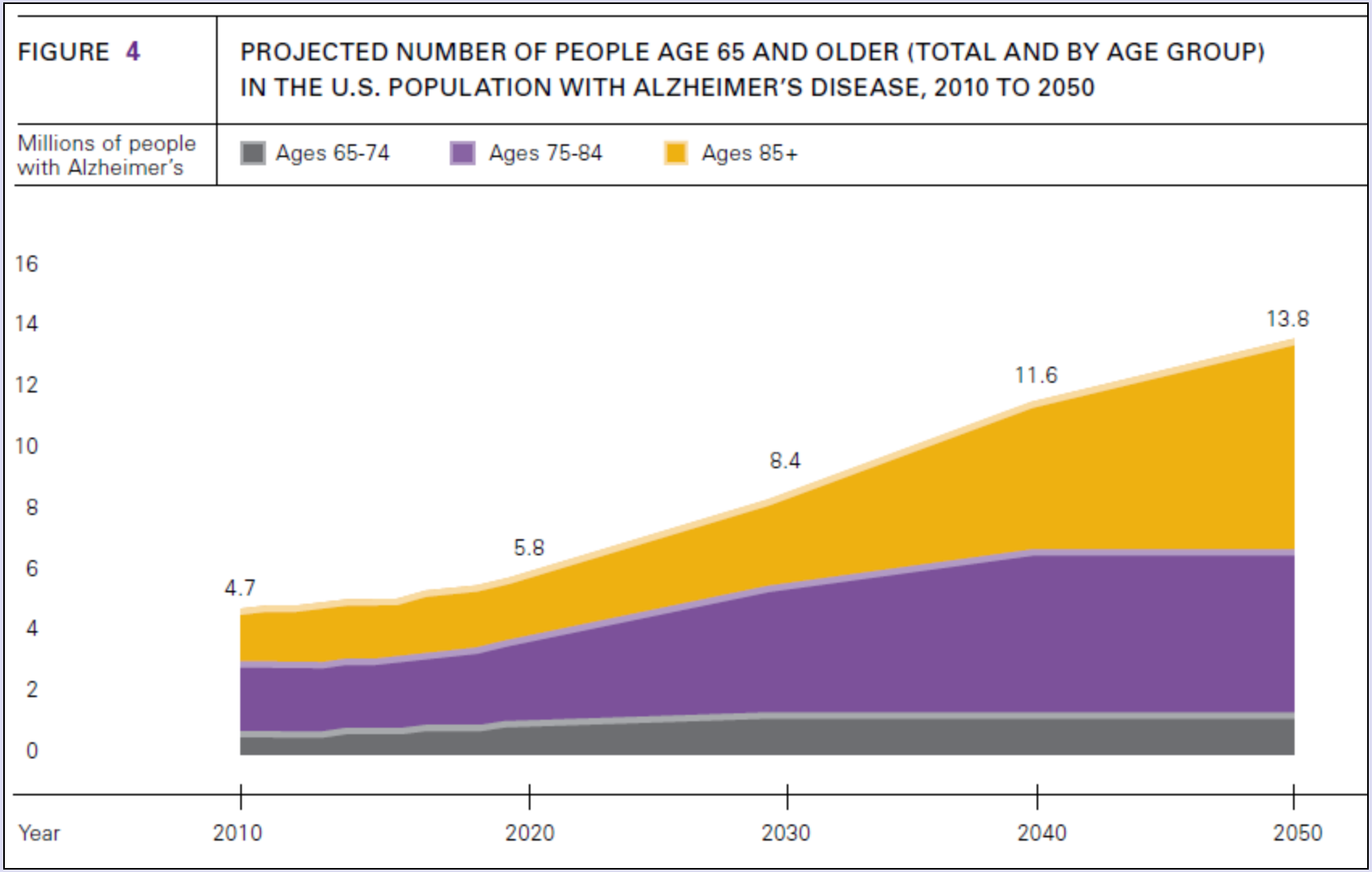
- To learn about the merits of early detection of dementia
- To better understand the integrated approach required to meet the needs of the patient, family, medical providers, and support service providers regarding a diagnosis of Alzheimer's disease and other dementias
- To better understand options for connection to community support service
- To learn about the state of Minnesota initiative "ACT on Alzheimer's"

Alzheimer's Disease International World Alzheimer Report 2011

Impact of Alzheimer's Disease

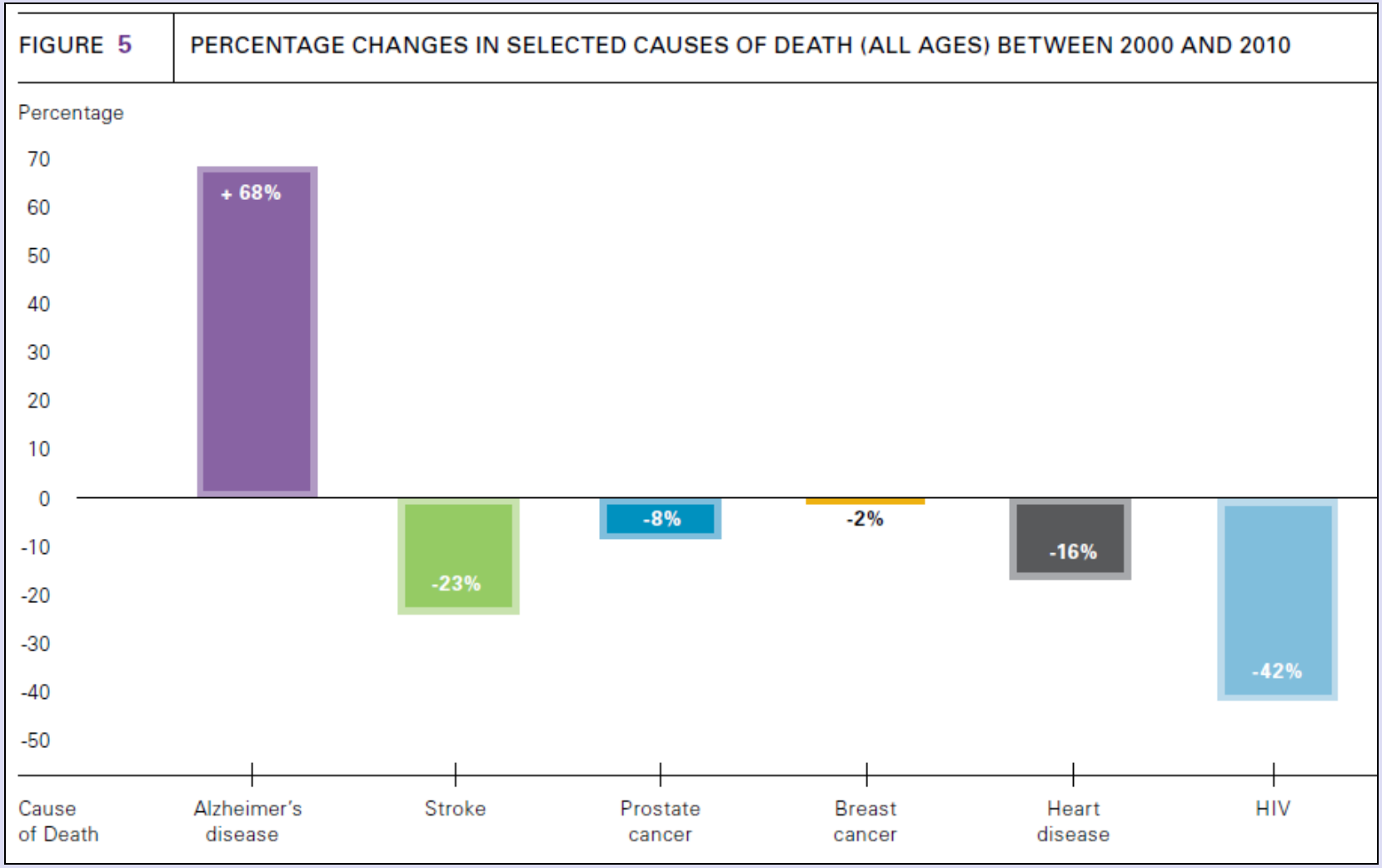
Impact of Alzheimer's Disease: Prevalence

FIGURE 4 PROJECTED NUMBER OF PEOPLE AGE 65 AND OLDER (TOTAL AND BY AGE GROUP) IN THE U.S. POPULATION WITH ALZHEIMER'S DISEASE, 2010 TO 2050



www.alz.org - *2013 Alzheimer's Disease Facts and Figures*

Impact of Alzheimer's Disease: Mortality

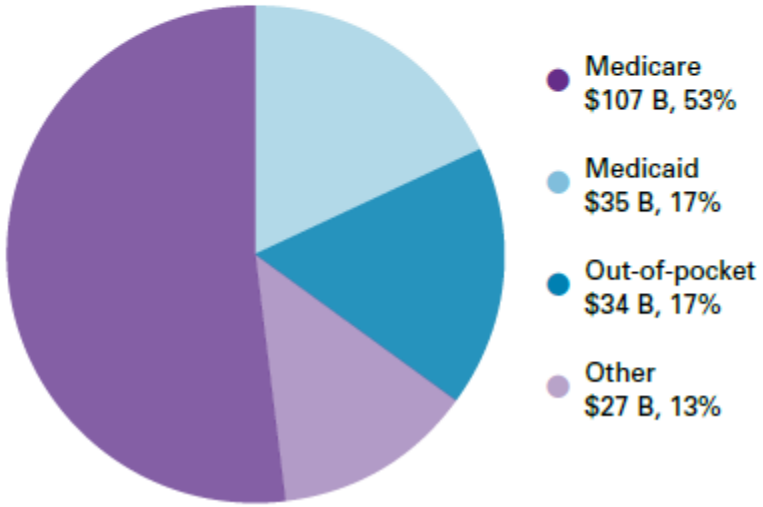


www.alz.org - *2013 Alzheimer's Disease Facts and Figures*

Impact of Alzheimer's Disease: Cost

FIGURE 10 AGGREGATE COSTS OF CARE BY PAYER FOR AMERICANS AGE 65 AND OLDER WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS, 2013*

Total cost: $203 Billion (B)



www.alz.org - 2013 Alzheimer's Disease Facts and Figures

Merits of early detection of Alzheimer's disease and related dementias

Benefits of Early Diagnosis

- Optimize current medical management
- Improve clinical outcomes
- Relief gained from better understanding
- Maximize decision-making autonomy
- Open the door to service delivery
- Risk reduction
- Plan for the future
- Avoid or reduce future costs
- Diagnosis as a human right

Alzheimer's Disease International World Alzheimer Report 2011

Barriers to Early ID & Treatment

- Cognitive Assessment
  - Medicare Annual Wellness visit cognitive assessment not yet integrated into usual care
  - Assessment tools/ measures & methods not defined by CMS
- AD Diagnosis
  - less than 50% diagnosed in primary care
  - less than 35% have diagnosis in medical record
- AD Treatment
  - less than 50% of those diagnosed receive any drug or non-drug treatment (disease education, etc)
  - 2 year delay from MD referral to patient action

Physician Barriers to Early Diagnosis

- Insufficient training, knowledge
  - Limited knowledge of screening/diagnostic/management tools
  - Mistaking signs of dementia for normal aging
- Perceived limitation of treatment options
  - Lack of appreciation for the impact of early intervention
- Disclosure discomfort
  - Fear of delivering a “death sentence”
  - Fear of patient, family reaction
  - Concern about making the wrong diagnosis
  - Fear of opening Pandora’s box and managing a patient’s complex needs
  - Potential negative implications for the provider/patient relationship

Barriers to Community Connection

1. Under-diagnosis
2. Lack of understanding about benefits of non-drug treatment
3. Lack of knowledge about available resources
4. Missed / delayed connection to resources
5. Unprepared communities

Universal Themes in Dementia

1. Lack of knowledge / education
2. Need for support and respite
3. Emotional stress, burden
4. Role changes
5. Interplay of family dynamics
6. Communication difficulties
7. Neglected health of caregivers
8. Need to support individual with dementia
9. Challenging behaviors
10. Planning for the future

Integrated approach required to meet the needs of the patient, family, medical providers, and support service providers

Essentia Health: Challenges and Opportunities

- Problem:
  - Essentia Health is an integrated health care system (68 clinics, 18 hospitals, > 1500 providers, > 900,000 patients) in MN, WI, ND, ID
  - *There is an urgent need to improve all aspects of dementia care*
    - provide a standardized approach to dementia screening, diagnosis, and management of dementia and other chronic conditions
    - imperative in order to sustain quality of life for the individual with dementia and for their family

Dementia Care at Essentia Health

- Critical issues
  - standardized and centralized care
  - improved access
  - delivery of services on a timely basis
- Overcome barriers to making a diagnosis of dementia
  - doubts about value of diagnosis given limited treatment options
  - concern over risk of misdiagnosis
  - lack of knowledge of local dementia support services

Recognize barriers and then propose/evaluate ways to overcome them through training, education, and facilitation

Dementia Care at Essentia Health

- Development
  - Advisory workgroup
    - primary care (providers, nurse practitioners, and staff in family medicine, elder care, internal medicine)
    - Specialty care (neurology, neuropsychology)
    - Community partners (Alzheimer's Association-local and state, Arrowhead Area Agency on Aging, and Family Memory Care Consultants)
  - SmartSet for electronic medical record (EPIC/Encompass) created based on ACT on Alzheimer's Physician tool kit of screening, diagnostic, post-diagnostic algorithms

Essentia Health
Dementia Capable Health Care Homes

- Integration and implementation
  - Goal: implement and evaluate standardized approach to dementia diagnosis and care to improve outcomes for patients and families
  - Pilot testing to occur at two HCH sites

Clinic	Setting	Population 65+	HCH
EH-Ely	Rural	1,900	Established
EH-West Duluth	Urban	2,200	New

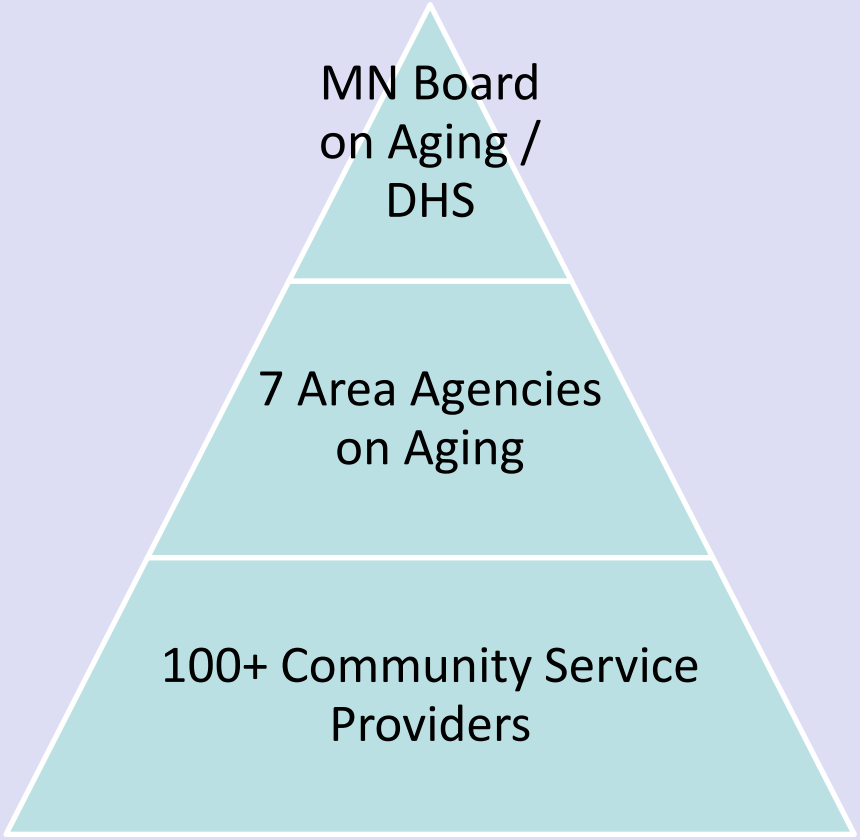
Essentia Health
Dementia Capable HCH Lessons

- Expectations for lessons learned from pilot testing phase
  - Evaluate effectiveness of implementation into existing care management models
  - Improve efficiency and flow throughout EH system
  - Evaluation impact on individuals and their families
  - Cost of care
  - Provide foundation to inform integration and implementation throughout the EH system

Options for connection to support service providers

ARDC Arrowhead Area Agency on Aging (AAAA)

MN's Aging Network



How Area Agencies Have Impact

- Consult *one-on-one* with older adults and their families about services, housing choices, caregiver support, Medicare, benefits, county services
- Help older adults transition across care settings
- Identify needs and distribute federal and state resources to fund services for seniors and caregivers
- Partner to develop effective services and programs

Minnesota's Aging Network

Minnesota Board on Aging designated Area Agencies on Aging for statewide coverage

- Experts on community services, caregiving, volunteer support, housing options, Medicare and public benefits
- Hub organization for local vendor networks and regional "Aging Network"

Integrated delivery of early detection and support from Aging Network perspective

Opportunities

- Aging Network has been seeking this opportunity to partner with health care in systematic way for a long time. Our services, many targeted to people not on Medicaid programs, are important affordable supports to help individuals achieve their health care goals.
- Area Agencies on Aging / Senior LinkAge Line® will bring our expertise on community services (and local networks) , community service navigators, housing, financing options, Medicare and other public programs to the table.

Challenges

- Need better infrastructure for efficient and secure communication between community providers to allow sharing and coordinating care plans.
- Service coverage for many services in rural areas not uniform – service voids in some areas.
- Multiple “coordinator/ navigator” roles emerging on health care and community care side. Finding one another and role sorting will take time.

AAAA: Response to Essentia's Dementia Initiative

- Facilitating small work group of community service providers serving pilot clinic locations
  - AAAA / Senior LinkAge Line®
  - Alzheimer's Association
  - Minnesota Family Memory Program (VSCCI)
- All share capacity to offer counseling in some form and connection to other community services
- Exploring care planning tools/protocols / communication processes within (and beyond) the group to understand best way to collectively support clinic efforts to identify persons with dementia.
- Goal is quality consumer experience / minimize duplication / maximize use of scare counseling resources.

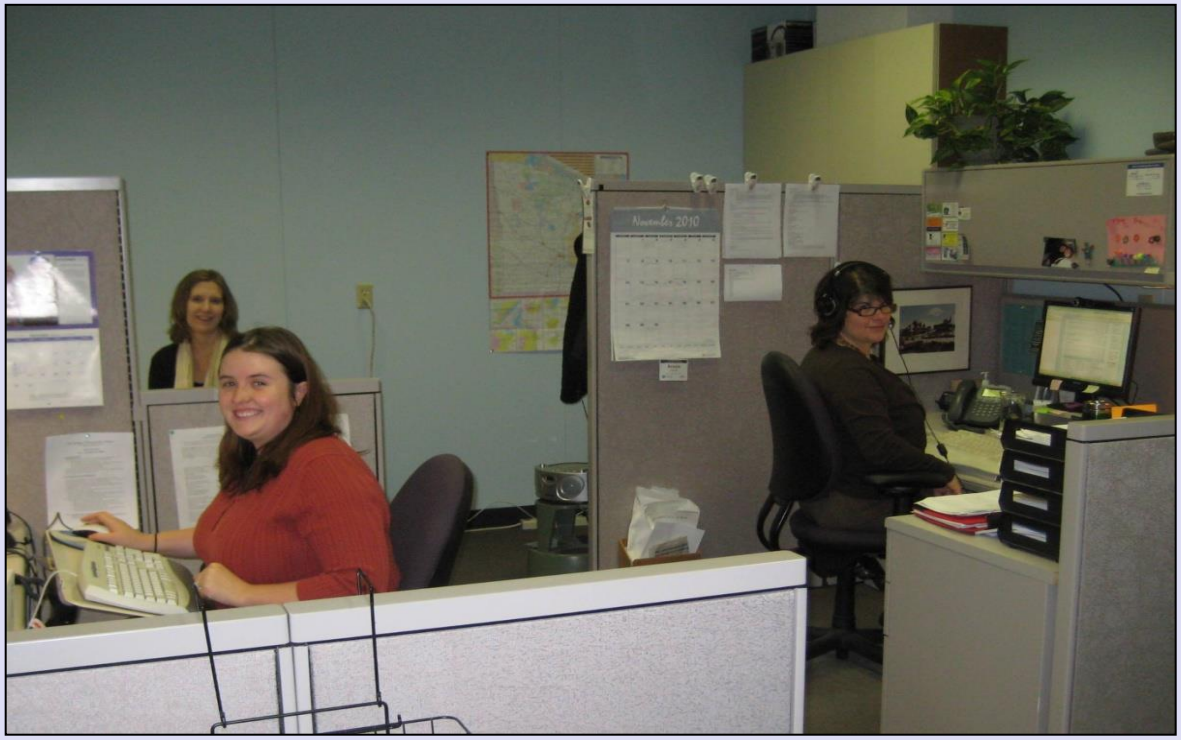
Minnesota Aging Network
Select Services - 2012

Service	Consumers
Caregiver Services	12,500
Chore/Homemaker	5,000
Home Delivery Meals	11,400
Transportation	13,000
Legal Assistance	4,900
Matter of Balance Chronic Disease Self Management	1,400
Information and Assistance **Senior LinkAge Line®**	87,800

Average Age: 78
71% Rural
50% Live Alone
? % with memory loss

100+ Contracted Community Providers
330,000 volunteer hours

Senior LinkAge Line®
Arrowhead Contact Center



ARDC Arrowhead Area Agency on Aging
Duluth, MN

Senior LinkAge Line®

Free, objective and comprehensive counseling

- ✓ **By phone** 1-800-333-2433
- ✓ **In-person** at outreach locations
- ✓ **On-line** chat at MN Help Network at www.MinnesotaHelp.info®
- ✓ Provided via 7 contact centers across the state - employees of Area Agencies on Aging
  - Warren, Fergus Falls, St. Paul, Slayton, Rochester, Duluth, St. Cloud

MN law on Referrals to Senior LinkAge Line®

Minnesota Statute 2010, Section 256B.0911

Requires Senior LinkAge Line® to develop referral protocols and processes that will assist certified health care homes and hospitals to identify older adults at risk of nursing home placement (and those with current and anticipated long term care needs) and determine when to refer these individuals to the Senior LinkAge Line® for long-term care options counseling.

Referral forms to connect Senior LinkAge Line® to patients

- https://mnhelpforms.revation.com/hhcreferral/form.php
- http://www.mnaging.net/~/media/MNAging/Docs/Advisor/LTCCE/LTCCE_HCH-HospitalReferral_FaxForm_2013-01.ashx

A glimpse of what rural community support can look like

Care Consultant
Caregiver Consultant

Photo courtesy of Community Partners Living at Home Program – Two Harbors, MN

Exercise Buddies: helping to maintain function

Photo courtesy of Northwoods Hospice Respite Partners – Ely, MN

Providing companionship and respite for caregiver while caregiver attends a support group

Photo courtesy of Northwoods Hospice Respite Partners – Ely, MN

A ride to the doctor’s office

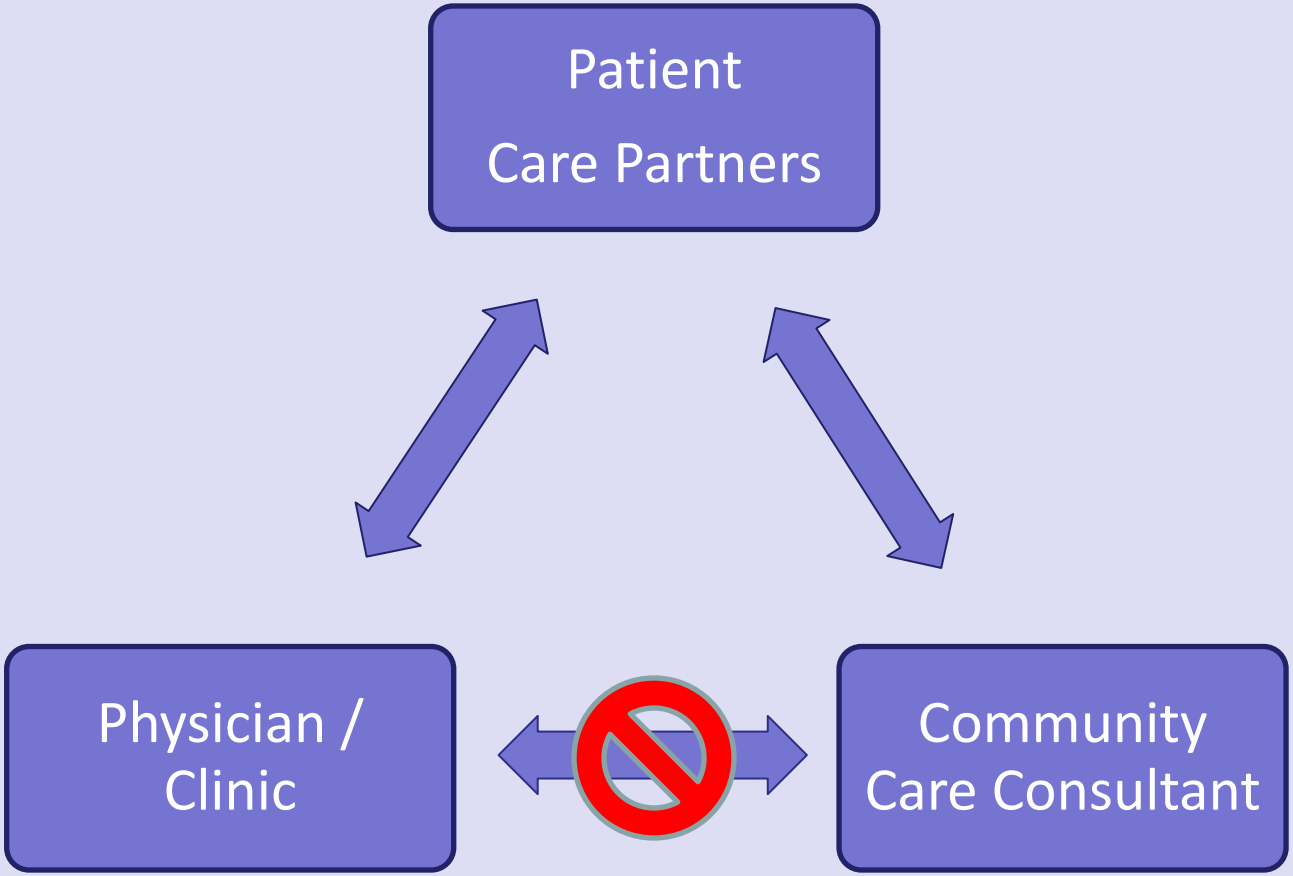
Photo courtesy of Volunteer Services of Carlton County, Inc.

Adult Day Program

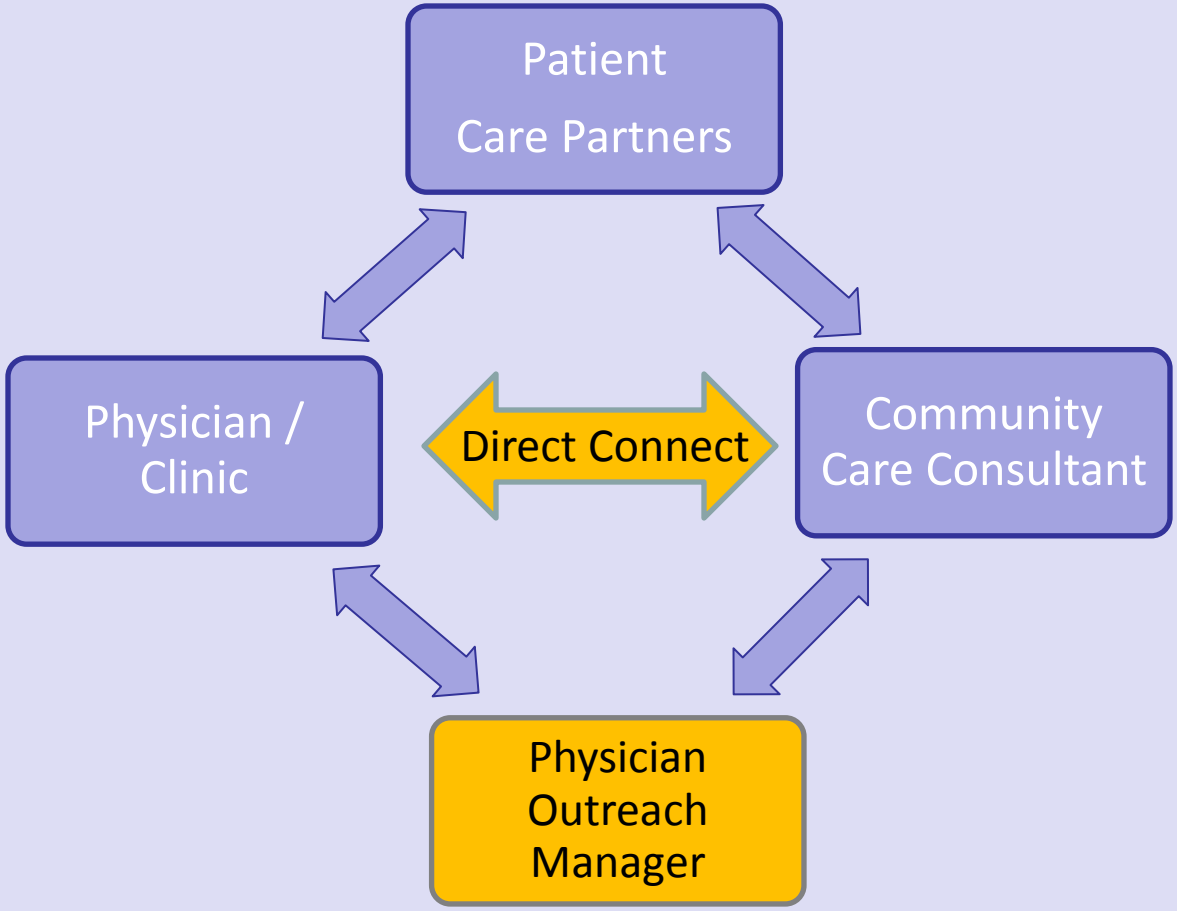
Photo courtesy of ElderCircle Adult Day Program – Grand Rapids, MN

The role of warm connection

Usual Care


Patient
Care Partners
Physician / Clinic
Community Care Consultant

Program Example:
Alzheimer's Association Direct Connect



Direct Connect Goals

- Strengthen physician relationships
- Encourage earlier diagnosis
- Increase physician referrals
- Reduce the time between diagnosis & non-drug treatment from 2 years to 2 weeks
- Support families through education, planning assistance, and connection to programs & services that improve quality of life

Direct Connect Process

- MD recommends non-drug treatment as part of care plan upon diagnosis
- Patient signs records release waiver
- Waiver with patient information faxed to secure line at Alzheimer's Association
- Care Consultant follows up with patient
- Plan developed, patient introduced to services
- Plan communicated to physician

Patient Referral Form

Provider: Please *FAX* to 1-(866) 555-5555

Patient

I give permission for my physician to give my name, address, phone number, and the patient information below to the Alzheimer's Association so that a representative from the Association may contact me or my personal representative about support and educational opportunities that are available to me and my family. I understand that the Association will be providing feedback to my physician based on our contact.

Patient's Signature_____ Date_____

(Please Print)

May we identify ourselves as the Alzheimer's Association when we contact you? □ Yes □ No

* * * * * *

Personal Representative's Name_____ Date_____

(Please Print)

Phone Number_____Relationship to Person with Memory Problem: _____

Name of Patient_____MoCA/MMSE/SLUMS Score_____

Diagnosis_____Date of diagnosis_____

Primary Concerns/Reason for Referral:

- Discuss medical and legal powers of attorney
- Mentor program
- Provide options for adult day programs in the community
- Caregiver respite options, in home care aids
- Discuss medication compliance and management
- Caregiver stress reduction strategies
- Early Stage programs
- Alternative living planning (Memory Care, Assisted Living)
- Safe Return Program
- Support groups

Physician's Signature _____

Progress Report

alzheimer's association

To Referring Partner: Dr. James Smith

Phone #: 651-551-5151

Fax #: 651-254-0012

RE: John Erickson (pt) Jill Erickson (spouse)

Address: 3700 Sunset Blvd Minneapolis, MN 55439

Dear Dr. Smith,

Thank you for referring John and Jill for care consultation at the Alzheimer's Association. This correspondence indicates that we have received the referral and we have taken steps to contact the individual listed above.

At this time we are successful with talking with the caregiver. The following is what transpired during our contact:
- Scheduled in person individual/family meeting
- Meeting scheduled for: 2/2/12

Additional information provided:

Medic Alert Safe Return
Meeting of the Minds conference brochure
Trial Match- clinical trials brochure
Education about dementia and progression, importance of asking for help from friends/family
Education on senior housing, day programs and home health care
Living Well workbook

**See attached care plan

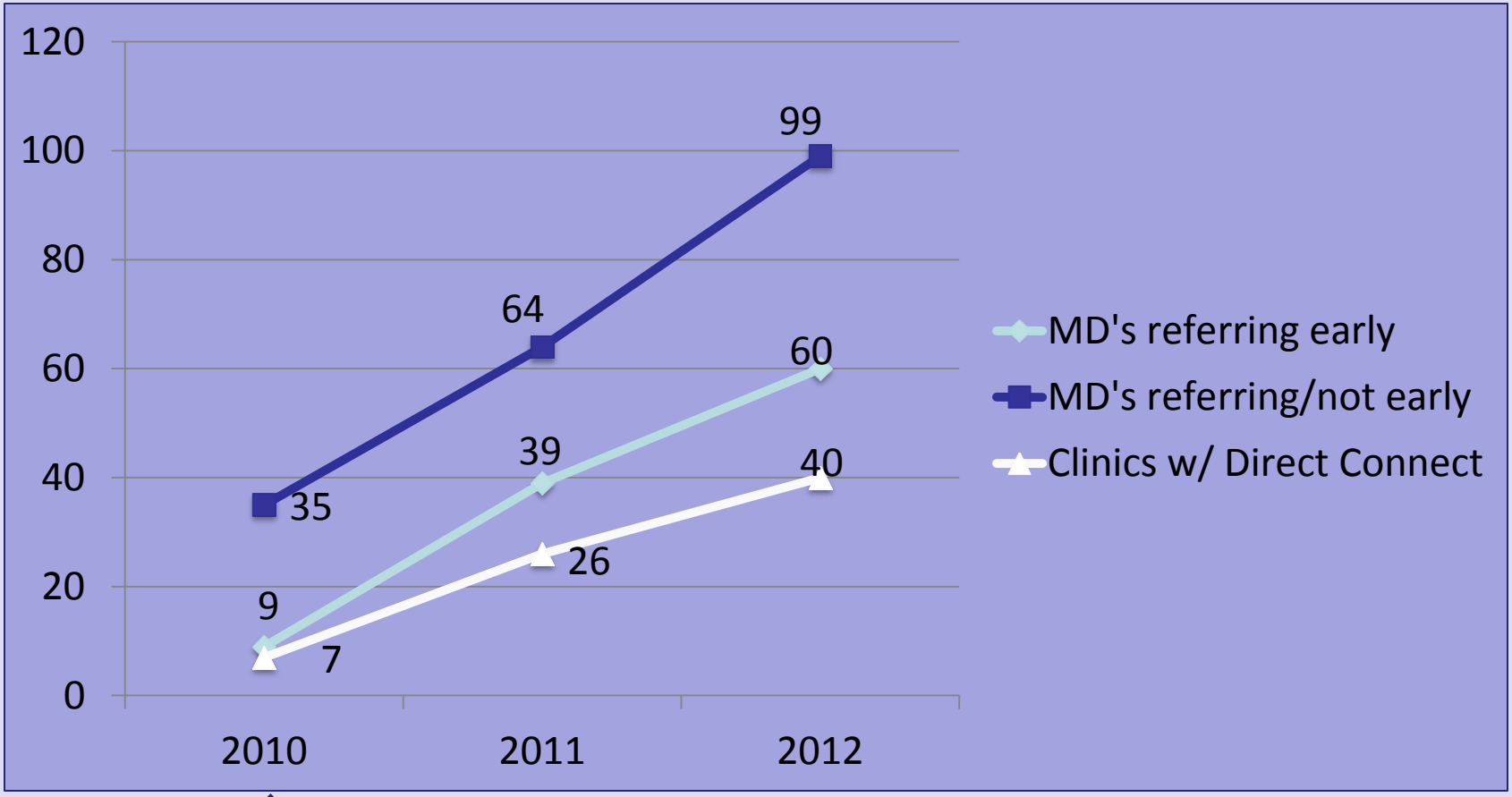
Thank you for the opportunity to work with this individual/family. Please contact us if we can be of further assistance!

Direct Connect Program Video

Direct Connect Outcomes

- Increased physician referrals & number of physicians referring
- Strengthened physician relationships
- Encouraged earlier diagnosis / treatment
- Reduced the time between diagnosis & non-drug treatment from 2 years to 2 weeks
- Increased the number of families supported through education, planning assistance, and connection to community-based programs & services that improve quality of life

What type of referrals do we get?



MD Outreach Manager Hired

Challenges

- Direct Connect must be explained in detail and reinforced for doctors to adopt / begin using
- Need the right staff person for MD outreach
  - Social workers may not be trained in physician outreach and engagement
- Time constraints: it takes patience and ongoing / multiple clinic visits to make referrals happen
- Direct Connect is only maintained if feedback loop with care consultant is in place

State of Minnesota initiative: ACT on Alzheimer's

What is ACT on Alzheimer's

statewide

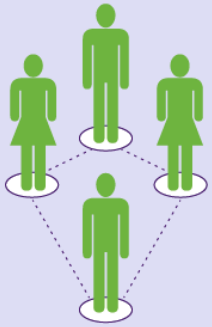
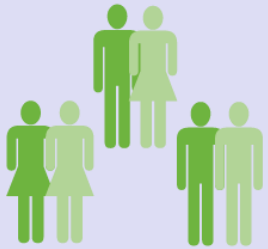
50+
ORGANIZATIONS

150+
INDIVIDUALS

voluntary

collaborative

IMPACTS OF ALZHEIMER'S

BUDGETARY	SOCIAL	PERSONAL
		

Genesis of ACT on Alzheimer's

- 2009 Legislative Mandate for Alzheimer's Disease Working Group (ADWG)
- Legislative Report Filed in January 2011
- ACT on Alzheimer's is second generation of work focusing on implementation

Goals of ACT on Alzheimer's

identify & invest in promising approaches

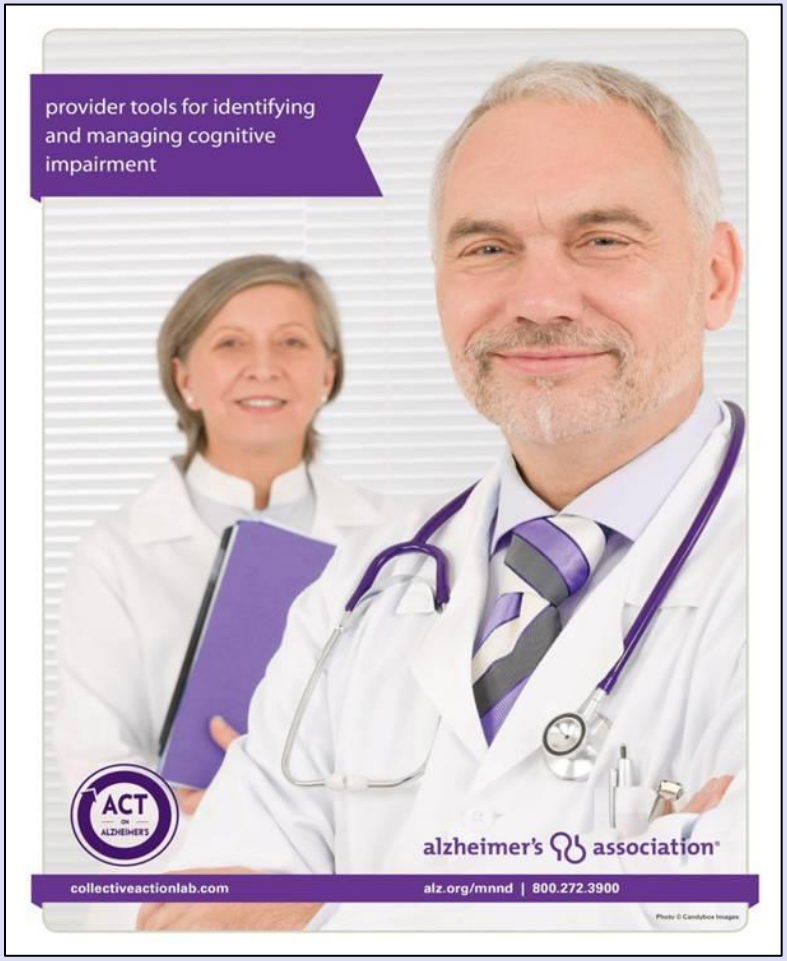
increase detection & improve care

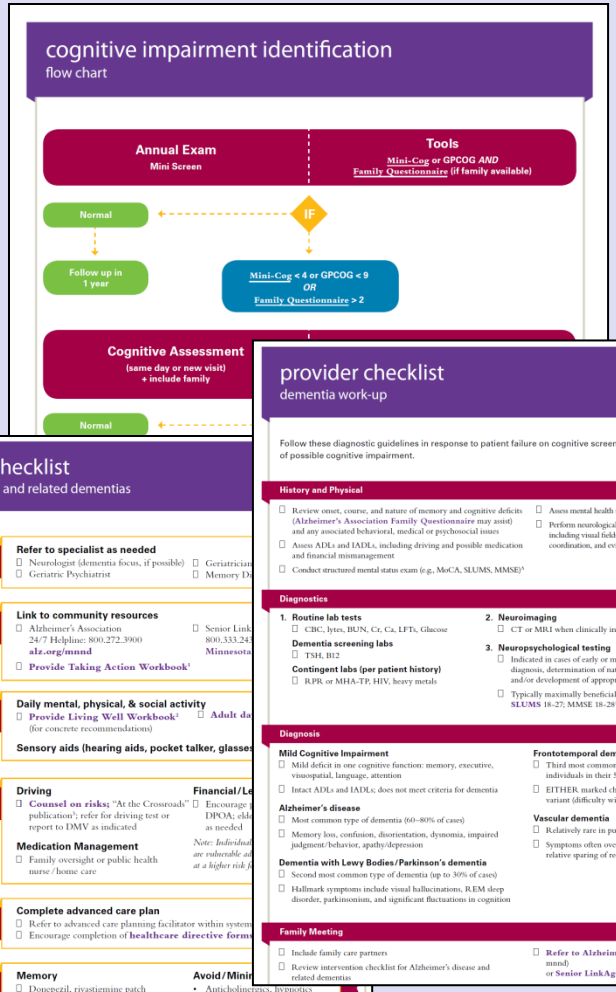
raise awareness & reduce stigma

sustain caregivers

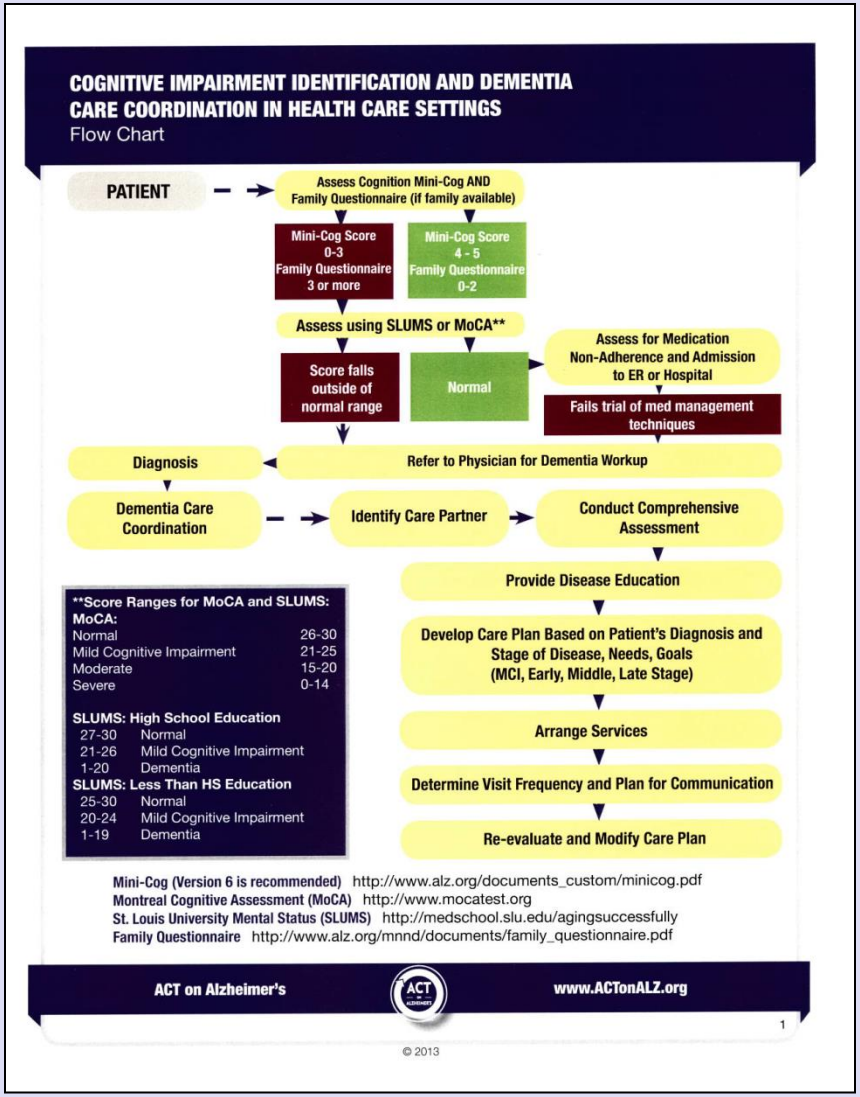
equip communities

Provider Practice Tools





Improving Care Coordination

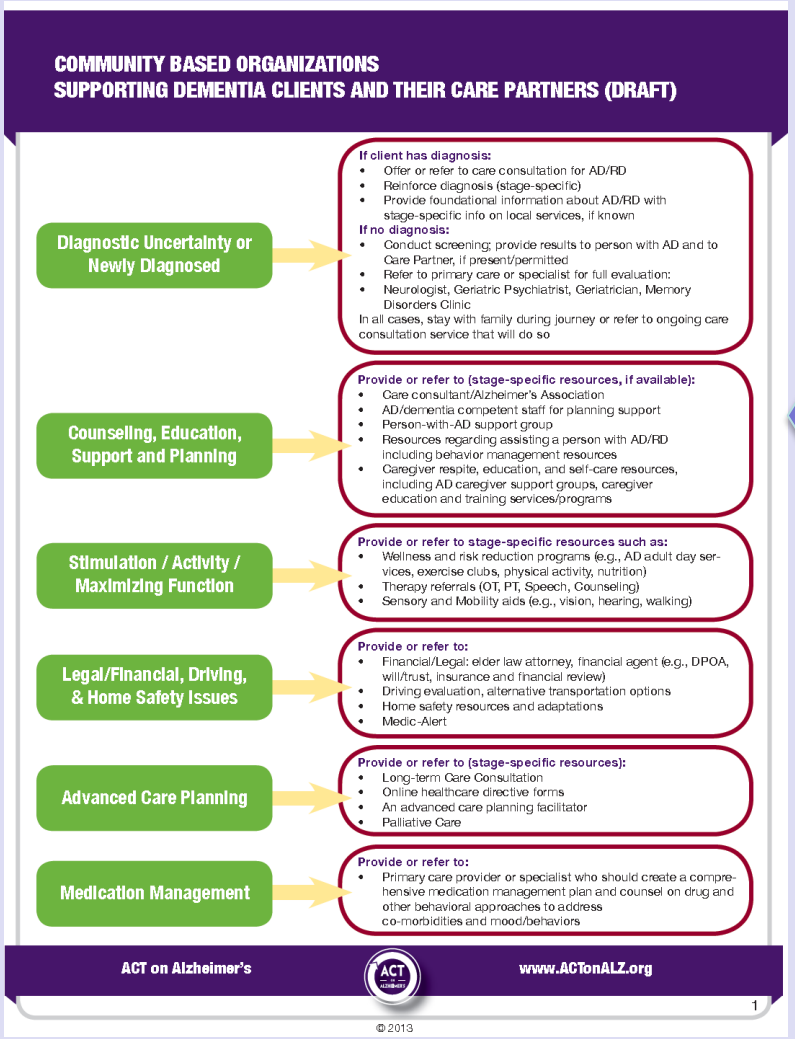


- Care Coordinators in Health Care Homes
- Care Coordination Checklist
- Care Plan Checklist
- Disease Stages

Dementia Care Plan Checklist

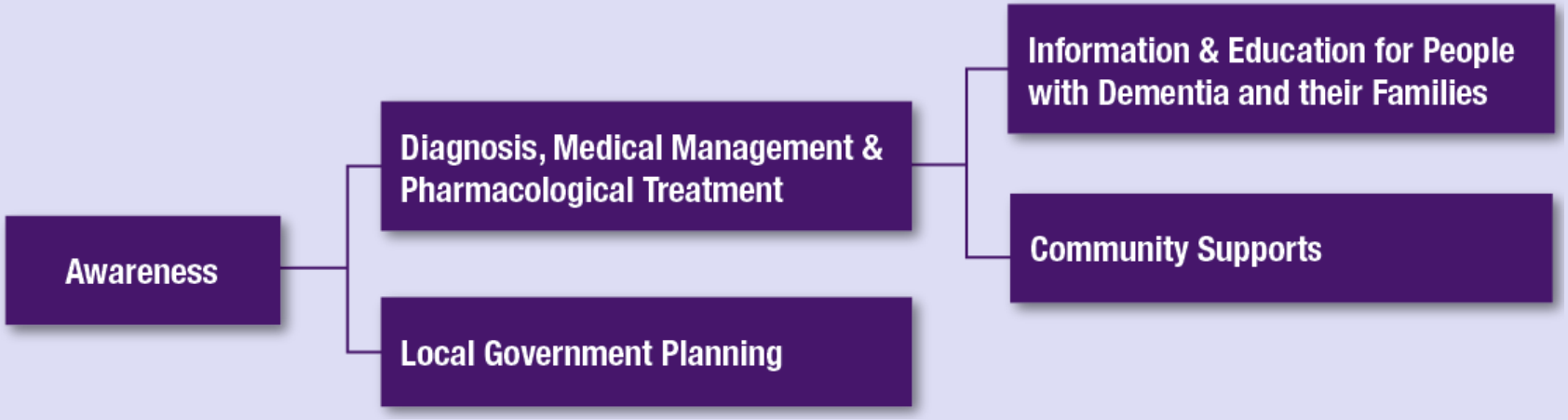
- Patient / Care Partner Education
- Medication Therapy / Disease Management
- Reduce Excess Disability
  - Treat / manage co-existing conditions
  - Health, Wellness and Engagement
  - Address Safety Risk
- Planning Assistance
- Connection to Community Supportive Services / Therapies
  - Direct / Warm Referral + Follow-Up

Community-Based Agencies & Programs



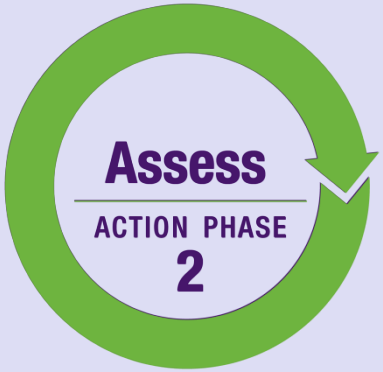
- Distribute a simple guide with a checklist and resource information.
- Equip community agencies that assist caregivers with information.
- Strive for consistency in information and support.
- www.actonalz.org

Key Elements of a Dementia Capable Community

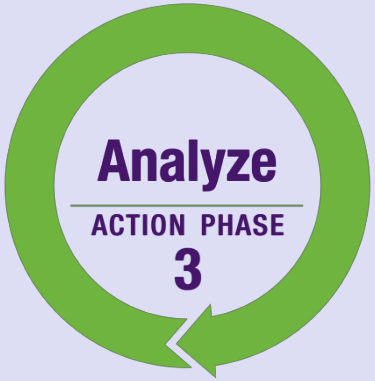


Phases of Community Action

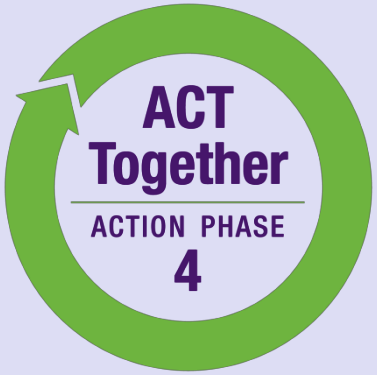
Convene key community leaders and members to form an Action Team.



Assess current strengths and gaps within the community.



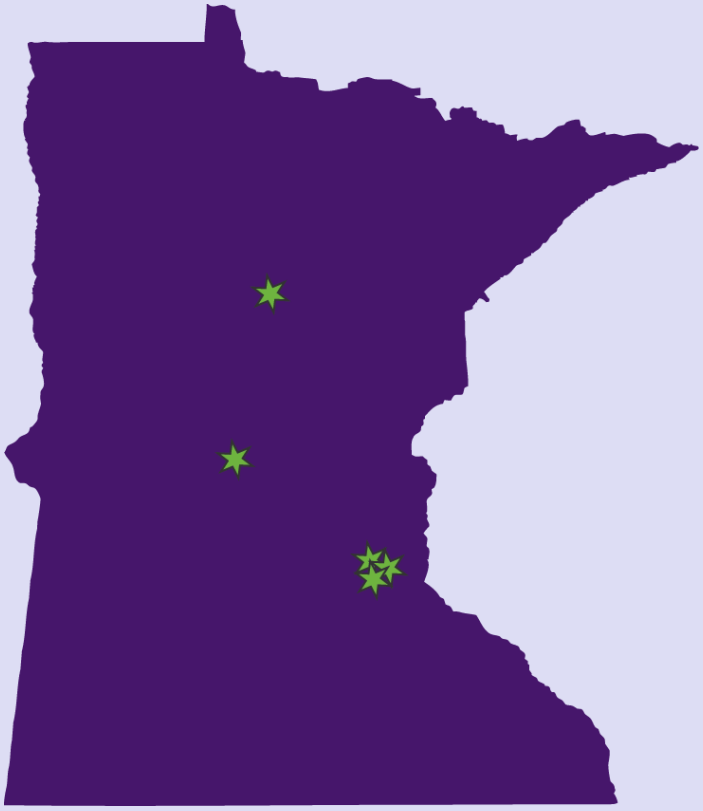
Assess community needs and develop a plan to take action.



ACT Together to pursue priority goals to foster community readiness for dementia.

Building an Action Team

Pilot Action Communities



- Willmar Area Dementia Network (Willmar Area)
- Walker Community Coalition (Walker, MN)
- Twin Cities Jewish Community Alzheimer's Task Force
- St. Louis Park/Hopkins Coalition
- St. Paul Neighborhoods Coalition

References

- Essentia Health: http://www.essentiahealth.org/Main/Home.aspx
- ACT on Alzheimer's website: www.actonalz.org
- MN Association of Area Agencies on Aging: http://mn4a.org
- Minnesota Health Care Homes: http://www.dhs.state.mn.us/
- Minnesota Board on Aging: http://www.mnaging.org/
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