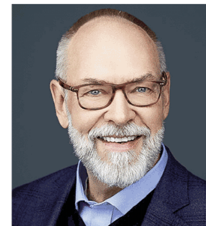
Welcome
to today's webinar

CULTURE CHANGE in ACTION WEBINARS

Growing Person-Centeredness

MAY 23, 2019

Person Centered Dementia Care: First Came the Recommendations, Now Let's Explore the Outcomes!



Guides: Sam Fazio and Doug Pace

TRANSFORMING DEMENTIA CARE

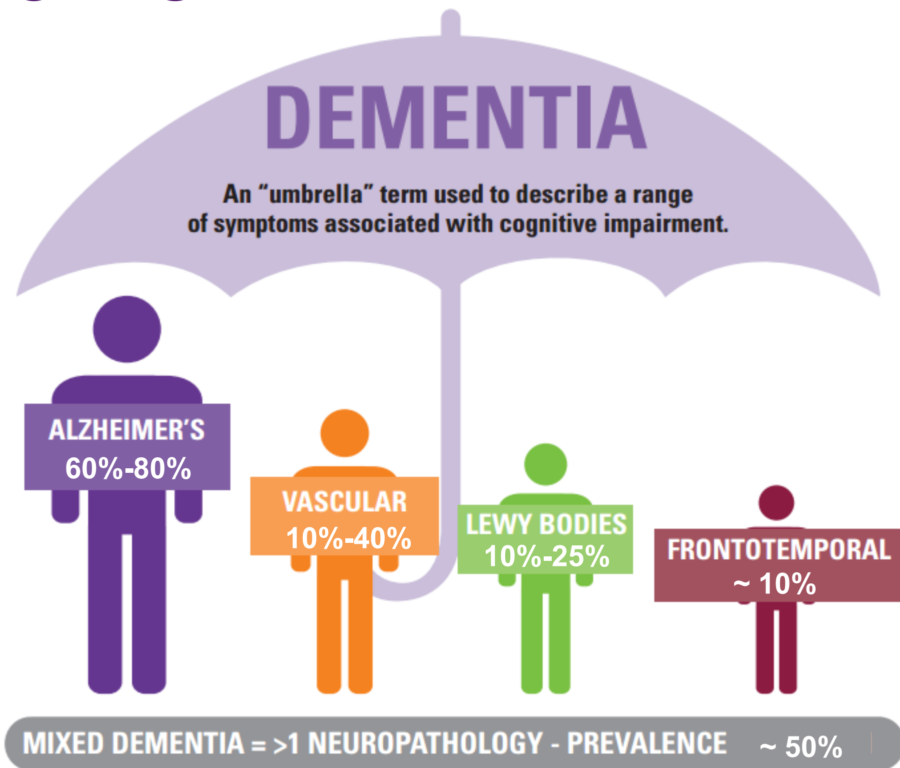
800.272.3900 alz.org®

Our Work is About People and Science

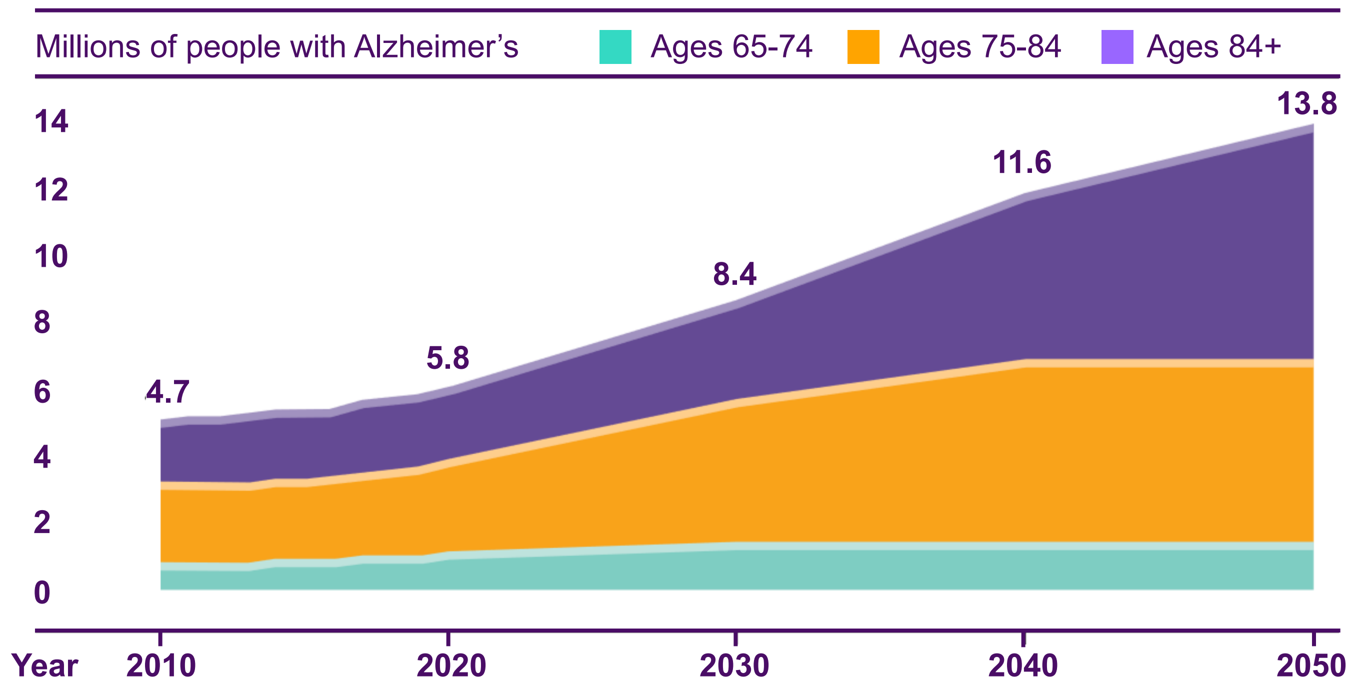
The Alzheimer's Association is a global organization working to advance care, support and research across the world

Dementia is a Syndrome

- Dementia is a collection of symptoms related to cognitive decline
- Due to biological changes in the brain
- Alzheimer's is most common cause
- Mixed dementia is very prevalent
- Some causes of cognitive decline are reversible and not truly dementia



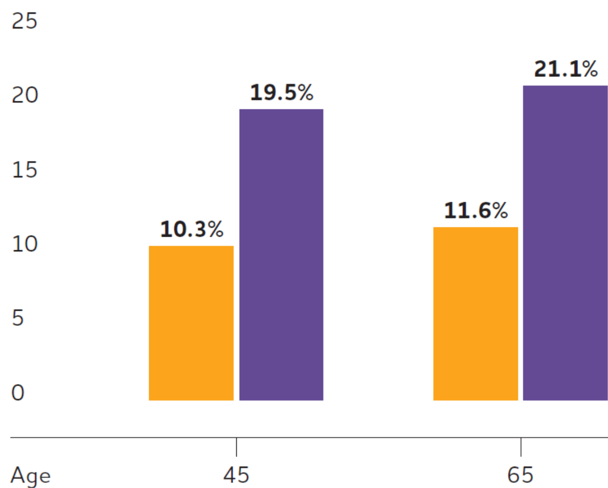
Prevalence and Incidence



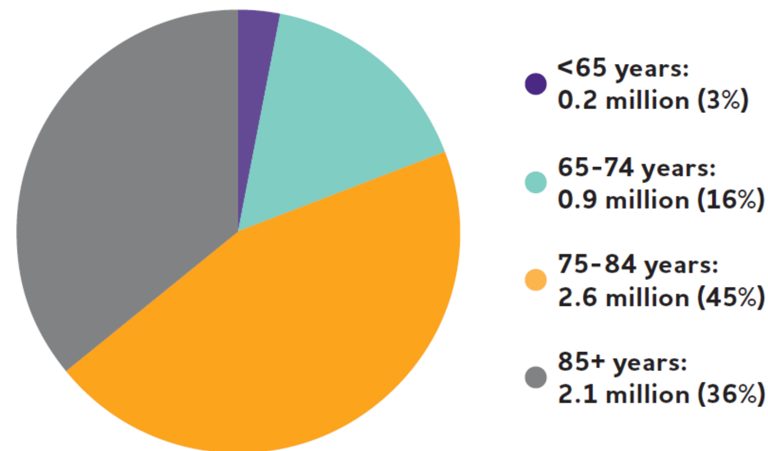
Every 65 seconds someone in the United States develops Alzheimer's disease.

Estimated Lifetime Risk for Alzheimer's Dementia, by Sex, at Ages 45 and 65

Percentage | Men | Women



Ages of People with Alzheimer's Dementia, 2019



Impact of Alzheimer's

$290B

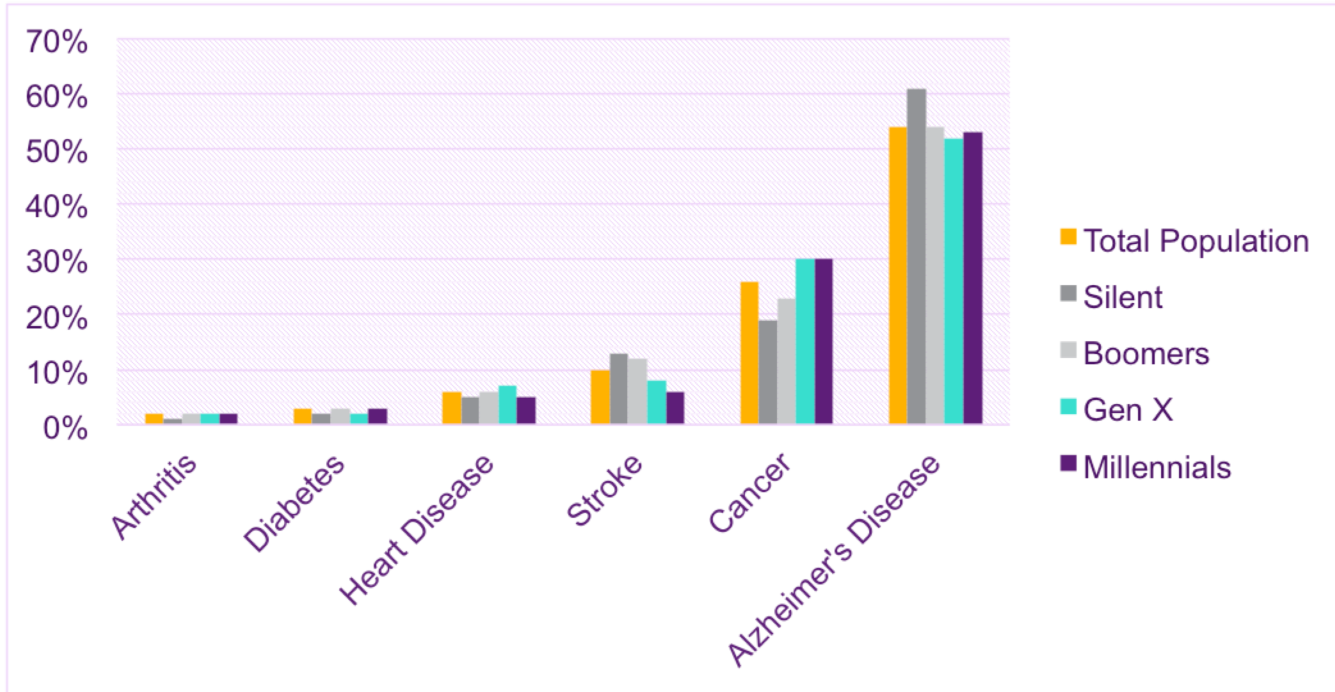
Total cost of care for those with Alzheimer's, with more than two-thirds paid by Medicare and Medicaid

6TH LEADING CAUSE OF DEATH IN THE U.S.

Of the top 10 killers, Alzheimer's is the only one that cannot be prevented, cured or even slowed.

Alzheimer's is the disease most are worried about –

more than cancer, stroke, heart disease, diabetes & arthritis combined!

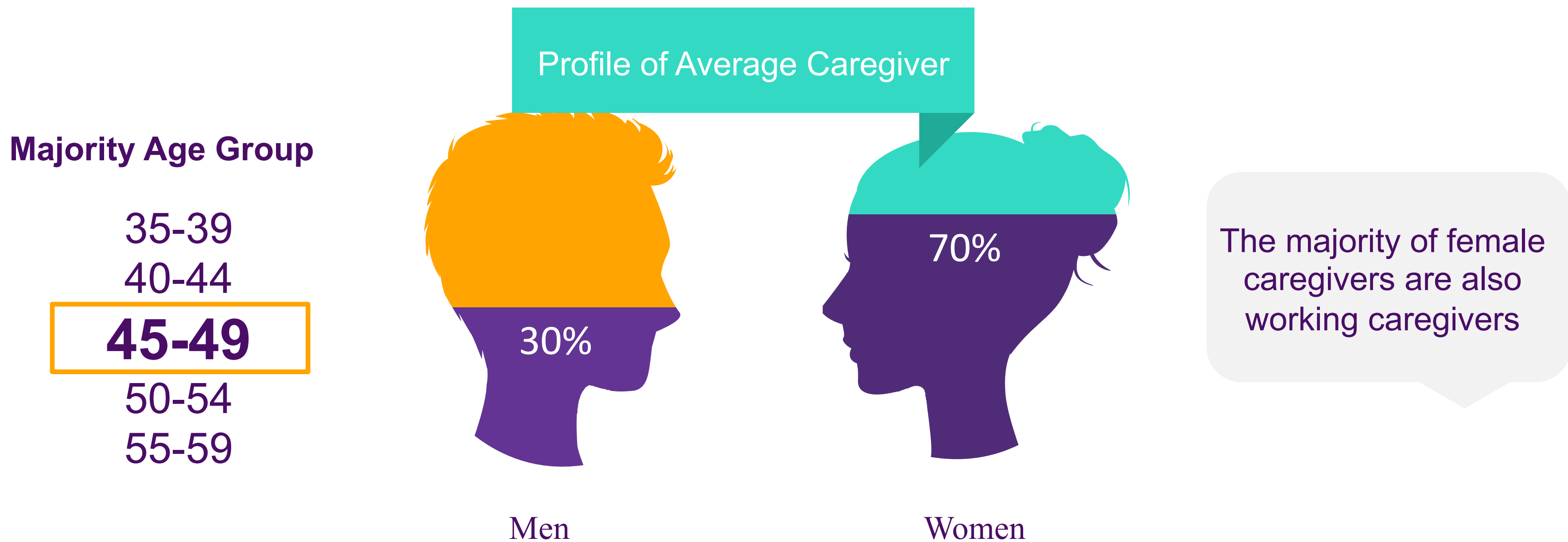


% who say the disease they are most fearful & concerned about is......................
Source: Merrill Lynch/Age Wave Study: Health & Retirement September 2014 (N = 3,303 US Adults 25+)

Reasons

1	Being a burden on my family
2	Losing dignity
3	Being more isolated from friends and family
4	Not being able to do the things I enjoy
5	Health care costs and related expenses

16.1 Million Alzheimer's Caregivers – 43 Million Total



**National Alliance for Caregiving, Caregiving in the US, 2015*

Emotional impact on Caregivers

Nearly

59 percent

of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high

and approximately

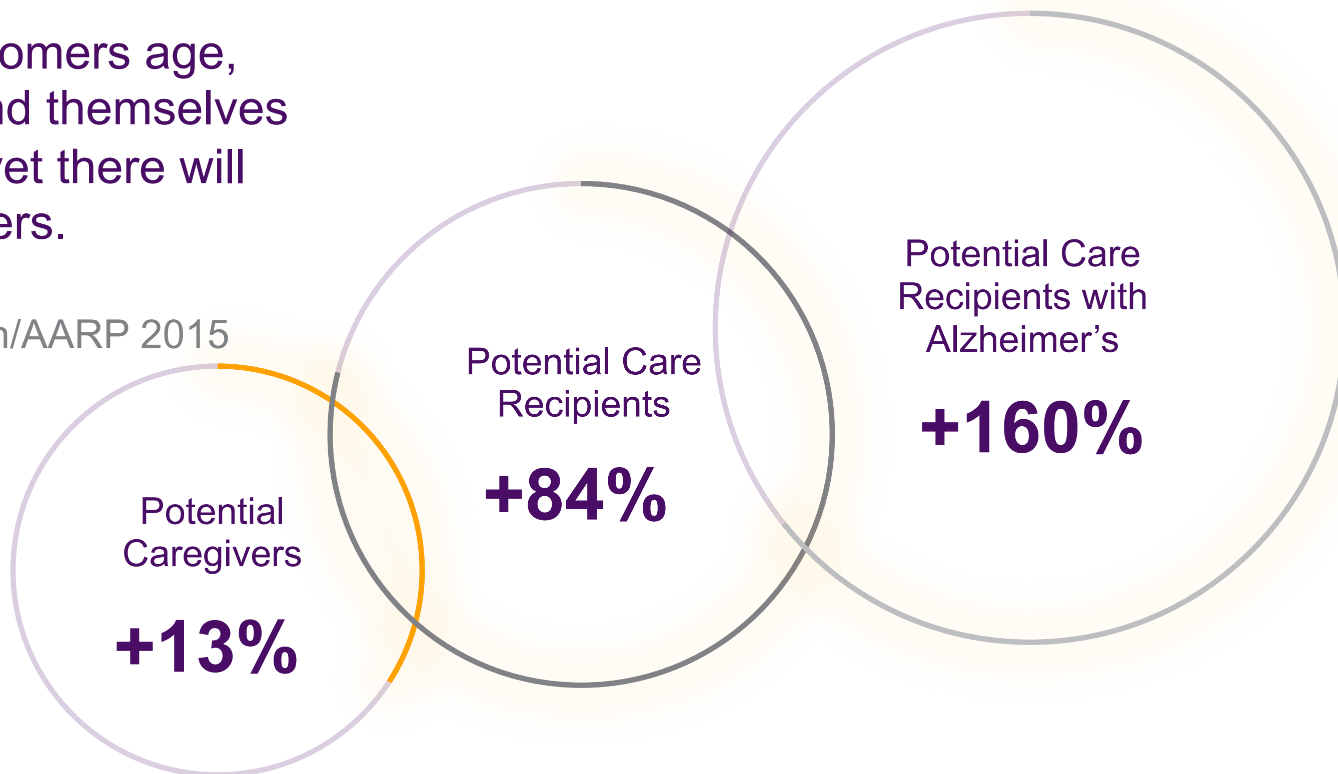
40 percent

report symptoms of depression

How Caregiving is projected to Change 2015-2050

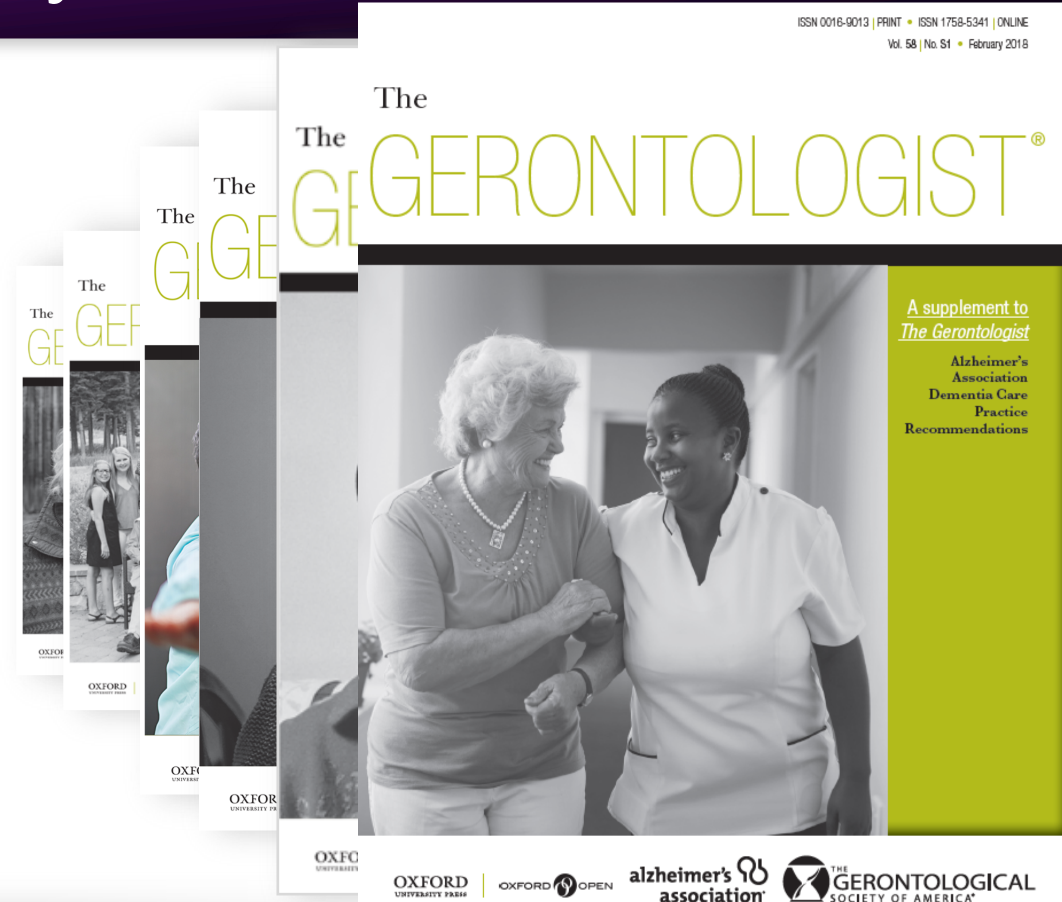
As more baby boomers age, Americans will find themselves in need of care, yet there will be fewer caregivers.

Source: Merrill Lynch/AARP 2015

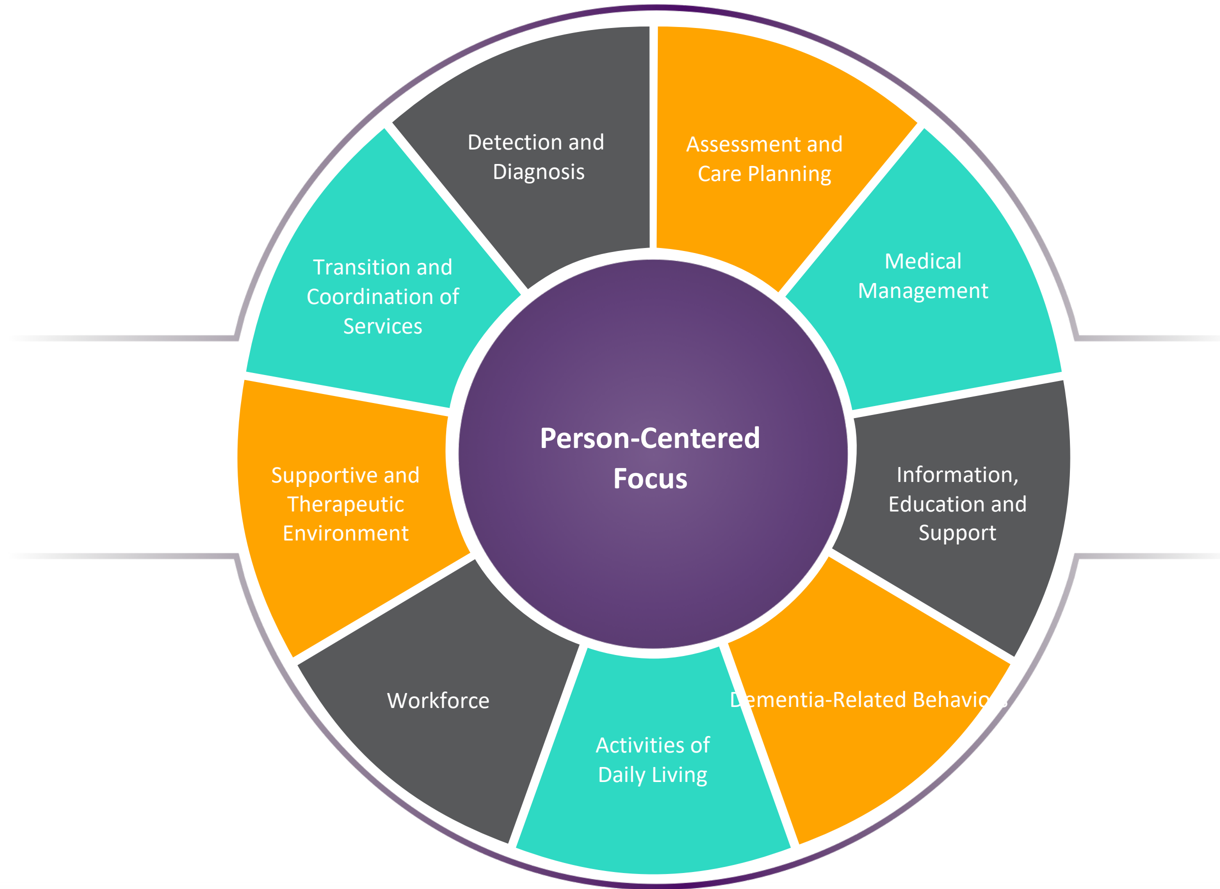


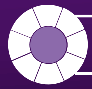
Quality Care: Today

- Evidence-based practices
- 56 recommendations by 27 expert authors
- Applicable to various care settings and throughout the disease continuum
- Published as a supplement to Feb 2018 issue of The Gerontologist
- Foundation for quality person-centered care



Dementia Care Practice Recommendations





PERSON CENTERED FOCUS

Recommendations

- Know the person
- Person's reality
- Meaningful engagement
- Authentic, caring relationship
- Supportive community
- Evaluation of care practices

Effects of Person-Centered Care

Individuals	Li and Porock (2014)	24 studies—15 culture change and 9 person-centered practices	Beneficial effects on psychological wellbeing. Significant effects on decreasing behavioral symptoms and psychotropic medication use
Staff	Barbosa, Sousa, Nolan, & Figueiredo (2015)	7 studies—PCC approaches, including DCM; stimulation-oriented approaches, emotion-oriented approaches; and behavioral-oriented approaches.	Reduction in stress, burnout and job dissatisfaction
Individuals and staff	Brownie and Nancarrow (2013)	9 articles—multi-component person-centered interventions	Positive influences on staff satisfaction and capacity to provide care; lower rates of boredom and feelings of helplessness and reduced levels of agitation in residents

Themes in Evidence to Provide Support for ADLs

Dressing	Toileting	Eating/Nutrition
Dignity/respect/choice	Dignity and respect	Dignity/respect/choice
Dressing process	Toileting process	Dining process
Dressing environment	Toileting environment	Dining environment
		Health/biological considerations
		Adaptations/functioning
		Food/beverage/appetite

Sensory Practices

Practice	Evidence	Presumed Mechanism of Action	Implementation
Aromatherapy	Moderate, mixed • Positive for agitation	Nervous system regulation; social and physical contact	Well accepted, no known harmful effects, low investment
Massage	Small • Positive for agitation, aggression, other	Physiological response and social/physical contact	Well accepted, no known harmful effects (but honor preferences), low investment
Multi-sensory stimulation	Large • Positive for agitation, anxiety, other	Social contact	Well accepted, no known harmful effects, moderate investment
Bright light therapy	Moderate, mixed • Positive for agitation	Change circadian rhythm	Acceptance varies by light source, some potential for harmful effects, moderate

Psychosocial Practices

Practice	Evidence	Presumed Mechanism of Action	Implementation
Validation therapy	Small, mixed • Positive for agitation, apathy, other	Alleviate negative feelings, enhance positive feelings	Well accepted, no known harmful effects (but monitor emotions), low investment
Reminiscence therapy	Moderate • Positive for mood, depression	Increase well-being, provide pleasure and cognitive stimulation	Well accepted, no known harmful effects (but focus on positive), moderate investment
Music therapy	Moderate • Positive for anxiety, agitation, other	Promote well-being and sociability, aid reminiscence, reduce anxiety/stress, provide distraction	Acceptance varies, no known harmful effects, moderate investment
Pet therapy	Small, preliminary • Positive for agitation, apathy,	Socialization/bonding, emotional support, sensory stimulation	Acceptance varies, may be negative effects, low/moderate investment

Structured Care Protocols

Practice	Evidence	Presumed Mechanism of Action	Implementation
Mouth care	Small, preliminary • Positive for care-resistant behaviors	Reduce threat, anxiety fear, and pain	Well accepted, no known harmful effects, low investment
Bathing	Small • Positive for agitation, aggression, other	Reduce fear, pain	Well accepted, no known harmful effects, low investment

Care Coordination Interventions

Author	Setting	Intervention	Description	Outcomes
Naylor et al. (2014)	Hospital to home	Transitional Care Model (TCM)	Augmented Standard Care versus Resource Nurse Care versus TCM	Time to first rehospitalization was longest for those in the TCM, and rehospitalization or death was accelerated for both other groups
Samus et al. (2014)	Home	MIND at Home	Dementia care coordination versus usual care	Significant delay in time to transition from home and remained in home 51 days longer
Bass et al. (2014)	Home	Partners in Dementia Care (PDC)	Care coordination program versus usual care	Fewer hospitalizations and fewer emergency department visits
Bellantonio et al. (2008)	Assisted living	Geriatrics Team Intervention (GTI)	Four systematic inter professional geriatric team assessments	Reductions in the risk of unanticipated transitions, including hospitalizations, ED visits and nursing home placement, as well as death

Quality Care in Long-Term & Community-Based Care

Dementia Care Practice Recommendations

INFLUENCERS

Federal and State Policies

National Provider Member Organization Partnerships

Accreditation Bodies

PROGRAMS

- Organization-Wide Consultative Coaching
- Curriculum Review
- essentiALZ® Certification
- Project ECHO
- Dementia Care Provider Roundtable
- Dementia Care In-Person Training

IMPACT

Number of Covered Lives

Number of Organizations

Outcomes Research

Model Overview

QUALITY, DATA & OUTCOMES

"In God we trust, all others bring data"
W. Edwards Deming

National Strategy for Quality Improvement in Health Care

The Affordable Care Act (ACA) required the secretary of the Department of Health and Human Services (HHS) to establish a National Strategy for Quality Improvement in Health Care, also known as the National Quality Strategy.

The strategy, submitted to Congress on March 21, 2011, is the first policy to set national goals to improve the quality of health care. It sets standards and regulations to measure the quality of health care and its impacts on public health. Updated annually – www.ahrq.org

Improving health and health care quality
can occur only if all sectors, individuals, family members, payers, providers, employers and communities
make it their mission.

Members of the health care community can align to the National Quality Strategy by doing the following:

Adopt the 3 Aims

BETTER CARE

Improve overall quality by making health care more patient-centered, reliable, accessible, safe

HEALTHY PEOPLE & COMMUNITIES

Improve health of U.S. population by supporting proven interventions to address behavioral, social and environmental determinants of health, in addition to delivering higher-quality care

AFFORDABLE CARE

Reduce cost of quality health care for individuals, families, employers & government

NAPA -National Alzheimer's Project Act

- Signed into law in 2011
- Advisory Council on Alzheimer' s Research, Care and Services
- National Alzheimer' s Plan – annually updated
- Five goals are the foundation of the plan:
  - Prevent and Effectively Treat Alzheimer' s Disease by 2025
  - **Enhance Care Quality and Efficiency**
  - Expand Pubic Supports for People Living with the Disease and their families
  - Enhance Public Awareness and Engagement
  - Track Progress and Drive Improvement

National Alzheimer’s Plan
Research on Care and Services

Goal 2 -“Enhance care quality and efficiency”

“All persons living with Alzheimer’s disease and related dementias, regardless of location, race, ethnicity, sexual orientation or socioeconomic class, should receive high quality **person/family-centered** by well-trained practitioners and workers from detection and diagnosis through end-of-life, across all health care and **long-term services and supports**.”

2025 Endpoint

QA and PI

Quality Assurance	Performance Improvement
Reactive	Proactive
Episode or event-based	Aggregate data & patterns
Prevent recurrence	Optimize process
Sometimes anecdotal	Always measurable
Retrospective	Concurrent
Audit-based monitoring	Continuous monitoring
Sometimes punitive	Positive change

QAPI
Five Elements

- Element 1 – Design & Scope
- Element 2 – Governance & Leadership
- Element 3 – Feedback, Data Systems & Monitoring
- Element 4 – Performance Improvement Projects (PIPs)
- Element 5 – Systematic Analysis & Systemic Action

PDSA – Plan, Do, Study, Act

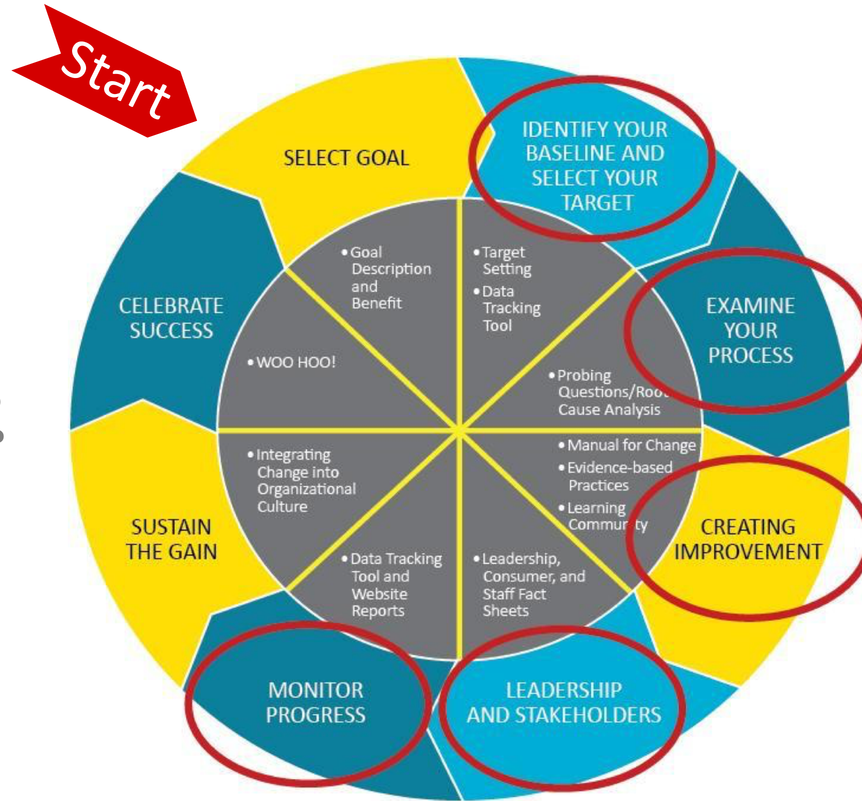
How do I know where I am?

Where do I want to be?

What processes are associated with my outcome?

When I change a process, how do I know it had the effect I wanted?

How am I doing compared to other communities homes working on this goal?



NNHQI Campaign Overview

- The National Nursing Home Quality Improvement (NNHQI) Campaign* provides free evidence-based and model-practice resources to support data-driven quality improvement projects in long term care settings.
- The Campaign promotes focus on individuals' preferences, staff empowerment, and involving all staff, consumers and leadership in creating a culture of continuous quality improvement.

*In August 2016, the Advancing Excellence in Long Term Care Collaborative turned over the operation of the Advancing Excellence in America's Nursing Homes Campaign to CMS. The Campaign has been renamed the National Nursing Home Quality Improvement (NNHQI) Campaign.

Quality Improvement Organizations
Sharing Knowledge. Improving Health Care.
CENTERS FOR MEDICARE & MEDICAID SERVICES
Telligen

NNHQI Campaign Overview

- It’s not either/or: Campaign resources help your work on QAPI, the Nursing Home Collaborative, and the Partnership to Improve Dementia Care. Read more about Nursing Home Quality Initiatives.

- Participation is voluntary.

- Resources, website functionality, and technical assistance are FREE.

Quality Improvement Organizations
Sharing Knowledge. Improving Health Care.
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Nine goals, multiple outcomes for each goal

Organizational

- Staff Stability
- Consistent Assignment
- Person Centered Care
- Hospitalizations

Clinical

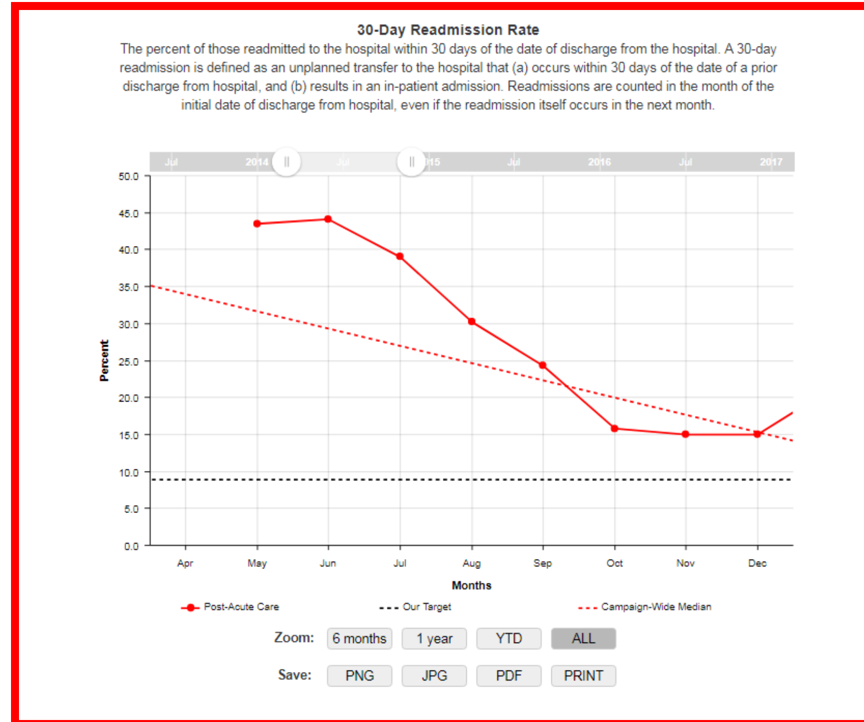
- Pain
- Pressure Injuries
- Mobility
- Dementia Care
- Infections (*C. diff*)

*Most workbooks include monthly progress measures as well. The outcomes collected on the website are available to the providers who enter the data and to third parties with whom providers may choose to share their outcomes.

Data displays for providers

Providers entering data on the website access customizable trend graphs of their progress. Data are displayed real-time, making them ideal for tracking rapid-cycle quality improvement projects.

Providers may customize the timeframe displayed, set and plot their target, and for several goals, display the Campaign-wide median for comparison.



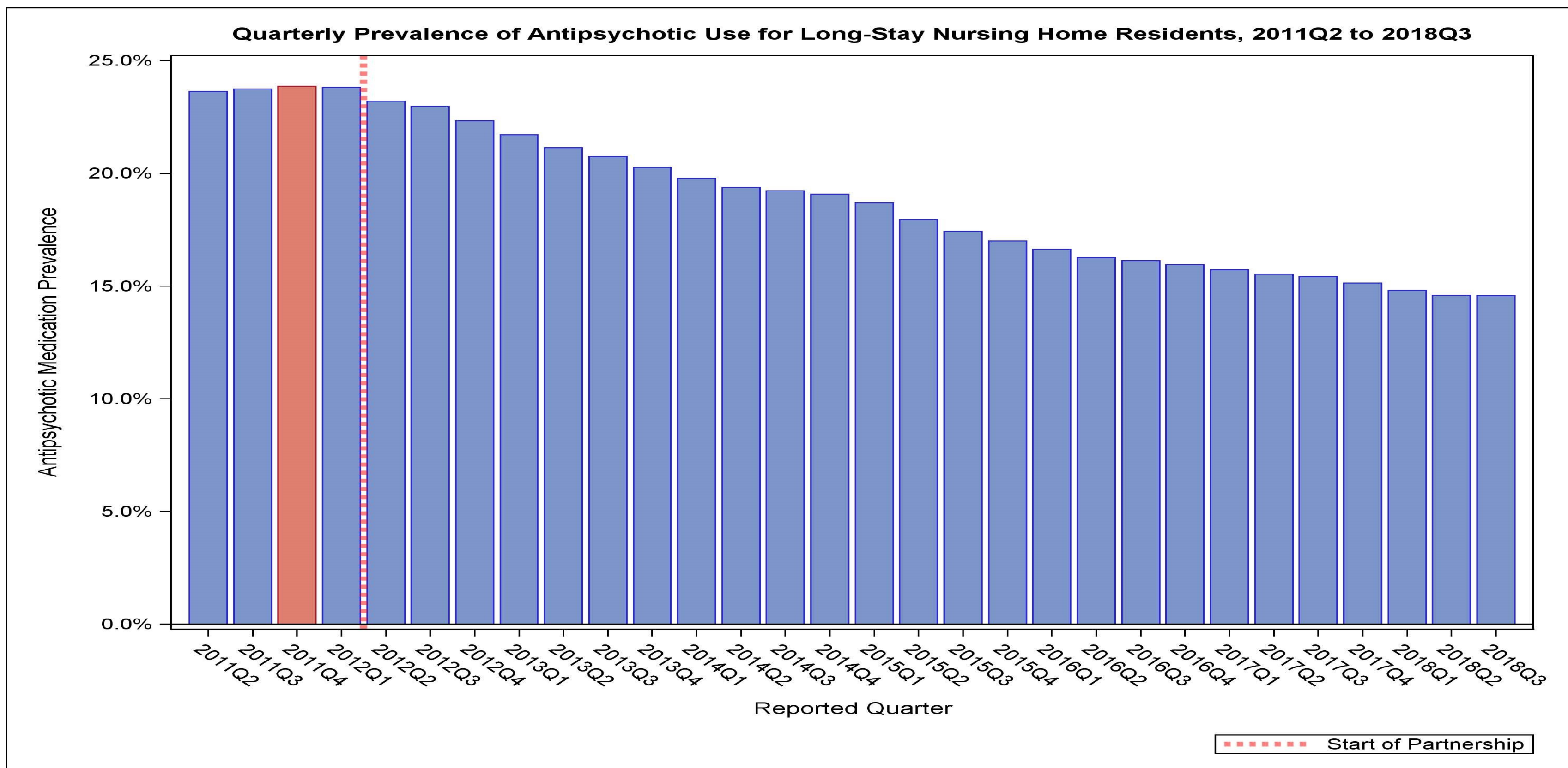
Consistent Assignment

Separately for Long Stay and Short Stay Residents

- Maximum Number of Caregivers for Any Resident During the Time Period
- Minimum Number of Caregivers for Any Resident During the Time Period
- Average Number of Caregivers per Resident During the Time Period
- Percent of Residents with Maximum 12 Caregivers During the Time Period *

*Consistent Assignment is measured over a 4-week period for long stay residents and two 2-week periods for short stay residents

National Partnership to Improve Dementia Care



Separately for Long Stay and Post Acute Residents

Individualizing Care measures

- Percent of individuals for whom signs of distress / **expressions** of unmet need have been recorded
- Percent of individuals for whom signs of distress / **expressions** of unmet need AND **approaches** to address those have been recorded
- Percent of individuals for whom 4 or more **pleasant moments/meaningful activities** have been recorded

Psychotropic Medication measures

- Percent of individuals **living with dementia** with **no psychotropic medication** orders
- Number of **PRN antipsychotic** medication orders active at any time during month
- Percent of individuals receiving psychotropic medication who have **multiple psychotropic** medication orders
- Percent of psychotropic medication orders for which **GDR requirements are current** (long-stay only)
- Percent of individuals admitted this month for whom **structured medication reconciliation** is noted as complete (post-

Board Member Organizations

AALNA
American Assisted Living Nurses Association

American Seniors Housing Association

LeadingAge

NCAL
NATIONAL CENTER FOR ASSISTED LIVING

PC-PAL Toolkit

Two questionnaires and scoring instructions

Residents: 49 items

Staff: 62 items

Additional questions

Residents: 26 items

Staff: 40 items

Available at

www.theceal.org

www.shepscenter.unc.edu

TOOLKIT FOR PERSON-CENTEREDNESS IN ASSISTED LIVING

University of North Carolina at Chapel Hill (UNC)
and the
Center for Excellence in Assisted Living (CEAL)

INFORMATIONAL GUIDE
AND
QUESTIONNAIRES OF PERSON-CENTERED PRACTICES IN ASSISTED LIVING (PC-PAL)

Sheryl Zimmerman, Lauren Cohen, David Reed, Philip Sloane
Collaborative Studies of Long-term Care
Cecil G. Sheps Center for Health Services Research
University of North Carolina at Chapel Hill
http://www.shepscenter.unc.edu

Josh Allen, Jackie Pinkowitz
Center for Excellence in Assisted Living
http://www.theceal.org

Jayne Clairmont, Walter Coffey, Lisa Demeter, Bob Detrick, Susan Frazier, Pat Giorgio, Michael Lepore, Peter Reed
Community Partners

Organizations that support use of the PC-PAL

© 2014 UNC-CEAL Collaborative

Scoring the PC-PAL

II. Individualized Care and Services These questions are about the **care and services** that caregiving, administrative, and other community staff provide you.						
To what extent do you disagree or agree that...		Strongly disagree ▼	Disagree ▼	Agree ▼	Strongly agree ▼	Don't know ▼
1	I was welcomed when I moved in and provided information about activities and services here.	1	2	(3)	4	DK
2	Caregivers, administrative, and other staff introduced me to residents who have common interests so we could develop friendships.	1	2	3	4	DK
3	Caregivers, administrative, and other staff treat me with respect and dignity.	1	2	3	(4)	DK
4	Caregivers respect and know my abilities, life history, needs, and personal preferences.	1	2	(3)	4	DK
5	Caregivers, administrative, and other staff address me using my preferred name.	1	2	3	(4)	DK

a. Sum the scores for the items (3+4+3+4); this equals 14. Write ‘14’ in the box.

b. Count the number of items answered (notice the second item was skipped). Write ‘4’ in the circle.

c. Divide the number in the box (the sum, 14) by the number in the circle (the number of items, 4) -- 14/4 = 3.5; then, multiply that number (3.5) x 25 = 87.5 (out of a possible 100)

SCORE = ([14] / (4)) X 25 = _87.5_

Measures & Instruments for Quality Improvement in Assisted Living

- Prepared for CEAL by the Program on Aging, Disability, and Long-Term Care, Cecil G. Sheps Center for Health Sciences Research, University of North Caroling at Chapel Hill
- Environmental scan of evidence-based tools (measures and instruments) suitable for quality improvement in assisted living
- Result – 254 tools: 136 measures and 118 instruments
- Workforce (107 tools)
- Resident/patient outcomes (60 tools)
- Care coordination/transitions (32 tools)
- Medication Management (24 tools)
- Person-centered care (22 tools)

- Medicaid Program; HCBS Final Rule
  - The final Home and Community-Based Services regulations set forth new requirements for several Medicaid authorities under which states may provide home and community-based long-term services and supports. The regulations enhance the quality of HCBS and provide additional protections to individuals that receive services under these Medicaid authorities.
    - Published in the Federal Register on January 16, 2014
    - Over 2000 comments received during comment period
  - "In this final rule, CMS is moving away from defining home and community-based settings by 'what they are not,' and toward defining them by the nature and quality of individuals' experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics."

CEAL recommendations to CMS on guidance for implementing the HCBS Final Rule

- Why Do People Seek Out Secured Assisted Living Communities Designed to Serve People with Dementia?
  - The family cannot meet the needs of the person affected by the disease and when they are no longer safe in their own homes because they are at heightened risk of unsafe exit seeking.
  - 40% of residents in residential care communities have a diagnosis of Alzheimer's disease of other dementias
  - 6 in 10 people with Alzheimer's disease will engage in "wandering" behavior at some point over the course of the disease.
  - Balancing safety and autonomy
- CEAL Comments to CMS 2-26-16
- CEAL comments to CMS 6-29-16
- CMS FAQs – HCBS Final Rule 12-15-16

Putting It All Together

- Develop a Plan
- Create short and long term goals
- Include staff
- Take small steps
- Get help if needed
- Build support
- Recognize and celebrate accomplishments

Questions?

We're here. All day, every day.

24/7 Helpline: 800.272.3900

alz.org®

Hot Topics Series Webinars

TUESDAY, JUNE 25, 2019

Sharing the Vision

It's Happening: How Anti-Ageism Activists are Changing the Culture of Aging!

Guide: Ashton Applewhite

Pioneer Network™

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Hot Topics Series Webinars

THURSDAY, JULY 18, 2019

Growing Person-Centeredness

Applying Person-Centeredness to Trauma-Informed Care: A planned person-centered approach to the new CMS Trauma-Informed Care Regulations

Guide: Cynthia E. Baker

making it happen!

Pioneer Network

Pioneering a New Culture of Aging Conference

Registration is Open!

August 4 - 7, 2019

Galt House

Louisville, Kentucky

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webinars, research news, events and more.

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