



Oregon Alzheimer's & Caregiving Data for Public Health

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For Alzheimer's Disease: Public Health Core Functions

- **Assessment**

The starting place for evidence-based public health

- Data on incidence, prevalence & impact.
- Data on early indicators (memory changes)
- Caregiving & impact of families & institutions

Jon provided summary data on Oregon statistics

Surveillance Initiative Nationally & in Oregon

- **Behavioral Risk Factor Surveillance System (BRFSS) data**
 - Caregiving module available since 2005
 - Cognitive impairment module available since 2009
- **Oregon is collecting both BRFSS modules during 2012 & 2013**
- **Preview of caregiving data: single question asked on BRFSS 2009**
- **Background on both modules & examples of state reports**

Public Health Framework

- ***Healthy People 2020***

- ***DH-2.2 & 2.6 caregiver surveillance***

- **Baseline: 2 States & the District of Columbia conducted health surveillance for caregivers of people with disabilities in 2010 Target: 51 States & the District of Columbia**

- ***DH-2.3 & 2.7 health promotion programs for caregivers***

- **Baseline: 0 States & the District of Columbia had health promotion programs for caregivers in 2010. Target: 16 States & the District of Columbia**

BRFSS Caregiver Module Development

- **National stakeholders met to establish critical surveillance elements**
 - Information about care recipients
 - Functional & diagnosis aspects
 - Caregiver health
 - Methods *partially* fit **CBPR**
- **Result: 10-question core module**
- **Fielded in North Carolina, 2005**

Identifying Caregivers on the BRFSS

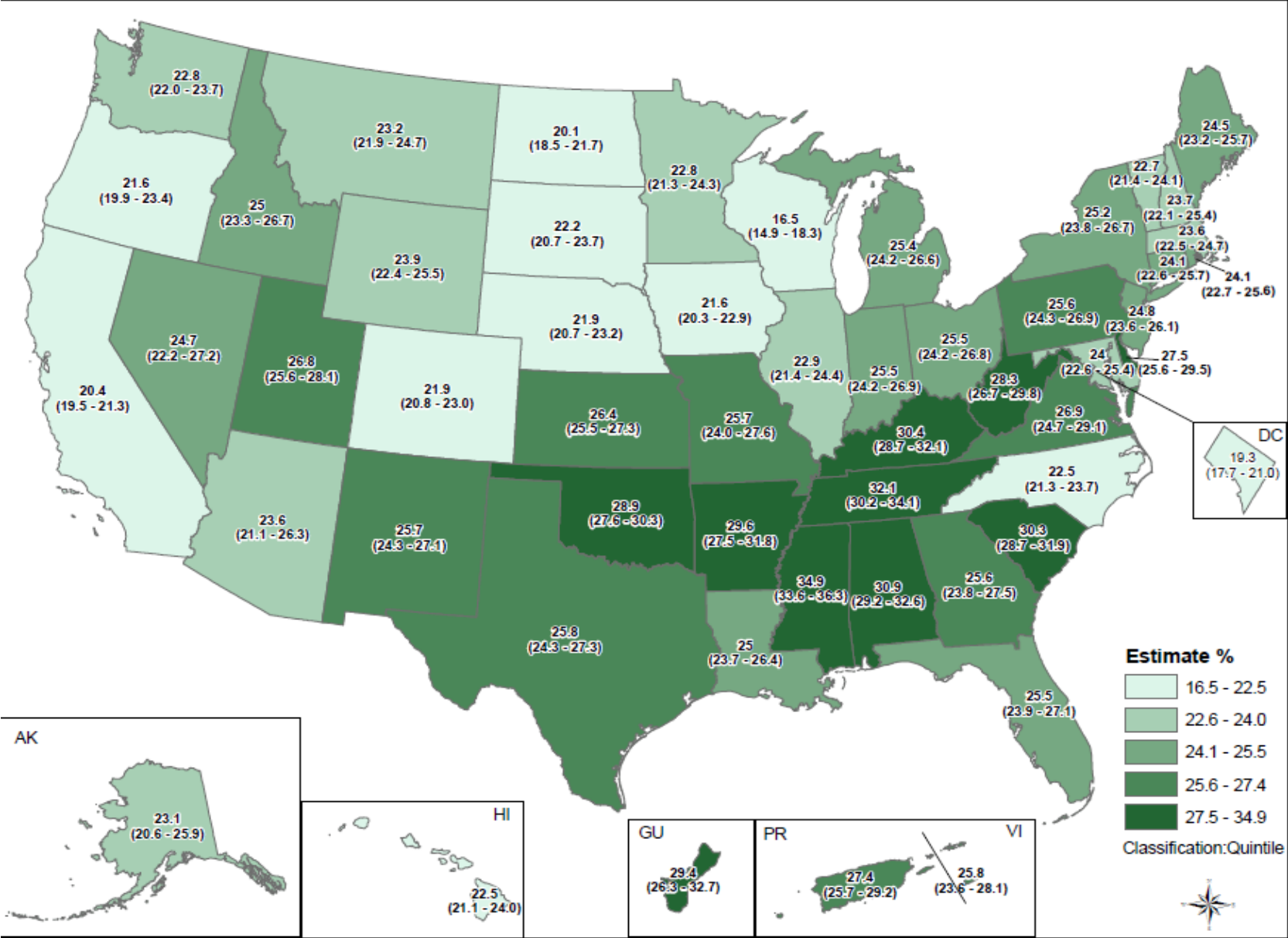
- **Caregiver Module screening question:**

“People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?”

Identifying Caregivers 2009

- **Single screening question was asked of all BRFSS respondents in all states & territories**
 - **A state-based report on prevalence is forthcoming from the CDC**
 - **States can examine details of their own populations for the health of caregivers using these data**

2009 State caregiving estimates 15%-35%



The Full Caregiver Module

- **Care recipient age, gender, relationship to caregiver, major health problem/ disability**
- **Duration of caregiving (days, weeks, years)**
- **Hours per week of caregiving**
- **Area with which care recipient needs most help**
 - Self-care, transportation, seeing/hearing, etc.
- **Greatest difficulty faced by caregiver**
 - Financial, stress, etc.
- **Change in care recipient's thinking or memory in past year**

Policy?

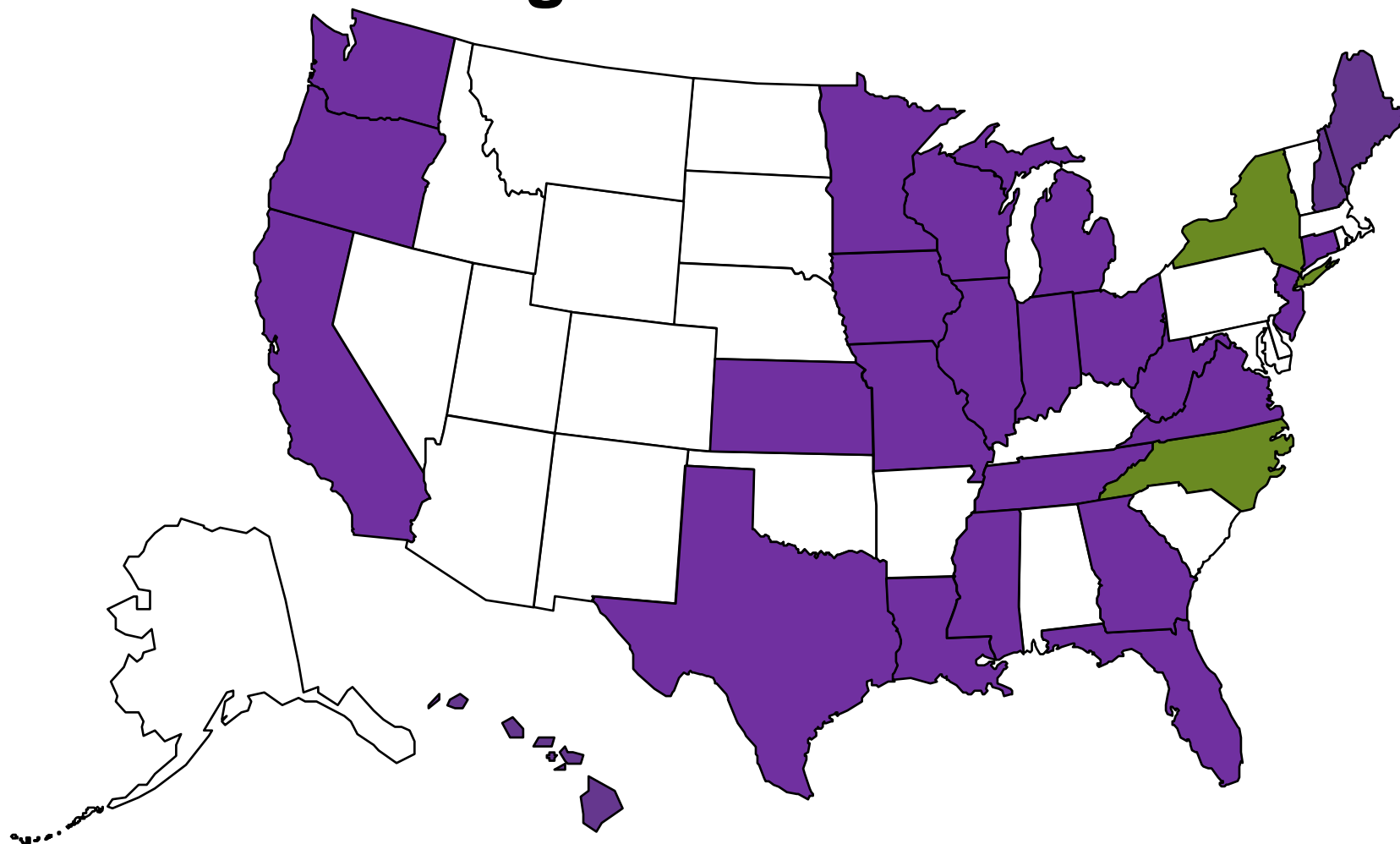
- **Mrs. Rosalynn Carter (former First Lady).**
 - Her social & policy interests include programs to train & support family caregivers
 - She was the family caregiver for parents & is a strong, respected voice in the USA
- **Her Institute's recent (fall 2010) twelve-point plan includes recommendations on**
 - Research & development including BRFSS surveillance
 - System design
 - Public & tax policy

Policy Examples

Caregiver data used in Illinois & Ohio to maintain respite services

Illinois, caregiving data also used in a coalition effort fighting cuts to community & home-bases services

BRFSS Caregiver Module: 2005 - 2012



■ State conducted module once (24, including District of Columbia)

■ State conducted module twice (2)

□ No Activity

Note: The core questionnaire included caregiver questions in 2000 & 2009.

Updated February 17, 2011

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“Cognitive Impairment” module from the CDC’s *Healthy Brain Initiative* is newer

As with the *Caregiver Module*, this was generated by scientists & Stakeholders & subjected to iterative testing (cognitive testing with respondents)

Oregon is collecting these data during 2012 & 2013 (Funding from the Alzheimer’s Association & Northwest Health Foundation)

BRFSS module cognitive status

“The next few questions ask about difficulties in thinking or remembering that can make a big difference in everyday activities. This does not refer to occasionally forgetting your keys or the name of someone you recently met. This refers to things like confusion or memory loss that are happening more often or getting worse. We want to know how these difficulties impact you or someone in your household.”

(if no to screener, then questions asked about another member of the household)

Optional BRFSS module cognitive status

1. During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse? (*If no, proxy question*)
2. [*If Q1 = no*]; Not including yourself, how many adults 18 or older in your household experienced confusion or memory loss that is happening more often or is getting worse during the past 12 months?
3. Of these people, please select the person who had the most recent birthday. How old is this person?

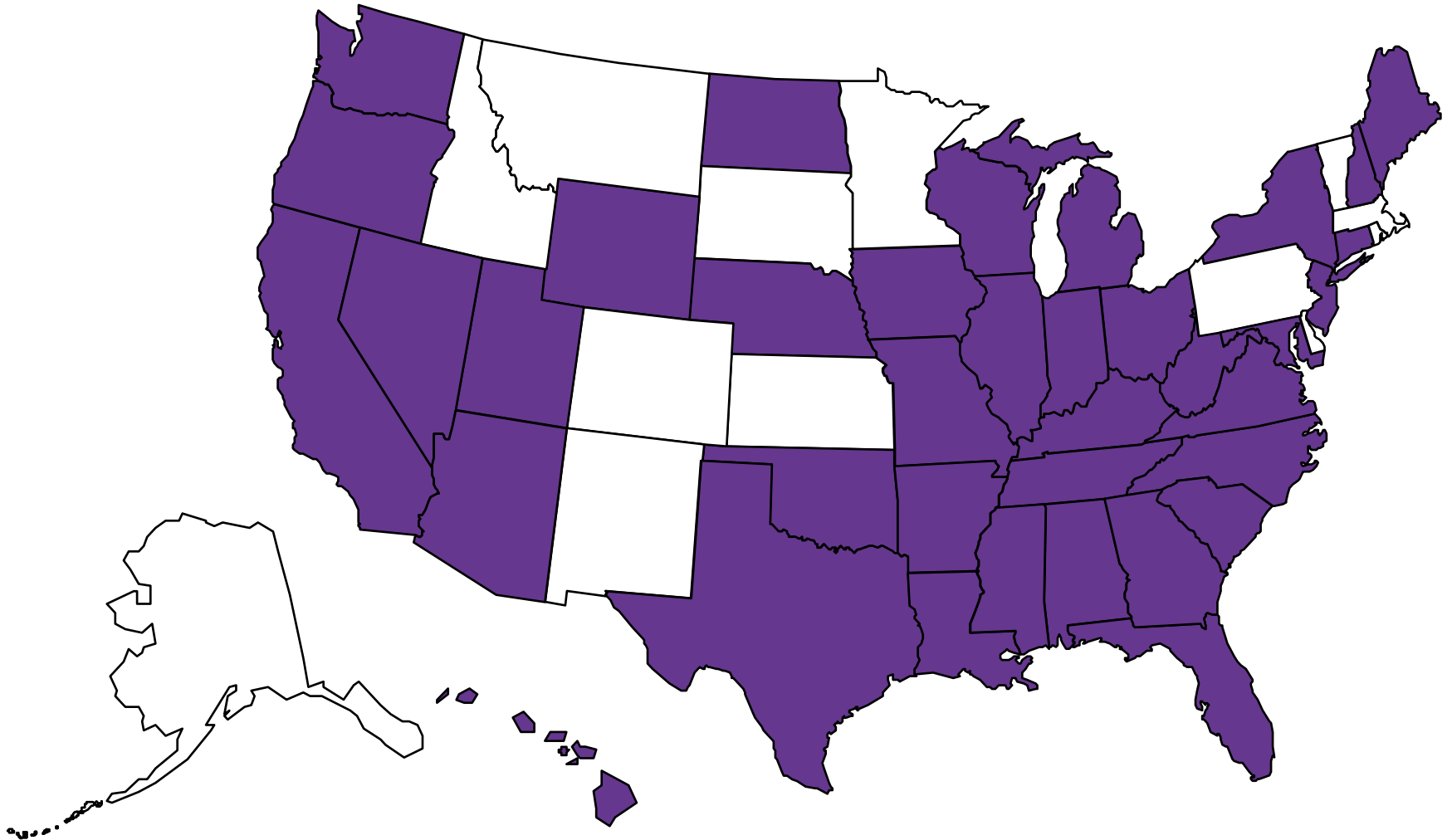
Then the remainder of questions are about the respondent or another person who screens in with confusion/memory (if no one, then stop)

4. During the past 12 months, how often [have you/this person] given up household activities or chores [you/they] used to do, because of confusion or memory loss that is happening more often or is getting worse? (*always – never*)

Optional BRFSS module on cognitive status

5. As a result of confusion or memory loss, in which of the following **four areas** [do you/this person] need the **MOST** assistance? *Safety, transportation, household activities, personal care, other, none*
6. During the past 12 months, how often has confusion or memory loss interfered with ability to work, volunteer, or engage in social activities? *Always to never*
7. During the past 30 days, how often a family member or friend provided any care or assistance for [you/this person] because of confusion or memory loss? *Always to Never*
8. Has anyone discussed with a health care professional, increases in confusion or memory loss? *Yes/No*
9. Have received treatment such as therapy or medications for confusion or memory loss? *Yes/No*
10. Has a health care professional ever said that Alzheimer's disease or some other form of dementia? *Yes, Alzheimer's Disease; Yes, some other form of dementia but not Alzheimer's disease; No diagnosis has been given*

BRFSS Cognitive Impairment Module: 2009 - 2012



- State conducted module (38, including District of Columbia)
- State has not conducted the module (13)

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Updated January 3, 2012

From both (caregiving, cognitive) optional BRFSS modules Oregon 2012

2012 Oregon sample = 2,500 respondents

- We expect to sample 550 caregivers including 185 who care for someone with a primary problem (“diagnosis”) of dementia.
- The Cognitive Module experience suggests 10% of adults “screen in” for cognitive problems (Oregon expected n=250): more from the proxy sampling
- Among those who report perceived cognitive changes, about 20% (Oregon expected n=50) may say it affects their activities “sometimes or always”.

BRFSS State Reports

State caregiving summaries on the Florida Office on Disability & Health website <http://fodh.phhp.ufl.edu>

Centers for Disease Control & Prevention website
(Cognitive Health in California, Florida, Iowa, Louisiana)
<http://www.cdc.gov/aging/healthybrain/surveillance.htm>