

What? Medicare doesn't pay for this!

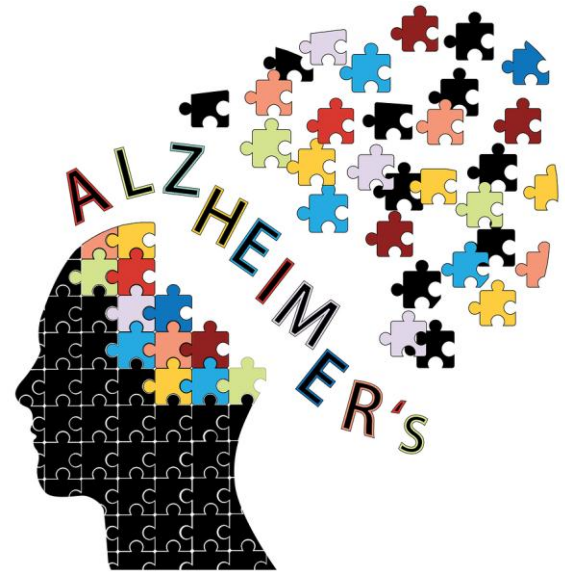
Long-term care financing for
complex, chronic, disabling
conditions in California

Who needs long-term care financing?



Alzheimer's disease perspective

- The disease doesn't discriminate on income or assets or savings
- The disease does discriminate by gender & ethnicity
- The disease is not episodic or intermittent, it's progressive and degenerative
- The disease strikes people in their working years
- The disease demands caregiver time, attention & resources
- The disease co-exists with other chronic conditions
- The disease ultimately limits self-management and community-based options



% of LTC users with Alzheimer's and other dementias

Recognizing Alzheimer's disease and related dementias are:

- Under-recognized
- Under-diagnosed
- Under-reported
- Under-treated

Adult day services – 23.7%

Home health care – 31.6%

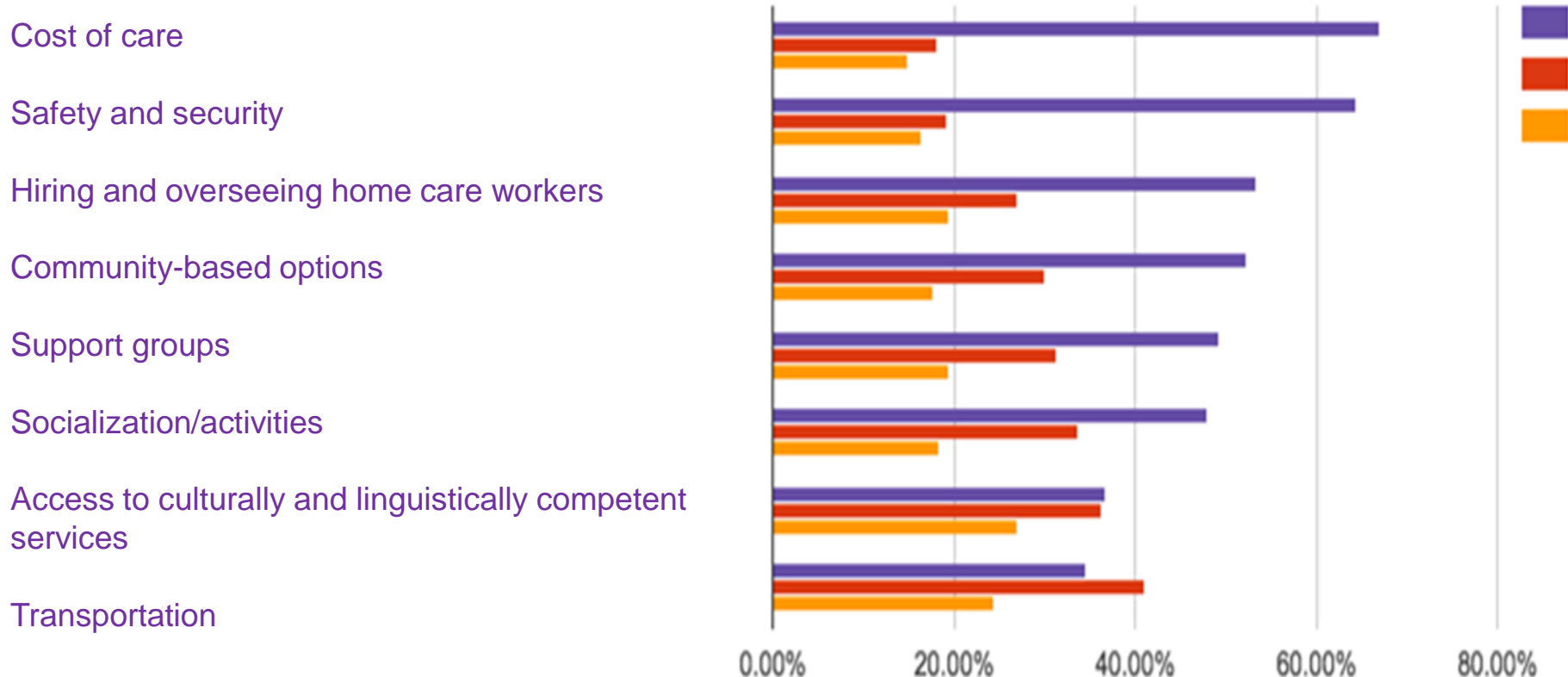
Hospice – 31.7%

Nursing home – 39%

Residential care – 32.3%

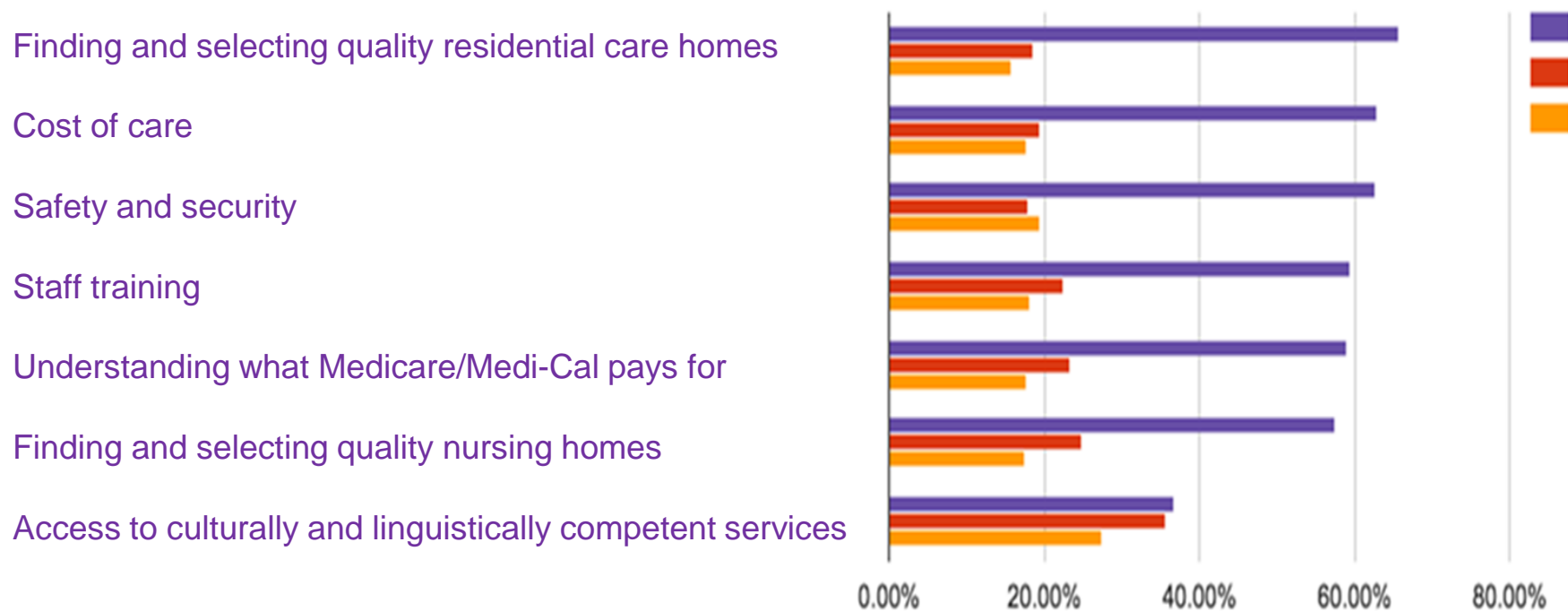
Statewide survey conducted in June 2015

living at home with community supports



Statewide survey conducted in June 2015

living in a 24 hour care facility



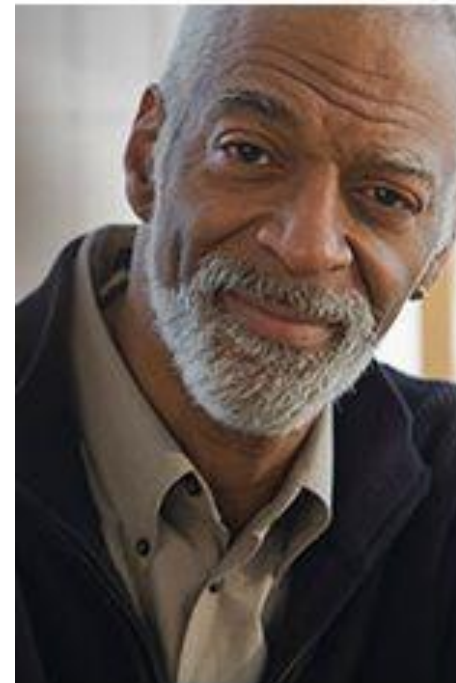
Words respondents used to describe their challenges

- Cost Fears
- Financial Burden
- Quitting my job
- Financial Help
- Need for Affordable Price
- Looking for Reasonable Cost
- Cost Concerns
- Financial Worries
- Living on What's Left of my Income
- Unable to Derive an Income to Support my Family



One man's story – San Diego, Ca

- Wife was employed as high school biology teacher
- She was diagnosed with early onset Alzheimer's disease
- Applied for SSI disability and waited 2 years for Medicare eligibility
- They paid out of pocket for in home care until it was no longer safe
- He quit his job to provide 24 hour in home care
- Before age 65, **both** were no longer employed, no longer saving, no longer funding their retirement, drawing down on their limited resources



One couple's story – Redding, Ca

- Wife is diagnosed with Alzheimer's disease
- Husband living with Parkinson's disease
- Self-employed, family business
- She needs 24 hour care, he needs support with ADLs
- Assisted living for two = \$12,000+/mo.
- Hired around the clock in home care @ \$14,400/mo.
- Other costs: medicine, doctor visits, food & utilities



Take away messages

- Help takes many forms
- Help comes in small and large dollar amounts
- Help may be intermittent, episodic or ongoing
- Crisis is often the impetus for action
- What consumers want most is expensive and inefficient
- Typically, at least two people need help (the affected individual and the caregiver)

Susan DeMarois
State Policy Director
Alzheimer's Association
www.alz.org