

THE MANY FACES OF FAMILY CAREGIVING: REALITIES, CHALLENGES, OPPORTUNITIES

**REFORMING STATES PRE-CONFERENCE ON FAMILY
CAREGIVING**

NOVEMBER 29, 2017

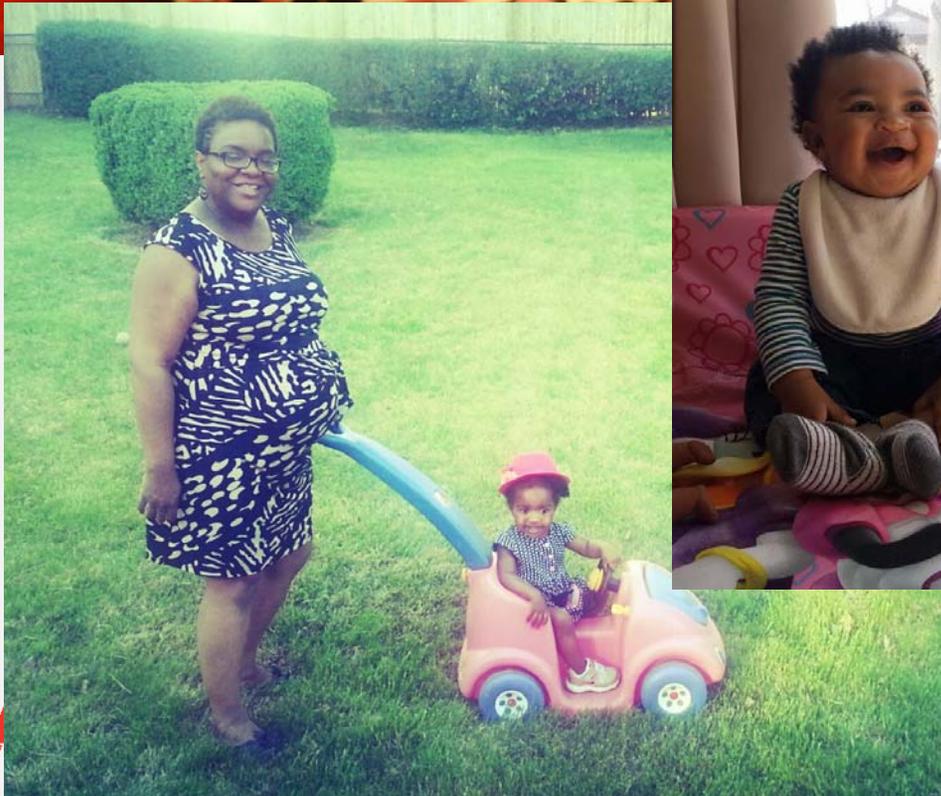
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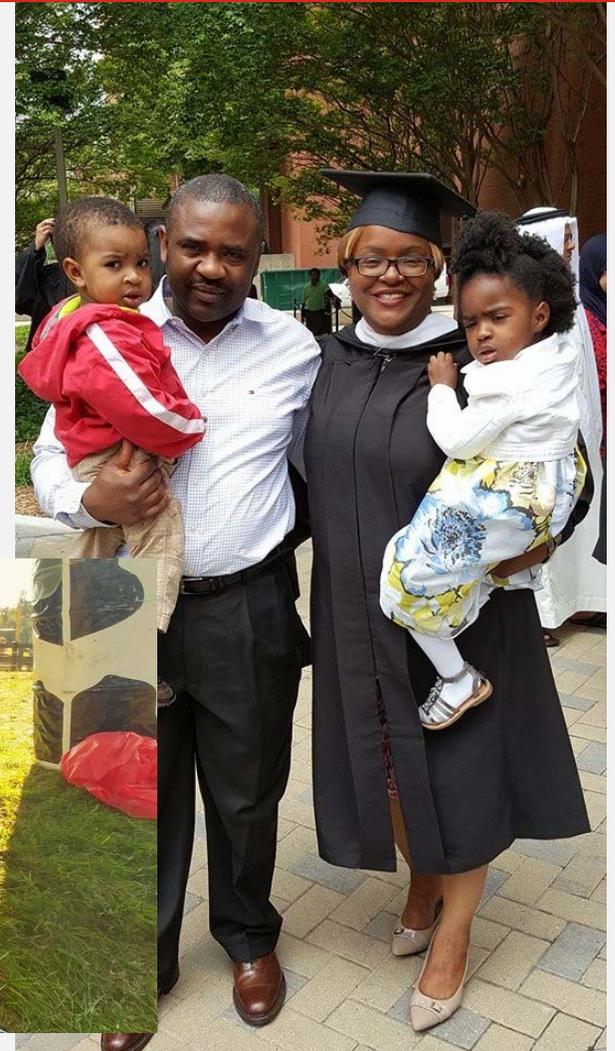


Overview

- Personal Caregiving Journey
- Diversity in Health Care
- Multicultural Family Caregivers
- Rural Family Caregivers
- Opportunities to Support Diverse Family Caregivers













DIVERSITY IN HEALTH CARE



Health Conditions in Multicultural Communities

- Among older adults, a higher proportion of African Americans and Latinos (as compared to Whites) report having:
 - \geq the following seven chronic conditions:
asthma, cancer, heart disease, diabetes, high blood pressure, obesity, or anxiety/ depression.
- African Americans and American Indians/Alaska Natives are more likely to be limited in an activity (e.g., work, walking, bathing, or dressing) due to chronic conditions.
- African Americans and Hispanic/Latinos are more likely to have Alzheimers and other Dementias

Health Conditions in Multicultural Communities

- Communities are disproportionately burdened by chronic illness.
- Higher morbidity and mortality from chronic diseases.
- The consequences can range from greater financial burden to higher activity limitations.

Health Conditions – Rural Communities

- A recent study by the Centers for Disease Control and Prevention shows a striking gap in health between rural and urban communities in the United States.
- more likely to live with following chronic conditions: heart disease, cancer, chronic lower respiratory disease, stroke.
- are working to better understand and address the health threats that put rural Americans at increased risk of early death.”
- Approx. 46 million Americans — 15 percent of the U.S. population — currently live in rural areas.

Health Conditions – Rural Communities

- Demographic, environmental and socioeconomic factors at-risk factors include:
 - tend to be older and sicker than their urban counterparts
 - higher rates of cigarette smoking, high blood pressure, and obesity.
 - higher rates of poverty, less access to healthcare, and are less likely to have health insurance.

Diversity and Healthcare Delivery

- Increased diversity of populations served provide opportunities and challenges for delivery of culturally competent services
- Services should be culturally and linguistically appropriate in order to reduce disparities.
- Cultural competence - the ability of providers and organizations to effectively deliver health care services that meet the social, cultural, and linguistic needs of patients and their family caregivers.

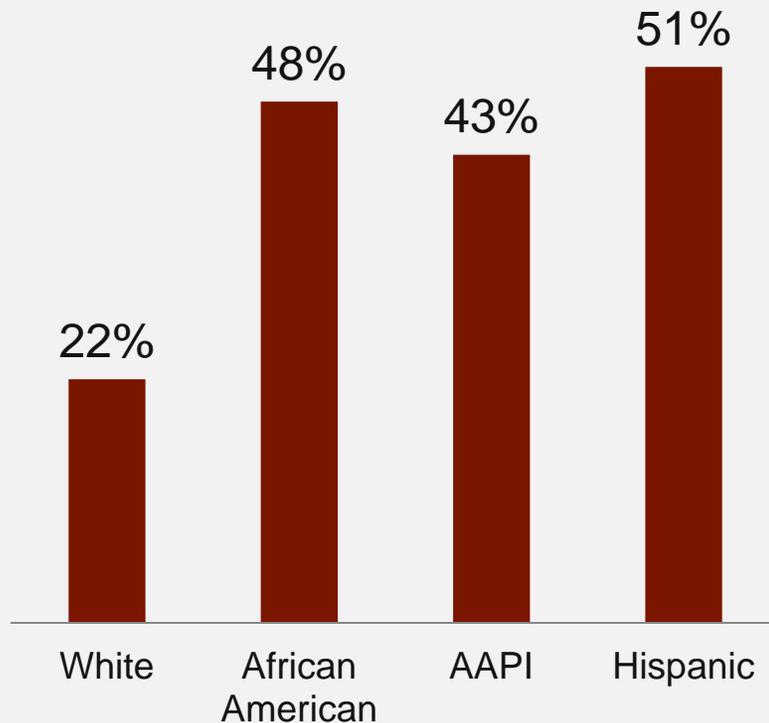
MULTICULTURAL FAMILY CAREGIVERS

Multicultural Family Caregivers: How Many?

	Percent who are Family Caregivers	Estimated Number of Caregivers
White (Non-Hispanic)	16.9%	26.5 million
African American	20.3%	5.6 million
Asian American/Pacific Islander (AAPI)	19.7%	2.7 million
Hispanic	21.0%	7.6 million

Multicultural Family Caregivers Tend to be Younger

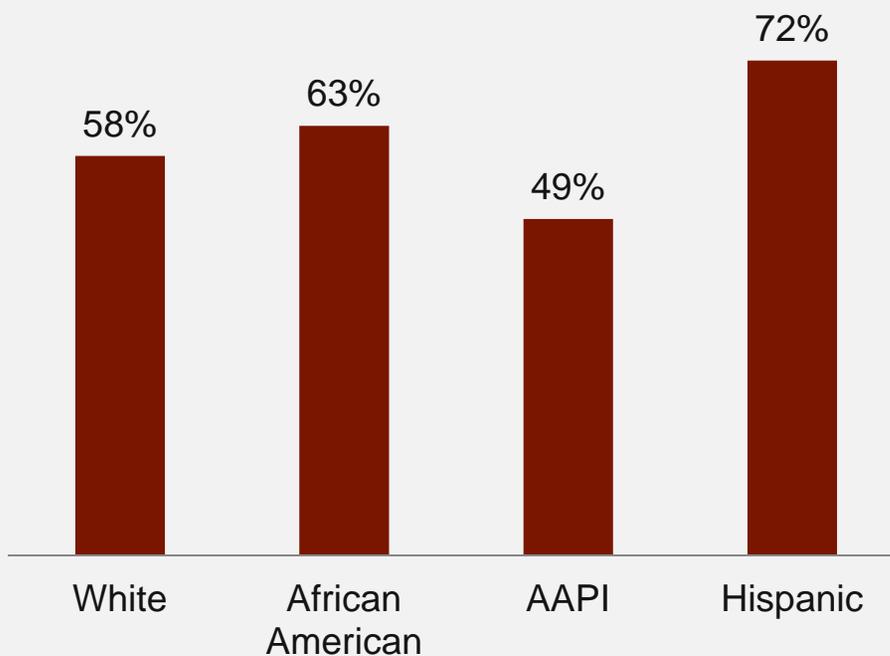
Percent of Family Caregivers Ages 18-49*



- Caregiver age varies by race/ethnicity.
- African American, Hispanic, and Asian American caregivers are, on average, younger than white caregivers.
- Age often plays a role in how people receive and absorb information.

Medical/Nursing Tasks

Family Caregivers Who Perform Medical/Nursing Tasks*



- Hispanic and African American family caregivers are more likely to perform medical/nursing tasks.
- These include:
 - Medication management
 - Wound care tasks
 - Mobility

\$6,954

Average Out-of-Pocket Expenses for Family Caregivers in 2016

Family Caregivers in the U.S. Provide \$470 Billion in Unpaid Care

Source: Valuing the Invisible 2015 Update: Undeniable Progress, but Big Gap Remains, AARP Public Policy Institute

More than three in four family caregivers (78%) are incurring out-of-pocket costs as a result of caregiving

78%

\$11,923

Average Out-of-Pocket Expenses for Long-Distance Caregivers in 2016

20%

Family caregivers are spending, on average, nearly 20% of their income on caregiving activities

AFRICAN AMERICAN

\$6,616

Average Out-of-Pocket Expenses in 2016

34%

of Income Spent on Caregiving Activities, on Average

HISPANIC/LATINO

\$9,022

Average Out-of-Pocket Expenses in 2016

44%

of Income Spent on Caregiving Activities, on Average

ASIAN AMERICANS & PACIFIC ISLANDERS

\$2,935

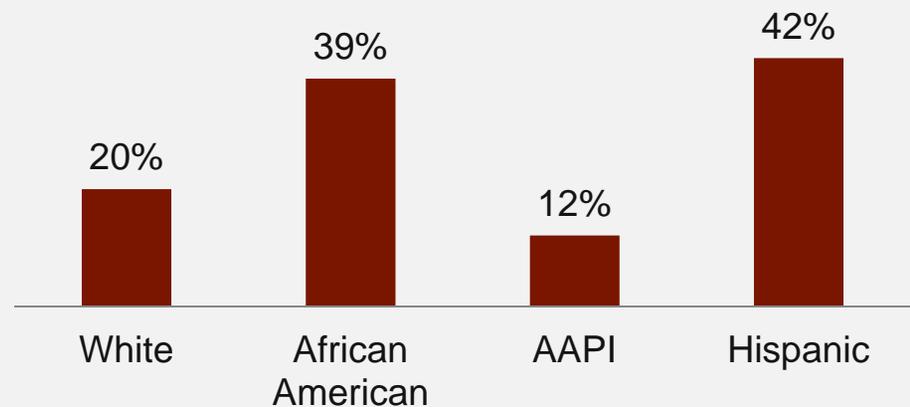
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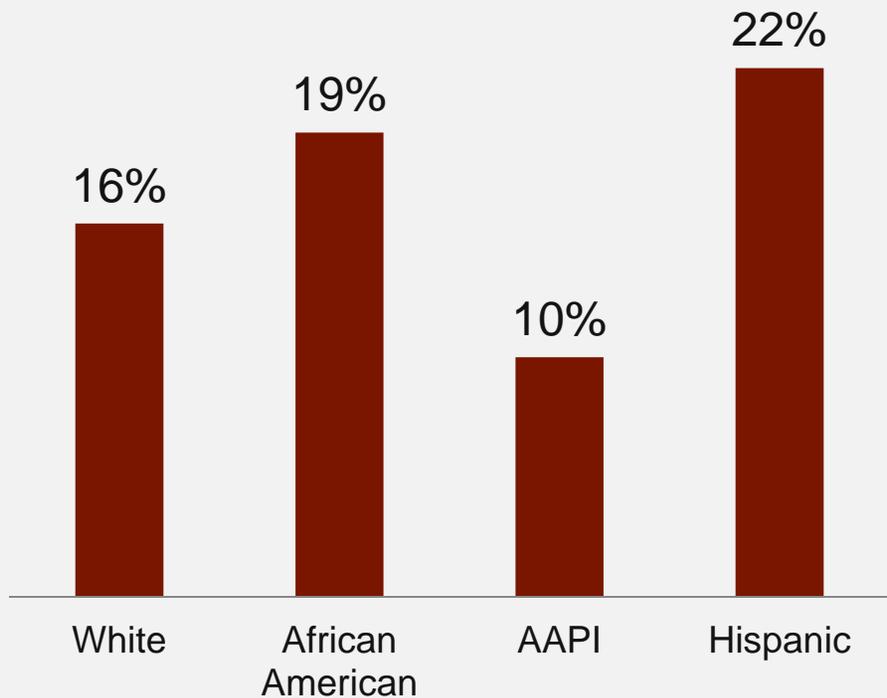
Incomes Vary Among Multicultural Groups

Family Caregivers with Annual Incomes Below \$30,000*



Mental Health and Caregiving

Family Caregivers of People with emotional or mental health problem(s)



African American Family Caregivers

- African American caregivers are more likely to care for a nonrelative (23 percent vs. 13 percent of all other race/ethnic groups).
- Along with Hispanic caregivers, more likely to report difficulty accessing local, affordable care services.
- Most likely of all groups for the caregiver to be a Veteran.

Hispanic Family Caregivers

- More likely to live in the same household as the person for whom they care.
- More often perform 21+ hours of caregiving per week than the general population (41 percent vs 32 percent).
- Compared with all caregivers, less likely to have internet access at home (76 percent vs 85 percent).
- More likely to seek resources available in languages other than English (22 percent).
- Fifteen percent are LGBT- a higher rate than other groups.

Asian American Pacific Islander Family Caregivers

- Reported greater need for information on key topics:
 - Keeping the someone safe at home (57 percent vs 42 percent).
 - incontinence/toileting problems (19 percent vs 11 percent)
- More likely to seek resources available in languages other than English (19 percent)
- More likely to believe their caregiving role will continue during the next 5 years (66% vs. 52% all other racial/ethnic groups)

Words Matter

- “Caregiving is not a burden...”
- “[insert ethnicity] all feel, act, look...”
- Mult-modal Research Methodologies

RURAL FAMILY CAREGIVERS

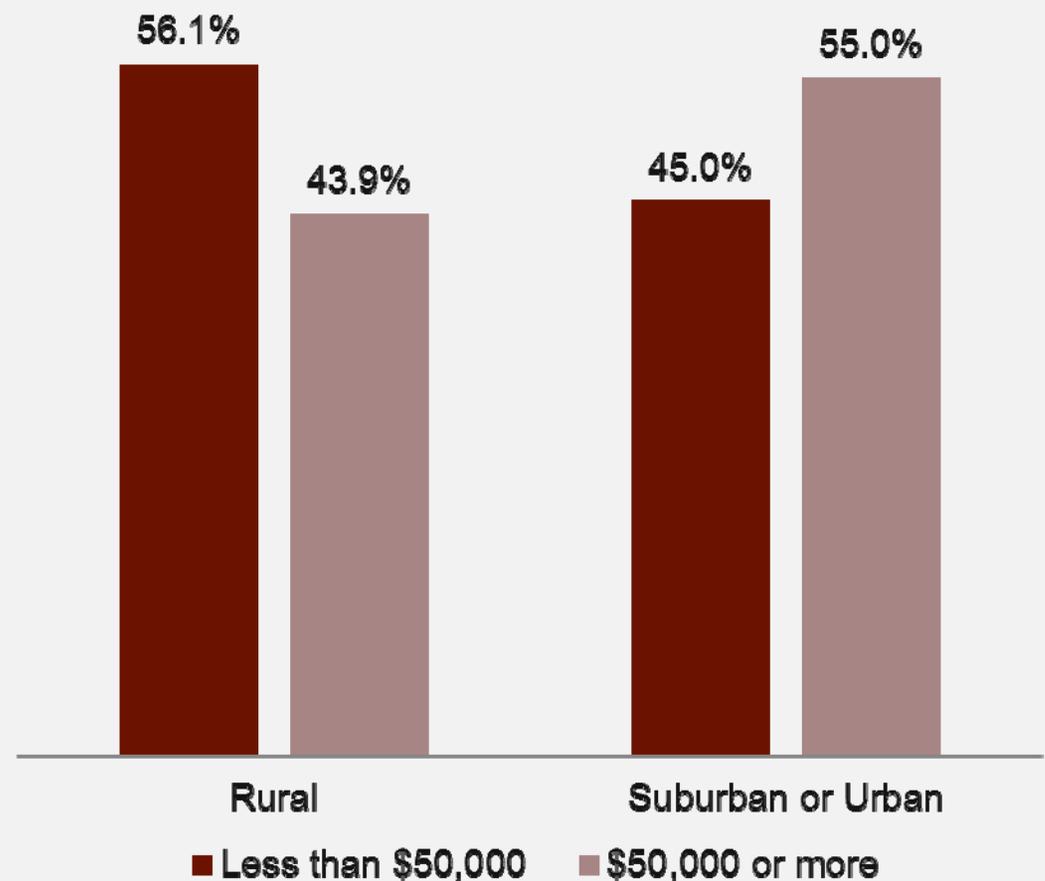
About Rural Family Caregivers

- Approximately 1 in 6 family caregivers live in rural areas.
 - More than three-fourths of rural family caregivers care for someone who also lives in a rural area.
- Rural family caregivers are less likely to have a college degree.
- Rural family caregivers are more likely to be older (65+) and whiter relative to suburban and urban family caregivers.

Rural family caregivers are more likely to have low or moderate incomes

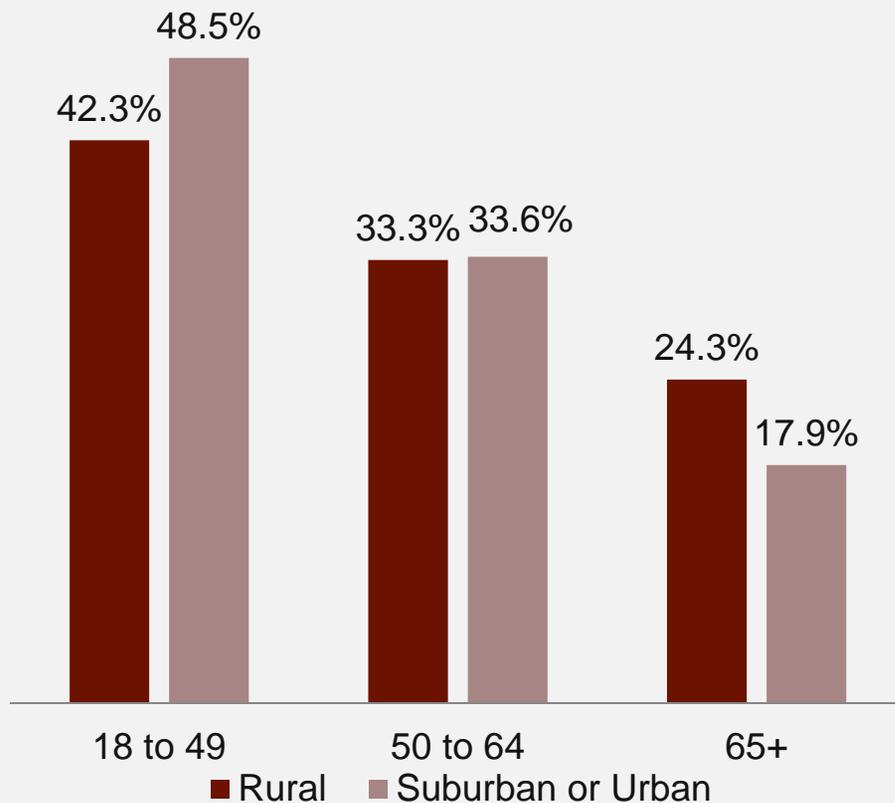
- More than half of rural family caregivers have incomes lower than \$50,000.
- Conversely, more than half of urban and suburban caregivers have incomes higher than \$50,000.
- More than 30 percent of rural family caregiver have incomes lower than \$30,000.

Family Caregiver Income by Setting



Rural Family Caregivers and Age

Family Caregiver Age by Setting



- Rural family caregivers tend to be older than other family caregivers.
- One in four rural family caregivers are 65+, while just 18 percent (less than one in five) urban and suburban caregivers are 65+.
- About 83 percent of care recipients of rural family caregivers are 50+.

Tasks Performed by Rural Family Caregivers

Common ADLs

- Helping with transfers in and out of beds and chairs (41 percent).
- Getting Dressed (25 percent).
- Getting to and from the toilet (25 percent).

Commons IADLs

- Doing grocery or other shopping (77 percent).
- Providing transportation (77 percent).
- Helping with housework (75 percent).

- In addition to ADLs and IADLs, more than half of rural caregivers reported performing medical/nursing

Telehealth Policies that Support Rural Caregivers

- In recent months, the U.S. Department of Veterans Affairs has expanded the availability of telehealth to its patients.
 - The VA Video Connect Program
- Pending legislation could help Medicare beneficiaries access telehealth.
 - The CHRONIC (Creating High-Quality Results and Outcomes Necessary to Improve Chronic Care) Care Act has passed the Senate
- Increasing the use of telehealth could help family caregivers.

OPPORTUNITIES TO SUPPORT DIVERSE FAMILY CAREGIVERS

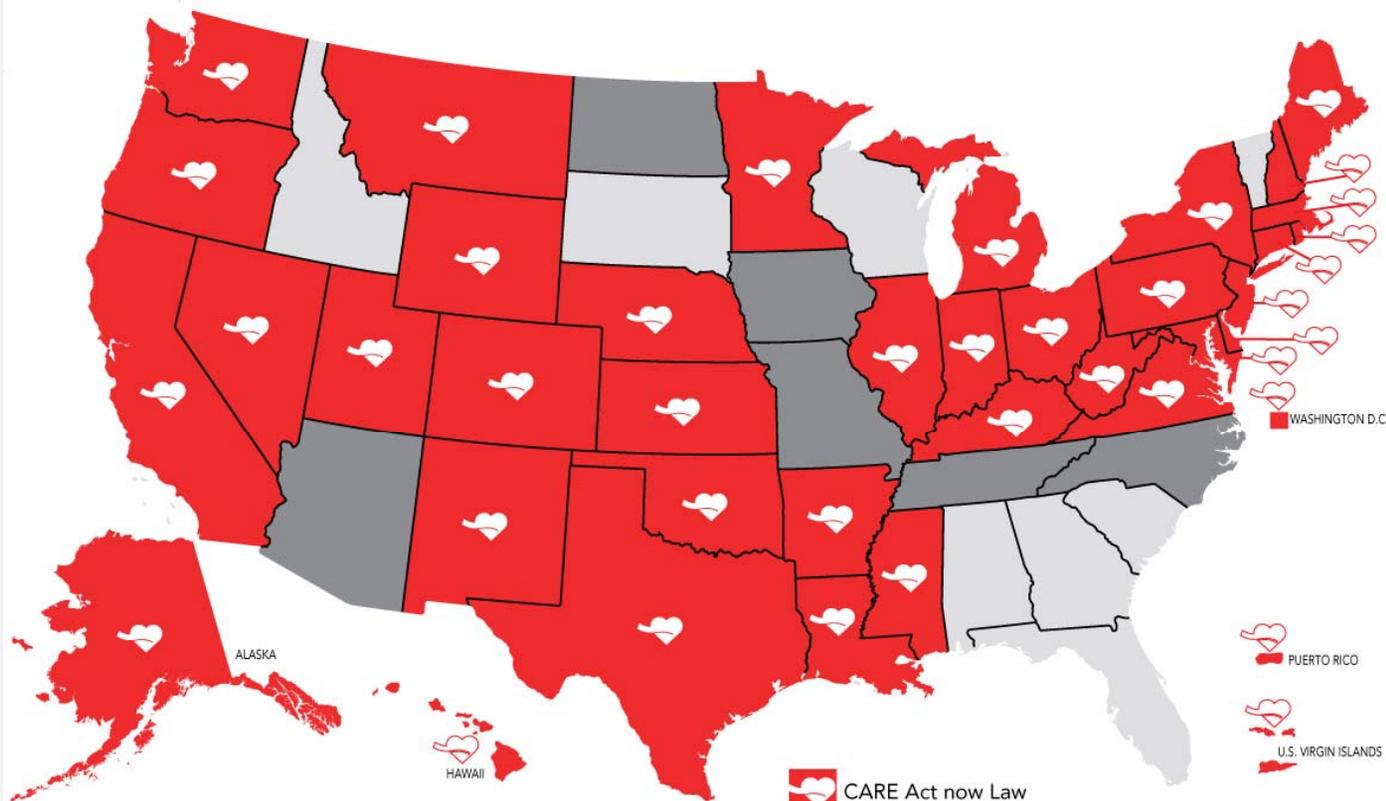
stereotypes

Translating Research Into Policy: The CARE Act

- AARP developed model legislation to support family caregivers- the Caregiver Advise, Record and Enable (CARE Act).
- Under the CARE Act:
 - Hospitals must identify a family caregiver for inpatient admissions and record the family caregiver in the medical record.
 - Hospitals must notify the family caregiver of discharge plans for the person in the hospital.
 - Family caregivers must be offered training on medical/nursing tasks they may be asked to perform.
- The law supports patients and family caregivers of all ages, and for any diagnosis
- Law in 39 states and territories- and counting!

The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.



CARE Act goes into effect:

Oklahoma, 11/5/14; Colorado, 5/8/15; New Jersey, 5/12/15; West Virginia, 6/8/15; New Mexico, 6/17/15; Mississippi, 7/1/15; Virginia, 7/1/15; Arkansas, 7/22/15; Connecticut, 10/1/15; Nevada, 10/1/15; Maine, 10/15/15; Puerto Rico, 12/31/15; California, 1/1/16; Indiana, 1/1/16; New Hampshire, 1/1/16; Oregon, 1/1/16; Illinois, 1/27/2016; Utah, 2/10/16; Nebraska, 3/30/16; Virgin Islands, 3/30/16; New York, 4/23/16; Washington, 6/9/16; Wyoming, 7/1/16; Washington D.C., 7/6/16; Michigan, 7/12/16; Louisiana, 8/1/16; Maryland, 10/1/16; Alaska, 1/1/17; Delaware, 1/1/17; Minnesota, 1/1/17; Rhode Island, 3/14/17; Ohio, 3/20; Pennsylvania, 4/20/17; Kentucky, 6/29/17; Hawaii, 7/1/17; Montana, 10/1/17; Kansas, 7/1/2018; Massachusetts, TBD; Texas, TBD

**Updated on 6/10/2017

Caregivers **AARP** Real Possibilities

Transforming Practice: National CARE Act Scan

- AARP is leading a national scan of states and health systems that are implementing the CARE Act to identify and diffuse promising practices and to determine where gaps remain.
- Interviews with cross-disciplinary professionals, and family caregivers. Examples include:
 - Nursing
 - Pharmacy
 - Physical Therapy
 - Information Technology
- Focused on key areas of implementation including:
 - Identifying the Family Caregiver
 - Information Technology and Electronic Health Records
 - Identifying Training Resources

2017 Site Visit Profile:

- 18 visits with 16 health systems and 45 hospitals
- 7 states - NJ, NY, VA, MI, CO, NV, CA
- Community and teaching hospitals
- Rural and urban
- Non-profit, government, and for profit providers
- Bed size ranging from 25 to 837

Promising Practices from the National CARE Act Scan

Other promising practices include:

- Handouts that explain the CARE Act and the role of the family caregiver at admission.
- Multi disciplinary rounds– including patients and family caregivers during provider rounds and shift changes.
- Audio recording platform that captures all the discharge instructions for use by patient and caregiver after discharge.
- Redesign of the bedside “white board” to include the family.

The National CARE Act Scan will continue through 2018 in additional states!

The Home Alone AllianceSM

- Collaborative of public, private, and nonprofit sector organizations dedicated to creating solutions that support family caregivers performing complex care tasks.
- Currently includes fifteen member organizations.
- A key resource from the Home Alone AllianceSM are instructional videos.



- Find our videos and resources at:
www.aarp.org/nolongeralone

Home Alone AllianceSM Members

AARP*	Atlas of Caregiving	National Alliance for Caregiving
Betty Irene Moore School of Nursing, UC Davis*	Center to Advance Palliative Care	National League for Nursing
United Hospital Fund*	Coalition to Transform Advanced Care	Nurses Improving Care for Healthsystem Elders (NICHE)
Family Caregiver Alliance*	Easterseals	NYU Rory Meyers College of Nursing
The John A. Hartford Foundation	Hartford Institute for Geriatric Nursing	Pfizer, Inc.
American Journal of Nursing	Home Instead Senior Care	Rosalyn Carter Institute for Caregiving
		U.S. Department of Veterans Affairs

Thank you...

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