



FAMILY CAREGIVING IN THE U.S. : POLICY, RESEARCH AND PRACTICE

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RESEARCH REPORT

MAY 2020

2020 Report

Caregiving in the U.S.



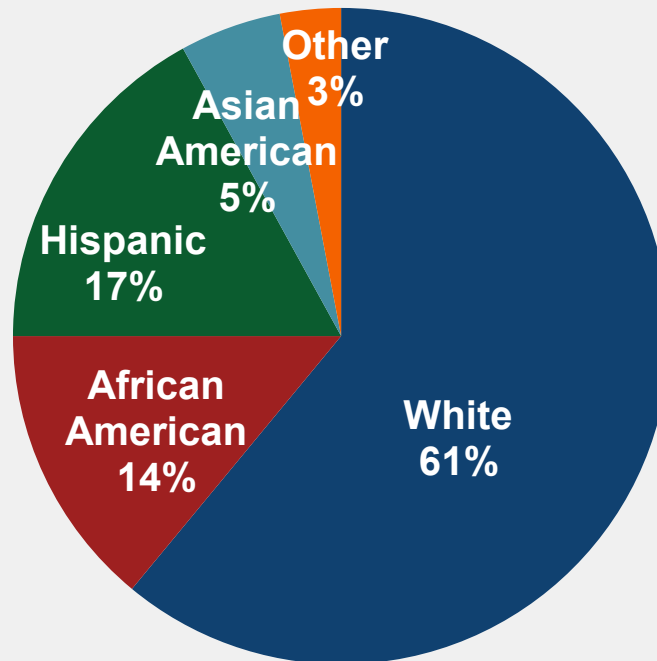
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Family Caregiving™

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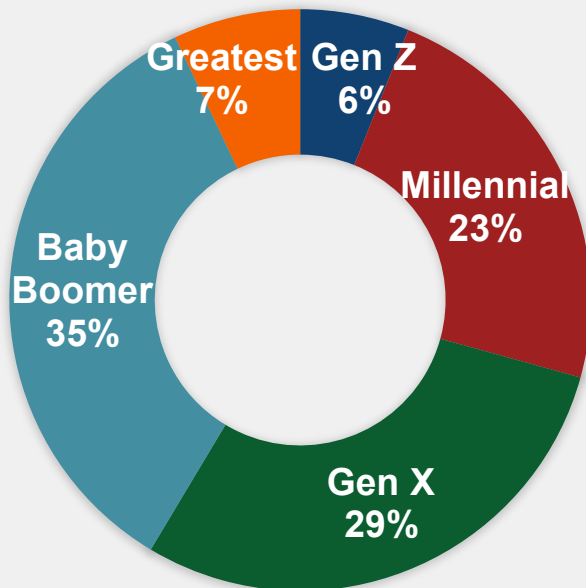
CAREGIVERS REFLECT THE DIVERSITY OF THE U.S. POPULATION

**Caregivers of adults, 2019
(total 48 million)**



CAREGIVERS REFLECT THE DIVERSITY OF THE U.S. POPULATION

- **39% men, 61% women**
- **9% identify as LGBTQ**



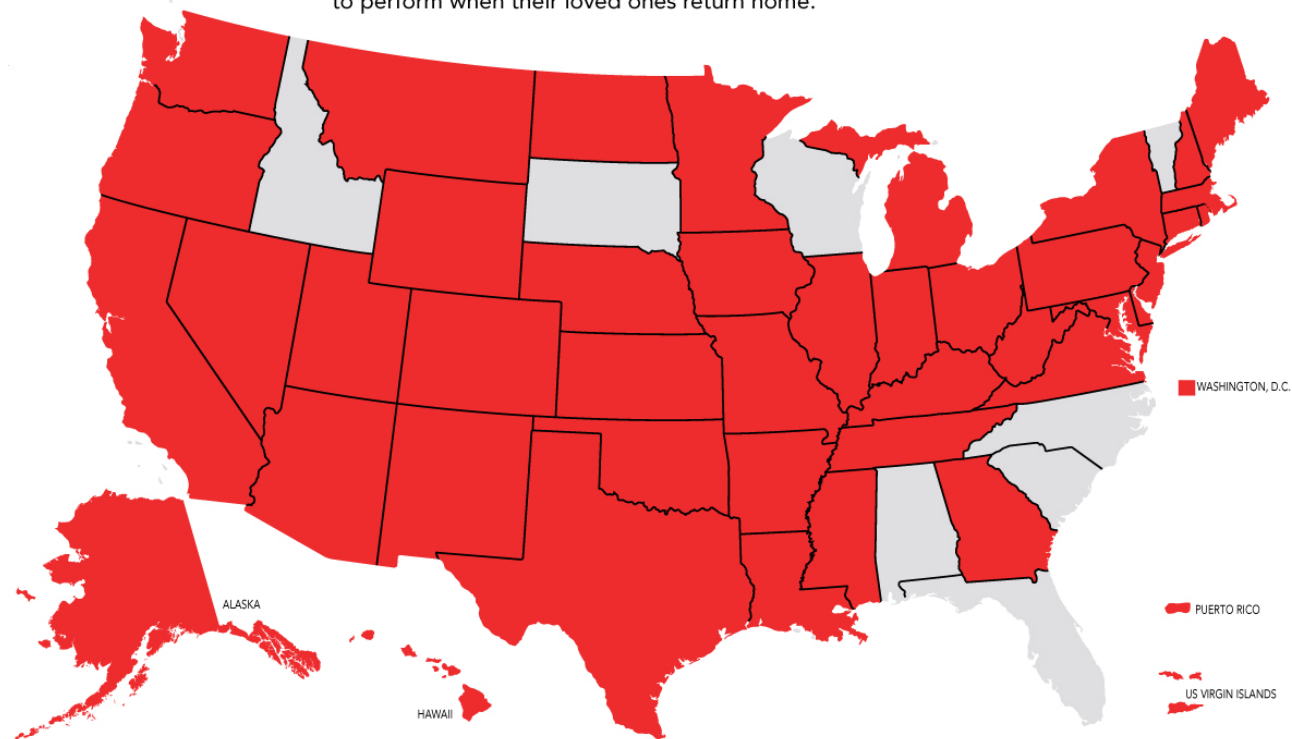
RAISE NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS

- Collaboration of 15 federal agencies committing to 350 support actions organized around five goals:
 - Increase awareness of and outreach to family caregivers
 - Advance partnerships and engagement with family caregivers
 - Strengthen services and supports for family caregivers
 - Ensure financial and workplace security for family caregivers
 - Expand data, research, and evidence-based practices to support family caregivers



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 ones return home.



TENANTS OF 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.

HOSPITAL AT HOME HISTORY: LONG HISTORY OF MINOR ROLE

1995

Researchers at the Johns Hopkins Schools of Medicine & Public Health developed the first HaH program in the U.S. in 1995



2000-
2002

National Demonstration & Evaluation Study tested model in four settings; extensive international growth of model



2010

Modified HaH model tested with home-based care provided by nurses, physician consult via two-way telemedicine video

CMS WAIVER: REGULATORY FLEXIBILITY & REIMBURSEMENT MECHANISM

- CMS waiver implemented Nov 2020 allows acute care to be provided within patient's home
- New regulatory flexibility waives certain hospital conditions of participation
- Waiver hospitals paid the same as if care was provided in traditional IP setting

Currently 256 hospitals in 37 states approved under the waiver



AARP PPI HOSPITAL AT HOME RESEARCH

- Landscape analysis of leading HaH programs & review of existing research
- Interviews with program operators, stakeholders, caregiver advocates
- Roundtable with operators, stakeholders, caregiver advocates
- Minimal formal expectations of caregivers, no caregiver assent sought

FAMILY CAREGIVER CONSIDERATIONS

Ensure choice, access, and equity - make clear participation is voluntary for patients & family caregivers, eliminate all barriers related to access & equity

Be clear and understandable to the patient and family caregiver - provide clear information to patients & family caregivers about program, expectations, and services

Recognize and support the family caregiver - recognize & support caregivers by ensuring their needs are met and incorporating their voice & preferences

Allow for appropriate levels of research and learning

STATE CAREGIVER TAX CREDIT ESTIMATION PROJECT

- Innovative work to estimate state budgetary impact of various types of caregiver tax credits in the states
- Using AARP Caregiving in the US data, Caregiver OOP Cost Survey and UI Tax Policy Center's tax model



PAID FAMILY LEAVE & SICK LEAVE



- Paid Family Leave in 11 states plus DC
- 16 states and DC passed laws specific to paid sick leave
 - 8 states' laws are specific to public health emergencies
- In the absence of federal and state laws, paid family and medical leave and paid sick leave may be granted voluntarily by employers

Research

Policy

Practice

- Research: identify and name the problem, from here potential policy solutions can be explored
- Policy: identify viable policy solutions, broad impact of the problem key to successful coalition building and bipartisan support
- Practice: diffusing policy into practical application is a continuing effort



QUESTIONS

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