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# Policy Solutions to Support Family Caregivers

January 27, 2021

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# Agenda

- Review current state of family caregiving in the United States
- Describe key research findings on caregiver stress and impact
- Provide overview of local, state and national policy solutions

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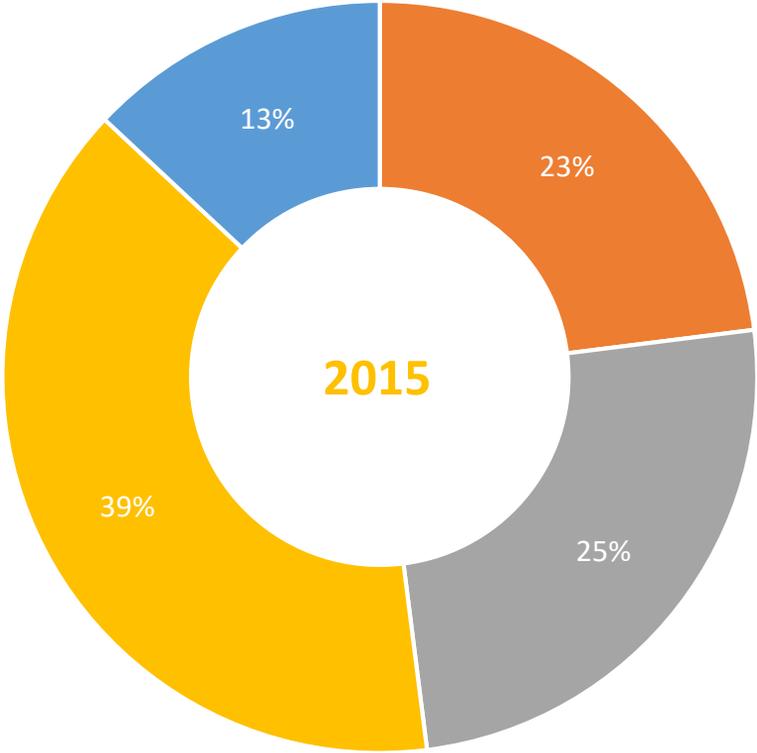


# Definition of family caregiving

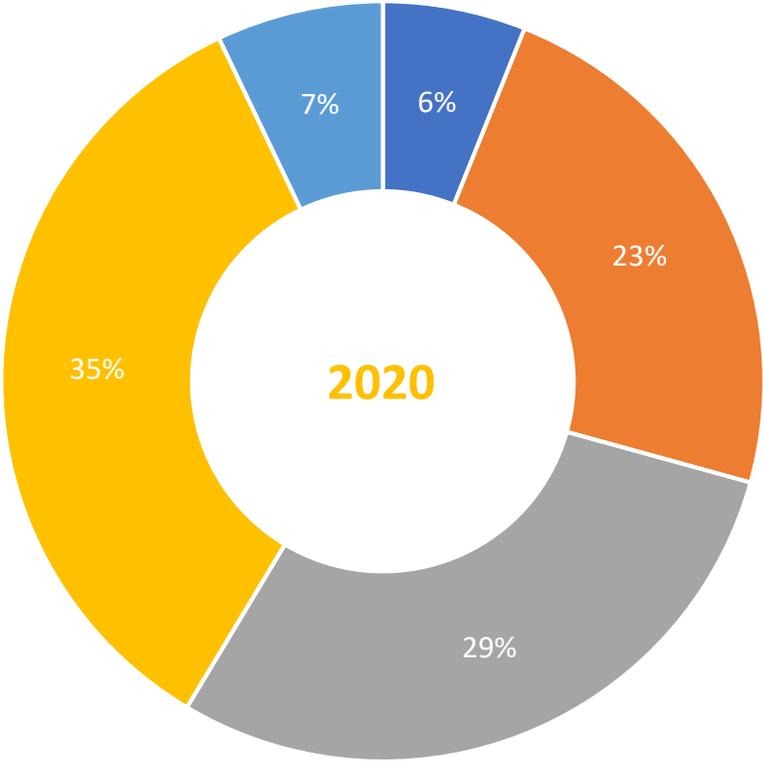
- Providing a broad range of unpaid assistance to an individual who has a chronic or other serious health condition, a disability, or a functional limitation that interferes with daily activities
- Such assistance may include help with:
  - Bathing, dressing, paying bills, handling insurance claims, preparing meals, transportation
  - Administering multiple medications, wound care, handling medical equipment
  - Coordinating services and supports, communicating with providers, implementing care plans
  - Hiring and supervising direct care workers (such as home care aides)
  - Serving as an “advocate” during medical appointments or hospitalizations



# In 2020, one in five adults were caregivers, shifting over time to younger generations



Comprises 18% of US Adult Population



Comprises 21% of US Adult Population

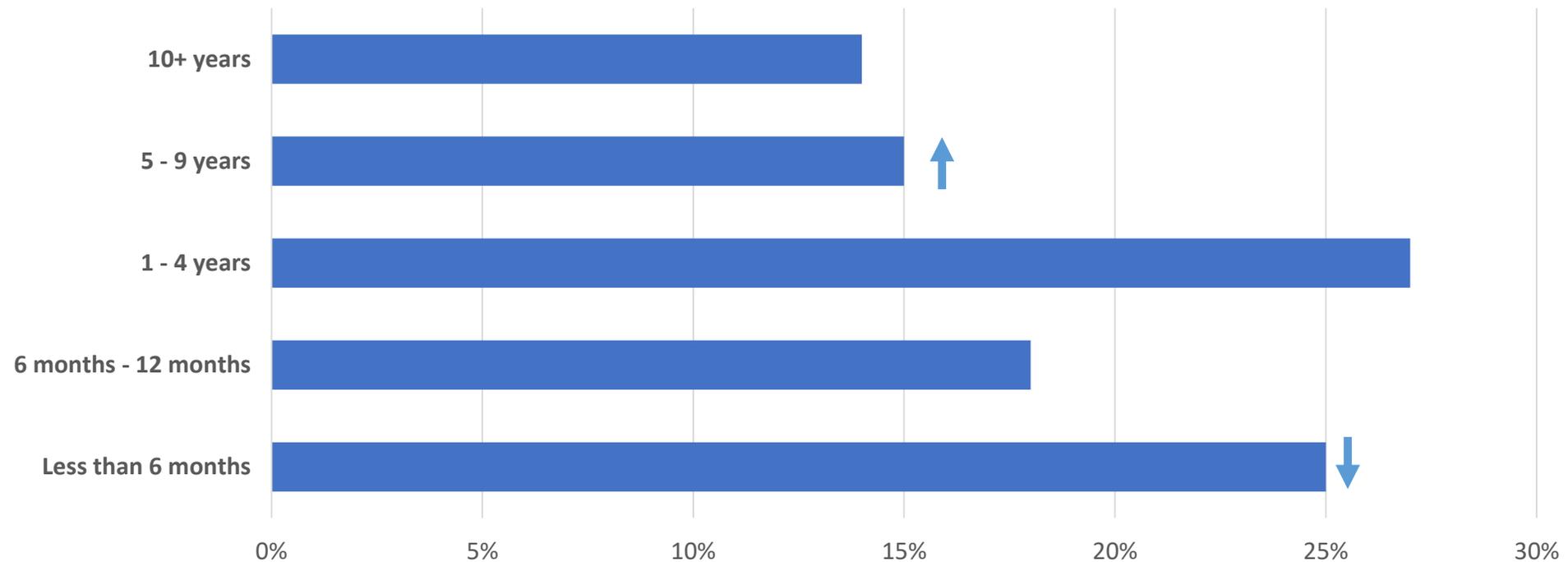
- Generation Z
- Millennial
- Generation X
- Baby Boomers
- Silent/Greatest



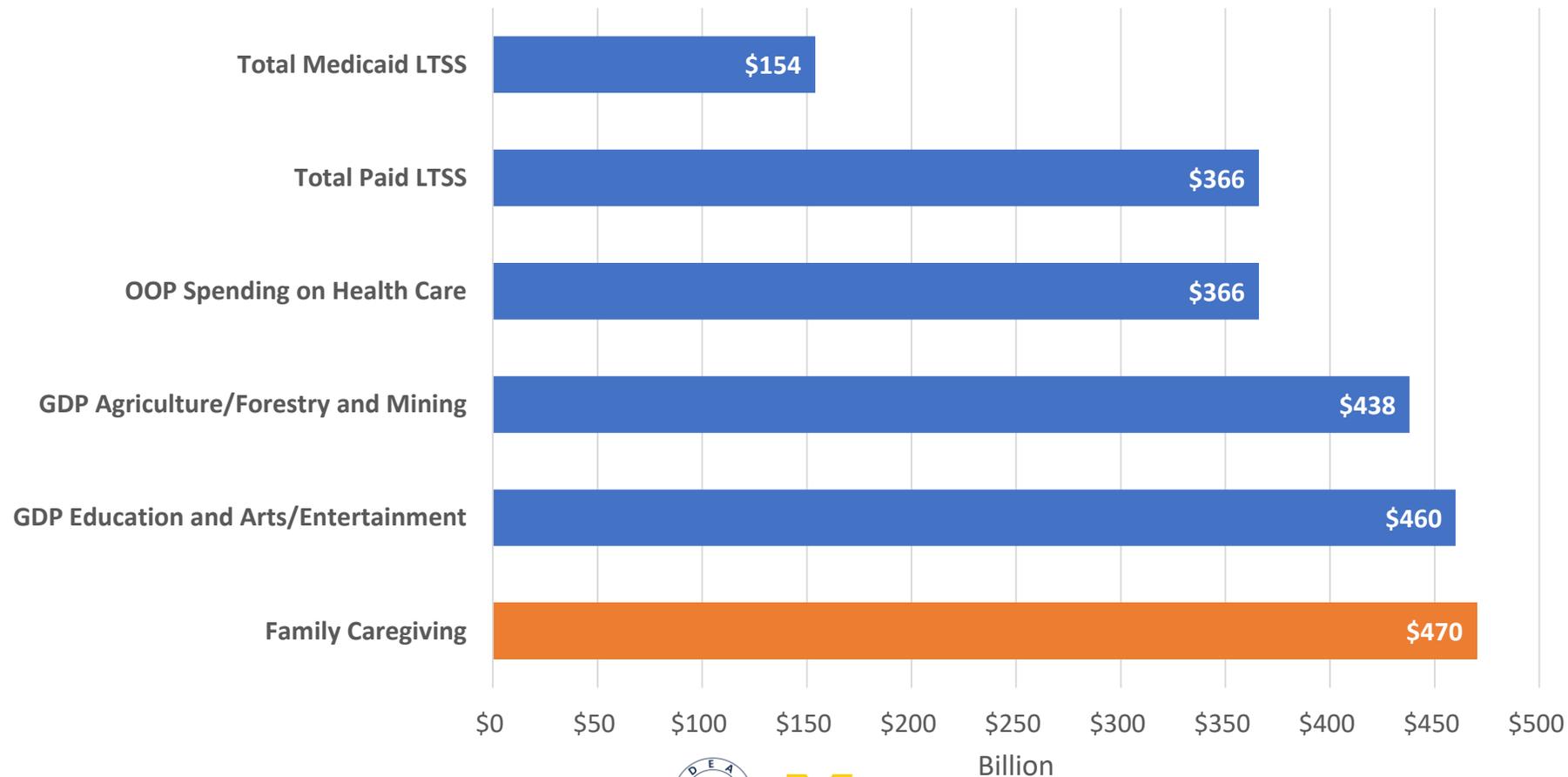
Source: AARP, Caregiving in the US 2020

# Average years of care provided is 4.5

Duration of Care for Recipient



In 2017, about 41 million family caregivers provided care to adults with limitations in daily activities;  
Economic value - approximately \$470 billion



# Who are family caregivers?

- We all have our own caregiver stories
- PBS stories: COVID-19 has made life much harder for family caregivers

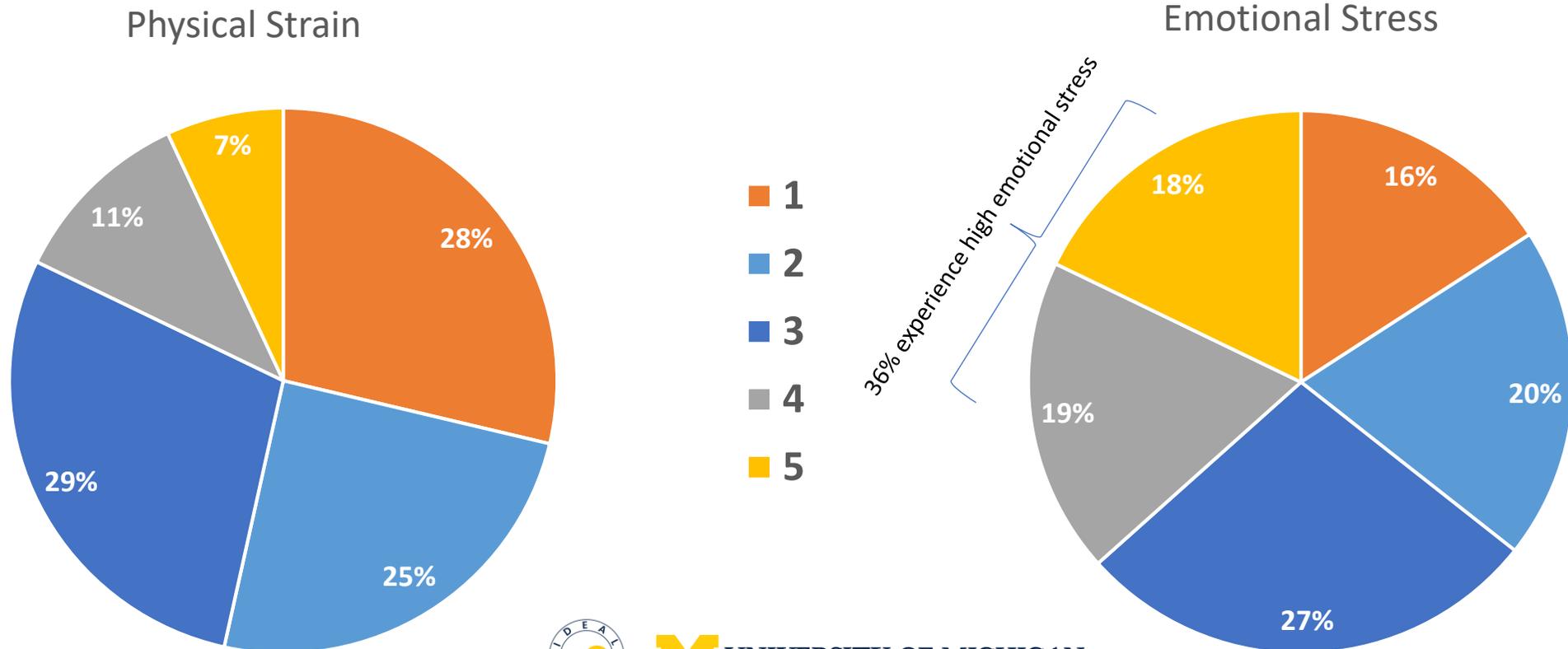
# Key research findings: Caregiver stress

- When caregivers experience anxiety, depression, or stress, research has shown that their care recipients are more likely to report poorer self-efficacy, treatment adherence, and symptom monitoring.
- Uncoordinated caregiver interactions with the health care system add to their stress, “you have to talk to so many health care professionals or suppliers,” (57% of younger caregivers and 44% of boomer caregivers report this as a stress factor).



Almost 40% of all caregivers find their caregiving situation to be emotionally stressful. When caregivers felt they had no choice in assuming caregiving responsibilities, this percentage increases to 53%

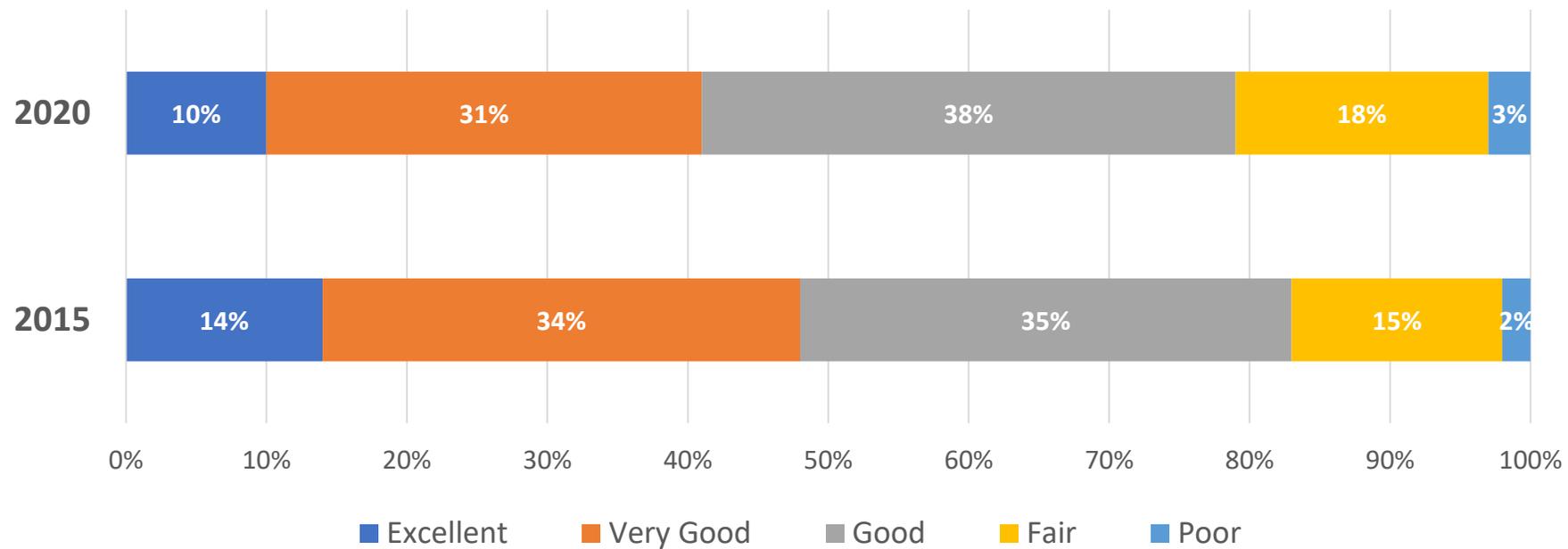
Ranked from 1 (no stress/strain) to 5 (very stressful/strenuous)



# Key research findings: Caregiver health

- A caregiver's health is strongly correlated to their household income. Only 31 percent of caregivers with less than \$50,000 in household income rate themselves in excellent or very good health, compared to 47 percent of higher-income caregivers.
- Unpaid family caregivers can expect to spend roughly 20 percent of their personal income on out-of-pocket costs associated with helping their care recipient, adding to their stress.

In 2015, nearly twice as many caregivers indicated their health was fair or poor compared to the general population (17% vs. 10%). By 2020, this had increased to 21% for caregivers.



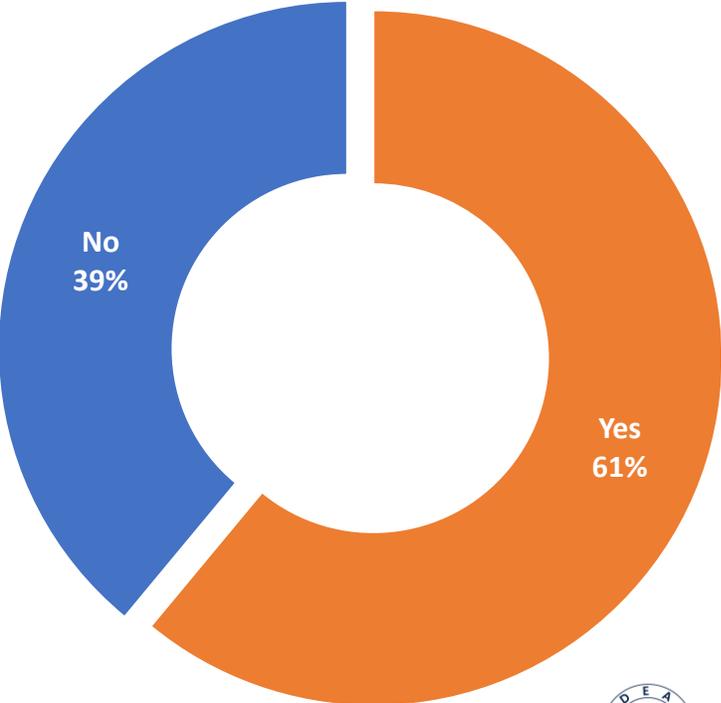
# Key research findings: Caregiver employment

- More than half of employed caregivers have had to take time off from their main job, reduce their working hours, or quit to accommodate their caregiving responsibilities.
- Most employed caregivers have indicated that their caregiving had interfered with their employment.

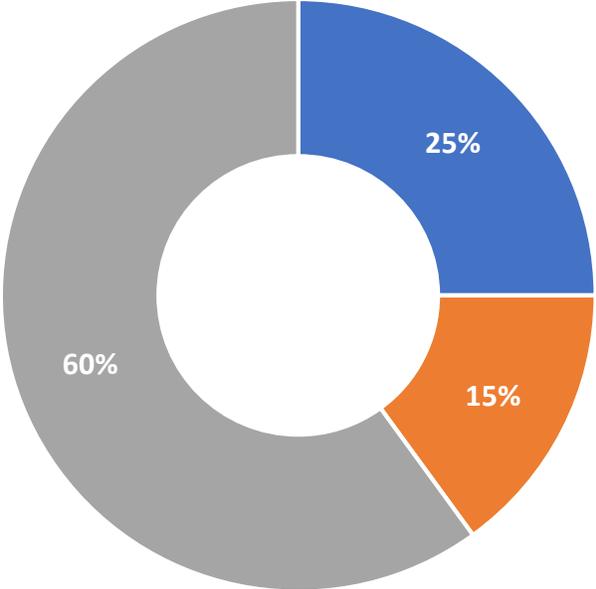


61% of caregivers were employed at some point in the past year while also caregiving. Among all employed caregivers, 60% worked full time.

Employed While Caregiving



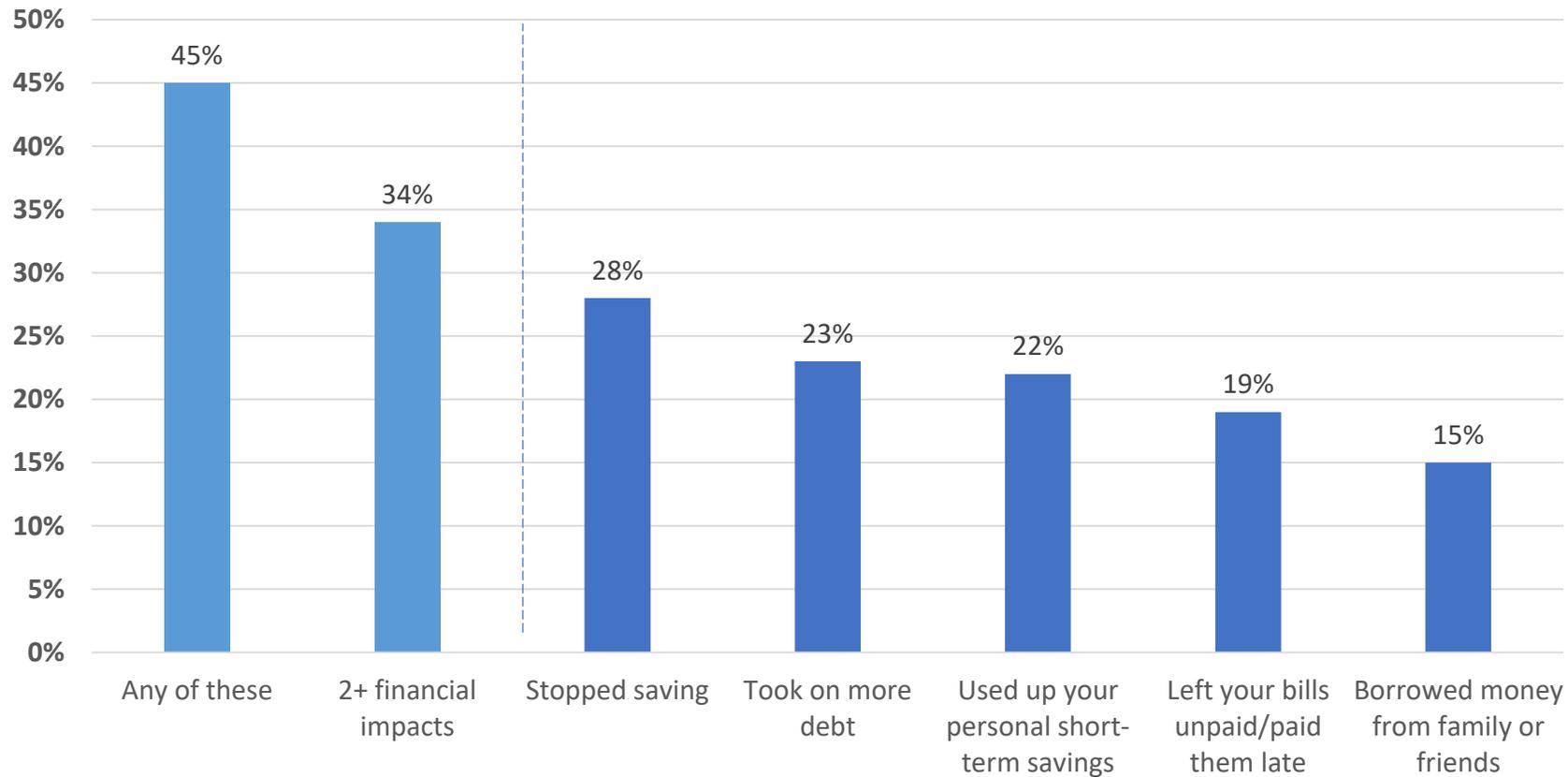
Hours Worked



- Less than 30
- 30 - 39
- 40 or more



# Nearly half of caregivers have experienced at least one financial impact as a result of caregiving



# Who pays for caregiving / caregiver support?

- Family
- Medicaid – waiver programs, etc.
- Medicare (minimal)
- Veterans Administration



# Caregiver benefits for veterans with disability

## **Program of Comprehensive Assistance for Family Caregivers**

- An eligible veteran can designate a primary caregiver, and up to 2 secondary caregivers to provide personal care services.
- Eligible primary and secondary family caregivers can receive education and training; mental health counseling; travel, lodging, and financial assistance.
- Eligible primary family caregivers may also receive a monthly stipend, access to CHAMPVA health care benefits, and 30 days of respite care per year.

**Program of General Caregiver Support Services** provides resources, education and support to caregivers of Veterans. The Veteran does not need to have a service-connected condition, for which the caregiver is needed.



# Impetus for caregiver policy changes

- By 2050, there will be only three potential family caregivers for every person age 80 or older. In 2010, the ratio was seven potential caregivers to every person age 80 or older.
- Recent federal and state policy trends are shifting care from institutional to home-based settings.
- Increased societal awareness of the need for caregiver support due to the isolating impact of the COVID-19 pandemic.



# Local initiatives that can support caregivers

- Local initiatives can help pilot new ideas, targeted to unique community needs, and may be transferable to other communities.
- Examples:
  - Community Aging in Place—Advancing Better Living for Elders (CAPABLE) is a program developed by nurses at Johns Hopkins University in Baltimore, that has expanded to 25 sites nationally.
  - County senior millages
  - County Commissions on Aging; Councils on Aging



# CAPABLE overview

- The CAPABLE team includes a registered nurse, an occupational therapist and a licensed handyman who work with individual seniors and their caregivers to keep them at home, functional and safe.
- CAPABLE costs: \$3,300 per participant for 4 months; up to \$1,200 in home repairs.
- Community implementation includes funding environments such as: Accountable Care Organizations, PACE, Meals on Wheels, Medicaid waiver, or private philanthropy.

## Research Outcomes

- Research indicates that CAPABLE saves on average, in relation to comparison group, \$2,765 per quarter, which translates into more than \$10,000 in cost-savings per year for Medicare for at least two years.
- Demonstration project results also showed a 2x improvement in functionality and symptoms of depression, the ability to shop, and to manage medications.



## County senior millages

- Some counties across the U.S. have voter-approved senior millages to help people live independently in their own homes. Funded services often include home delivered meals, personal care, transportation, home repairs, respite care, senior centers and more.

## County commissions on aging / councils on aging

- Generally established by the county Board of Commissioners with representation from each district in the county.
- In counties that also have a senior millage, may include management of funds.



# Michigan example

- Michigan currently has over 20 county Commissions on Aging and several county level Councils on Aging (83 total counties).
- Monroe County Commission on Aging: [Caregiver resources](#)
  - Established in 1973.
  - Mission: The Commission is charged with recommending the prudent spending of public dollars to promote the health, dignity and independence of Monroe County residents sixty years of age and older.
  - Programs are funded by the Monroe County Senior Millage (.5 mills per \$1,000).



# State-level family caregiving policy solutions

- Expand and continue Medicaid waivers
- Expand Programs of All-Inclusive Care for the Elderly (PACE)
- Funding initiatives: Washington's Long-Term Care Trust Act payroll premium



# Medicaid waivers

- States use Medicaid waivers to support family caregivers through various means including: payment, training, or other services.
  - Waivers allow states to make specific changes to their Medicaid program that differ from standard federal requirements.
  - For Long-term Services and Supports (LTSS), the most common waivers are 1115 waivers and 1915(c) waivers.
- Seven states have used these waivers to provide education and training services for unpaid caregivers through their Medicaid programs.
- Many states also use waivers to provide support groups, non-psychiatric counseling services, coping skills building, and consultation services.



# PACE overview

PACE provides comprehensive medical and social services to community-dwelling elderly individuals, primarily dual eligibles, who qualify for a nursing home level of care. Caregivers are provided with respite, training, and in some states, they may also receive some payment for providing care.

## Research outcomes

- PACE reduces the costs associated with emergency room visits, unnecessary hospital admissions and long-term nursing home placements.
- A recent survey on caregiver stress found that 96.6 percent of family members are satisfied with the support they receive through PACE, and 97.5 percent of family caregivers would recommend PACE to someone in a similar situation.



# PACE policy issues: Access to care & eligibility limitations

- Currently, there are only 263 PACE centers in 31 states.\*
- Because there are so few available programs, in some areas it can take as long as 9 months to apply and get approval.
- PACE only provides care to individuals age 55 and over.

\* <https://www.npaonline.org/pace-you/pacefinder-find-pace-program-your-neighborhood>



# Washington's long-term care payroll premium

- In 2019, Washington became the first state to create a public long-term care insurance program.
  - Funded through a payroll tax of 0.58 percent on employees.
  - Will pay benefits of up to \$36,500 to those who need assistance with 3 or more activities of daily living (provided they meet some additional criterion).
    - Includes payment for respite care, meals on wheels, home modifications, and family caregiving.



# National family caregiving policy solutions

- The Recognize, Assist, Include, Support, and Engage Family Caregivers Act (RAISE), which became law on Jan. 22, 2018, directs the Secretary of Health and Human Services to develop a national family caregiving strategy.
- The National Alzheimer's Project Act (NAPA) was signed into law on Jan. 4, 2011. NAPA led to the creation of a national strategic plan to improve the health outcomes of people with AD/ADRD and reduce their financial burden.
- Expand Family Medical Leave Act (FMLA) to better protect family caregivers.
- Increase funding for the Older Americans Act, National Family Caregiver Support Program.
- Provide Social Security working "credits" for family caregivers who leave workforce.



# RAISE overview

- Established the Family Caregiving Advisory Council
  - Tasked with creating a National Family Caregiver Strategy that includes:
    - Recommending actions that various stakeholders (federal, state, local governments, health care providers, communities, etc.) may take in an effort to support and recognize family caregivers.
    - Assessing the impact of family caregivers on the Medicaid program and Medicaid's role (current and future) in family caregiver support.
  - Adopted 26 recommendations in November 2020 that will be the foundation for the National Family Caregiving Strategy that will begin development in 2021.



# National Alzheimer's Project Act (NAPA) overview

- The NAPA Advisory Council recommendations include specific provisions that would support caregivers.
  - By 2025, programs beyond Medicaid that provide LTSS should be expanded to support individuals and their caregivers with unmet needs, including diverse, under-served, and high-risk populations living with Alzheimer's Disease-Related Dementias
    - Congress should expand the FMLA; States should expand supports for paid leave for caregivers
    - States should expand voluntary long-term care savings accounts
    - Congress and States should expand tax credits for caregivers
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# FMLA potential expansion overview

Potential Policy Solution	Impact on Family Caregivers
Expand the definition of “family” to include more family caregiver relationships, such as siblings, in-laws, and grandparents	More than 25% of family caregivers provide care for an adult family member that does not fall under the law’s definition
Broaden the work requirements to include smaller employers and part-time employees	Nearly 40% of all workers in the US are excluded from FMLA benefits
Include provisions for paid leave	FMLA currently only offers protection from job loss



# Older Americans Act, National Family Caregiver Support Program (NFCSP)

- The NFCSP was created under the Older Americans Act in 2000 and provides grants to states and territories that fund various caregiver support initiatives
- In 2020, about 9% of the funding for the Older Americans Act was allocated to the NFCSP (\$186.9 million)

Potential Policy Solution	Impact on Family Caregivers
Allocate more funding to the NFCSP to better assist the growing number of family caregivers	Enable more competent and confident caregivers, reduce the risk of adverse outcomes and burnout, and increase the number of care recipients who can remain in the home



# Social security working credits for family caregivers

- Amend Social Security to provide working “credits” for family caregivers who leave the workforce to provide care for a family member that is ill, elderly, or has a disability
- This will support the future of individuals who must forgo employment when their caregiving duties demand a lot of time and energy
  - Strengthens retirement benefits
  - Keeps caregivers out of poverty later in life



# What can you do to influence caregiver policy?

- Stay informed, e.g., follow the RAISE advisory council's development of a national family caregiver strategy.
- Learn more about local initiatives that support family caregivers in your community and how to get involved.
- Consider telling your story, or writing a policy brief to inform policy makers.
  - A short document that explores an issue, summarizes key findings from research, succinctly defines lessons learned, and presents recommendations
  - A call for action based on research and facts



# Questions?



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