

Introduction: family caregiving

Definition

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.



Cost

In 2017, the value of family caregiving was \$470 billion – this is 28% higher than total out-of-pocket spending on health care, valued at \$366 billion.

—Source: AARP Public Policy Institute

Who pays?

- Family (majority of care)
- Medicaid (waivers)
- Medicare (minimal)
- Veterans Administration

23% of Michigan adults are caregivers

Family Caregiver Programs in Michigan

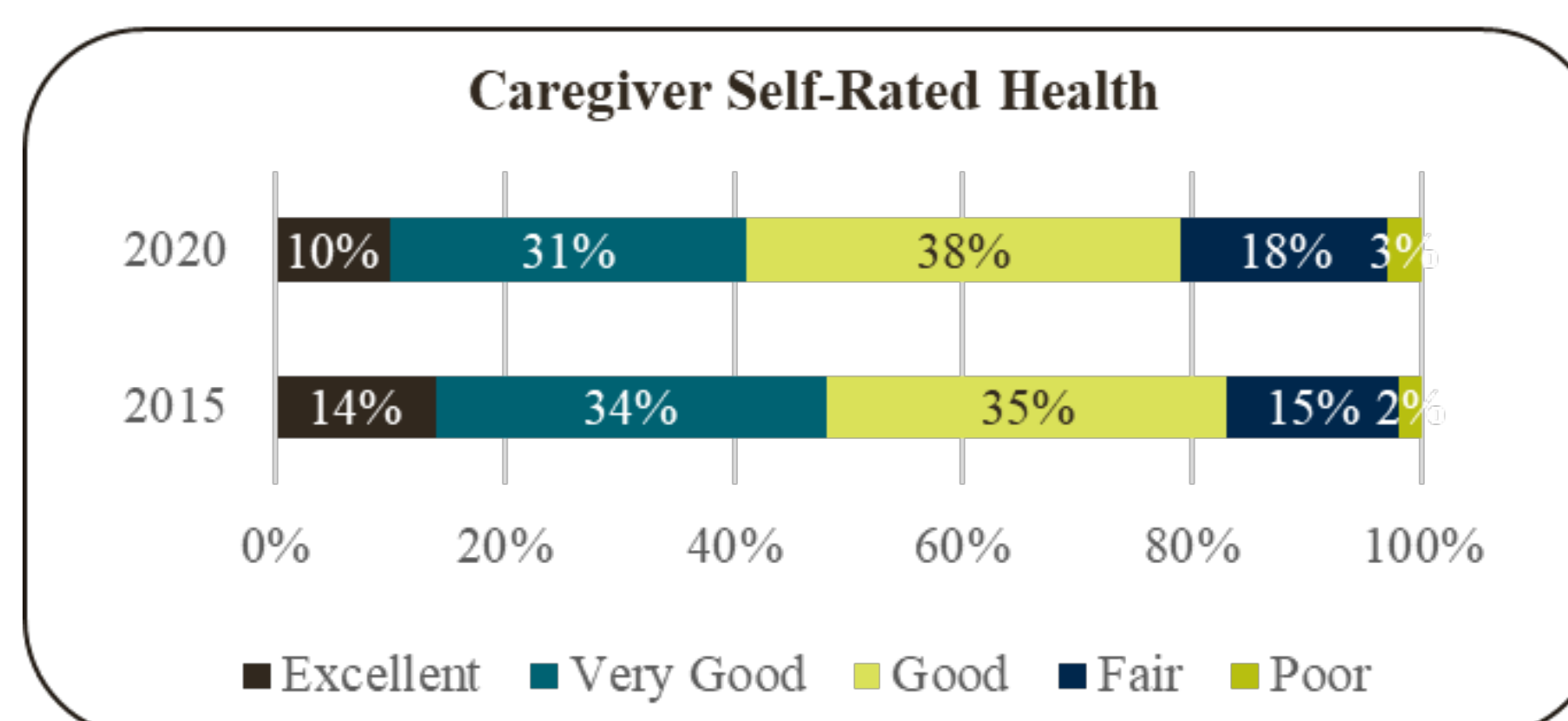
- Approximately 23 percent of adult Michiganders (1.73 million) provide unpaid care to another adult.
- Many caregivers are not being reached by current caregiver programs and services, including younger caregivers, male caregivers, and caregivers of color.
- Racial and ethnic data is essential to identifying best practices and scaling-up effective interventions.

—Source: CHRT, study funded by MI Health Endowment Fund

Impact of COVID-19 pandemic

- A Wisconsin survey of 500 older adults and individuals with disabilities found that every respondent experienced a **disruption** in their caregiving service during the early months of the pandemic.
- Caregivers without ancillary supports (respite, personal care assistants, adult day care) experienced **burnout**, increased fatigue, irritability, changes in sleeping patterns, feelings of anxiety and depression, and health problems.
- Caregiver **stress** can worsen physical, mental, and emotional health, as well as social and financial well-being.

—Source: <https://khn.org/news/pandemic-upends-the-lives-of-people-with-disabilities-and-of-their-caregivers>



- In 2020, 21 percent of caregivers felt their **health was fair or poor** (compared to 10 percent in the general adult population).

—Source: AARP Caregiving 2020

Caregivers had 2X the rate of fair/poor health

What is the impetus for caregiver policy changes?

- By 2050, there will be only 3 potential family caregivers for every person aged 80 or older, compared to 7 in 2010.
- Policy trends are shifting care from institutional to home-based settings.
- Increased societal awareness due to COVID-19 pandemic.

Family Caregiving Policy Solutions

- Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act; includes national family caregiving strategy development.
- National Alzheimer’s Project Act (NAPA) with targeted supports.
- Family Medical Leave Act (FMLA); currently limited by workplace size and immediate family relationship.
- Older American Act, National Family Caregiver Support Program; funding has not increased with need.
- Washington state’s public long-term care insurance program, funded through a payroll tax. Benefits will include payment for family caregiving.

REFERENCES

The Hidden Cost of Unpaid Caregivers: Supporting Caregivers in Michigan, published by the Center for Health and Research Transformation, CHRT

Family caregiver support: state and federal policy and programmatic solutions, November 2021, CHRT / IDEAL RRTC

COVID-19 adds stress for family caregivers – why that matters, November 2021, CHRT / IDEAL RRTC

Policy recommendations

Local initiatives

- Voter-approved county millages to help people live independently.

State-level

- Medicaid waivers and PACE programs for flexibility in caregiver services and payment.
- State-wide payment innovations.

National-level

- Expand FMLA to cover more caregivers.
- Provide Social Security working “credits” for family caregivers who leave the workforce.
- Increase National Family Caregiver Support Program funding.
- Support additional research on the impact of paid family caregivers for recipient quality of life and reductions in nursing home cost and use.

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