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The Unpaid Caregiver Dilemma & Why It Matters

By Monica E. Oss

Many of the strategies for improving the U.S. health and human service system are based on moving more consumers with chronic conditions and complex support needs to home-based care that is tech-enabled and supported by unpaid caregivers. There are two big assumptions here. First, that there is stable housing for this population—a topic that we have covered before (see [Leveraging Medicaid To Address The Housing Issue](#) and [Making Choice A Community Living Option](#)). The second assumption is that there is a supply of willing and able unpaid caregivers for these consumers. If you look at the numbers, this assumption is problematic.

There are 53 million unpaid caregivers in the U.S. today—that's one in five Americans—that have provided care to an adult or child with special needs at some time in the past 12 months. This is up 22% from the estimated 43.5 million caregivers in 2015 (see [Caregiving In The U.S. 2020](#)). And that number is expected to keep growing, as the population 65 years and older is expected to double between 2000 and 2030. So currently there are seven potential family caregivers per adult but by 2030, there will be only four potential family caregivers per adult (see [Caregiving](#)).

Between 2015 and 2020, caregivers report that adults who receive care have increased health and functional needs—because of long-term physical conditions (59% to 63% increase), emotional or mental health issues (21% to 27%), memory problems (26% to 32% percent), and dementia (22% to 26%). The comorbidity of conditions that require care is also increasing which means unpaid caregivers are dealing with more complex medical and support needs, likely without adequate and affordable services and supports in place. Only 31% of unpaid caregivers reported that their care recipient has any paid help and more caregivers say it is difficult to coordinate their recipient's care across various providers (26 % in 2020, up from 19% in 2015).

CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.*



NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**

More Americans are caring for more than one person.



More family caregivers have difficulty coordinating care.



More Americans caring for someone with Alzheimer's disease or dementia.

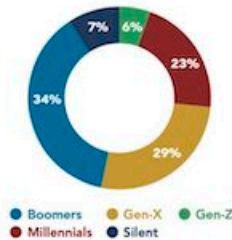


More family caregivers report their own health is fair to poor.



23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today's family caregivers?



45%
HAVE HAD AT LEAST ONE FINANCIAL IMPACT



AARP
Family Caregiving™


*Provided care to an adult or child with special needs.
**The remainder of this data is based on the 19% or 48 million caregivers caring for an adult.
URL: www.aarp.org/uscaregiving DOI: <https://doi.org/10.26419/ppi.00103.002>

naac
National Alliance for Caregiving

Caregiving in the U.S. 2020,
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And, as with every other aspect of life and health, COVID-19 has taken a toll on unpaid caregivers. The Centers for Disease Control and Prevention reports that “Unpaid caregivers for adults, many of whom are currently providing critical aid to persons at increased risk for severe illness from COVID-19, had a higher incidence of adverse mental and behavioral health conditions compared with others” (see [Mental Health, Substance Use, & Suicidal Ideation During The COVID-19 Pandemic — United States, June 24–30, 2020](#)).

The recently released Carer Well-Being Index (see [Carer Well-Being Index](#)) found that the average time Americans spend caregiving has grown 7.4 hours per week since the pandemic began in the U.S. and shows no sign of letting up. Nearly a third (30%) of American caregivers believe they’ll spend 41 or more hours per week caregiving in the future due to the impact of the pandemic. This is likely due in part to the growth of caregiver distrust of congregate living arrangements—72% of these caregivers expressed concern that they will need to spend more time caregiving in the future because COVID-19 has made them distrust these institutions. And, the pandemic has had a negative impact on 68% of caregivers’ mental health. One of the top reasons why caregivers feel their mental health has worsened is the physical distancing/sequestering orders that cause them to feel isolated and alone.

The supply and abilities of unpaid caregivers are an important strategic issue for any payer, health plan, or provider organization serving consumers with complex needs—one that we will continue to cover. For more, check out the recent coverage by the *OPEN MINDS* team of these issues. 

Reference

Oss, Monica. 2020. "The Unpaid Caregiver Dilemma & Why It Matters | OPEN MINDS". *OPEN MINDS*. <https://openminds.com/market-intelligence/executive-briefings/the-unpaid-caregiver-dilemma-why-it-matters/>.