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POLICYNOTE

U.S. CAREGIVING SYSTEM LEAVES SIGNIFICANT UNMET NEEDS AMONG AGING ADULTS

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Elevator Pitch: America's eldercare system relies on families to provide care to aging adults, leaving those without family or wealth particularly vulnerable to having their care needs go unmet. 8.3 million people, or 42 percent of adults who have difficulty with tasks like getting dressed, using the toilet, or preparing meals did not receive any help in 2020 (the latest data available). Older adults who do not get the care they need face higher negative health outcomes and disability levels. Expanding Community Medicaid would help all older Americans receive the care they need in old age.

As the U.S. population ages,[i] pressure mounts to provide long-term care and acknowledge the enormous contribution of unpaid caregivers to elders.[ii] However, this conversation has failed to address the population of aging adults (those 55 and up) who have difficulties with necessary activities like bathing or getting in and out of bed, but who are not receiving any help with those tasks. This gap in care leaves a significant population of older adults vulnerable to unmet care needs that threaten older adults' long-term health. Seniors who do not get the care they need are more prone to accidents and have more negative health outcomes, such as more emergency department visits[iii] and increased risk of mortality.[iv] Adults struggling through daily life without the help they need are more likely than those who receive help to injure themselves while performing a difficult task. Research shows that unmet long-term care needs of older adults are associated with higher disability levels.[v] Those with unmet care needs may see their health deteriorate more rapidly.

Due to the U.S.'s heavy reliance on unpaid family caregivers, adults without spouses or adult children may have to rely on the option of professional care from the expensive private market, which many cannot afford. Yet getting care is not entirely a matter of how much money someone has. In a counter-intuitive result, significant shares of people in all wealth quartiles do not receive the care they need – whether from professional or unpaid sources. Household wealth does not determine how much care one receives because many lower-income adults get care from family members or qualify for Medicaid assistance, while wealthier adults buy more professional care than lower-income adults. The gaps in care across the wealth distribution underscore the necessity of universal care for all elderly people.

Unmet care needs will expand as more adults age into disability without partners or offspring due to declining marriage and fertility rates[vi] and higher divorce rates.[vii] Greater access to low- or no-cost home and personal assistance care can help meet the U.S.'s ballooning care needs.[viii]

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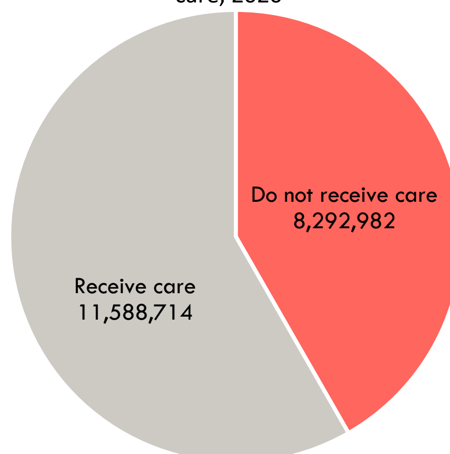
Over 40 Percent of Adults Who Have Difficulty with Necessary Activities Do Not Receive Any Eldercare

In 2020[1], nearly 20 million (20 percent) adults aged 55 and older had difficulty with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs).[2] Only 11.6 million of these seniors reported receiving any help with those activities. That means over 40 percent of adults who have difficulty with tasks like getting dressed, using the toilet, or preparing meals are not receiving any help.

Figure 1: Millions of Adults Aged 55 and Older Do Not Receive Needed Care



Source: SCEPA calculations using 2020 Health and Retirement Study data.
Notes: Sample includes all individuals aged 55 and older, using combined respondent and nursing home resident weight.

There are significant gaps in care for all necessary daily and instrumental activities. Over half of older adults receive no assistance with the most common difficulties, such as getting dressed, bathing, or walking across a room. Meanwhile, over a quarter of older adults receive no help for difficulties with managing their money, making phone calls, or taking their medication (see Appendix).

Older Adults Without Close Family Are Particularly Vulnerable to Not Getting Care

Close family ties are pivotal in receiving eldercare given inaccessible professional care options. For the 11.6 million older adults with difficulties who do receive help, unpaid family care is the most common source of assistance. In 2020, the most common family caregivers were spouses and offspring, with 53 percent of adults who got care receiving some care from offspring or grandchildren and 44 percent receiving some care from a spouse.

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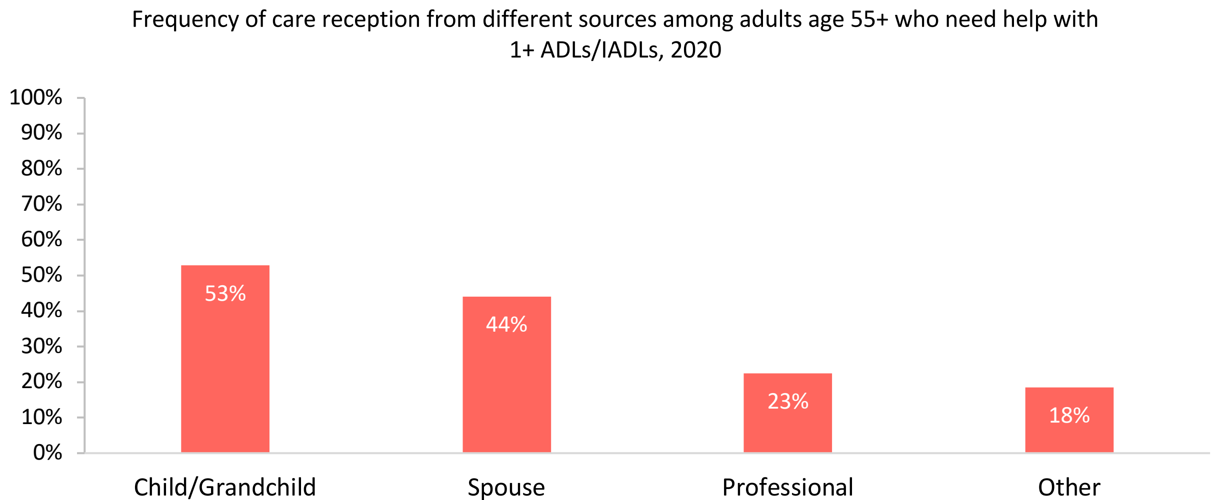
[1] 2020 data is the most recent survey year of available RAND HRS data.
[2] ADLs and IADLs are terms used by health professionals and researchers who work on issues of aging. ADLs are routine, self-care tasks that most healthy individuals can perform daily without assistance. There are six ADLs: walking across a room, eating, getting dressed, getting in and out of bed, using the toilet, and bathing. IADLs, in comparison, are necessary activities that allow a person to continue living independently, including grocery shopping, managing money, making phone calls, taking medication, and preparing meals.

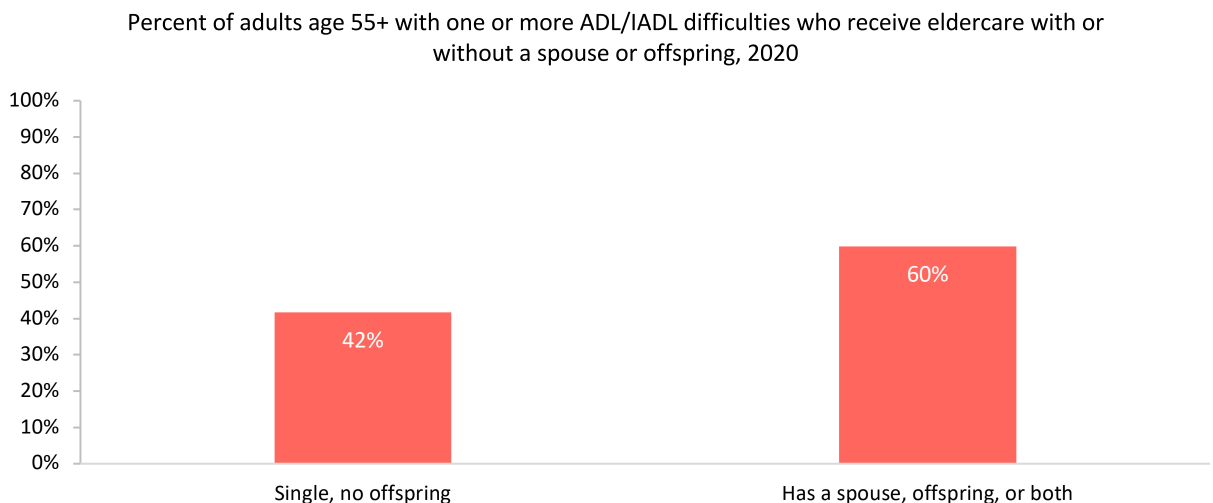
Figure 2: Older Adults Are Most Likely to Receive Care from Offspring and Spouses



Source: SCEPA calculations using 2020 Health and Retirement Study data.
Notes: Sample includes all individuals aged 55 and older, using combined respondent and nursing home resident weight. Individuals can receive care from multiple sources simultaneously. Other includes individuals like neighbors and friends or other family like siblings.

Only 23 percent of adults aged 55 and older who have difficulty with one or more ADLs or IADLs received some care from a paid professional. This is almost half the rate of care received from spouses or offspring. As a result, receiving care is highly dependent on available family. Among adults aged 55 and older who have difficulty with one or more ADLs or IADLs, those with offspring who live within a 10-mile radius are most likely to receive some eldercare (63 percent), followed by those with spouses (58 percent). Those without a present partner or living offspring are a third less likely to receive any care compared to their partnered or parent peers.[ix]

Figure 3: Single Individuals Without Offspring Are Least Likely to Receive Care



Source: SCEPA calculations using 2020 Health and Retirement Study data.
Notes: Sample includes all individuals aged 55 and older, using combined respondent and nursing home resident weight.

Adults without spouses and offspring are most vulnerable to experiencing unmet care needs due to heavy reliance on family caregivers in the U.S. There are 7.2 million adults over the age of 55 who have no spouse and no living offspring. Another 12.6 million adults do not have partners but do have offspring who live more than 10 miles away, which reduces their likelihood of receiving care from them.

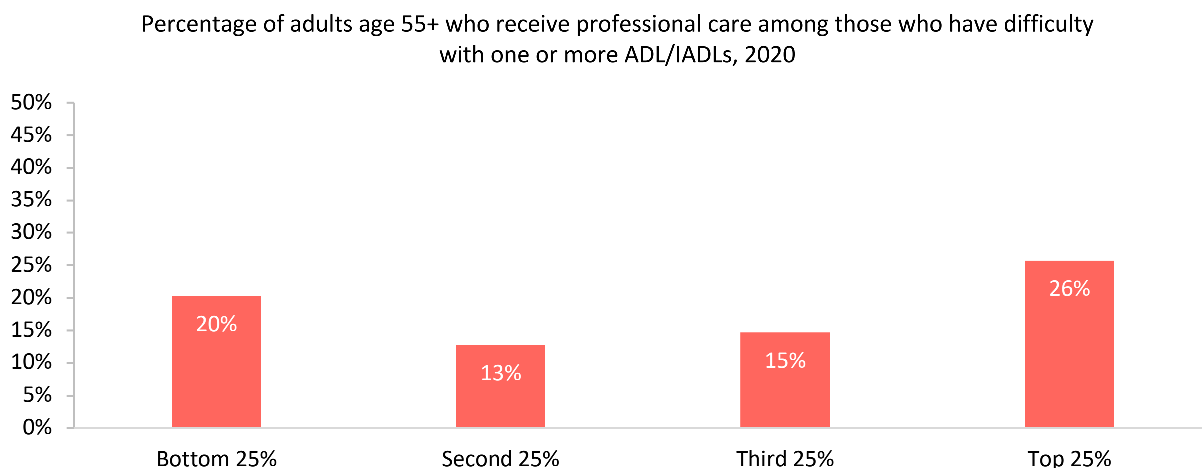
With marriage and fertility rates declining[x] in the U.S., adults who will age into disability are facing the prospect of having to find alternate care options, such as through community or paid professionals. Yet, professional care in the U.S. is prohibitively expensive for many. For example, in 2016 the average cost[xi] of assisted facility living ranged from $3,628 to $6,844 a month, depending on the accommodations, while hourly rates of home-based care were $20-$20.50 an hour, and costs have only increased since then.[xii] Adults who do not have family to help with care are increasingly at risk of dealing with ADL and IADL difficulties on their own.

Wealth Does Not Guarantee Elders Will Receive Care

The chances of receiving needed eldercare – from both paid and unpaid sources – vary little across wealth quartiles. Between 42 and 48 percent of people across all wealth quartiles do not receive any eldercare despite having difficulties with daily and instrumental activities (see Appendix). While it is surprising that gaps in care persist across all levels of wealth, this lack of a wealth gradient is explained in part by different family structures and caregiving behavior across communities. Many lower and middle-income families provide eldercare by relying on unpaid family members. For example, multigenerational households, where caregiving for older generations is more integrated into daily life, have lower median household incomes even after adjusting for household size.[xiii] Among those in higher income households, family members can better afford to either pay for professional care, reduce their work hours, or quit their job to care for a loved elder.

Rates of professional care provision remain lower than might be expected, even for those in the highest wealth quartile. We see a U-shaped curve in professional care provision as wealth increases; Adults aged 55 and older who are in the second wealth quartile receive the least professional care (just 13 percent), while those in the highest quartile receive the most (26 percent).

Figure 4: Rates of Professional Eldercare Provision Are Low Across All Wealth Levels



Source: SCEPA calculations using 2020 Health and Retirement Study data.
Notes: Sample includes all individuals aged 55 and older, using combined respondent weight and nursing home resident weight. Wealth quartile ranges are (1) $68,000 and less; (2) $68,100 to $283,999; (3) $284,000 to $814,000; (4) over $814,000.

Why are those in the lowest wealth quartile the second-most likely to receive professional care? Lower-income adults without much wealth can access professional care services through means-tested Medicaid programs. Access to these programs depends on demonstrating need, typically through ADL and IADL difficulties, as well as being below certain income and asset thresholds. In the majority of states, single individuals cannot have assets worth more than $2,000 (excluding the value of a primary residence) in order to qualify for Medicaid benefits that provide long-term care.[xiv] Indeed, 45 percent of adults who receive professional help in the bottom wealth quartile pay for that help in part through Medicare, Medicaid, or other insurance, compared to just 15 percent of those in the top quartile.[xv] This contributes to the U-shape of the professional care curve as those on the lowest end of the wealth spectrum can obtain professional care through public programs while those on the top end of the wealth distribution can afford professional care privately – leaving the middle class most unable to afford care.

These results suggest that programs like Community Medicaid likely alleviate eldercare gaps for some by increasing access to professional care for the lowest-wealth households, but these programs miss middle-class individuals who do not qualify for public assistance yet often cannot afford to pay for care out of pocket. Expanding access to benefits like Community Medicaid will help Americans across the wealth spectrum get help without having to rely on unpaid family caregiving or pay for high-cost professional care.

Policy Recommendation

Expand Community Medicaid

Community Medicaid provides financial subsidies to Medicaid beneficiaries to receive care services in their own home or community through two primary programs: Home and Community Based Services (HCBS) waivers; and Aged, Blind, and Disabled (ABD) Medicaid. These programs cover a wide range of benefits, from personal care services that help with activities of daily living to homemaking services for cleaning, laundry, or essential shopping, as well as medical devices and assistive technology, among other options.[xvi] Yet access varies significantly across states[xvii] with a range of income and asset limits. Depending on the state, ABD Medicaid eligibility rules cap incomes for single individuals at between $900 to $1,600 a month, and HCBS waivers between $914 to $2,761. Both programs typically cap assets at around $2,000 for single individuals in most states, but the range goes as low as $1,600 in Connecticut. Cutoffs additionally vary depending on marital status, as well as whether both spouses need aid or just one.

Even meeting eligibility requirements, however, does not ensure access to Community Medicaid because some states have additional enrollment caps and waiting lists that can last years. States are limited in the number of individuals they can serve through HCBS waivers, sometimes leading to greater needs than programs can accommodate. For example, 38 states currently have waiting lists for HCBS waivers with a combined nearly 700,000 people on those lists.[xviii] Expanding access and raising enrollment caps in all states, but especially in states with long waiting lists or low-income and asset-eligibility caps, can help to remove the disproportionate burden of caregiving from families and ensure that all elders, regardless of family ties or ability to pay for professional care, are able to age in comfort.

Appendix

Data and Methods

We use data from the 2020 wave of the Health and Retirement Study (HRS), a nationally representative longitudinal study of adults aged 50 and older. As part of the HRS survey, respondents are asked a series of questions regarding their ability to perform six activities of daily living (ADLs) and five instrumental activities of daily living (IADLs); as well as whether they require any assistance with ADLs or IADLs, and if so, who provides that assistance. Activities of daily living include walking across a room, bathing, getting dressed, getting in or out of bed, using the toilet, and eating. Instrumental activities of daily living are grocery shopping, preparing meals, managing money, making phone calls, and taking medication. Respondents can list multiple caregivers in response to who helps them with an activity.

We consider adults aged 55 and older with one or more ADL and IADL difficulty as needing help or needing some level of care. We include those in the 55-64 age to include individuals who are already experiencing difficulties with activities instrumental to independent and/or daily living but who do not yet qualify for Medicare and Medicaid. Among those with difficulties, we calculate percentages of people receiving care based on whether adults with one or more ADL/IADL difficulty receive help performing one or more ADL/IADL difficulty.

Additional Figures

Appendix Table A: Prevalence of Difficulty with Activities and Rate of Getting Help

Activity of Daily Living (ADL) or Instrumental Activity of Daily Living (IADL)	% of older adults that have difficulty with the activity	% of those with difficulty who get help
Walking across a room (ADL)	9%	49%
Bathing (ADL)	9%	83%
Getting dressed (ADL)	6%	58%
Getting in/out of bed (ADL)	6%	37%
Using the toilet (ADL)	6%	44%
Shopping for groceries (IADL)	6%	80%
Eating (ADL)	5%	75%
Preparing meals (IADL)	5%	31%
Managing money (IADL)	3%	71%
Making phone calls (IADL)	3%	74%
Taking medication (IADL)	3%	42%

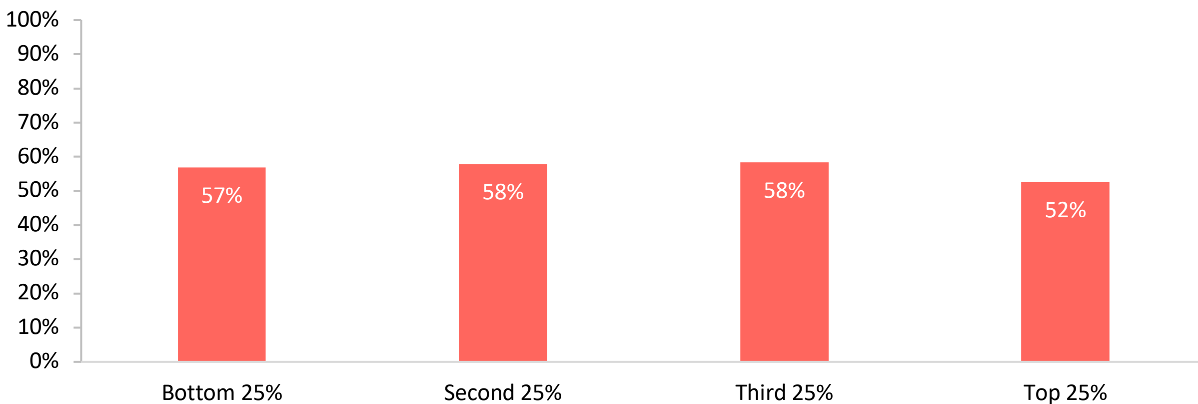
Source: SCEPA calculations based on 2020 Health and Retirement Study data.
Notes: Sample includes all individuals aged 55 and older, using combined respondent and nursing home resident weight.

Rates of receiving help vary significantly across difficulty with different activities, with some activities having 80 percent of difficulties met while others reaching only 31 percent. This is likely due in part to some difficulties occurring later in aging after other difficulties have already occurred. Likewise, some difficulties may be easier to endure without help, while others may be alleviated by assistive devices

rather than care from a person. For example, someone who has difficulty walking across a room may use a walker or cane.

Rates of help for some individual difficulties are slightly higher than the aggregate rate of help for anyone with one or more difficulty (58 percent), because some individuals have multiple difficulties while others have difficulty with one or a few activities. This can lead to a greater rate within individual activities compared to the overall rate of help in the aggregate. For example, some of the 31 percent of individuals who do not receive help with preparing meals are also part of the 44 percent who do not receive help with using the toilet. But there are individuals in each category of difficulty that are not present in the other. Individuals who do not receive help are less likely to overlap across activities since the probability of getting care increases as the number of difficulties do. When added together these dynamics lead to a higher or lower overall rate in the aggregate compared to in individual activities.

Appendix Chart A: Getting Help with Necessary Activities Is Not Wealth Dependent



Source: SCEPA calculations using 2020 Health and Retirement Study data.
Notes: Sample includes all individuals aged 55 and older, using combined respondent and nursing home resident weight. Wealth quartile ranges are (1) $68,000 and less; (2) $68,100 to $283,999; (3) $284,000 to $814,000; (4) over $814,000.

Rates of caregiving for elders do not vary significantly when we combine paid professional care and family care. When looking across all caregiving sources, those in the middle quartiles are most likely to receive care (58%), while those in the top quartile are least likely (52%), though the difference is relatively minor. This result largely reflects that caregiving for elders in the U.S. is a nuanced issue given the wide range of caregivers and current policies designed to support caregiving and caregivers, which often vary from state to state.

Endnotes

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