VITAL AND UNDERVALUED
The Growing Need to Recognize the Work of Unpaid Family Caregivers

U.S. PIRG Education Fund
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Introduction

From aiding the elderly, to raising children or helping someone recover from an illness, all of us at one time need care, and most of us also participate in the work of caring. Caregiving is vital. You would think that we, as a society which purports to value children and the family, would make sure that care work would be protected, but public policy undervalues care work and sets up barriers to participating in the care of our own loved ones. Some of these barriers do not exist for other types of work, including work that is clearly less meaningful or valuable to society. As America faces a shortfall of care workers to meet rising demand, we must take steps to value caregiving as valuable work, such as by including caring for a loved one as qualifying "work" for the Earned Income Tax Credit.

A parent makes pizza for their adult child with disabilities who cannot cook for themselves. A child picks up soup from the store for their parent who cannot shop for themselves anymore. Every day millions of Americans devote their time and effort to make sure their loved ones can live a dignified life. Almost 1 in 6 American adults, over 41 million people, is an unpaid family caregiver caring for an aging loved one throughout the year.1 Almost 1 in 5 American adults cares for a child on an average day.2 Family caregivers are essential to every community and the need for them is growing.

The Census Bureau projects the number of Americans over age 65 will almost double by 2050.3 As America ages, the work of family caregivers will be more needed than ever as the likelihood of needing help with daily tasks increases with age.45 There are many ways to meet the care needs of our elders, people with disabilities, and children. However, supporting family caregivers must be part of how we prepare for a future with greater caregiving needs. Unfortunately, the essential contributions of caregivers are undervalued in our economy as we officially recognize only work that earns a paycheck. To provide for the wellbeing of all Americans, we must redefine work to more accurately reflect the immense and inherent value of caregiving.

This report will review studies of the prevalence and importance of unpaid family caregiving today, summarize the reasons to expect the need for caregiving will grow with an overview of several individual states, and discuss how policymakers should respond.

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How Prevalent Is Unpaid Family Caregiving?

It is intuitive and obvious that family caregiving is common. None of the institutions that support a good life would be possible without the unpaid work of caregivers — from schools to hospitals to basketball games and book fairs. Everyone benefits from the time and attention of a loved one in their lives. While the structures of families and the relationships within them vary widely, everyone was once a child in need of care, many of us need some help actively, and still more of us will one day need help as we age. Estimates vary, but as many as half of all older Americans need some help with daily activities. It is thus unsurprising that, during any year, a large percentage of Americans are engaged in caregiving.

According to a 2017 analysis by the Bureau of Labor Statistics (BLS) of data ranging from 2015 to 2016, 16 percent of Americans are providing unpaid eldercare. In 2018, the BLS American Time Use Survey found 18.8 percent of Americans are caring for a child on an average day. A 2018 Pew Research Center analysis found that 12 percent of parents caring for a child are also caring for an adult. Aside from the government, AARP and the National Alliance for Caregiving have conducted the most extensive surveys of caregivers providing unpaid eldercare. According to these surveys, as many as 1 in 3 households contain someone who provided unpaid caregiving in the course of a year. AARP’s findings on eldercare are also consistent with BLS findings, estimating that 16.6 percent of American adults engage in unpaid caregiving for an elder. To estimate the total number of all kinds of caregivers, combining those caring for children, anyone with a disability, and elders, AARP concluded in 2009 that 65.7 million Americans were caregivers.

The Growing Need for Caregiving

Even before considering the future demand for caregiving, the care needs of many people are going unmet today. In the most comprehensive recent review of its kind, the National Health and Aging Trends Study, found that around 1 in 5 people needing help with “activities of daily living” have unmet needs. This finding is remarkably consistent across other studies which also find that around 20 percent of community-residing adults surveyed who need help with activities of daily

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7 See note 1 and note 2.
10 Ibid.
living have unmet needs.\textsuperscript{12,13} Once we consider demographic trends, it is clear the need for caregivers will only grow.

America is aging. The total number and proportion of older Americans is growing.\textsuperscript{14} Longer lives with more healthy years is wonderful news. However, longer lives increase the demand for caregiving as people become more likely to need help as they age.\textsuperscript{15} As we expect the demand for caregiving to increase, we also expect the potential pool of people who might become caregivers to shrink.\textsuperscript{16} Today there are approximately three and a half working-age adults for every person of retirement age, but by 2060 the Census Bureau projects there will be only two and a half working-age adults for each older American.\textsuperscript{17}

There is also some reason to be concerned that the likelihood of needing help from a loved one is increasing. While there are varied findings in different reports, some research suggests that middle-aged Americans are showing an increased need for help with daily tasks and that growing chronic health problems could further increase demand for daily help.\textsuperscript{18}

Professional caregiving and the public provision of caregiving supports, including home care workers and the home and community based services funded by Medicaid, are critical components to any plan that would meet the needs of all Americans. Professional, paid and “informal,” unpaid caregiving are often necessary compliments to each other rather than substitutes. Even if they have other supports, the vast majority of American adults who need help with a daily activity have some amount of care provided by a loved one.\textsuperscript{19}

Benefits of Caregiving

Caregiving is invaluable. It is impossible to capture the full worth of the care of a loved one. Simon Kuznets, a central contributor to the creation of the most important economic metric, gross domestic product or “GDP,” recognized the importance of unpaid caregiving, or “nonmarket production,” to the prosperity of a country even though it was not included in primary government

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\textsuperscript{15} See note 4.
The most comprehensive attempt to value at least the time spent by caregivers for the elderly concluded that the approximate dollar-value was $470 billion per year. A comparable valuation that expanded to include the time of caregivers for children and adults with disabilities could easily exceed $1 trillion per year at a minimum. A study of the value of unpaid care for children which included the value of factors such as the time managing care or maintaining vigilance “on-call” estimated the value to be in excess of $2 trillion per year. Such estimates give some sense of the benefits of caregiving. It is also possible to measure some discrete benefits of caregiving to the wellbeing of the people giving care or receiving care or both.

The presence of a caregiver means the recipient of care is less socially isolated. Avoiding social isolation is linked with a host of indications of wellbeing, both physical and psychological. Everything from cardiovascular health and recovery from illness to the more obvious problem of depression appears tied to social connections. There is evidence that people living with mental illnesses such as dementia and schizophrenia benefit from their loved ones being engaged in their care. When involved in discharge and able to help with recovery, caregivers can improve the chances that people avoid hospital readmission. In one study, cash-support to caregivers improved the health outcomes of the people for whom they cared.

**State Profiles**

To better understand the picture of the growing need to recognize the vital work of unpaid family caregivers, what follows summarizes demographic trends in select states and estimates the potential supply of family, friends and neighbors who are caregivers.

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22 Assuming an equal time-value by the number of people engaged in caregiving, resulting in a rough doubling of the total value given the slightly higher prevalence of caring for a child.
30 All states’ caregiver estimates are the 2018 adult population Census Bureau estimate multiplied by the BLS prevalence for eldercare and ATUS prevalence for childcare.
California

With an estimated adult population of 30,577,596 in 2018, as many as 4,892,415 Californians care for an aging loved one each year and as many as 5,748,588 Californians care for a child on an average day.\(^{29}\)

The fastest growing age group of all Californians is Californians older than 65.\(^{30}\) Whereas the rest of the United States may see the population over 65 years of age double by 2060, the same result will occur much sooner in California. According to projections by the California Department of Finance, the number of Californians over age 65 will double by 2036, totaling more than 10,444,000 people.\(^{31}\) If this projection proves to be true, 23 percent of Californians will be over the age of 65 in 2036. As of 2019, 6.7 percent of the population of California under the age of 65 lives with a disability.\(^{32}\)

Wisconsin

With an estimated adult population of 4,534,583 in 2018, as many as 725,533 Wisconsinites care for an aging loved one each year and as many as 852,501 Wisconsinites provide care to a child on an average day.\(^{33}\)

We expect the population of Wisconsinites over the age of 65 to nearly double by 2040, increasing from 777,500 in 2010 to 1,535,500.\(^{34}\) By 2040, the population of Wisconsinites over age 85 is projected to grow the fastest of all age groups, increasing from 118,505 to 283,600.\(^{35}\) At the same time the share of Wisconsinites aged 18-64 will shrink from 62.8 percent of the population in 2010 to 55.1 percent of the population in 2040.\(^{36}\) As of 2019, 8 percent of the population of Wisconsin under the age of 65 lives with a disability.\(^{37}\)

Colorado

With an estimated adult population of 4,431,149 in 2018, as many as 708,984 Coloradans care for an aging loved one each year and as many as 833,056 Coloradans provide care to a child on an average day.

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\(^{30}\) Ibid.


\(^{35}\) Ibid.

\(^{36}\) Ibid.

\(^{37}\) United States Census Bureau, QuickFacts Wisconsin (fact sheet), accessed 20 December 2020, https://www.census.gov/quickfacts/WI.
We expect the population of Coloradans over 65 years of age to almost double between 2020 and 2050, rising from 895,873 to 1,745,193. The proportion of Coloradans over age 65 will also increase from 2019 to 2050, rising from 14.59 percent to 20.1 percent. As of 2019, 7.2 percent of the population of Colorado under the age of 65 lives with a disability.

**Massachusetts**

With an estimated adult population of 5,535,524 in 2018, as many as 885,684 Bay Staters care for an aging loved one each year and as many as 1,040,678 Bay Staters provide care to a child on an average day.

Massachusetts is already older than the rest of America and is expected to age further. The total population of Massachusetts age 65 and older is projected to grow from 1,247,842 in 2020 to 1,679,917 by 2035. The proportion of Bay Staters over the age of 65 is projected to grow from 18 percent in 2020 to 23 percent by 2035. As of 2019, 7.8 percent of the population of Massachusetts under the age of 65 lives with a disability.

**Illinois**

With an estimated adult population of 9,887,078 in 2018, as many as 1,581,933 Illinoisans care for an aging loved one each year and as many as 1,858,771 Illinoisans provide care to a child on an average day.

The total population of Illinoisans over the age of 65 is projected to grow in coming years. While all of Illinois is projected to age, the senior population in metropolitan Chicago is projected to double by 2040. As of 2019, 7.2 percent of the population of Illinois under the age of 65 lives with a disability.
Oregon

With an estimated adult population of 3,319,045 in 2018, as many as 531,047 Oregonians care for an aging loved one each year and as many as 623,980 Oregonians provide care to a child on an average day.\(^{48}\)

Older Oregonians are projected to increase in number, growing by 40 percent between 2018 and 2030.\(^ {49}\) The proportion of Oregonians over the age of 65 is projected to grow from 17.5 percent in 2018 to near 22 percent by 2030.\(^ {50}\) As of 2019, 9.9 percent of the population of Oregon under the age of 65 lives with a disability.\(^ {51}\)

Texas

With an estimated adult population of 21,296,769 in 2018, as many as 3,407,483 Texans care for an aging loved one each year and as many as 4,003,793 Texans provide care to a child on an average day.\(^ {52}\)

Although Texas is younger than America as a whole, the fastest growing group of Texans are those over the age of 85, a group projected to be almost four times larger in 2050 than in 2010.\(^ {53}\) The number of Texans aged 65-84 is also projected to grow. By 2050, Texas is projected to have more than 8.3 million residents over the age of 65.\(^ {54}\) Even with Texas’ expected massive overall population increase, the proportion of Texans over the age of 65 is projected to increase from 13.2 percent of the population in 2020 to 17.6 percent of the population in 2050.\(^ {55}\) As of 2019, 7.9 percent of the population of Texas under the age of 65 lives with a disability.\(^ {56}\)

Maryland

With an estimated adult population of 4,701,235 in 2018, as many as 752,198 Marylanders care for an aging loved one each year and as many as 883,832 Marylanders provide care to a child on an average day.\(^ {57}\)

The fastest growing group of Marylanders is the population over the age of 65, a group projected to grow from 838,970 in 2015 to 1,406,660 in 2040.\(^ {58}\) The proportion of Marylanders over the age of 65 is projected to grow from 14 percent of the population in 2015 to 20.4 percent of the


\(^{50}\) Ibid.

\(^{51}\) United States Census Bureau, QuickFacts Oregon (fact sheet), accessed 20 December 2020, https://www.census.gov/quickfacts/OR.


\(^{54}\) Ibid.

\(^{55}\) Ibid.

\(^{56}\) See note 47.

\(^{57}\) United States Census Bureau, QuickFacts Texas (fact sheet), accessed 20 December 2020, https://www.census.gov/quickfacts/TX.


population in 2040. As of 2019, 7.5 percent of the population of Maryland under the age of 65 lives with a disability.

**Arizona**

With an estimated adult population of 5,529,339 in 2018, as many as 884,694 Arizonans care for an aging loved one each year and as many as 1,039,516 Arizonans provide care to a child on an average day.

Arizona’s population over the age of 65 is projected to grow from 1,171,267 in 2018 to 2,444,428 in 2055. The proportion of Arizonans over the age of 65 is projected to rise from 16.6 percent in 2018 to 23.3 percent in 2055. As of 2019, 8.7 percent of the population of Arizona under the age of 65 lives with a disability.

**Why Recognizing the Work of Family Caregivers Matters**

The value of policy is to foster what we as a country believe is good and to prevent what we believe is bad. It would be hard to find a politician who directly argues caregiving does not matter and is not worth doing. To understand why, despite outstanding and growing need, policymakers have failed to invest in caregivers, we should scrutinize how we make economic policy. The main metrics for economic policy neglect the obvious importance of caregivers to their families and to society.

Family caregivers contribute nothing that counts for GDP. Taking care of your own loved one without pay does nothing to create jobs. If anything, family caregiving reduces jobs or at least reduces hours worked in the formal economy. Growing GDP and creating jobs are often the principal stated aims of policymakers. The logic of focusing on GDP is that our society needs to produce more in order for everyone to enjoy better lives. The logic of a focus on job creation is that we expect everyone who can to contribute to society, so we need to put them to work. These two claims always had damaging consequences for people and the planet. They also have always neglected the work of lots of people. Common sense demands that we question both of these supposedly logical claims. The urgency of the caregiving challenge should force greater clarity about what metrics really matter, about what logic serves the interest of all Americans.

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59 Ibid.
60 United States Census Bureau, QuickFacts Maryland (fact sheet), accessed 20 December 2020, archived at https://www.census.gov/quickfacts/MD.
Rewarding the contributions of family caregivers would mean prioritizing the work that matters most to people. Proposals to expand the Child Tax Credit or create a virtually universal “child allowance” would recognize the importance of raising children. Some states have moved in the direction of supporting unpaid caregivers through Medicaid programs. However, major programs that are designed to reward contributions to society, like the Earned Income Tax Credit, still fail to count family caregiving as a contribution.

Even if their value is not tracked by GDP, family caregivers are essential for all of us to live good lives. Family caregivers do not need to be made to do “real” work. Family caregivers are working every single day, engaged in some of the most important work there is. For the sake of stronger families and more vibrant communities, policymakers have to move beyond the narrow definition of work that excludes the indispensable efforts of family caregivers. Fortunately the Biden administration, members of Congress of both parties, and states are now considering various methods of investing in family caregivers. As Americans begin to recover and heal from the horror of the pandemic this past year, investments in family caregiving are a crucial way to create a new foundation for a healthier country.

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65 AARP, “Can I Get Paid to Be a Caregiver for a Family Member?” 15 May 2020, 