BURNING THE CANDLE AT BOTH ENDS:

SANDWICH GENERATION CAREGIVING IN THE U.S.

IN PARTNERSHIP WITH

National Alliance for Caregiving

Caring Across Generations

MassMutual

Special Care
FOREWORD

By Sarita Gupta, Co-Founder, Caring Across Generations

With this report, we are excited to finally shed light on what many of us have long referred to as sandwich generation caregivers, henceforth referred to as **sandwich caregivers**; those who are caught between the demands of both childcare and caring for an adult family member. This report is a critical tool to educate policymakers and stakeholders on this growing group of family caregivers who live at the heart of a system of care in this country that no longer works for today’s families.

For this population in particular, caregiving responsibilities for children and adult family members are forcing families to cut back on work hours and navigate a system of care with little to no formal supports. We know that women, who make up the majority of family caregivers, are especially strained from these competing demands of work and care.

I know all too well that being pulled in both directions can be complicated and overwhelming; I am a working sandwich caregiver. My father was diagnosed with Alzheimer’s disease about five years ago. For a while, my mother served as his sole care provider but in recent years she has developed health issues of her own and now relies on my sister and me to navigate both of their care needs as they age. At the same time that I’m caring for my parents, I also have a young daughter to raise.

Like many families, both my husband and I work full time outside of the home. According to the Department of Labor, in roughly 60 percent of two-parent households with children under age 18, both parents work.¹ For some parents, it is a choice, but for most, two incomes are required to make ends meet. With both parents working, families must rely on a system of childcare that is unaffordable for most.

On the other end of the spectrum, in an unprecedented demographic shift, 10,000 baby boomers reach retirement age every single day.² Stagnant incomes and diminished savings are no match for longer life spans, the rising cost of treating chronic medical conditions, and long-term care needs. Often the financial burden of care falls directly onto family caregivers, who, on average, spend almost $7,000³ out-of-pocket per year on caregiving. It’s not hard to see how we, the sandwich caregivers, are being squeezed like never before.

Millions of us are headed down this road, attempting to juggle the challenges of caring for their children, their aging parents, and family members. Our system for supporting caregiving as a whole – from childcare to long-term care – is broken and we face a real care crisis that affects us all. The time is now for us to come together and work with policymakers to build a flexible system of care that reflects the financial and cultural realities of today’s modern families and sandwich caregivers. We simply cannot afford to simply maintain the current status quo.

# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>02</td>
<td>Acknowledgments</td>
</tr>
<tr>
<td>02</td>
<td>Authors</td>
</tr>
<tr>
<td>02</td>
<td>Project Directors</td>
</tr>
<tr>
<td>02</td>
<td>Contributing Editors</td>
</tr>
<tr>
<td>02</td>
<td>Advisory Committee</td>
</tr>
<tr>
<td>02</td>
<td>Foreword By Sarita Gupta, Co-Founder, Caring Across Generations</td>
</tr>
<tr>
<td>04</td>
<td>Introduction By C. Grace Whiting, President &amp; CEO, National Alliance for Caregiving</td>
</tr>
<tr>
<td>05</td>
<td>Methodology</td>
</tr>
<tr>
<td>05</td>
<td>Study Limitations</td>
</tr>
<tr>
<td>06</td>
<td>Reading This Report</td>
</tr>
<tr>
<td>07</td>
<td>Key Findings</td>
</tr>
<tr>
<td>08</td>
<td>Policy Recommendations</td>
</tr>
<tr>
<td>09</td>
<td>Detailed Findings</td>
</tr>
<tr>
<td>09</td>
<td>Prevalence</td>
</tr>
<tr>
<td>09</td>
<td>Basics of the Caregiving Situation</td>
</tr>
<tr>
<td>09</td>
<td>Age, Gender, Race/Ethnicity of the Caregiver</td>
</tr>
<tr>
<td>10</td>
<td>Duration of Care</td>
</tr>
<tr>
<td>10</td>
<td>Relationship</td>
</tr>
<tr>
<td>11</td>
<td>Spotlight: Caring for a Parent When Kids Are at Home</td>
</tr>
<tr>
<td>12</td>
<td>Distance and Location</td>
</tr>
<tr>
<td>12</td>
<td>Rural Status</td>
</tr>
<tr>
<td>13</td>
<td>Spotlight: Hispanic/Latino Sandwich Caregivers</td>
</tr>
<tr>
<td>14</td>
<td>Spotlight: Millennial Sandwich Caregivers</td>
</tr>
<tr>
<td>15</td>
<td>A Team-Based Care Approach</td>
</tr>
<tr>
<td>15</td>
<td>Primary Reasons Recipient Needs Care</td>
</tr>
<tr>
<td>16</td>
<td>Reasons for Requiring Care</td>
</tr>
<tr>
<td>16</td>
<td>Caregiving Activities and Intensity of Care</td>
</tr>
<tr>
<td>16</td>
<td>Length of Care</td>
</tr>
<tr>
<td>17</td>
<td>Activities of Daily Living (ADLs)</td>
</tr>
<tr>
<td>18</td>
<td>Instrumental Activities of Daily Living (IADLs)</td>
</tr>
<tr>
<td>18</td>
<td>Medical/Nursing Tasks</td>
</tr>
<tr>
<td>19</td>
<td>Caregiving Support Activities</td>
</tr>
<tr>
<td>20</td>
<td>Hours of Care</td>
</tr>
<tr>
<td>20</td>
<td>Burden of Care Index</td>
</tr>
<tr>
<td>20</td>
<td>Strain and Stress</td>
</tr>
<tr>
<td>21</td>
<td>Working Caregivers</td>
</tr>
<tr>
<td>22</td>
<td>Snapshot: Childcare and Sandwich Caregivers</td>
</tr>
<tr>
<td>23</td>
<td>Workplace Support</td>
</tr>
<tr>
<td>23</td>
<td>Information and Support Needs</td>
</tr>
<tr>
<td>23</td>
<td>Service Costs, Policy, and Long-Range Planning</td>
</tr>
<tr>
<td>24</td>
<td>Spotlight: Gen X Sandwich Caregivers</td>
</tr>
<tr>
<td>25</td>
<td>Expert Commentary</td>
</tr>
<tr>
<td>25</td>
<td>Feylyn Lewis, PhD, University of Sussex: Young Caregivers</td>
</tr>
<tr>
<td>26</td>
<td>Margaret L. Longacre, PhD; Department of Public Health, College of Health Sciences, Arcadia University: Health Systems</td>
</tr>
<tr>
<td>28</td>
<td>Joe Caldwell, PhD; Community Living Policy Center, Lurie Institute for Disability Policy, Brandeis University: Disability</td>
</tr>
<tr>
<td>29</td>
<td>Demographic Profile</td>
</tr>
</tbody>
</table>
INTRODUCTION

By C. Grace Whiting, President & CEO, National Alliance for Caregiving

Recently, I was sitting in a presentation on sandwich caregivers – those unpaid friends or family members who are juggling care for children with care for an adult. “I feel less like a sandwich and more like a panini,” one woman shared. It is true that now, more than ever, families are feeling the squeeze and that they need support.

This report shines a light on the current state of sandwich caregiving. Impacting at least 11 million Americans, sandwich caregivers represent that generation that so often gets lost in headlines between baby boomers and millennials. The typical sandwich caregiver was born between 1965-1980, and is, on average, 41 years old, about 12 years younger than caregivers without children living in the home. These families are asked to juggle numerous care responsibilities. The way families care for one another is changing, too – rather than the nuclear family of the mid-twentieth century, most households are now dual-income without a dedicated individual to take on care work. Caregiving becomes a chore, as families try to fit caregiving in between school, work, self-care, and other responsibilities of daily living.

Typically, when it becomes difficult to balance caregiving with work, or if the demands of work come into conflict with one’s caregiving responsibilities, caregivers are forced to compromise. The findings outlined in this report support the need for policymakers to find sustainable solutions, such as workplace flexibility, long-term care improvements, and a robust national infrastructure sufficient to support and augment the care provided by caregivers across the lifespan. Robust family friendly policies will not only provide support to today’s sandwich caregivers, but also future generations. After all, the need to balance life and care with increasing demands on time and family is a challenge facing Gen X that may repeat as the millennial generation comes of age.

To tell the story of the sandwich caregiver, we partnered with Caring Across Generations and three researchers serving in our Advisory Committee: Joe Caldwell, PhD, Brandeis University; Feylyn Lewis, PhD, University of Sussex; and, Margaret Longacre, PhD, Arcadia University, who all graciously ensured that the most significant data was being shared with the reader. The Advisory Committee also drafted “Expert Commentary” on this subpopulation based on their own research and professional experience. These sections include data from sources beyond Caregiving in the U.S. 2015 to help broaden the scope of the report. They each focus on key aspects of caregiving that can be used to further the work being done to understand and address the needs of this group of caregivers.

With grants from Caring Across Generations and Mass Mutual, we are honored to share this report on sandwich caregivers. We look forward to continuing the conversation on how to foster research and advocacy for caregivers. Let us know your thoughts as we embark on this endeavor, either by emailing NAC’s Hunt Research Director, Gabriela Prudencio, at gabriela@caregiving.org, or by calling 202-918-1022.

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METHODOLOGY

Caregiving in the U.S. 2015 is a nationally representative study of adults, ages 18 and older, conducted in late 2014 using GfK’s probability-based online KnowledgePanel®. Caregiving in the U.S. 2015 aimed to achieve two goals for the National Alliance for Caregiving and the AARP Public Policy Institute. The first goal was to estimate the prevalence of caregiving for persons of any age as a share of both the U.S. population and U.S. households. The second was to describe the characteristics, roles, and needs among caregivers who provide care to an adult age 18 or older.

To qualify for the study, respondents must have self-identified as a current unpaid caregiver of an adult or one who has provided care at some point during the 12 months prior to the survey. Self-identified caregivers also had to report providing help with at least one Activity of Daily Living (ADL), Instrumental Activity of Daily Living (IADL), or medical/nursing task. Surveys were conducted between September 18 and November 5, 2014 and averaged 24 minutes to complete.

This paper examines the responses of 328 sandwich caregivers identified in the Caregiving in the U.S. 2015 study, with select comparisons to 906 caregivers who had no children living in their home (non-sandwich caregivers). Results about select subgroups of sandwich caregivers are presented as a snapshot or profile.

Caregiving in the U.S. 2015 used a complex, six-part sampling design, with four parts comprising the nationally-representative sample. All data about sandwich caregivers and the comparison group of non-sandwich caregivers are drawn from this four-part nationally-representative sample and use the individual-level weight as developed for analysis of that sample.

STUDY LIMITATIONS

As you consider findings in this report, it is important to consider some limitations. These are primarily due to availability of data from the larger study, Caregiving in the U.S. 2015. The current report defines sandwich caregiver as an individual providing care to an adult of any age while simultaneously having a child under 18 years of age residing in their home. Other studies, however, have varied in how this population is conceptualized and defined. For example, a major study by PEW in 2013 defined sandwich caregivers as individuals providing financial support to a child under 18 or an adult child (18 or over) while also caring for a parent 65 and older. Of particular note, the PEW study emphasized the rise of intergenerational families in the U.S., where adult relatives are continuing to reside with parents or rely on them for financial support.

In addition to intergenerational families, caregivers of adults (over 18) with disabilities may also be caring for aging parents or other older individuals. It is common for adults with lifelong intellectual and developmental disabilities and significant mental illness to co-reside with aging parents. In these situations, aging parents may provide care to an aging spouse. Siblings, who typically take over care when aging parents can no longer continue, may even find themselves in a situation where they face triple caregiving roles: caring for their adult sibling with disabilities, an aging parent, and their own children. These variations and other situations of so-called “compound” caregiving are not fully captured in this report.

6GfK’s KnowledgePanel® is a probability-based online panel, designed to be representative of the U.S. population.
7To see complete study results, questionnaires, or detailed study methodology, please see Caregiving in the U.S. 2015 full report and Appendices A and B. https://www.caregiving.org/research/caregivingusa/.
8Note that this report features a Snapshot titled Childcare and Sandwich Caregivers. This snapshot does not include the experiences of any of the 328 sandwich caregivers identified in the Caregiving in the U.S. 2015 report.
Another limitation to consider is the lack of detail about the child caregiving situation. No information is available about the age of the child, the relationship, whether the child has a disability or special health condition, or if care is being provided to multiple children. Given the changing demographics of American families, some individuals may provide shared childcare to children not living in the same home. Additional information about these households would provide opportunities to examine, in greater detail, how these characteristics impacted responses.\textsuperscript{12}

### READING THIS REPORT

This report, in select places, compares the experience of sandwich caregivers to that of caregivers who do not have any children or grandchildren under the age of 18 living in their home – for brevity, referred to as non-sandwich caregivers. This report also highlights subgroups of sandwich caregivers to better understand the unique and diverse experiences of these caregivers.

All demographic information about caregivers is based on the period of caregiving of the provider – either current caregiving or caregiving provided in the past 12 months. All data are in reference to the caregivers’ experience and situation at the time of survey or 12 months prior to it.

The sample sizes (n) noted in each table or graphic represent the unweighted number of respondents who answered each question. All reported results shown are weighted and rounded to the nearest whole number. Note that “don’t know” or “refused to answer” responses are not always presented in charts and tables, therefore, some charts and tables will not total 100 percent. The results for multiple-response questions may total more than 100 percent. All results were tested for statistical significance at the 95 percent confidence level using the appropriate test, depending on the result presented.\textsuperscript{13} All differences between sandwich caregivers and non-sandwich caregivers discussed in the text are statistically significant. In all tables and graphs, a notation of * shown on a result indicates that the value is statistically significantly higher than that of the comparison group.

\textsuperscript{12}The limitations section of this study was authored by Joseph Caldwell, PhD, Lurie Institute for Disability Policy, Brandeis University.

\textsuperscript{13}Statistical testing applied to comparison of dementia caregivers and non-dementia caregivers were: Independent t-test for means with assumption of equal variances and independent z-test for percentages with assumption of unpooled proportions.
KEY FINDINGS

• We estimate **11 million caregivers (28 percent of all caregivers) provide unpaid care to an adult while also caring for children living in their home.** We refer to this sub-group as sandwich caregivers.

• A distinctive characteristic of sandwich caregivers is that they are more ethnically diverse, younger, and newer to caregiving. At an average age of 41, these caregivers are about 12 years younger than caregivers without children at home and are often from the Gen X and millennial generations.

• Sandwich caregivers are often a part of a care team. About half of sandwich caregivers report having help from other unpaid caregivers (53 percent) and one in four report receiving help from paid aides or services (26 percent) in order to care for their adult care recipient.

• Sandwich caregivers help their care recipient with Instrumental Activities of Daily Living (IADLs), Activities of Daily Living (ADLs), or more complex and skilled medical/nursing tasks. Sandwich caregivers most commonly help with transportation (80 percent), housework (76 percent), and preparing meals (62 percent). Very few are prepared to do the medical/nursing tasks (19 percent).

• These sandwich caregivers are often juggling work responsibilities in addition to caring for both an adult and a child in their home. They report dedicating, on average, 22 hours per week to caring for their loved one.

• **Sandwich caregivers often lack workplace benefits,** such as paid leave, that might help them manage their multiple responsibilities. As a result, sandwich caregivers miss work or cut down work hours during their prime working and long-term saving years. One in five sandwich caregivers report feeling financial strain as a result of being a caregiver.

• Not surprisingly, roughly a third of sandwich caregivers report a high level of emotional stress, and a fifth of these caregivers report a high level of financial and physical strain. Among these sandwich caregivers, those co-residing with their care recipients and those caring for a close relative are most likely to report high strain.

• Younger sandwich caregivers are more likely to receive preparation than older, non-sandwich caregivers – perhaps because of their newer ‘tenure’ as caregivers, or because they grew up in an era where information has always been accessible, often at their fingertips.

• 85 percent of sandwich caregivers report needing more information on at least one caregiving related topic, including managing stress (44 percent).

• About 25 percent of sandwich caregivers said it was difficult to find affordable services for their care recipient.

• Rural caregivers were more likely to report that their care recipients live in their own home (66 percent) or alone (35 percent).

• Rural caregivers living and caring in rural areas find themselves with few supports or services, such as transportation (15 percent) and respite care (17 percent), meaning responsibility for performing these services falls on the caregiver.

• Among financial supports programs to offset caregiving related costs, sandwich caregivers found paid-care programs that compensate caregivers for some of their time (33 percent) and income tax credit programs (31 percent) most appealing.
POLICY RECOMMENDATIONS

To ensure a wholistic approach in addressing the needs and challenges of sandwich generation caregivers across the entire lifespan, we have identified a set of policy recommendations, which you can find here. We have also inserted a variety of policy considerations throughout the report to incite further discussion.

Address Needed Improvements to Our Long-Term Care System

- Lift asset requirements as a qualifier for Medicaid eligibility.
- Document and educate caregivers upon discharge of those needing care from care facilities.
- Add non-acute long-term services and supports with a focus on home and community-based services to Medicare.
- Create a national strategy to recruit and retain direct-care workers and increase the national wage floor so that direct-care workers earn a living wage and have access to additional training.
- Provide an expansive definition of family to include individuals with which the employee has a close association that is the equivalent to a familial relationship, such as a child, parent, domestic partner, grandparent, grandchild, or sibling.

Provide Family Caregiver Tax Credits

- Provide a refundable tax credit to help families defray the cost of caregiving roles and responsibilities.
- Credits must be available to caregivers across the lifespan.
- Credits must cover all caregiving-related expenses.

Increase Access to Affordable Quality Childcare and Early Learning Options

- Address childcare needs for children 0-13.
- Address populations that are especially challenged in finding childcare such as families with non-traditional work hours and families with a child with a disability.
- Allow families to have childcare options in the setting of their choice without excluding family, friend, or neighbor providers.
- Provide all families with access to quality childcare. Any quality investments and requirements for programs must take into consideration both families and child providers, including the need to compensate childcare providers with a living wage.

Increase Use and Standardize Caregiver Assessment Tools

- Ensure all health systems and caregiver support programs work with appropriate stakeholders to increase the use of evidence-based caregiver assessment tools.
- Assessment tools should determine specific problems, needs, strengths, and resources of family caregivers, and provide referrals for family caregiver supportive services.

Social Security Caregiver Credit Act

- Provide a Social Security credit so that time taken off from work to provide care would count towards future Social Security benefits.
- Ensure that caregivers are not losing Social Security retirement benefits while taking time out of the workforce to care for a loved one.
DETAILED FINDINGS

PREVALENCE

For this report, sandwich generation caregivers are defined as those who provide unpaid care to an adult, while also having responsibility for children living in their home, referred to in this report for shorthand as sandwich caregivers. Caregiving in the U.S. 2015 – from which the data for this report are drawn – estimates that 39.8 million Americans are providing care to an adult age 18 or older. Approximately 28 percent of those caregivers (or 11 million caregivers) also had a child or grandchild living in their home while also providing care to an adult.

BASICS OF THE CAREGIVING SITUATION

Age, Gender, Race/Ethnicity of the Caregiver

Approximately three in five sandwich caregivers are female (61 percent), while two in five are male (39 percent). At an average of 41 years of age, sandwich caregivers are about 12 years younger than caregivers without children at home. Eighty percent of sandwich caregivers are millennials (31 percent) and Gen X (49 percent). In comparison, non-sandwich caregivers are predominately baby boomers (46 percent).14

Figure 1: Generational Profile of Sandwich Caregivers

![Pie chart showing generational profile of sandwich caregivers.]

For this report, sandwich caregivers are those who provide unpaid care to an adult, while also having responsibility for children living in their home.

14For the purposes of this report, generations are based on respondent age reported at the time of the survey in late 2014. Millennials at the time were between 18 and 34 years old, (born between or during 1981 and 1996); Gen X includes those who reported ages between 34 and 51 (born between or during 1964 and 1980); baby boomers were 51 – 70 years old (born between or during 1944 and 1963).
Sandwich caregivers are more racially and/or ethnically diverse than non-sandwich caregivers. About one in five are either Hispanic (22 percent) or non-Hispanic Black (16 percent) and about half are non-Hispanic White (53 percent). This is in line with the race/ethnicity composition of the United States generally, where younger generations are more diverse than older generations.\(^\text{15}\)

**Figure 2: Racial/Ethnic Diversity of Sandwich Caregivers Compared to Non-Sandwich Caregivers**

Please see Demographic Profile (beginning on page 29) for additional demographic information about sandwich and non-sandwich caregivers.

**Duration of care**
Approximately 67 percent of sandwich caregivers are caring for a woman who is 66 years old, on average, five years younger than non-sandwich caregivers’ care recipients (71 years old, on average).

**Figure 3: Care Recipient Age (n=328)**

Relationship
Half of sandwich caregivers are caring for a parent or parent-in-law (53 percent). About one in ten provide care to a grandparent or grandparent-in-law (11 percent) or to a spouse (8 percent).\(^\text{16}\) Gen X and millennial sandwich caregivers reported caring for a friend or neighbor (15 percent vs. 8 percent of baby boomers). Millennial sandwich caregivers are more often providing care to a grandparent or grandparent-in-law (23 percent vs. 10 percent of Gen X sandwich caregivers). Lower income sandwich caregivers are more than twice as likely to care for a friend or neighbor (18 percent vs. 8 percent of those with $50,000 or more in household income).
NATURE OF THE CAREGIVER

- Typically, a 41-year-old daughter caring for her 70-year-old mother. 81 percent of these sandwich caregivers live with their care recipients or within 20 minutes.
- Has provided care for 3.2 years, on average.
- Fifty-two percent are also employed while providing care.

CARE SITUATION

- Provides 24 hours of care each week, on average.
- More often has helped with managing finances (58 percent) and advocating with providers (56 percent).

IMPACT ON THE CAREGIVER

- Forty percent face high levels of emotional stress.
- Twenty-three percent report high financial strain.
- Have other unpaid caregivers helping (58 percent).

A hallmark of these sandwich caregivers is the proximity of the caregiver and their parent: 82 percent live within 20 minutes of their parent (including one third who live in the same home). These sandwich caregivers are mostly women (61 percent) caring for their mother or mother-in-law (70 percent). Most commonly, the parent needs care due to surgery or wounds (11 percent), “old age” or frailty (9 percent), Alzheimer’s confusion or dementia (9 percent), or diabetes (8 percent).

More than three in five sandwich caregivers perform medical/nursing tasks (63 percent), with one in five reporting difficulty doing so. They perform 1.8 ADLs and 4.3 IADLs and spend 24 hours a week providing care, on average. Perhaps because they are caring for a parent, they often take on the businesses of care: managing finances, paying bills, filling out insurance claims (58 percent), and advocating for their parent with providers or agencies (56 percent).

Four in ten report a high level of emotional stress and nearly half want more help or information about managing that stress (48 percent). One in four report a high level of financial strain due to caring for their parent (23 percent), more than double the financial strain of caring for another relative or friend (10 percent). Around half report working while also providing care to their parent (52 percent). Many have help in providing care: 58 percent report having at least one other unpaid caregiver helping their parent; only 26 percent say they alone are the primary caregiver for their parent.
Sandwich caregivers tend to live close to their care recipients, with 82 percent living with or within twenty minutes of their care recipient (compared to 72 percent of non-sandwich caregivers). Half reported that their care recipient lives in their own home and only 6 percent live in a care community or facility (e.g., independent living or retirement community, assisted living, nursing care, or long-term care facility). Only one in four sandwich caregivers report that their recipient lives alone (25 percent).

**Policy Consideration:** Increased Funding for Caregiver Programs, such as the National Family Caregiver Support Program and Lifespan Respite

**Figure 5: Care Recipient Living Arrangements and Distance from Sandwich Caregiver (n=326)**

<table>
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<th>Distance</th>
<th>With caregiver</th>
<th>Less than 20 minutes away</th>
<th>20 minutes to 1 hour</th>
<th>1 hour +</th>
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<tr>
<td>Their own home</td>
<td>51%</td>
<td>8%</td>
<td>7%</td>
<td>6%</td>
</tr>
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Hispanic sandwich caregivers more often reported that their care recipient lives with them or in someone else’s home (59 percent compared to 40 percent of non-Hispanic whites).

For sandwich caregivers whose care recipient lives in a rural area, that recipient is more often living in their own home (66 percent vs. 44 percent of non-rural care recipients) and more often living alone (35 percent vs. 20 percent).

**Rural Status**

Fewer than one in five sandwich caregivers live in a rural area (15 percent), although 33 percent reported their care recipient lives in a rural area. Therefore, one in five sandwich caregivers lives in an urban/suburban area and travels to a rural area to provide care (20 percent), doing so more often than non-sandwich caregivers (15 percent). Two out of three sandwich caregivers live and provide care in a suburban/urban setting (65 percent), 13 percent live and provide care in a rural area, and only 2 percent live in a rural setting and travel to the suburbs/city to provide care.
NATURE OF THE CAREGIVER

- Typically, a 40-year-old caring for a 63-year-old, on average.
- Seventy-seven percent typically caring for a female.

CARE SITUATION

- Recipient less often lives alone (15 percent).
- 28.5 hours of care provided weekly, on average.
- More often assist with at least one Activity of Daily Living (74 percent).
- High Burden of Care Index (47 percent).

IMPACT ON THE CAREGIVER

- 66 percent work while providing care for 35.4 hours a week on average.
- 22 percent cut back work hours to provide care.
- 63 percent have household income under $50,000.

Hispanic sandwich caregivers are slightly younger on average, reflecting some general demographic trends in the U.S. population as a whole. Hispanic sandwich caregivers have a relatively demanding care situation: they spend a high number of hours providing care weekly (28.5 hours on average), more often perform Activities of Daily Living (74 percent), and have a relatively high Burden of Care (47 percent vs. 29 percent of non-Hispanic whites).

Hispanic sandwich caregivers, however, reported high emotional stress as a result of caregiving less often (30 percent vs. 41 percent of non-Hispanic whites). The impact of this demanding care situation may be eased by the many hands around to help: few care recipients live alone (15 percent vs. 28 percent for non-Hispanics) and many report the presence of other unpaid caregivers (60 percent).

While 66 percent have worked in the past year while providing care, 22 percent report having to cut back their work hours to provide care (compared to 9 percent of non-Hispanic whites). The median household income of Hispanic sandwich caregivers is $40,700, about $23,000 less than non-Hispanic whites; yet only 18 percent of Hispanic sandwich caregivers report high financial strain from caregiving (compared to 21 percent of non-Hispanic whites).
SPOTLIGHT: MILLENNIAL SANDWICH CAREGIVERS

Nearly a third (31 percent) of sandwich caregivers are millennials (age 18 to 33 at the time of caregiving in late 2014).* The nature of their caregiving is distinct from other sandwich caregivers.

NATURE OF THE CAREGIVER

- Typically, a 27-year-old caring for someone 60 years old, on average.
- 34 percent care for a parent; 23 percent a grandparent; 16 percent a friend or neighbor.
- Has been providing care for 2.1 years, on average.

CARE SITUATION

- Provides 17.3 hours of care per week, on average.
- Less often performing medical/nursing tasks (52 percent).
- Less often arranging outside services (22 percent), advocating for recipient (35 percent), or communicating with care providers (51 percent).

IMPACT ON THE CAREGIVER

- 76 percent are employed while providing care.
- Only 44 percent have flexible work hours, 31 percent have sick leave, and 13 percent have employee support programs.

One in three millennial sandwich caregivers provide care for a parent (34 percent) and 23 percent care for a grandparent (more than older generation caregivers), indicating an intergenerational aspect to millennial caregiving. Millennials have been providing care for a shorter amount of time (2.1 years), on average, and more often expect it to be a temporary role, with just 37 percent expecting to be caring for any adult five years in the future.

Millennial sandwich caregivers tend to play a supporting role in caregiving for their adult care recipient, providing 17.3 hours of care per week and helping less often with formal care or services and supports tasks such as: medical/nursing tasks (52 percent compared to 72 percent of baby boomer sandwich caregivers), arranging outside services (22 percent vs. 45 percent of baby boomer sandwich caregivers), advocating for their care recipient (35 percent vs. 57 percent of baby boomer sandwich caregivers), or communicating with care professionals (51 percent vs. 73 percent of baby boomer sandwich caregivers). On average, millennial sandwich caregivers help with 1.7 Activities of Daily Living and 4.0 Instrumental Activities of Daily Living weekly.

The majority of millennial sandwich caregivers work while providing care (76 percent), but fewer report having workplace benefits like flexible work hours (44 percent), paid sick days (31 percent), or employee support programs (13 percent). Millennial sandwich caregivers report comparable levels of financial strain (15 percent high strain).

Figure 6: Urbanicity of Sandwich Caregiver (CG) and Care Recipient (CR) (n=328)

A Team-Based Care Approach

Often, sandwich caregivers are a part of a network of people who contribute to the care of the recipient. Slightly more than half indicated that someone else has provided unpaid care during the last twelve months (53 percent), including 13 percent who indicated that they are the primary unpaid caregiver among others, 11 percent who shared caregiving equally with others, and 29 percent who reported that someone else provided the bulk of unpaid care.

A care team may include a direct care worker as well. In fact, 26 percent of sandwich caregivers reported employing a direct care worker, such as home health aides or housekeepers. Nearly 19 percent of sandwich caregivers reported having difficulty coordinating care among all the care providers, payers, and servicers of their care recipient. Sandwich caregivers who provide the most care – 20 or more hours each week – are especially likely to have difficulty with care coordination (29 percent).

Figure 7: Caregiving Responsibility (n=328)

Primary Reasons Recipient Needs Care

Sandwich caregivers indicate a variety of main conditions or illnesses prompting the need for care. Most common is aging or frailty (12 percent), followed by wounds or surgery (10 percent), mobility issues (7 percent), mental illness or behavioral health issues (7 percent), or diabetes (7 percent).
Figure 8: Main Condition for Which Recipient Requires Care

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Old Age” / frailty</td>
<td>12%</td>
</tr>
<tr>
<td>Wounds or surgery</td>
<td>10%</td>
</tr>
<tr>
<td>Mobility issues</td>
<td>7%</td>
</tr>
<tr>
<td>Mental illness or behavior health issues</td>
<td>7%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>7%</td>
</tr>
<tr>
<td>Cancer</td>
<td>6%</td>
</tr>
<tr>
<td>Back problems</td>
<td>6%</td>
</tr>
<tr>
<td>Alzheimer’s confusion or dementia</td>
<td>6%</td>
</tr>
</tbody>
</table>

Although only 6 percent of sandwich caregivers specify Alzheimer’s as the main condition requiring care, 20 percent of sandwich caregivers are providing care to someone who suffers from Alzheimer’s or other mental confusion, either as the main condition or co-morbid condition.

Policy Consideration: Expand and Implement the CARE Act

Reasons for Requiring Care

More broadly, sandwich caregivers most often describe their care recipient’s condition as a long-term physical condition (55 percent) requiring ongoing care. Four in ten describe the reason for care as a short-term physical condition, although one in four cite memory problems and emotional or mental health problems.

Figure 9: Care Recipient Condition Categories (n=328)

- Long-term physical condition: 55%
- Short-term physical condition: 39%
- Memory problems: 27%
- Emotional or mental health problems: 25%
- Behavioral issues: 5%
- Developmental or intellectual disorder: 4%

Policy Consideration: Expand Medicaid’s Ability to Compensate Family Caregivers

Caregiving Activities and Intensity of Care

Length of Care

The majority of sandwich caregivers have been providing care for five years or less (80 percent), averaging 3.1 years of care (compared to 4.4 years among non-sandwich caregivers). This shorter length of care seems to reflect the younger age of sandwich caregivers. Sandwich caregivers are overwhelmingly millennial and Gen X. Millennials reported a shorter average duration of care at 2.1 years and Gen X reported 3.4 years of care. Baby boomers and the silent/greatest generation, who make up the bulk of caregivers without children in their home, reported an average of 4.9 and 5.6 years of care, respectively. For both sandwich caregivers and those without children in their home, as caregiver age increases, so too does length of time having provided care.
**Activities of Daily Living (ADLs)**

Activities of Daily Living, or ADLS, are personal care and mobility tasks that an unpaid caregiver may help their adult care recipient with, such as dressing, bathing, or feeding. Three in five sandwich caregivers help their loved one with at least one Activity of Daily Living (ADL), on average, performing 1.7 ADLs (out of a possible six tasks). The most common ADL that caregivers help with is getting in and out of chairs or beds (45 percent).

**Figure 11: ADLs Performed by Sandwich Caregivers (n=328)**

- None: 42%
- One: 14%
- Two: 10%
- Three: 13%
- Four: 8%
- Five: 7%
- Six: 5%

- Any activity: 58%
  - Getting in and out of beds/chairs: 45%
  - Getting dressed: 35%
  - Getting to and from the toilet: 29%
  - Bathing or showering: 24%
  - Feeding care recipient: 23%
  - Dealing with incontinence or diapers: 15%
Roughly two in ten sandwich caregivers reported having difficulty assisting with these Activities of Daily Living (18 percent), fewer than non-sandwich caregivers (25 percent). ADLs tend to be physically demanding tasks, so sandwich caregivers’ relative youth compared to non-sandwich caregivers may make them more easily able to handle ADLs.

**Instrumental Activities of Daily Living (IADLs)**

Instrumental Activities of Daily Living, or IADLS, are household tasks that an unpaid caregiver may help their adult care recipient with, such as shopping, chores, or arranging services. On average, sandwich caregivers assist their care recipient with 4.2 Instrumental Activities of Daily Living (IADLs) out of seven total tasks. Sandwich caregivers most commonly help with transportation (80 percent), housework (76 percent), and preparing meals (62 percent).

Sandwich caregivers who are the primary caregiver more often help with IADLs, such as housework (82 percent vs. 68 percent of non-primary sandwich caregivers), shopping (82 percent vs. 63 percent), meal preparation (70 percent vs. 50 percent), and managing finances (62 percent vs. 33 percent).

**Figure 12: IADLs Performed by Sandwich Caregivers**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any activity</td>
<td>100%</td>
</tr>
<tr>
<td>Transportation</td>
<td>80%</td>
</tr>
<tr>
<td>Housework</td>
<td>76%</td>
</tr>
<tr>
<td>Grocery/other shopping</td>
<td>75%</td>
</tr>
<tr>
<td>Preparing meals</td>
<td>62%</td>
</tr>
<tr>
<td>Managing Finances</td>
<td>50%</td>
</tr>
<tr>
<td>Giving medicine/pills/injections</td>
<td>49%</td>
</tr>
<tr>
<td>Arranging outside caregiving services</td>
<td>30%</td>
</tr>
</tbody>
</table>

**Medical/Nursing Tasks**

Nearly three out of five sandwich caregivers help their care recipient with medical/nursing tasks, a body of highly skilled caregiving tasks that may have typically been handled by someone such as a healthcare aide, nurse, or other healthcare professional. Such tasks include, but are not limited to, injections, tube feeding, and catheter and colostomy care.

About four in ten sandwich caregivers reported that they are performing these skilled tasks without any prior preparation or training (41 percent). About one in five reported they have gotten some preparation prior to taking on these tasks, although it is important to note that a minority of caregivers, regardless of their age, are receiving this kind of training. 15 percent of sandwich caregivers say it is difficult to perform medical/nursing tasks.

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*This includes giving medicines like pills, eye drops, or injections; preparing food for special diets; tube feedings; wound care; monitoring blood pressure or blood sugar; helping with incontinence; or, operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes. See: Reinhard, S.C., Levine, C., & Samis, S. Home Alone: Family Caregivers Providing Complex Chronic Care. AARP Public Policy Institute & United Hospital Fund, 2012.*
Sandwich caregivers who are the primary caregiver more often take on the advocate role (57% vs. 40% of non-primary), as well as the role of care communicator (68% vs. 53% of non-primary).

**Policy Consideration: Increase Caregiver Training and Education**

**Caregiving Support Activities**

Sandwich caregivers often perform other activities to help support their recipient’s care, such as monitoring condition severity (68 percent) and communicating about care with providers (62 percent). Half of sandwich caregivers advocate for their recipient with various providers or services.

In general, sandwich caregivers providing care to a parent/parent-in-law (61 percent) or spouse (56 percent) more often take on the role as an advocate than those caring for a recipient with some other relationship (40 percent). Similarly, sandwich caregivers who are the primary caregiver more often take on the role as an advocate (57 percent vs. 40 percent of non-primary), as well as the role of care communicator (68 percent vs. 53 percent of non-primary).

**Figure 13: Medical/Nursing Tasks and Training**

- Does medical/nursing tasks (untrained): 41%
- Doesn’t do medical/nursing tasks: 19%
- Does medical/nursing tasks (trained): 39%

**Figure 14: Caregiving Support Activities (n=328)**

- Monitor the severity of condition in order to adjust care accordingly: 68%
- Communicate with healthcare professionals like doctors, nurses, or social workers about care: 62%
- Advocate for care recipient with health care providers, community services, or government agencies: 50%
**Hours of Care**

To assist with the many caregiving tasks they perform, sandwich caregivers must dedicate a considerable portion of their week to caring for their adult recipient: on average, 22 hours per week—the equivalent of a part-time job. Those caring for a spouse spend 47 hours weekly while those caring for a parent/parent-in-law provide care for 24 hours weekly, on average.

**Figure 15: Hours of Care Provided by Sandwich Caregivers by Relationship to Care Recipient (n=328)**

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The Burden of Care Index was created to gauge the complexity and challenges of caregiving. About one in three sandwich caregivers (36%) are in a high burden care situation.

**Burden of Care Index**

The Burden of Care Index was created to gauge the complexity and challenges of caregiving. This index combines information about the care tasks and hours of care performed. This index measures the burden of care situation on the caregiver. About one in three sandwich caregivers (36 percent) are in a high burden care situation. For more information on the construction of the Burden of Care Index, refer to Appendix B of the Caregiving in the U.S. 2015 report.

**Figure 16: Burden of Care Index Among Sandwich Caregivers (n=328)**

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**Strain and Stress**

Many sandwich caregivers face challenges as a result of caring for an adult while also having responsibility for children living in their home. One in three reported a high level of emotional stress due to caregiving (33 percent). One in five reported a high level of financial strain (20 percent) and physical strain (18 percent) as a result of caregiving, while 20 percent reported that caregiving has made their health worse.
DETAILED FINDINGS

Figure 17: Stress and Strain on Sandwich Caregivers (n=342)

- 33% High level of emotional stress (4-5 out of 5)
- 20% High level of financial strain (4-5 out of 5)
- 20% Caregiving made my health worse
- 18% High level of physical strain (4-5 out of 5)

Slightly more than half of sandwich caregivers feel they had a choice in taking on their role of caregiver (54 percent). For the 45 percent of sandwich caregivers who felt they had no choice, the perception of emotional and physical strain can often be worse.\(^\text{22}\)

**Working Caregivers**

Sandwich caregivers have the dual responsibilities of providing care to an adult recipient and a child on top of their work responsibility. Sandwich caregivers more often reported being employed while also caregiving (67 percent), as compared to 57 percent of non-sandwich caregivers. On average, sandwich caregivers work 36 hours per week.

As with all working caregivers, sandwich caregivers find that caregiving can impact their work. Six in ten working sandwich caregivers reported at least one impact on their work (60 percent). This most commonly includes having to go in late, leave early, take time off (49 percent), or taking a leave of absence (19 percent, more common than among working non-sandwich caregivers at 12 percent).

**Policy Consideration: Pass the EITC Modernization Act**

**Figure 18: Impact of Caregiving on Employment**

Impact on Employment

- 40% none
- 60% any impact

- Went in late, left early, took time off: 49%
- Took a leave of absence: 19%
- Went from full-time to part-time/cut back hours: 14%
- Received warning about performance or attendance: 10%
- Turned down promotion: 6%
- Gave up working entirely: 4%
- Retired early: 4%
- Lost job benefits: 2%

**INSIGHTS**

Female sandwich caregivers more often reported higher levels of emotional stress (38 percent vs. 27 percent of men).

Sandwich caregivers who live with their care recipient may be especially at risk because of the demands of caring for children and an adult in the same household. They reported higher levels of physical strain (26 percent high strain vs. 13 percent not living together), financial strain (27 percent vs. 16 percent), and a more negative impact on their health (30 percent vs. 14 percent). They also less often feel they had a choice in taking on their role (40 percent vs. 62 percent).

Those caring for a close relative, such as a parent/parent-in-law or spouse, also seem to have greater stress and strain: 40 percent reported high emotional stress and 26 percent say that they are facing high financial strain (compared to 22 percent and 10 percent respectively among those caring for other relatives or non-relatives).

Sandwich caregivers who are caring for a spouse may be at special risk due to their co-residing and close relationship status: 41 percent reported high financial strain and 40 percent say caregiving has negatively impacted their health.\(^\text{23}\)

\(^\text{22}\)In Caregiving in the U.S. 2015, results showed that having no choice in taking on the caregiving role could result in feeling higher levels of emotional stress and strain, with 53 percent of those who had no choice feeling high levels of emotional stress (compared to 28 percent of caregivers overall).

\(^\text{23}\)Confidence in these figures as representative of the population is moderate due to a small sample size. Further study of sandwich caregivers caring for a spouse or partner is recommended in order to further investigate the impacts of spousal caregiving with children in the home, especially related to household finances and ability of the caregiver to maintain or improve their own health.
SNAPSHOT: CHILDCARE AND SANDWICH CAREGIVERS

In 2015, Alexis’s mother was diagnosed with Alzheimer’s disease. At the time, Alexis had an eleven-year-old daughter and a three-year-old son. Alexis’s mother needed more care than her father, who was in his 80s and had health problems of his own, was able to provide. Alexis and her husband were both working outside the home and paying a mortgage on a new house. They decided to move in with Alexis’s parents to help. The move to Virginia meant additional childcare costs for which they hadn’t planned. It also required the family to face new, unexpected challenges related to caregiving. Looking back on this arrangement, Alexis says, “we didn’t have a plan.” They were simply trying to make it all work.

The lack of affordable, quality childcare is a critical issue for sandwich caregivers like Alexis, who, on top of the cost of care for their children, face out-of-pocket caregiving costs of nearly $7,000 per year. Studies show that access to high-quality, affordable childcare allows families with care responsibilities to continue to work. This is especially relevant to working sandwich caregivers. It is also critical for direct-care workers in order to support their own families, continue to support the families for whom they provide care, and allows them to remain in an industry that is desperate to retain workers.

Research has shown, however, that high-quality childcare is unaffordable for many families across all 50 states. The out-of-pocket costs of childcare vary greatly from state to state, but the national average is almost $10,000 per year. Of those who qualify for state childcare assistance programs, only one in six children who are eligible actually receive the benefit. Most families are left to shoulder this burden without any public assistance. Families with children with disabilities, parents of infants and toddlers, those with nontraditional work hours, and families that rely on after school and summer childcare are all faced with additional barriers in accessing high-quality and affordable childcare options that fit their needs.

In short, the lack of access to high-quality, affordable childcare can perpetuate the cycle of poverty and force families of all income levels to make impossible choices between caregiving and work. Affordable and accessible childcare options would allow more sandwich caregivers, especially women, to be able to enter and remain in the workforce. Additional targeted research is needed to further understand the impact of the childcare and early learning landscape on sandwich caregivers.

Looking back, four years into this caregiving arrangement, Alexis says, “we didn’t have a plan... we’re simply trying to make it all work.”
**Workplace Support**

Increased workplace support could help all caregivers, including sandwich caregivers, to juggle these multiple demands on their time. About half of employed sandwich caregivers reported having flexible work hours (54 percent), only 36 percent reported having enough paid leave available to be able to take time off from work to care for a family member. Just one in four are offered telecommuting opportunities (24 percent) or an employee assistance program (EAP) that might help caregivers manage better (26 percent).

**Information and Support Needs**

Most sandwich caregivers indicate that they need more help or information about at least one caregiving-related topic (85 percent). The most reported needs for support or information are help managing their own emotional and physical stress (44 percent) and help keeping their care recipients safe at home (43 percent). One in five would like more help or information about making end of life decisions (19 percent).

**Figure 19: Support for Sandwich Caregivers (n=212)**

Seeking help?

- Managing own emotional and physical stress: 44%
- Keeping care recipient safe at home: 43%
- Making end-of-life decisions: 19%
- Managing care recipient’s challenging behaviors: 15%
- Managing care recipient’s incontinence or toileting problems: 10%
- Finding non-English language educational materials: 8%

**Policy Consideration: Increase and Enhance the Existing National Support Infrastructure for Family Caregivers**

**Service Costs, Policy, and Long-Range Planning**

About one in four sandwich caregivers say it is difficult to find affordable services for their care recipient in their local area or community (25 percent rating this need as 4 or 5 on a 5-point scale). When asked about financial support needed to assist in offsetting or paying for care,24 the most popular policies among sandwich caregivers are paid-care programs (33 percent), where caregivers are compensated for some hours of care, or income tax credits (31 percent). Some sandwich caregivers would like relief from the dual burden of employment and caregiving: 13 percent prefer a partially paid leave of absence from work.25 About a quarter of sandwich caregivers, however, were unsure which financial support policy they would find most helpful (23 percent).

Many sandwich caregivers reported a lack of long-range planning, either for themselves or their care recipient. Less than half indicate their care recipient has future care plans in place for living arrangements, health care decisions, or financial matters (43 percent). Even fewer sandwich caregivers have their own long-range plans (37 percent vs. 45 percent of non-sandwich caregivers).

24Financial support policies described as: 1) a program where caregivers could be paid for at least some of the hours they provide care; 2) an income tax credit to caregivers, to help offset the cost of care; 3) a partially paid leave of absence from work, for caregivers who are employed.

25For further reading on the workplace impacts of caregiving and how employers can address the need for paid leave, see https://hbr.org/2018/11/caring-for-your-companys-caregivers.
SPOTLIGHT: GEN X SANDWICH CAREGIVERS

Gen X is the largest group of sandwich caregivers in the U.S., comprising nearly half (49 percent) of all sandwich caregivers.

NATURE OF THE CAREGIVER

- Typically, 42 years old caring for a 67-year-old, on average
- 59 care for a parent or parent-in-law; 14 percent for a friend or neighbor
- Has been providing care for 3.4 years, on average

CARE SITUATION

- Average of 22.6 hours of care provided weekly
- More often in care situation with high Burden of Care (42 percent)
- 56 percent expect to be providing care in the next five years

IMPACT ON THE CAREGIVER

- Most often experience negative work impacts (65 percent)
- 26 percent have taken a leave of absence from work to provide care
- More often reported high financial strain (25 percent)

On average, Gen X sandwich caregivers are 42 years old. Three out of five Gen X sandwich caregivers provide care to a parent or parent-in-law (59 percent), with another 14 percent caring for a friend or neighbor. Three in ten Gen X sandwich caregivers reported that their recipient lives alone (29 percent vs. 18 percent of baby boomer sandwich caregivers).

Most Gen X sandwich caregivers are the primary caregiver for their recipient (61 percent) and provide 22.6 hours of care weekly. They help with 1.8 Activities of Daily Living and 4.1 Instrumental Activities of Daily Living, on average, with 59 percent helping with medical/nursing tasks. Four in ten are in a care situation that has a high burden of care (42 percent vs. 23 percent of millennial sandwich caregivers). 27 percent reported having paid help. They more often expect to continue to be a caregiver for some adult during the next five years (56 percent vs. 37 percent millennial sandwich caregivers).

Most Gen X sandwich caregivers reported having worked in the past year while providing care (64 percent), working 36.4 hours a week on average. These Gen X sandwich caregivers have experienced negative work impacts more often as a result of their caregiving role (65 percent vs. 46 percent of baby boomer sandwich caregivers), including 26 percent who took a leave of absence to provide care. Perhaps due to these work impacts, 25 percent of Gen X sandwich caregivers reported high levels of financial strain as a result of caregiving (compared to 12 percent for baby boomers).
EXPERT COMMENTARY

FEYLYN LEWIS, PHD, UNIVERSITY OF SUSSEX: YOUNG CAREGIVERS

While the reported figure of 11 million sandwich caregivers (taken from the National Alliance for Caregiving and AARP Public Policy Institute’s Caregiving in the U.S. 2015 study)26 may seem shocking, it is expected that this is only the tip of the iceberg. Indeed, the numbers of sandwich caregivers in the U.S. are likely much higher than reported. One reason for under-reported statistics include the issue of self-identification. Individuals providing care for family members often do not identify with the terminology of “caregiver” because they see themselves as loving, dutiful children or partners.27

Furthermore, to qualify for the Caregiving in the U.S. 2015 study, respondents must have self-identified as an unpaid caregiver providing help with at least one Activity of Daily Living or Instrumental Activity of Daily Living, or a medical/nursing task. These criteria may have excluded caregivers who perform emotional caregiving tasks, such as sitting with the care recipient, holding phone conversations, and general “spending time” with the care recipient. This can take a significant portion of time in the daily lives of caregivers, yet often goes unreported because of its informal nature.28 Therefore, it is likely that caregivers are supplying more care than is reported in the study, meaning that the impacts of caregiving on their daily life is likely more substantial than indicated in the findings. This type of care provision is often common among younger age caregivers (young adults and children) and may also be common among older generation caregivers.29

Finally, it follows that if caregivers only provide emotional tasks, they likely were not included in this study because of the exclusion criteria. Thus, this report should be considered with the understanding that the number of sandwich caregivers in the United States is likely much higher than reported, and the scope of the challenges facing this distinctive group of caregivers is far-reaching.

This report has revealed that sandwich caregivers most commonly provide long-term care to individuals with age and frailty issues. Much focus is directed toward the health condition of the care recipient and how particular conditions can impact the experience of the sandwich caregiver. However, there is the strong likelihood that sandwich caregivers will possess their own health condition requiring care. Previous research has found that adult family caregivers often neglect their own need for medical attention, due to their focus on the care recipient30 and the intensity of their caregiving responsibilities.31 Furthermore, family caregivers often experience health problems directly caused, or exacerbated by caregiving, such as depression or anxiety,32 or back strain from lifting the care recipient. The personal health issues of sandwich caregivers can compound the already stressful experience of care provision, and this aspect of caregiving should be reflected upon when considering the totality of “impact” upon sandwich caregivers.

As this report indicates that 31 percent of sandwich caregivers are millennials, it is important to draw attention to the issues particularly salient for this younger group of caregivers. This report highlights that millennial sandwich caregivers are more likely to engage in paid employment in comparison to other age groups of sandwich caregivers, but they are the least likely to have supportive workplace policies. Recalling that millennials may be at the beginning stages of their career, they may be in a more insecure employment position than older generations of sandwich caregivers. Their younger age may also mean that they have accumulated less personal wealth and assets and may in fact experience financial precarity.

This report highlights that millennial sandwich caregivers are more likely to engage in paid employment in comparison to other age groups of sandwich caregivers, but they are the least likely to have supportive workplace policies.

Previous research with the AARP found that one in three (34 percent) of employed millennial caregivers have an annual household income of less than $30,000, while spending a higher percentage of their income on family caregiving than any other age group. The unique economic burdens facing millennial sandwich caregivers warrant a prioritization of their needs in workplace policy, however, this group of caregivers remains overlooked. The only current federal leave policy available to some eligible millennial sandwich caregivers—the Family and Medical Insurance Leave Act (FMLA)—offers twelve weeks of leave within a one-year period; however, this leave is unpaid. Beyond paid leave policies, millennial sandwich caregivers would benefit from flexible working hours, a more empathetic workplace culture, and depending upon their job sector, the ability to telecommute.

Future research involving sandwich caregivers should examine the experience of sandwich caregivers who lack a care team, with particular attention given to single/unpartnered caregivers. The experience of those sandwich caregivers who identify as LGBT, as well as those from indigenous people groups, should also be included in future analysis. Previous research has shown that those groups of caregivers have unique experiences in their caregiving journey, and more often than not, face social isolation, financial difficulties due to caregiving, and barriers to accessing formal support. It is recommended that future studies involving sandwich caregivers center and prioritize the experience of those who may be particularly vulnerable and isolated from support services.

MARGARET L. LONGACRE, PHD; DEPARTMENT OF PUBLIC HEALTH, COLLEGE OF HEALTH SCIENCES, ARCADIA UNIVERSITY: HEALTH SYSTEMS

A growing body of literature is illuminating the collective caregiving experience as well as the experiences of caring due to specific conditions. We know less about stage-of-life caregiving, including those who provide informal or family care to an adult while also caring for a child or children in the home. Thus, this report on sandwich caregivers provides a needed glimpse into this population of caregivers. Key points of this report relate to the: 1) the emotional, financial and employment strain experienced by sandwich caregivers; and, 2) the potential need for varied communication skills as evidenced by findings on the reasons for which care is provided and the roles and dynamics of such care (i.e., “care team”).

First, 33 percent of these sandwich caregivers indicated that caregiving was highly stressful. Although lower in proportion compared to all caregivers in the Caregiving in the U.S. 2015 Report (38 percent) and to caregivers of people suffering with cancer (50 percent), this still represents approximately 3 in 10 caregivers. Caregiving is well known to be emotionally straining, presenting as elevated stress or distress or as clinical anxiety and/or depression. Having a poorer emotional response to caregiving can also have adverse implications for a caregiver’s own physical health as well as a care recipient’s emotional response.

Caregiver and caregiving characteristics, including employment, can influence a caregiver’s emotional response. Given the younger age of these sandwich caregivers (41 years of age, on average), financial strain and employment impact might be particularly important to consider with respect to emotional strain. Twenty percent of these sandwich caregivers expressed high financial strain due to caregiving, and, of those who were employed (67 percent), many (60 percent) indicated making at least one type of employment modification (e.g., modifying hours or taking a leave of absence). Just over half (54 percent) indicated flexibility with work hours and fewer indicated having support in other ways, such as paid time off or the ability to telecommute. Future research
should more fully explore the basis of financial burden for these caregivers, such as the cost of patient/care recipient care per disease/condition or employment impacts as well as the potential relationship with emotional strain. Previous research on working-age (18-65) caregivers for frail older adults showed an association between experiencing work impacts (e.g., as retiring early or taking time off work) and perceiving caregiving as highly stressful.\textsuperscript{43} Such analyses might contribute to broader policy support to enhance both the financial and emotional well-being of caregivers.

Findings in this report also suggest the potential need to consider communication demands and skills among sandwich caregivers. For example, the most frequent reason for which a sandwich caregiver provided care was due to the main condition of “old age”/frailty (12 percent). Care was also provided due to conditions such as mental illness (7 percent), cancer (6 percent), and Alzheimer’s disease/dementia (6 percent). Moreover, 20 percent indicated that the care recipient had memory deficits, which was occurring for some in addition to a primary condition other than dementia. Most (82 percent) of these sandwich caregivers also live within twenty minutes of the care recipient including 35 percent residing with the care recipient; thus, the child/youth might likely have consistent interaction with the care recipient. Therefore, these caregivers may need assistance in communicating the care experience to a child or children living in the home.

Moreover, there is growing focus on the importance of communication among dyads (caregiver and care recipient) and triads (caregiver, care recipient, and provider) as some caregivers do not always know how to interact in clinical care (e.g., what questions to ask, how to get updates),\textsuperscript{44} but are often part of clinical communication.\textsuperscript{45} A majority (62 percent) of these sandwich caregivers (and 73 percent of the baby boomer sandwich caregivers) indicated communicating with the care recipients’ health care professionals. Furthermore, the report also highlights that many caregivers share the caregiving role (53 percent) and some utilize paid help (25 percent). Thus, inherent with this care team is the need to arrange and communicate with other informal or formal care providers to adequately assist the care recipient.

In sum, this report provides important first understandings that prompt questions for further study – e.g., might employment strain impact the caregivers’ emotional response for these caregivers, and, if so, how could policy reduce this burden? Also, how is the care experience articulated to those children living in the home or other care team members, and what programming or assistance might be needed to facilitate understanding and communication? This report and subsequent work that stems from it will contribute to improved understanding for this important subset of family caregivers.


JOE CALDWELL, PHD; COMMUNITY LIVING POLICY CENTER, LURIE INSTITUTE FOR DISABILITY POLICY, BRANDEIS UNIVERSITY: DISABILITY

As the U.S. population ages, the number of individuals needing long-term services and supports is expected to more than double from approximately 12 to 27 million individuals by 2050. An inadequate national system of financing long-term services and supports is placing a great burden on American families. Those from the Generation X and millennial generations are increasingly finding themselves in the role of a sandwich caregiver, providing unpaid care to an aging parent or other adult as well as raising children. This report provides a valuable profile of this population of caregivers.

One of the key findings of the report is the extent to which this population of caregivers is juggling extensive caregiving time demands with work. Two-thirds (67 percent) of these caregivers are employed. On average, they are working 36 hours per week and devoting 22 hours per week to care for an adult, all on top of raising children. Given these time demands, it is not surprising that other studies have similarly found that these caregivers report feeling stressed, overwhelmed, and have less time to spend with friends and other family. Other studies have also found negative impacts on well-being and health-related behaviors, such as lower levels of exercise and self-care. Moreover, as highlighted in this report, the majority (60 percent) report negative impacts on their employment and many, particularly millennials, report not having adequate workplace supports and flexibility.

The report also provides useful snapshots of various subpopulations of sandwich caregivers which can help inform policy and improve interventions. Consistent with other research, the report highlights greater racial and ethnic diversity among this population of caregivers, particularly higher rates of Hispanic (22 percent) and African American (16 percent) caregivers. Racial and ethnic minority caregivers are less likely to receive formal services and face barriers in receiving culturally competent interventions and supports. The report also highlights important issues concerning care in rural areas. While a third of care recipients of sandwich caregivers reside in rural areas, their caregivers are less likely to also reside there, which requires commuting and other strategies to coordinate care from a distance.

The report contributes to a better understanding of a population of caregivers that will significantly grow in the coming decades as the baby boom generation ages and acquires needs for long-term services and supports. Many characteristics and issues facing sandwich caregivers mirror those facing caregivers in general. However, the report highlights some important differences, particularly greater time demands and potential implications for health and economic well-being. Moreover, not only are sandwich caregivers more racially/ethnically diverse, there is great variation within this population. As highlighted in the report, there are many subpopulations even within this population. Also, many are providing care within a network of other unpaid and paid supports. The report reminds us of the need to develop policies and practices that are flexible and approach families holistically, using a person and family-centered approach based on assessment of their unique situation and needs.

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46U. S. Senate Commission on Long-Term Care, “U. S. Senate Commission on Long-Term Care: Report to the Congress,” (Washington, D.C., 2013).
51Evercare and National Alliance for Caregiving, Hispanic Family Caregiving in the U.S. (Minnetonka and Bethesda: Evercare and National Alliance for Caregiving, 2008).
DEMOGRAPHIC PROFILE

Most sandwich caregivers are women (61%) and they are 41 years old, on average. Rural caregivers younger still at 37.6 years old. They are diverse with non-Hispanic Whites constituting just over half the racial/ethnic makeup.

Figure 20: Gender, LGBT Status, Age, Race and Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>Sandwich Caregivers</th>
<th>Non-Sandwich Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>61%</td>
<td>59%</td>
</tr>
<tr>
<td>Male</td>
<td>39%</td>
<td>41%</td>
</tr>
<tr>
<td><strong>Caregiver LGBT status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4%</td>
<td>10%*</td>
</tr>
<tr>
<td><strong>Age of Caregiver</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 to 34</td>
<td>33%*</td>
<td>20%</td>
</tr>
<tr>
<td>35 to 49</td>
<td>44%*</td>
<td>15%</td>
</tr>
<tr>
<td>50 to 64</td>
<td>18%</td>
<td>40%*</td>
</tr>
<tr>
<td>65 to 74</td>
<td>3%</td>
<td>15%*</td>
</tr>
<tr>
<td>75 or older</td>
<td>&lt;0.5%</td>
<td>10%*</td>
</tr>
<tr>
<td><strong>Mean age</strong></td>
<td>40.7</td>
<td>52.8*</td>
</tr>
<tr>
<td><strong>Race/Ethnicity of Caregiver</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White Non-Hispanic</td>
<td>53%</td>
<td>66%*</td>
</tr>
<tr>
<td>Hispanic</td>
<td>22%*</td>
<td>15%</td>
</tr>
<tr>
<td>African-American Non-Hispanic</td>
<td>16%</td>
<td>12%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
<td>2%</td>
</tr>
</tbody>
</table>
The majority (77%) of sandwich caregivers are between 18 and 49 years of age (mean 40.7), while most non-sandwich caregivers (65%) are over the age of 50 (mean 52.8). About four in ten have a high school degree or less (39 percent), while 31 percent have a college degree or more. In comparison, 35 percent of non-sandwich caregivers have a high school degree or less, while 37 percent have a college degree or more. Half have a household income of $50,000 or less with a median income of $51,900, slightly less than non-sandwich caregivers ($56,300). By comparison, the median household income in the United States in 2014 was $53,718. The table below further de-segregates income levels.

The table below further de-segregates income levels.

Figure 21: Martial Status and Household Income

<table>
<thead>
<tr>
<th>Caregiver Marital Status</th>
<th>Sandwich Caregivers</th>
<th>Non-Sandwich Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>67%*</td>
<td>53%</td>
</tr>
<tr>
<td>Living with a partner</td>
<td>12%*</td>
<td>6%</td>
</tr>
<tr>
<td>Single, never married</td>
<td>13%</td>
<td>22%*</td>
</tr>
<tr>
<td>Divorced</td>
<td>4%</td>
<td>9%*</td>
</tr>
<tr>
<td>Separated</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>Widowed</td>
<td>1%</td>
<td>7%*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver Education</th>
<th>Sandwich Caregivers</th>
<th>Non-Sandwich Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than high school</td>
<td>11%*</td>
<td>6%</td>
</tr>
<tr>
<td>High school graduate</td>
<td>28%</td>
<td>29%</td>
</tr>
<tr>
<td>Some college</td>
<td>25%</td>
<td>20%</td>
</tr>
<tr>
<td>Technical school</td>
<td>7%</td>
<td>8%</td>
</tr>
<tr>
<td>College graduate</td>
<td>21%</td>
<td>20%</td>
</tr>
<tr>
<td>Graduate school</td>
<td>10%</td>
<td>17%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver Household Income</th>
<th>Sandwich Caregivers</th>
<th>Non-Sandwich Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $50,000 (net)</td>
<td>49%</td>
<td>46%</td>
</tr>
<tr>
<td>Less than $15,000</td>
<td>10%</td>
<td>13%</td>
</tr>
<tr>
<td>$15,000 to $29,999</td>
<td>17%</td>
<td>15%</td>
</tr>
<tr>
<td>$30,000 to $49,999</td>
<td>21%</td>
<td>17%</td>
</tr>
<tr>
<td>$50,000 or more (net)</td>
<td>51%</td>
<td>54%</td>
</tr>
<tr>
<td>$50,000 to $74,999</td>
<td>17%</td>
<td>18%</td>
</tr>
<tr>
<td>$75,000 to $99,999</td>
<td>11%</td>
<td>14%</td>
</tr>
<tr>
<td>$100,000 or more</td>
<td>23%</td>
<td>23%</td>
</tr>
</tbody>
</table>

| Median Household Income          | $51,900             | $56,300                 |

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About one in seven sandwich caregivers lives in a rural area (15 percent), while 33 percent of their care recipients live in a rural area. Most were employed while caregiving (67 percent), 8 percent have served on active duty in the military, and 4 percent reported being lesbian, gay, bisexual, and/or transgender.

**Figure 22: Living Location, Employment Status, and Service in the Armed Forces**

<table>
<thead>
<tr>
<th></th>
<th>Sandwich Caregivers</th>
<th>Non-Sandwich Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Care Recipient Living Location</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Rural</td>
<td>67%</td>
<td>73%</td>
</tr>
<tr>
<td>Rural</td>
<td>33%*</td>
<td>26%</td>
</tr>
<tr>
<td><strong>Caregiver Living Location</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Rural</td>
<td>85%</td>
<td>84%</td>
</tr>
<tr>
<td>Rural</td>
<td>15%</td>
<td>16%</td>
</tr>
<tr>
<td><strong>Caregiver Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed in past year while caregiving</td>
<td>67%*</td>
<td>57%</td>
</tr>
<tr>
<td>Not employed</td>
<td>33%</td>
<td>43%</td>
</tr>
<tr>
<td><strong>Caregiver Service in Armed Forces</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ever served on active duty</td>
<td>8%</td>
<td>11%</td>
</tr>
<tr>
<td>Did not ever serve</td>
<td>92%</td>
<td>88%</td>
</tr>
<tr>
<td><strong>Care Recipient Service in Armed Forces</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ever served on active duty</td>
<td>10%</td>
<td>15%*</td>
</tr>
<tr>
<td>Did not ever serve</td>
<td>89%</td>
<td>83%</td>
</tr>
</tbody>
</table>
About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. NAC conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, NAC supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.