Caregiving in the U.S.: How Foundations Can Support Family Caregivers

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GIA “Care for All: Supporting Older Adults, Family Caregivers, and the Home Health Care Workforce”
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About the Alliance

• Nonprofit coalition of over 50 national organizations focused on family caregiving issues
• Established in 1996 with a dedication to improving the quality of life for families and their care recipients through research, innovation, and advocacy

• NAC Activities:
  • Conduct research and policy analysis;
  • Develop national programs;
  • Strengthen state and local coalitions;
  • Increase public awareness;
  • International work and awareness.
Today’s Family Caregiver

44 million caregivers of people 18 and older in the US today

Caregivers reflect the diversity of the United States: they come from every age, gender, race/ethnicity and socioeconomic status.

On average, they perform 2 Activities of Daily Living (ADLs); 4 Instrumental Activities of Daily Living (IADLs); and Medical/Nursing (M/N) Tasks

Responsibilities Include:
ADL- Bathing, Dressing & Feeding
IADL- Housework, Cooking & Managing Finances
M/N Tasks- Injections, Tube Feedings & Colostomy Care

Who Are They?

The typical caregiver is a 49 year-old female caring for a 69 year-old relative due to a long-term physical condition.

22% are caring for someone with Alzheimer’s or dementia.

About 1/3 are considered “higher-hour” -- providing 21 or more hours of care each week.

One quarter are Millennials


**SNAPSHOT**

- 60% Women
- 40% Men
- 13% African American/Black
- 6% Asian American Pacific Islander
- 17% Hispanic/Latino
- 62% White
Caregiver Health

• 17% of caregivers say their health is *fair or poor*, vs. 10% of population as a whole

• 29% of higher-hour caregivers feel caregiving has had a negative impact on their health vs. 18% of lower-hour caregivers.

• One in five caregivers report a high level of physical strain (a rating of 4 or 5 on a 5-point scale) as a result of their caregiving duties.

• Four in ten caregivers report their caregiving situation to be highly stressful; 25% report moderate stress and 36% little to no stress.
# Balancing Caregiving & Work

60% of caregivers were employed at some point in the past year while also caregiving. Higher-hour caregivers who are employed are more likely to report experiencing nearly all of these work impacts.

**Base: Working Caregivers of Recipient Age 18+ (n=724)**

<table>
<thead>
<tr>
<th>Hours Caregiving per Week</th>
<th>0-20 (n=527)</th>
<th>21+ (n=194)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Go in late, leave early, take time off</td>
<td>49%</td>
<td>61%*</td>
</tr>
<tr>
<td>Leave of absence</td>
<td>15%</td>
<td>14%*</td>
</tr>
<tr>
<td>Reduce work hours/take less demanding job</td>
<td>14%</td>
<td>53%</td>
</tr>
<tr>
<td>Receive warning about performance/attendance</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>Give up working entirely</td>
<td>6%</td>
<td>12%*</td>
</tr>
<tr>
<td>Turn down promotion</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Retired early</td>
<td>4%</td>
<td>11%*</td>
</tr>
<tr>
<td>Lose job benefits</td>
<td>3%</td>
<td>2%</td>
</tr>
</tbody>
</table>

• Primary caregivers are more likely to report that caregiving impacted their work, as are caregivers who felt they had “no choice” in taking on the role

• 70% of caregivers who perform medical/nursing tasks reported that caregiving impacted their job

• Employees working 30+ hours a week were more likely to report workday interruptions as a result of caregiving

• 34% of caregivers who left their job did so due to lack of flexible work hours; 29% left because they couldn’t afford paid care

Costs of Caregiving

• In 2013, the estimated value of family caregivers' unpaid care for older adults was approximately $470 billion.

• The total cost to employers due to loss productivity for caregivers in the workforce is $33.6 billion.

• Total out-of-pocket costs (2007 study) were $5,531, and $3,000 more for long distance caregivers.

• For those who leave workforce, lost wages, pension, and Social security total $325,000.

Foundation Grants in Caregiving

- Weinberg: Caregiving demos around country, especially for underserved populations
- Archstone: Funding for dissemination of caregiving reports
- Gordon and Betty Moore: Awards to Alzheimer’s caregiver programs
- RWJF: -- Atlas of Caregiving
  -- Three Scenarios for Caregiving 2031
- MetLife Foundation (Past): Caregiving in the US studies (2004 and 2009)
How Can Foundations Make a Difference?

• Data studies to support public policy: e.g., long term care
• ROI demos: e.g., corporate eldercare
• Evidence-based interventions that are scalable (not evidence-lite)
• Be wary of manipulated numbers
Major Topics for Research in Caregiving

• Care coordination/care transition support
• Training for medical/nursing tasks
• Technology
• What interventions in what doses make a difference for caregivers
• Caregiver health
Thank you!

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