



# Family Matters

## Caregiving in America

By Sarah Jane Glynn and Jane Farrell      February 5, 2014

We generally tend to think—and hope—that we are the exception to the rule. We believe that nothing bad will happen to us or our loved ones, that we will stay healthy and mobile until we pass away, quietly and many years down the road, with minimal strain or stress on our families. Unfortunately, life is rarely this simple or predictable. Instead, families across the country navigate countless and varied caregiving challenges every day.

All Americans need care at some point in their lives, and there are currently 41.6 million family caregivers across the United States, almost half of whom provide complex chronic care and perform medical tasks.<sup>1</sup> The estimated economic contribution of unpaid family caregivers, approximately two-thirds of whom are women, was \$450 billion in 2009, up \$100 billion from 2006 and a number that is likely to grow as our population ages and lives longer.<sup>2</sup> This issue brief will examine the breadth of caregiving challenges facing many different communities—from families with aging relatives, to people with disabilities, to individuals dealing with their own illnesses, and more. It will highlight the diverse needs of families and caregivers alike and explore what steps we can take—now and in the future—to find responsive solutions that work for everyone.

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### The scope of the challenge

#### Millions of Americans struggle to find affordable and dependable care

More than 12 million Americans rely on long-term care support.<sup>3</sup> Approximately 4 in 10 are under the age of 65, while the rest are older people coping with physical impairments and/or dementia.<sup>4</sup> By the time they reach retirement age, 72 percent of American workers will have experienced at least one period of disability.<sup>5</sup> Some disabling conditions are relatively short lived, while others can continue for the rest of the individual's life. Nevertheless, the majority of workers will spend at least part of their adult lives living with a disability.<sup>6</sup> Two in three adults ages 65 and older report needing help in the form of devices, people, or other accommodations to perform activities of daily living, and 21 percent rely on another person for support.<sup>7</sup> Among veterans, 21 percent report

applying for disability compensation benefits, 7.3 percent report needing the aid of another person, and 11.2 percent report requiring assistance doing household chores.<sup>8</sup> People with disabilities may also require support or assistance from a caregiver. Frailty, illness, and disability can happen to anyone; we are all likely to suffer from these ailments at some point in our lives.

The needs of those reliant on care also range widely and vary by population and community. Support or care can come in the form of self-care for people dealing with their own disabilities or serious illnesses; family-coordinated care provided to seriously ill, disabled, or aging relatives by nonprofessionals; and paid care in a facility or at home.

### *Self-care*

Disability is not simply a medical issue but also a complex interaction between bodily differences and one's surrounding environment. What constitutes a disability can change depending on individuals' situations and the time and place in which they live. Imperfect eyesight, for example, can still place severe restrictions on the lives of individuals without access to optical care, while for others it may only represent a minor inconvenience that is easily addressed. Notwithstanding the decidedly social nature of disabilities, the fact remains that nearly three-quarters of Americans will live with a disability at some point in their lives, though the length and severity of the disabling conditions can vary widely.<sup>9</sup>

There are only a few public policies to address the needs of people living with disabilities in the United States today. Social Security Disability Insurance, or SSDI, provides partial wage replacement to workers who are no longer able to work as the result of a disability, and Supplemental Security Income, or SSI, provides support to low-income individuals with disabilities. Several policies, such as the Americans with Disabilities Act and the Fair Housing Amendments Act, also prevent discrimination based on disability.<sup>10</sup> However, few policies are in place to directly address the self-care needs of employed people with disabilities, who may need time away from work to obtain medical treatment or recover from an episodic flare-up of their condition.

Title I of the Americans with Disabilities Act requires employers to offer "reasonable accommodations" to eligible workers in order to facilitate their employment, which can include modified or part-time work schedules and access to unpaid leave as necessitated by the worker's disability.<sup>11</sup> While the Americans with Disabilities Act has certainly helped many adults with disabilities maintain employment, it does not stipulate that leave must be paid. And while slightly more than half of all leave taken under the Family and Medical Leave Act is for self-care, that legislation only provides job protection, not compensation.<sup>12</sup> Workers who experience the onset of a disability have a drop in earnings, even when they stay employed, and part of this is likely due to the fact that medically necessary time off is often unpaid.<sup>13</sup>

## *Family care*

Family caregivers may need to assist loved ones around the house or shuttle them back and forth to doctor's appointments. Some families require full-time, paid professionals or direct care workers to manage the workload. Other families need this level of care, but the cost is prohibitive, so they find other—still costly—ways to manage, often taking on the caregiver role themselves on top of jobs and other responsibilities.<sup>14</sup> Regardless of their unique situation, securing care comes at a cost, and most families will make sacrifices—both financial and emotional—to provide care.

In spite of these widespread challenges but also because of their complexities, the United States has no set system for helping Americans who need care.<sup>15</sup> The bipartisan federal Commission on Long-Term Care wrote in its final report to Congress in 2013 that services and support for those who need care “are highly fragmented and difficult for individuals and family caregivers to access: they lack the focus and coordination across agencies and providers necessary to ensure the best outcomes for the person and family.”<sup>16</sup> Moreover, the report concluded that services are often “expensive and inefficient.”<sup>17</sup> For too many Americans, this means struggling daily to make sure that they or their loved ones have the care and support they need.

One in four caregivers report caring for two or more loved ones, and nearly half care for both their parents and children.<sup>18</sup> Remarkably, almost half of caregivers report performing medical tasks for a chronically ill or disabled relative, including caring for wounds and administering medication.<sup>19</sup> Caregivers across America juggle work and family responsibilities, often without any public support or assistance, spending an average of more than three hours each day providing care.<sup>20</sup>

Fulfilling these obligations is not easy. According to recent polling, one in five caregivers report a decline in their happiness, satisfaction with their social life, or health routines.<sup>21</sup> Negative repercussions also extend to their careers and professional goals. Nearly 20 percent of employed caregivers and 10 percent of unemployed caregivers report “missed professional opportunities, financial losses, and time off from work” due to caregiving responsibilities.<sup>22</sup>

Many caregiving choices depend on a combination of personal preferences, financial resources, and employer policies on family leave and workplace flexibility. Paying for care is costly, but taking unpaid leave from work is also financially taxing, especially as families are increasingly reliant upon two incomes to make ends meet. Sixty-two percent of caregivers also have full-time jobs, and three-quarters are between the ages of 35 and 64—the peak years for employment.<sup>23</sup>

Since women are now sole or co-breadwinners in two-thirds of families, they are less likely than in previous decades to have as much spare time available to help an aging or disabled relative with unpaid care.<sup>24</sup> However, as 56 percent of today's caregivers, they remain more likely than men to drop out of the workforce or reduce their hours to part time to provide care for a relative.<sup>25</sup> This exacerbates the existing 23 percent gender wage gap and can have negative repercussions on women's earnings down the road. In 2011, one in five women reported that caregiving obligations were a strain on household finances.<sup>26</sup>

Providing care to individuals suffering from Alzheimer's or other forms of dementia consumes more than 15 million informal caregivers, who provided 17.5 billion hours of unpaid care in 2012 alone. Fifteen percent were long-distance caregivers, and one-third reported symptoms of depression due to the high emotional stress of caring for a loved one with Alzheimer's or dementia. The financial value of this care is estimated to be more than \$200 billion.<sup>27</sup>

### *Paid care*

Paying for private care is a costly alternative to informal family care, and most Americans struggle to afford even the most basic professional care. A home health aide costs approximately \$21 per hour, paying for an assisted living facility averages \$3,300 per month, and a semiprivate room in a nursing home costs \$6,200 per month.<sup>28</sup> Americans spent \$45.5 billion out of pocket on long-term support services in 2011 alone.<sup>29</sup> While private long-term care insurance is available, it is often prohibitively expensive, and only 8 percent of adults over age 50 report having it.<sup>30</sup> Furthermore, purchasing long-term care insurance may not be an option for the elderly, individuals who already use long-term care services, and those who have a serious chronic condition.<sup>31</sup> One in six workers in his or her 50s is declined coverage, as is one in three in his or her 60s.<sup>32</sup> Critics of long-term care insurance also point out that policies generally have a 90-day deductible, though most policyholders will only need this type of care for less than 90 days.<sup>33</sup>

The majority of Americans do not have enough money to adequately cover the high costs associated with long-term or end-of-life care. Fewer than one-third of adults over age 50 have started saving for long-term care, one in three working Baby Boomers ages 55 to 64 has no savings for retirement, and another one-third have less than one year's salary in savings.<sup>34</sup> Many Americans who did save adequately saw their retirement nest eggs severely hit during the Great Recession.<sup>35</sup> Combined with the overall low savings rates across the United States, it is incredibly challenging for most families to take unpaid leave from work to care for their relatives or pay for professional care.

There is also confusion about which costs Medicare covers.<sup>36</sup> Many Americans mistakenly believe that Medicare or another form of insurance will cover the long-term care costs when a serious illness or disability strikes.<sup>37</sup> While Medicare will cover the cost of treating a patient's immediate, or "acute," care needs, Medicare does not cover the majority of long-term care services that patients require, such as help with daily activities and supervision.

Medicare will partially cover the cost of home visits or short-term stays in a skilled nursing facility or hospice but only in limited circumstances where patients first meet a number of conditions, such as a need for therapy to regain function and a prior hospital stay.<sup>38</sup>

Because the vast majority of Americans do not have private long-term care insurance or the necessary savings to pay for long-term care out of pocket after using up these “post acute” Medicare benefits, patients are forced to spend down their own savings until they eventually qualify for Medicaid.<sup>39</sup> Medicaid pays nearly \$130 billion annually for long-term care, accounting for approximately two-thirds of all Medicaid spending.<sup>40</sup> Furthermore, federal law requires states to recover the amount of money spent by Medicaid on long-term care services after the patient dies. This generally includes patients’ homes and other assets, though the estate recovery is delayed if their spouses are still alive.<sup>41</sup>

The most costly Medicare beneficiaries are those who require long-term care because they have both functional limitations—such as limited independent mobility—and the need for medical care. They make up approximately 15 percent of Medicare beneficiaries but account for one-third of total Medicare spending.<sup>42</sup> Across the board, Medicare beneficiaries who have physical limitations are at least twice as costly as their counterparts with the same number of chronic conditions but no functional restrictions. Consequently, cost control and the reduction of financial incentives for costly hospital or nursing home stays must be a top priority for any solution to the long-term care crisis, and we need to better recognize and compensate the valuable work of at-home caregivers.

## Direct care workers also face hardships

Two of the top four occupations with the most projected growth in the coming decade are home health aides and personal care aides, largely because of the challenges outlined above.<sup>43</sup> Of the 40 million seniors in America, only 1.5 million—less than 4 percent—currently reside in nursing homes.<sup>44</sup> This leaves approximately 5.5 million seniors who live in independent homes or assisted living facilities, where they are more likely to rely on direct care workers.

Eighty-seven percent of home health aides and personal care aides were women and half were women of color in 2010.<sup>45</sup> The median wage for these jobs is \$20,000 per year, and many do not offer important benefits.<sup>46</sup> Less than half of home health aides and personal aides have employer-provided health insurance, and even fewer have access to paid sick leave.<sup>47</sup> Women who work in these jobs frequently rely on public benefits such as food stamps, public housing, or energy assistance to make ends meet, even though they are employed full time.<sup>48</sup> While providing important care to other people's families, they are often forced to choose between missing a day's pay or caring for their own loved ones.

Home health and personal care aides are not currently receiving the compensation they deserve, but they provide vital services for elderly and

disabled Americans. Millions of Americans currently rely on home health and personal care aides, and that number is only going to grow.<sup>49</sup> Moreover, the home care industry is thriving, bringing in more than \$84 billion in revenue in 2009 alone.<sup>50</sup> Fairly compensating workers will not hurt this highly profitable and growing industry.

Since home health and personal care aide positions do not provide decent wages or benefits, they suffer from turnover rates of 40 percent to 60 percent, which is hard on both employers and the families who receive their care.<sup>51</sup> High turnover rates take a toll on employers' bottom lines because the costs of replacing and training an employee are very high. Replacing an employee making \$30,000 or less per year can cost an employer as much as 16 percent of the employee's annual salary.<sup>52</sup> Turnover may also affect the quality of care patrons receive. Having a workforce always in flux likely limits consumer access to highly experienced home care providers and the benefits that come from continuity of care.

The services professional caregivers provide are vital to our society, and we must offer wages and benefits that make these jobs sustainable. Until we recognize and reward the work of these professionals we are unlikely to make headway in solving our caregiving crisis.

Our caregiving challenges are growing, but our policies remain woefully out of date.

The number of Americans who rely on long-term care services will more than double in the coming decades, from 12 million people in 2010 to 27 million people by 2050, due largely to aging Baby Boomers.<sup>53</sup> More startlingly, the ratio of potential caregivers—adults ages 45 to 64—to people ages 80 and older will decline from 7-to-1 to 3-to-1 in just three decades.<sup>54</sup> By 2030, seniors will make up nearly 20 percent of the population, up from 12 percent in 2000.<sup>55</sup> This means that a larger share of working adults—nearly half of whom also have children or partners relying on their care and income—will need to help their aging parents.<sup>56</sup> Elder care can already be especially complex, as the longer Americans live, the more likely they are to develop multiple chronic conditions and disabilities.<sup>57</sup>

As life expectancies steadily increase, the stress on families and elder care support systems will continue to grow.<sup>58</sup> Aging Americans are increasingly likely to have cognitive impairments such as Alzheimer's. More than 5 million Americans are currently living with Alzheimer's, and one in three seniors will eventually experience some form of dementia.<sup>59</sup> Alzheimer's alone cost the United States \$203 billion last year—Medicare and Medicaid paid three-quarters of those costs—but it is estimated this figure will increase fivefold to \$1.2 trillion by 2050.<sup>60</sup>

Advances in medical technology and policies such as the Americans with Disabilities Act have enabled millions of adults with disabilities to remain in the labor force. But recent trends in employment show we need to do more to support those who want to contribute to economic growth. Although 70 percent of those who are employed report little to no difficulty completing their current work duties,<sup>61</sup> the employment rate for people with disabilities has declined since the 1980s.<sup>62</sup> Only 18.2 percent of people with disabilities are employed, and 12.8 percent are looking for work.<sup>63</sup> Americans who want to work should have the opportunity to do so, but we lack policies to help working adults with disabilities manage self-care and paid employment.

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## Rethinking caregiving

In its 2013 report to Congress, the Commission on Long-Term Care—a bipartisan group of 15 leading experts on health, aging, and care—outlined many of the challenges we are facing. While they failed to come to a consensus on how to best address long-term care issues, a number of existing proposals serve as a good starting point. Building a streamlined long-term care system that is patient and family centered but also efficient will require better coordination of care across services. We also need to help ensure that Americans are financially prepared to shoulder the costs of long-term care so that they are not forced into debt or bankruptcy. Lastly, we must acknowledge that family members will continue to play an important role as unpaid caregivers in our communities and empower them with paid family leave and workplace flexibility so they will never have to choose between their jobs and their families.

## The Affordable Care Act

The Affordable Care Act, or ACA, originally included voluntary public long-term care insurance called the Community Living Assistance Services and Supports, or CLASS, Act.<sup>64</sup> This section of the ACA would have provided a government alternative to private long-term care insurance plans, allowing more elderly Americans to receive financial assistance for long-term care. Unlike Medicare, however, enrollment in the CLASS program was voluntary, making it difficult for the program to be financially sustainable, since younger, healthy people would be less likely to sign up. Due to these financing concerns, the Obama administration suspended and Congress later formally repealed the CLASS Act, leaving Americans without a public long-term insurance option. Policymakers must work to develop a financially sustainable long-term care model to meet future needs.

While the financing structure of CLASS was not viable, other sections of the ACA can improve the coordination of care for patients needing long-term care services. For instance, the ACA increased funding for programs testing innovative new health care models, such as Accountable Care Organizations, or ACOs, and Patient-Centered Medical Homes.<sup>65</sup> These models of care delivery promote more coordinated, streamlined care by increasing the quality of care and lowering excess costs, and they are particularly helpful for patients with multiple conditions who see numerous health care providers. Under the ACA, it would be possible to include a patient's long-term care as part of the coordinated care arrangement.<sup>66</sup> Additionally, ACOs and medical homes often assign a care manager to oversee and coordinate a patient's care and provide information to families.<sup>67</sup>

The ACA also increased funding to community-based programs that work to help people better understand the long-term care services available to them, such as the Aging and Disability Resource Center, or ARDC, Program, which was set up in collaboration with the Administration for Community Living, the Centers for Medicare & Medicaid Services, and the Veterans Health Administration.<sup>68</sup> The ADRC Program works to streamline access to long-term services and support options for older adults and individuals with disabilities.<sup>69</sup>

In addition to incentivizing better care and streamlining services, the ACA also helps Americans with disabilities by ensuring that they cannot be denied coverage due to a preexisting condition and removing lifetime dollar limits on health benefits. It also launched the Balancing Incentive Program, which provides states with funding to help disabled people receive services at home and in their communities instead of institutional care or nursing homes.<sup>70</sup> This will result in additional cost savings and more options for patients who do not want to be institutionalized.

### Provide workers with paid family leave through the FAMILY Act

The Family and Medical Insurance Leave, or FAMILY, Act of 2013 (S. 1810, H.R. 3712) is a proposal for paid family and medical leave that was introduced by Sen. Kirsten Gillibrand (D-NY) and Rep. Rosa DeLauro (D-CT). The legislation would guarantee up to 12 weeks of paid leave each year for workers for the birth or adoption of a new child, the serious illness of an immediate family member, or the worker's own medical condition. The FAMILY Act would also provide partial wage replacement for working caregivers or individuals taking time off due to their own disabling conditions.<sup>71</sup>

There are currently only five states—California, New Jersey, Rhode Island, New York, and Hawaii—with temporary disability insurance programs that give access to wage replacement if an individual is physically unable to work for a few weeks or months.<sup>72</sup> The FAMILY Act would expand that benefit to workers in the other 45 states.

The FAMILY Act would also offer wage replacement to family members providing care, allowing more aging Americans to stay in their homes and resulting in cost savings for taxpayers and families alike.<sup>73</sup> The FAMILY Act would provide family caregivers with the sorely needed economic and legal support to take time off to care for ill and aging loved ones when no other option is available and encourage men and women to divide this work more equitably, since neither would risk losing necessary income.

### Increased access to workplace flexibility

Not all workers need to take weeks of time off in order to coordinate self- or family care, while the 12 weeks provided by the FAMILY Act may not be sufficient in some scenarios involving a chronic condition. While there will certainly be cases where self- or family care simply cannot be integrated successfully with paid employment, access to workplace flexibility would be enough in other instances to ensure that workers did not have to choose between their care responsibilities and their jobs. In 2009, nearly 7 in 10 caregivers reported making work accommodations to meet their responsibilities, such as leaving work early or starting late, cutting back hours, or leaving their jobs because of caregiving obligations.<sup>74</sup> Providing workers with optimal access to workplace flexibility will promote full-time employment and increase families' economic security.

Workplace flexibility allows workers to alter the schedule and/or location of their work. Currently, 44.2 percent of workers do not have access to any form of workplace flexibility, and higher-income workers are more likely to have access to the benefit than those with lower salaries.<sup>75</sup> This means that those who are the least likely to be able to afford paid care and the most likely to provide family care themselves also have the least access to workplace flexibility.

One way to provide greater access to flexibility is implementing “right to request” policies, following the lead of the United Kingdom, New Zealand, and Australia.<sup>76</sup> These policies do not mandate that employers provide flexibility, but they do require employers to set up a process to discuss and negotiate workplace flexibility and only allow the employer to turn down the requests for certain business reasons. An alternative, stronger model can be found in the Australian state of New South Wales, where employees are protected against discrimination based on care responsibilities and employers are required to affirmatively provide reasonable, flexible work schedules unless doing so would cause the employer undue hardship.<sup>77</sup>

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## Conclusion

Despite the best efforts of some policymakers and health care innovators, it is unlikely that we will see a drop in the need for informal and unpaid caregivers anytime soon. Consequently, it is especially important for workers to have access to benefits such as workplace flexibility and paid family leave should they need to take time to care for themselves or a loved one. Supporting caregivers with these policies will go a long way toward recognizing our invaluable informal care community and increasing cost savings for taxpayers by reducing costly hospital and nursing home stays.

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