

# Long-term care: Support for family caregivers

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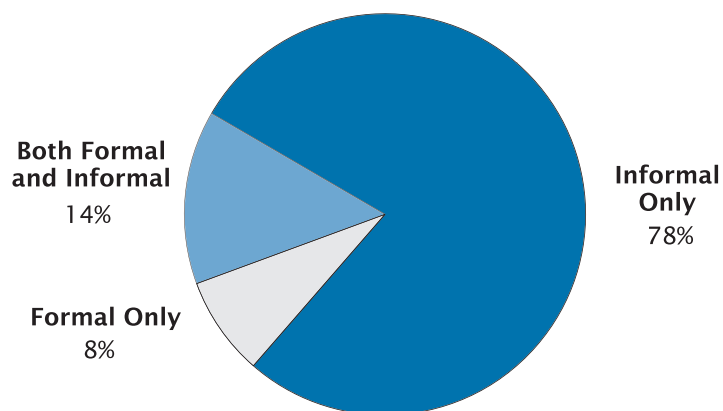
Family members are the predominant providers of long-term care—that is, personal assistance with essential, everyday activities—for people with disabilities. Family and other informal caregivers perform a range of tasks and invest varied amounts of time. But many caregivers assist people with severe disabilities for a major portion of time each week, often over a period of years. Although caregivers and care recipients value their relationships, caregiving often comes at significant cost—in health, resources, and opportunities foregone. By reducing this cost—through assistance and financial support—public policy can strengthen the ability of family caregivers to provide care.

## The role of family caregivers

Long-term care consists of the assistance and services provided to people who, because of disabling illnesses or conditions, are limited in their ability to perform basic activities such as bathing and preparing meals. These activities are often referred to as activities of daily living (ADLs)—fundamental routine tasks such as bathing, dressing, getting in and out of bed or chairs, using the toilet, and eating—and instrumental activities of daily living (IADLs)—additional activities necessary for independence such as shopping for groceries and necessities, preparing meals, managing medications, getting to places outside of walking distance, and doing light housework.

Over three-quarters—78 percent—of adults receiving long-term care at home rely exclusively on assistance from family members, friends, and volunteers, referred to as informal care (see Figure 1). The other 22 percent receive assistance

Figure 1  
Distribution of Adults Receiving Long-Term Care at Home, by Type of Care (1994–1995)



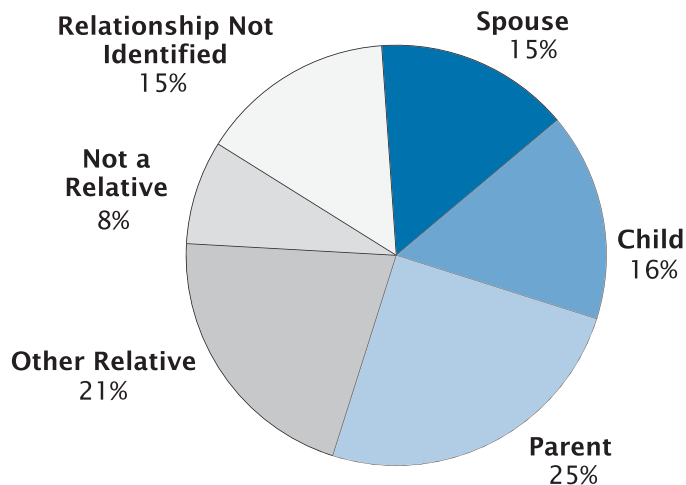
Note: Based on people age 18 or over who, because of disability or health condition, receive help from another person with activities of daily living or instrumental activities of daily living.  
SOURCE: Health Policy Institute, Georgetown University, analysis of data from the 1994 and 1995 National Health Interview Surveys on Disability, Phase II.

from paid providers such as personal assistants and home care aides; 14 percent use this formal care in conjunction with informal care and 8 percent depend on formal care alone. Even among adults in the community with substantial disabilities—limitations in three or more ADLs—two-thirds rely exclusively on informal care.<sup>1</sup> Family caregivers also provide hands-on assistance, such as help with bathing and eating, to persons in nursing homes and other residential settings.<sup>2</sup> In addition, caregivers may also help their family member or friend learn about his or her medical and long-term care needs and arrange for appropriate services.

### *Who are the family caregivers?*

Based on an analysis of the U.S. Census Bureau's Survey of Income and Program Participation (SIPP) by Alecxih and colleagues, about 9.4 million individuals were providing assistance to a relative or friend with a disability or chronic health problem in 1998.<sup>3</sup> The majority of informal caregivers are relatives of those with care needs (see Figure 2). Spouses and children represent similar proportions, and together account for almost one-third of caregivers. One-quarter of caregivers are parents, and about one-fifth are other relatives, including children-in-law. About 8 percent of caregivers reported that they are not related to the care recipient, and another 15 percent did not specify their relationship to the recipient.

Figure 2  
Informal Caregivers, by  
Relationship to Care Recipient (1998)



NOTE: Based on people age 15 or older who provide regular assistance to a relative or friend with a disability or chronic condition.  
SOURCE: L. Alecxih, S. Zeruld, and B. Olearczyk, *Characteristics of Caregivers Based on the Survey of Income and Program Participation*, National Family Caregiver Support Program: Selected Issue Briefs (Washington, DC: Administration on Aging, 2002).

Most people who need long-term care rely primarily on one or two key individuals.<sup>4</sup> About 70 percent of caregivers identify themselves as the primary caregiver.<sup>5</sup> Other family members, friends, neighbors, and volunteers may also help. According to Alecxi and colleagues, 44 percent of caregivers reside in the same household as the care recipient and over half—54 percent—do not.<sup>6</sup> The other two percent of caregivers provide assistance to more than one individual—at least one who lives with them and at least one who lives elsewhere.

Compared with the general adult population age 18 or older, informal caregivers are more likely to be between 45 and 64 years old and female (see Table 1). Some 43 percent of caregivers are age 45 to 64, compared with 29 percent of all adults. And about two-thirds of caregivers are women, compared with about half of the adult population.

It is common for caregivers to be working or have child care responsibilities. Slightly over half (51 percent) of caregivers are employed outside of the home. About one in three caregivers has children under age 18 at home, and nearly one in five is both employed and has children at home.<sup>7</sup> In 1998, over one-quarter—27 percent—of caregivers had a family income of less than \$20,000, and about one-third—32 percent—had a family income of \$50,000 or more.<sup>8</sup>

### *How much help do caregivers provide?*

According to an analysis by Donelan and colleagues of data from a 1998 national survey, Long-Term Care from the Caregiver's Perspective, family caregivers devote a substantial amount of time to helping a relative or friend.<sup>9</sup> About one-

Table 1  
**Characteristics of Informal Caregivers (1998)**

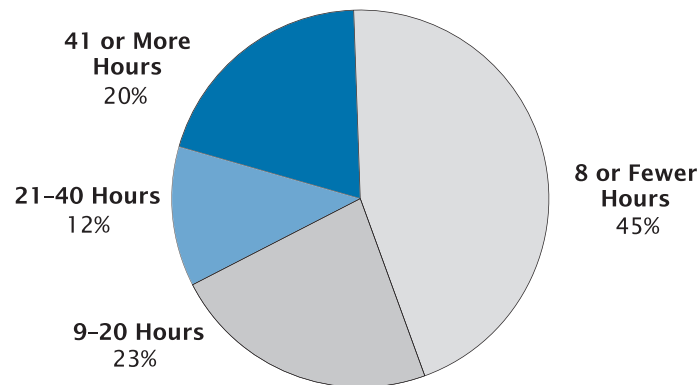
<b>Characteristic</b>	<b>Informal Caregivers (in percent)</b>	<b>All Adults (in percent)</b>
<b>Total</b>	100	100
<b>Age</b>		
Under 45	37	54
45-64	43	29
65 or over	20	17
<b>Gender</b>		
Male	35	48
Female	65	52
<b>Race<sup>a</sup></b>		
White	83	77
Black	12	11
Other	3	12
<b>Marital Status</b>		
Married	62	60
Not married	38	40
<b>Employment Status</b>		
Employed	51	64
Not employed	49	36

NOTE: Data for informal caregivers are based on people age 15 or older who provide regular assistance to a relative or friend with a disability or chronic health problem. Data for all adults are based on the non-institutionalized population age 18 or older.

a. Race was not reported for 2 percent of informal caregivers.

SOURCES: Data on informal caregivers are from L. Alecxi, S. Zeruld, and B. Olearczyk, *Characteristics of Caregivers Based on the Survey of Income and Program Participation*, National Family Caregiver Support Program Development: Selected Issue Briefs (Washington, DC: Administration on Aging, 2002). Data for all adults are from U.S. Census Bureau, *Statistical Abstract of the United States: 1999*, 119th ed. (Washington, DC: U.S. Census Bureau, 1999).

Figure 3  
Distribution of Informal Caregivers, by Hours of Care Provided per Week (1998)



NOTE: Based on people who provide unpaid help or arrange help for a relative or friend who is unable to do some things for herself or himself because of disability, illness, or aging.  
SOURCE: K. Donelan et al., "Challenged to Care: Informal Caregivers in a Changing Health System," *Health Affairs* 21, no. 4 (2002): 222-231.

third of caregivers report providing 21 or more hours of help per week (see Figure 3). In addition, many caregivers provide assistance for long periods of time—over 40 percent have been providing help for at least five years, and about one-fifth have been doing so for 10 or more years.<sup>10</sup>

### Challenges of family caregiving

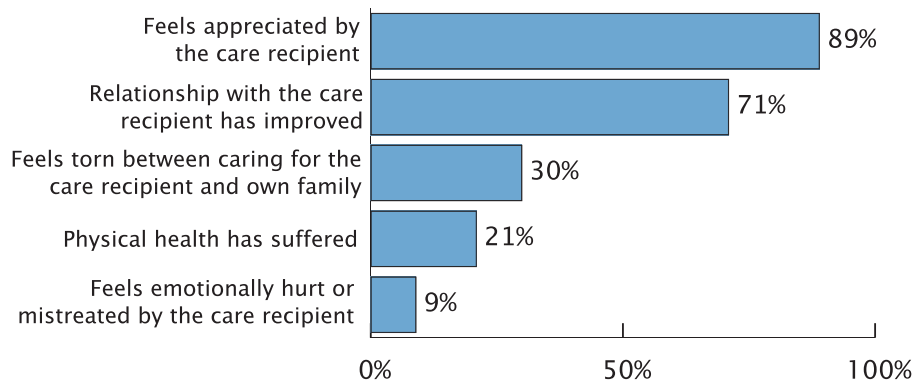
Donelan and colleagues' findings indicate that an overwhelming majority—89 percent—of informal caregivers feel appreciated by their relative or friend and 71 percent report that their relationship with the care recipient has improved (see Figure 4). Nevertheless, the costs of family caregiving can be considerable. About one in five caregivers report that their physical health has suffered as a result of caregiving.

Symptoms of depression and mental health problems are much more common among caregivers than among non-caregivers.<sup>11</sup> Proportions of caregivers reporting depressive disorders or symptoms range among studies from 30 percent to 59 percent. The physical and mental stress associated with caregiving can lead to increased use of health care services.<sup>12</sup>

Although most caregivers do not report high out-of-pocket costs, about 14 percent report that caregiving causes financial problems for their family.<sup>13</sup> Caregivers who live with the care recipient are much more likely to report experiencing financial problems than caregivers who do not—24 percent and 10 percent, respectively.

Family caregiving often affects employment and earnings. Some caregivers reduce their hours and others withdraw completely from the labor force.<sup>14</sup> In a 1996 national survey of caregivers of a friend or relative age

Figure 4  
**Rewards and Challenges Experienced  
 by Informal Caregivers (1998)**



NOTE: Percentages are the proportion of informal caregivers who strongly agree or somewhat agree with each statement.

SOURCE: K. Donelan et al., "Challenged to Care: Informal Caregivers in a Changing Health System," *Health Affairs* 21, no. 4 (2002): 222-231.

50 or older, about two-thirds of caregivers were working.<sup>15</sup> Although few caregivers in this survey reported giving up work entirely, about half of caregivers who had ever worked while providing care to the care recipient reported making changes to their daily work schedule. The long-term consequences of these actions, such as lost wages and benefits, can be substantial. One study estimated that women who reduced their hours to provide care to a parent or parent-in-law gave up an average of \$7,800 in pre-tax wages in 1994 (which was about 20 percent of median family income among these women).<sup>16</sup>

Other effects of caregiving include less time spent with other family members and friends. Recreational activities, such as hobbies and vacations, may also be limited. More than half—55 percent—of those caring for someone age 50 or older reported that they have less time for other family members or have given up their own leisure activities.<sup>17</sup> Family conflict or disagreement over caregiving obligations and other family responsibilities is another challenge that may arise.<sup>18</sup>

## Strengthening family caregiving

Many caregivers go without supportive services that could help mitigate the challenges of providing care. Some may not know where to turn for help. And even if they do, the services available to them may be limited both in amount and scope. Caregivers' needs vary, and may also change as their responsibilities change over time.

A variety of services can help support family and other informal caregivers. Supportive services that are designed to support caregivers include information and assistance services, technology, education and

training, support groups and counseling, respite care, and financial support. Formal home care and other paid services for people with disabilities can also help support the role of family caregivers by complementing informal care and reducing the demands on caregivers.

### ***Information and assistance services***

Information and assistance services can provide caregivers with many of the tools necessary to provide the appropriate level of care safely. Information about the condition or disability affecting the care recipient is important for caregivers to be able to understand the needs of their relative or friend. Additionally, information on the availability of paid care is important. Providing information may not be enough, however; caregivers often need help obtaining services for the care recipient.<sup>19</sup> Assistance or referral services help link caregivers, particularly long-distance caregivers, to paid services in the location where their family member or friend resides. They may also help caregivers locate services that will help them better cope with their caregiving responsibilities.

### ***Technology***

Technology, such as assistive devices and home modifications, has the potential to enhance the quality of life for individuals with long-term care needs and their caregivers.<sup>20</sup> Common assistive devices include mobility aids such as canes, walkers, and wheelchairs. Home modifications typically include grab bars and shower seats. Additional home modifications, such as widened doorways and ramps, may be necessary to accommodate assistive devices. The internet is another form of technology that has become an important resource for many caregivers. Caregivers may use the internet to obtain information, keep in touch with the care recipient (especially if they do not live nearby), and communicate with service providers and other family caregivers.<sup>21</sup>

### ***Education and training***

Many caregivers need training on how to assist with ADLs, including bathing, feeding, or moving a care recipient from a bed to a chair. Without proper training, the caregiver may be strained—both physically and mentally—and the care recipient may be at risk.<sup>22</sup> Additionally, many caregivers do not receive adequate formal training regarding the use of medical equipment, changing bandages, and administering medications. This may contribute to the finding that one in eight caregivers who helps with medications is aware of having made a mistake in the administration of medication.<sup>23</sup> Better training would not only reduce the stress experienced by caregivers, but would also help ensure that appropriate care is being provided safely.



### ***Support groups and counseling***

Support groups and counseling can also help strengthen family caregiving. Support groups and counseling help relieve some of the anxiety experienced by caregivers, as well as improve their psychological well-being.<sup>24</sup> Support groups also allow caregivers to share information about resources and coping strategies, and may reduce feelings of isolation.

### ***Respite care***

Respite care – temporary, short-term services provided to care recipients that enable caregivers to take a break – is another supportive service. Respite care may be provided inside or outside of the home, either during the day or overnight. It is the most common service provided by states to family caregivers.<sup>25</sup> The benefits of respite care for caregivers include improved psychological well-being and reduced stress levels.<sup>26</sup>

### ***Financial support***

Financial support can also strengthen caregiving. One approach is to provide a stipend or allowance to caregivers, which can help them defray the costs of caregiving.<sup>27</sup> A second approach is to provide caregivers with vouchers or direct payments specifically for the purchase of respite care. For example, a state-funded caregiver support program in California provides caregivers with a broad range of respite options including in-home respite, adult day services, and overnight respite. Caregivers who choose in-home respite care are given a voucher with which they can either purchase care from an agency or pay a friend or family member to provide care.<sup>28</sup>

Another means of financial support is to pay family members who are providing care. For example, under the federal Medicaid law, states have the option to pay family members—excluding those who are legally responsible for the care of the individual such as spouses and parents of minor children—who are providing personal care. In addition to paying some family members, friends and neighbors can also be paid.<sup>29</sup> Programs that pay family members to provide home care may improve the quality of life for both the caregiver and care recipient.<sup>30</sup>

A similar approach, which falls under the concept of consumer-directed care, is to provide the care recipient with the funds to pay a family member or friend who is providing assistance. For example, the Cash and Counseling Demonstration, which has been implemented in three states, provides a cash allowance to recipients of Medicaid personal care services or home and community-based services.<sup>31</sup> Recipients can use the cash allowance to purchase their own care, including paying family members for the care they provide. Care recipients may also use the

cash allowance to modify their home or vehicle, or to purchase assistive equipment.

### ***Comprehensive support initiatives***

All of the supportive services discussed above are encompassed in a new effort by the Administration on Aging to help family caregivers. The National Family Caregiver Support Program is a federally-funded program. In its first year (fiscal year 2001) it was funded at \$125 million; funding was increased to \$141.5 million for fiscal year 2002 and to \$155.2 million for fiscal year 2003.<sup>32</sup> States are allocated money, based on their share of the population age 70 or older, to provide five basic services to caregivers. These services are: information about available services; assistance in gaining access to supportive services; individual counseling, organization of support groups, and training to help them make decisions and solve problems related to their caregiving roles; respite care to enable them to be temporarily relieved from providing care; and supplemental services, including assistive devices and home modifications, on a limited basis, to complement the care they provide.<sup>33</sup>

### ***Formal care for people with disabilities***

Home care or other formal services for people with long-term care needs can also help support family caregivers. Supplementing family caregiving with formal services can help alleviate the demands on family caregivers, thereby reducing their stress and enabling them to meet their caregiving and other responsibilities. In addition, family caregivers may not have the skills or ability to meet all care requirements. In these cases, formal care may be needed to complement the family or other informal care being provided.

## **Conclusion**

The importance of family caregiving to people receiving long-term care cannot be underestimated. People are concerned about family members and friends with care needs and value being able to help them. However, experience with caregiving indicates that in addition to the time commitment, it comes at a significant cost. Caregivers may experience declining health or financial difficulties and may need to make difficult tradeoffs in terms of employment and other family needs. Although family caregiving involves personal relationships, costs to caregivers and inadequate care are policy problems. Policies that strengthen and support family and other caregivers are an appropriate response.



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## About the Project

The *Georgetown University Long-Term Care Financing Project* pursues analysis designed to stimulate public policy discussion about current long-term care financing and ways to improve it. The project is supported by a grant from the Robert Wood Johnson Foundation. Additional publications are available at <http://ltc.georgetown.edu>.



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