CAREGIVING in context

A study of family, friend, and community caregivers' networks of support

The age wave is beginning. More than 78 million baby boomers in America are poised to enter retirement age. Even in this healthiest of older generations, most older adults will rely on substantial help with everyday life in their later years. One of the most important challenges of our time for families, communities, and government leaders is how to best prepare for and provide that help.

Family and friend caregivers form an irreplaceable system of support for older adults. Their role grows even more critical in an era when formal, paid caregiving systems will be overwhelmed by sheer numbers. Yet informal caregiving is not a resource to be taken for granted. The demands on caregivers' energy, time, and expertise can be overwhelming, and family and friend caregiving systems are subject to the same demographic trends placing strain on public resources (fewer younger adults per older adult). The *Caregiving in Context* survey builds on prior research by deepening our understanding of the informal support available to caregivers and its impact on their challenges and needs.

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Who we talked to

This report outlines key challenges and sources of support for family, friend, and community caregivers in seven neighborhoods in St. Paul, Minnesota. We interviewed:

- **141 primary caregivers**, defined as the person mainly responsible for an older adult's care.
- **71 secondary caregivers,** who assist older adults but do not have primary responsibility.

DEMOGRAPHICS

In line with other, larger studies of older adults' caregivers, women (especially daughters) made up the majority of caregivers in our survey. However, caregivers are everywhere in our communities. We spoke with women and men of diverse age, education level, and family status. In addition:

- One in four caregivers (25%) are persons of color
- More than a quarter (28%) have household incomes at or below 200 percent of the federal poverty line (considered low income)
- Caregivers interviewed included spouses, children, friends, and neighbors

SENSE OF COMMUNITY

Caregivers express a strong sense of neighborhood cohesion, with a large majority saying their neighborhood feels like home, that people in their neighborhood are willing to help each other out, and that they generally trust their neighbors to look out for them. The majority of these caregivers are long-term community residents who live in single-family homes.

THE CAREGIVING ROLE

At about 37 hours per week on average, caregiving is nearly equivalent to a full-time job for the primary caregivers in this survey (by contrast, secondary caregivers spend about 9 hours per week on average). Among all caregivers, most (86%) had already spent at least a year providing care at the time of the survey. Four in ten caregivers interviewed share their home with the older adult in their care.

Companionship, help with shopping or errands, and transportation are the most common ways that primary and secondary caregivers assist older adults, though a multitude of tasks were described throughout the interview, illustrating the important role caregivers play in enabling older adults to remain in their current living arrangements.

THE LANDSCAPE

Approximately 43.5 million Americans provide part-time or full-time care for another adult age 50 or over. (National Alliance for Caregiving, 2009)

Conservative estimates peg the nationwide economic value of unpaid, informal care provided by family and friends at $306 billion per year. (University of Minnesota Extension, 2011)

The demand for informal caregivers is expected to increase by more than 20% in the next 15 years--and by 85% in the next 40 years. (U.S. Department of Health and Human Services, 2010)

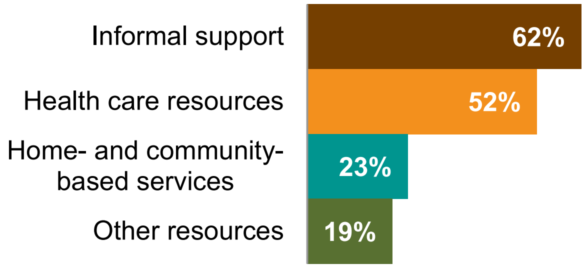
> *"I help keep him in contact with other family members.*
>
> *I help her with understanding the health care system and how to use it like when to call a doctor, medication issues.*
>
> *I translate for him; he does not speak English."*

Our approach

This summary looks specifically at primary caregivers providing home-based care, who bear more responsibility for the older adult in their care and spend more time in their caregiving role.

Given the wealth of information available about the burden, barriers, and challenges faced by caregivers, this research focuses on the support surrounding caregivers. We divided this support into two categories: informal support from family, friends, neighbors and faith communities, and formal support from home- and community-based services, health care providers, and employers.

What is the most important resource you have in place that supports you in your role as a caregiver?



We group respondents in several ways in order to understand caregivers' experiences from different perspectives. Specifically, we explore:

- The strength of their combined sources of informal support, referred to as a "network"
- Who assists them in their role as a caregiver
- Their relationship to the older adult in their care

Comparisons between groups are highlighted, especially concerning variations in signs of distress, allowing us to identify areas where strengthening support may be especially beneficial to caregivers.

WHAT WE LEARNED

First, informal support is very important to caregivers. In fact, 62 percent said it was the most important support they had in place, ahead of doctors, paid services, and other resources. Second, despite a wide range of information and services provided by state and county agencies and community-based organizations, **barriers to accessing formal systems remain**. These themes suggest that the most essential support for caregivers does and will continue to come from informal sources. **The most important role for formal supports may be to simplify their interactions with caregivers** to reduce stress, burden, and time spent accessing and navigating formal supports.

> *"Having reliable people, so that if I can't do something they back me up.*
>
> *Meals on Wheels, and the homecare nurse every couple of days. These helped me help him.*
>
> *It's a combination of things. We have a good doctor and get good outside help from our grandson, the things we can't do outside.*
>
> *My family—three brothers in the cities, also my daughter and two sons. They are the most important because my dad knows them and it's so much easier on him than going to an outside source."*

Informal support networks

The informal support of the people around them, supplemented with formal services, is the foundation that primary caregivers stand on when facing the challenges and distress of their role.

There is no standard metric for measuring informal support; therefore the survey asked a wide range of questions about who helps caregivers, and what kind of help they provide. To understand the collective impact of informal support, Wilder Research created a rough scoring system of the following items:

KEY FINDING

Strengthening informal support networks may reduce the hours per week caregivers spend on assisting older adults with daily tasks, improve caregivers' perceptions of their own health, and lessen the overall stress associated with caregiving.

HELP WITH CAREGIVING TASKS

- Whether someone could take over for the long term if the caregiver were unavailable
- Number of family members currently providing assistance to the caregiver
- Number of non-family members currently providing assistance
- Number of tasks the caregiver received help with in the past month

REACHING OUT FOR SUPPORT

- Number of people the caregiver reached out to for help, who then began to help
- Number of community activities the caregiver has used to support their caregiver role
- Number of different information sources the caregiver used to learn about their own role or to find resources for their care recipient

EMOTIONAL SUPPORT

- Whether the caregiver has weekly face-to-face, phone, or email contact with a close friend or family member about their caregiving role

Caregivers' informal support networks

🟨 Lower score (0 to 4) indicates the caregiver has less informal support overall.

🟦 Moderate score (5 to 7) indicates the caregiver has a range of informal supports in place

🟫 Higher score (8 to 14) indicates the caregiver is well supported and has a large network of informal resources

We discovered about a third (31%) of caregivers scored low, meaning they have less informal support overall. By contrast, a quarter (25%) had high scores, indicating a stronger network of informal support. We found caregivers' informal networks scores were related to several signs of distress.

For example, compared to those with higher scores, caregivers with lower scores:

- Felt the caregiving role fell solely to them
- More frequently described their caregiving role as "very stressful"
- Reported their health as "fair" or "poor"

Higher scores were associated with fewer hours spent per week on caregiving responsibilities, less frequently sharing a home with the older adult in need of care, and working full-time.

Who helps the caregiver?

Prior research has shown a key measure of informal support is whether caregivers have others to support them in their role as a caregiver. At first glance, we noted:

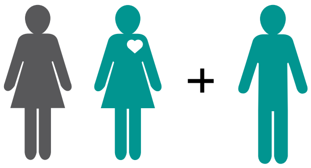
- Nearly one in six caregivers received no help from friends or family members
- 45 percent of caregivers relied on the help of one other person, most commonly a sibling or other relative

Looking closer at the rich information in the *Caregiving in Context* survey about who is helping caregivers and how they are acquainted, Wilder identified four main categories of informal support based on who helps the caregiver, shown in the figure below.

KEY FINDING

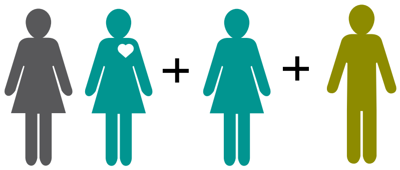
Our study shows caregivers are less stressed and better supported when assisted by both family members and others outside the family. However, the majority of caregivers (61%) have no one to rely on, or one other person who helps them.

Family-based assistance (N=66)



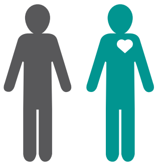
This is the most common situation: Just over half (56%) of primary caregivers have a relative who helps with care or, less commonly, two or more relatives who help.

Extended support (N=29)



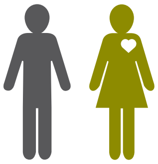
A quarter (25%) of caregivers have a combination of family members and non-relatives, such as friends or neighbors, who help.

Solitary caregivers (N=18)



15 percent of primary caregivers report no one helps them with caregiving.

A friend or neighbor (N=4)



This small but distinct group of older adults receives help from people not related to them or their care recipient.

Comparing these groups of caregivers revealed several subtle, but important, distinctions:

- Family-assisted caregivers more often reported their health as “fair” or “poor”—a sign of distress— compared to caregivers with extended support.
- Solitary caregivers, usually the spouse or son of the older adult, spend the most hours per week providing care and help with a high number of daily tasks. They also reported higher stress related to caregiving and poorer physical health.
- The handful of caregivers in this study who received support only from outside their family had a mix of experiences; two seemed well-supported with few signs of distress, and two resembled solitary caregivers in their weaker informal support and stronger signs of distress.

Caregivers’ relationships

Another way to understand caregivers’ roles and need for support is to look at their relationship to the older adult in their care. This relationship can have a deep influence on almost every aspect of caregiving, including the reasons, rewards, and burdens as well as how other people view the caregiving relationship.

Adult children caring for a parent make up the largest group of primary caregivers in this study, followed by spouses/partners, other relatives, friends, and neighbors.

KEY FINDINGS

Caregivers’ experiences differ, as do their support needs. For example, spouses experience the most distress and may be less likely to reach out for help. Sons lack informal support, and despite strong informal support networks, daughters are pressed for time and balance.

THEIR STORIES...

SPOUSE

Maria is 73, retired, and cares for her husband at home. Her role as a caregiver was expected and welcomed as his wife of 25 years. She spends over 40 hours per week helping him with most daily tasks and has done so for about 2 years now. Maria says she gets breaks from caregiving and help with some specific tasks, thanks to the help of her daughter who lives nearby. Maria doesn’t use formal services, even though she admits she could use some help with housekeeping and heavy chores. She’s in good health but she worries about something happening to her and how that would affect her husband’s care, “no one is available to care for him the way I would.”

“I think he feels like he is a burden, and he doesn't like to ask, but it is my responsibility-for better or for worse.”

DAUGHTER

Melissa, 50, balances many roles—wife, mother of a 17-year-old son, sister, full-time employee, volunteer (when she has time, that is), and now, a caregiver to her mother, who suffered an unexpected stroke four years ago. Even though life is hectic, she felt it was her responsibility to take on the role of caregiver, as her other siblings live in the suburbs, far away from her mother’s doctors. They help out when they can, but Melissa feels they could be doing more. She spends 25 hours a week providing care for her mother, and pays for home health aides who provide additional support with nursing care. She describes caregiving as “very stressful,” and does not have enough time to herself.

“I can only spread myself so thin, and as she gets older she needs more of my time.”

SON

Rather than place his mother in a long-term care facility, James, 58, became his mother’s primary caregiver. As the oldest child, and recently retired, he felt it was his responsibility to take on this role. He moved his mother into his home and on average spends 37 hours per week tending to his mother’s daily needs. He hired a part-time housekeeper and personal care aide to help him, but he does not have the support of his siblings or non-family members, so most of the work falls to him. He sometimes second guesses if he is doing all that he can for her, and thinks about “what ifs.” James has experienced symptoms of depression and anxiety recently but chose not to seek help, preferring to handle things on his own.

“I worry that I'm giving her the level of care that she needs and deserves without comprising her integrity.”

FRIEND OR NEIGHBOR

Maggie began her caregiving role by checking in on her neighbor with limited mobility. His family lives out of state, and she knew he could use a hand with shopping and errands, handling paperwork, and other basic needs. Eventually, she came to be his primary caregiver as his needs increased. She could use the help of paid services, but for now relies on the help of her other family members.

“He had no help at all—it didn't seem like it to me—so I just stepped up.”

Beyond informal support

Support surrounding caregivers goes beyond friends and family members. Health care resources and home- and community-based resources were also identified by caregivers as important, supportive resources (Page 1). In addition, working caregivers were asked to what extent their employer supports them in that role.

> *"If the social workers and case workers were not stretched so thin and could come over and spend more time with me and my mother that would help a lot. Even phone contact with them can be challenging.*
>
> *I really struggle to talk with doctors—my dad's doctor has a lot of legal, confidentiality stuff and HIPPA rules that I have to go through.*
>
> *I have a good relationship with her providers."*

Support surrounding caregivers

INTERACTIONS WITH FORMAL SYSTEMS

Use of supportive services. Over half (54%) of primary caregivers got help in the past month from an organization or business. The most commonly mentioned formal services are listed in the figure above. A caregiver's use of paid services was independent of their informal support network or household income. However, caregivers with health conditions that limited their own activities were more likely to use supportive services.

Source of information. Caregivers frequently sought information about assisting their care recipient or resources for themselves from formal systems, specifically: Health care providers (26%); case managers or social workers (16%); county or state services (14%); or community-based organizations (14%).

SUPPORT FROM EMPLOYERS

Of the employed caregivers, most (82%) are able to leave work as needed to handle caregiving responsibilities. Caregivers mainly mentioned time flexibility as the way their workplace supports their caregiver role, including informal flexibility and formal policies. About one in five employed caregivers said they receive no support from their employer, and others said they received support but with certain limitations.

> *"I can take off early if I need to as long as I let them know what is going on. But, I have to use my vacation to do that."*

Ideas for action

Family and friend caregivers form an irreplaceable system of support for older adults. *Caregiving in Context* findings show that when caregivers are able to build informal support networks— especially ones that include family members as well as friends, neighbors, or others—they may be able to reduce their stress and spend less time providing care, which could enable them to remain in and enjoy their caregiving role more.

Developing effective strategies for helping caregivers build strong informal support networks will be essential as the number of people providing care to older adults continues to grow. The reasons are twofold: 1) The capacity of formal systems will be inadequate to meet the growing need and 2) As our research demonstrates, caregivers look to and trust their informal networks in a unique and important way. One of the most significant ways for formal systems to support caregivers is to streamline the process of accessing services, allowing caregivers to invest their time and energy into caring for their loved one, as well as focus on building their informal support network.

The ideas below are organized to show how those surrounding caregivers, both informal networks and formal systems, can take action to support caregivers:

IF YOU ARE A:		YOU CAN HELP A CAREGIVER BY...
Family member, friend or neighbor of a caregiver	→	**Be proactive.** Start a conversation with a caregiver by asking a simple question such as "How's it going?" Caregivers can receive much needed emotional support that they may not even realize they need or rarely ask for. If you can provide direct support by picking up groceries or mowing the lawn at the caregiver's home, or at the home of the older adult they care for, you'll be a significant source of support.
Health care provider	→	**Ease system navigation.** Health care systems have successfully designed processes for parents to act as navigators for their children. Build on these models to better assist caregivers, who often struggle to navigate the system on behalf of their care recipient. **Ask questions.** Find out if patients are caregivers during regular screenings and check in with them about stress or other potential support needs.
Service provider	→	**Increase awareness.** Fewer than 15 percent of caregivers listed county or state social services or Senior LinkAge line as a valuable source of information. A wealth of information is available from these sources yet it remains underutilized by caregivers. Continued investments in increasing access and awareness of these resources need to be on par with the investments in improving their infrastructure. **Tailor services.** As seen throughout this summary, the experiences, strengths, and needs of caregivers vary significantly, yet many services are still one-sized. Design services for specific family members or caregiving situations to maximum benefits for caregivers.
Faith community	→	**Reach out.** Few caregivers (7%) had a member of their faith community helping them. Faith communities are a natural gathering place and a source of spiritual and emotional support which could be powerful in the lives of caregivers. Specific outreach and programs for caregivers may help to connect those willing to help with caregivers who need support.

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