A Study of Family, Friend, and Community Caregivers' Networks of Support

WHAT WE LEARNED

- **Informal support is very important to caregivers.** Strengthening informal support networks may reduce the hours per week caregivers spend on assisting older adults. This includes daily tasks, improving caregivers’ perceptions of their own health, and lessening overall stress.

- **Caregivers are less stressed and better supported when assisted by both family members and others outside the family.** Despite a wide range of information and services provided by state and county agencies and community-based organizations, the most essential support for caregivers does and will continue to come from informal sources.

- **Caregivers’ experiences differ, as do their support needs.** The most important role for formal supports may be to simplify their interactions with caregivers. This will reduce stress, burden, and time spent accessing and navigating formal supports.

Study overview

More than 78 million baby boomers in America are poised to enter retirement age. 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.

Wilder Research conducted the Caregiving in Context survey in 2012 to deepen our understanding of the informal support available to caregivers and its impact on their challenges and needs.

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). 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).

WHO WE TALKED TO

Wilder Research interviewed family, friend, and community caregivers in seven neighborhoods in Saint Paul, Minnesota:

- 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

We spoke with women and men of diverse age, education level, and family status.

- 1 in 4 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

What is the most important support for you as a caregiver?

<table>
<thead>
<tr>
<th>Support</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal support</td>
<td>62%</td>
</tr>
<tr>
<td>Health care resources</td>
<td>52%</td>
</tr>
<tr>
<td>Home- and community-based services</td>
<td>23%</td>
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<tr>
<td>Other resources</td>
<td>19%</td>
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Ideas for action

Caregiving in Context findings show that when caregivers are able to build informal support networks—especially ones that include family members, 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 capacity of formal systems will be inadequate to meet the growing need and 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 to focus on building their informal support network.

Here are some ideas about how 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 they remain 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. |

For more information

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