



In Their Own Words

Family Caregiver Priorities and Recommendations: Results from a Request for Information

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Executive Summary

This report¹ documents family caregiver concerns and recommendations for change, from the perspective of family caregivers themselves and the organizations that work with and serve them. Data informing this report was collected from responses to a Request for Information (RFI) from the Administration for Community Living (ACL), as it works to implement the requirements of the Recognize, Assist, Inform, Support and Engage (RAISE) Family Caregivers Act of 2017².

The responses reflected the diversity of family caregivers, who cared for many different types of care recipients and were from a range of socio-economic circumstances, living across the nation in cities, suburbs, and rural areas. The challenges they face are accordingly diverse, although certain themes dominated -- most notably the financial stress caused by caregiving and the need for services and supports targeted at family caregivers. Respondents specifically requested compensation to alleviate the financial pressures created by their caregiving responsibilities as well as greater investment in workplace accommodations to enable them to maintain employment. Similarly, there was demand for specific types of services to make the job of caregiving less difficult. The request for respite was the most pronounced, but respondents also said they needed information and advice as well as training for the more complicated tasks associated with providing care. Lastly, respondents linked the poor quality of the paid workforce to low pay and lack of training, emphasizing how this poor quality makes it harder to feel comfortable relying on these services, even where they are available and affordable. This leads to additional stress on family caregivers.

1 Funding supporting the research behind and the writing of this report was provided by The John A. Hartford Foundation through a subcontract with the RAISE Family Caregiver Resource and Dissemination Center in collaboration with the U.S. Administration for Community Living.

2 RAISE Act refers to “Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017” or the RAISE Family Caregivers Act of 2017

Background and Overview

Procuring public input is a key requirement of the RAISE Family Caregivers Act. One mechanism for obtaining such input was a Request for Information (RFI), published in the Federal Register (Vol. 84, No. 236) on December 9, 2019. (The opportunity to respond closed on February 7, 2020.) The RFI aimed to help ACL ensure that the activities and products of the Family Caregiving Advisory Council (the Council) are inclusive of the views of family caregivers and responsive to their needs, as well as the views of a wide range of stakeholders with an interest in supporting family caregivers.

Specifically, the RFI requested information to help the Council formulate goals, objectives and recommendations to help inform an Initial Report to Congress, develop the Family Caregiving Strategy (the Strategy), and identify topics to be explored in a series of public listening sessions. To obtain this information, three questions were posed. The first two questions were open-ended, asking for detailed responses to the following statements, based on respondents' caregiving experiences (or experiences working with caregivers):

- 1) "A pressing family caregiving need/ concern I would like to see addressed" and
- 2) "I would like to offer this specific recommendation to address my need/concern."

The third question was close-ended and built on the second question regarding recommended actions. Respondents were given a list of issue areas around these recommendations and asked to select all that were important to them. This list, from which respondents were asked to choose, is shown in in Table 2. If the respondent was affiliated with an organization serving caregivers, rather than an individual family caregiver, they were able to identify the organization with which they were affiliated. This data element enabled us to differentiate responses from individual family caregivers versus organizations or service providers associated with caregiving.

A Diversity of People and Organizations Responded to the RFI

Participation in the RFI was robust, with 1,613 unique responses. Notably, the RFI garnered nearly double the anticipated number of responses; this overwhelming response indicates the urgency of the topic. Table 1 shows the kinds of individuals and organizations that participated. The overwhelming majority -- three-quarters of respondents -- were individual family caregivers, while advocacy and community-based organizations comprised 11% and 10% of responses, respectively.

Table 1: RFI Respondents, by Category

Respondent group	N	%
Caregivers*	1203	75%
Advocacy	184	11%
Community-Based Organization	154	10%
Government	31	2%
University	26	2%
Other Research	15	1%
Total	1613	
*997 cases self-identified as individual caregivers. A further 206 were coded as such based on blank entries in the "organization" field, confirmed via the content of their responses.		

Respondents also represented a wide variety of caregiving experiences. While the researchers who analyzed the data were unable to know exactly what kind of caregivers were represented, responses often contained clues about the caregivers themselves, which made it clear that participants represented a wide range of socio-demographic characteristics, family configurations, and personal circumstances. And the responses were as diverse as the nation's rich melting-pot history: people responded as parents of children with complex health needs; as caregivers from a range of ethnic and racial backgrounds; as grandparents caring for grandchildren; as siblings of adults with mental illness; as long-distance caregivers; as people providing care in a rural environment; and as caregivers of people of all ages, from children to older adults. The health conditions of care recipients varied widely as well, requiring caregivers to navigate a variety of healthcare and other service systems.

Identifying Caregiver Priorities

Table 2 shows the responses to the close-ended question on the RFI which provided an opportunity to learn about key actions these caregivers felt were needed to address the challenges and issues they faced. Responses to this question also communicated caregiver priorities for the national strategy.

The response categories presented came from language in the RAISE Act itself and outline the recommended areas for action to be addressed by the National Caregiving Strategy; however, the categories were not defined precisely for respondents. Therefore, while we know how many respondents cited each as important, we cannot be sure that they understood them in the same way, making it difficult to interpret responses in a more granular manner.

Table 2: Responses Regarding Needed Actions to Address Caregiver Priorities

	All Respondents (N=1,407)		Caregiver Respondents (N=997)	
	N	%	N	%
Service planning and or delivery	766	54.4%	538	54.0%
The greater adoption of person/family centered care	697	50.0%	480	48.1%
Respite options	647	46.0%	452	45.3%
Care transitions or coordination	633	45.0%	444	44.5%
Financial security	595	42.3%	423	42.4%
Information, education, training, and/or referral	556	39.5%	398	39.9%
Assessment	375	26.7%	272	27.3%
Workplace issues	373	26.5%	266	26.7%
Care coordination in hospice	302	21.5%	211	21.2%
Palliative care	302	21.5%	211	21.2%
Advance care planning	301	24.4%	211	21.2%

Notes: These responses were to the RFI item: “This recommendation addresses needed actions that pertain to (Check all that apply)”

**The study had 1613 respondents, 1407 of whom provided answers to the close-ended questions.*

Overall, respondents prioritized issues around how services are delivered: issues around service planning and/or delivery were cited as the top priority in the responses, with person-centered care coming second, and care transitions/coordination coming fourth. Respite was also high on the list, coming third. Financial security was also seen as important, along with information, education, training and/or referrals. Although end of life issues were less frequently selected, more than one in five respondents indicated that they were important. Interestingly, the priorities of family caregivers did not differ significantly from those of all respondents.

In Their Own Words – Caregiver Priorities and Recommendations

In contrast to the close-ended question, open-ended questions typically allow respondents to provide useful context, more nuanced and in-depth responses, and therefore allow us to more effectively link their personal circumstances to their expressed needs. Responses to these questions raised an exceptionally broad range of issues – unsurprising, given that caregiving impacts all facets of life, including caregivers’ physical and mental health as well as their financial circumstances. Moreover, the needs of care recipients can be difficult to disentangle from the needs of caregivers, as any change in circumstances for the care recipient will affect the caregiver, and vice versa. Thus, in these open-ended responses, caregivers often combined comments about services for care recipients with their reflections on the issues that impact them most as caregivers. Most importantly, the quality, cost, and level of access to services for care recipients have significant implications for caregivers, who struggle to identify appropriate services and may be reluctant to leave their family member with providers, given these barriers.

But what is even more evident among the responses is the level of dedication and sacrifice shown by these family caregivers, and the extent to which providing care impacts their lives. Americans have long been dedicated to their families – a dedication that endures regardless of the many social, economic, and demographic changes that this country has faced. The quote below sums this up best:

“The most important thing that my husband and I want for my 23 year old special needs daughter is to provide and care for her in our home for as long as we possibly can. Since she is mentally challenged and on the spectrum ... her behaviors are sometimes challenging.... My daughter continues to depend on [us], more and more for everything.... We have always done the best for our daughter; all we want is help to support her and to keep her happy.”

“I would like to offer for any 'decision maker' to spend a day with me and my family and see what it truly takes to care for someone with significant impact of a disability. I think only then can we move forward with an actual picture of what we as a commonwealth are up against.”

Although caregivers’ lives are as varied as are the challenges that family caregivers face, the needs they express fall into clear themes even across those varied life experiences, providing concrete directions for policy action.

Caregiver Finances

Prominent among the themes found in the responses and recommendations were concerns about caregivers' personal finances and future financial security, which caused caregivers significant stress and worry. This theme included concern about the ability to accommodate care recipients' needs (including costs associated with healthcare, health supplies and equipment, housing, and support services) as well as concerns about caregivers' own financial needs, both in the short and longer terms. Concern about personal finances also frequently incorporated family caregivers' ability to support other family members in addition to the care recipient.

“Burn out, or stress is a concern. My sister was financially broke because of our parents, and lost a lot. She was the main care provider for both parents, and also cared for her own children. She died at an early age. Now, I cannot say it was because of stress. However I cannot say it wasn't.”



“Our family was devastated by my son's accident, and then further devastated by the financial ruin that has followed.”

A key issue raised in these comments was frustration that caregiving made it difficult both to work and to qualify for Social Security benefits, placing caregivers and the people they care for in financial peril (both in the short- and long-term) -- particularly given the added financial burden associated with certain care needs.

Even where care recipients had access to supportive services, it was frequently noted that such services were not compatible with full-time employment; caregivers also commented that workplaces were not accommodating of caregiver needs, such as the need to accompany care recipients to medical appointments during the working day, or to take unplanned time off to respond to emergencies. Lack of access to services and worries about service quality function as further barriers to employment for family caregivers.

“Many families quit their jobs to care for family members, and lose not only the difference in income, but also the pay into Social Security.”

“Pay families and caregivers... so they don't rely on welfare, as many cannot work while caring for their loved one.”

“I am unable to work because of care needed for [my] husband 24/7. We will lose years of income and retirement is 15 years away.”

“If you take care of a permanently severely disabled person then you should get paid to take care of them.”

“Family members that don't feel comfortable leaving the care of their loved ones in the hands of a stranger [should get] compensation for their lost wages or just simply to care for them.”

“If we are paying foster parents to take in these children, and we know that they do better with relatives, then it seems the caregivers should be compensated.”

Given this incompatibility between the need to work for income and the need to provide care, the single most prevalent recommendation raised in the open-ended responses was the need to compensate family caregivers. Caregivers also noted that if they were unable to provide care, someone would be paid to provide that care. Grandparents looking after grandchildren specifically noted that foster parents receive compensation for which they, as relatives, are not eligible.

The recommendation for compensation took various forms. Although many respondents directly requested pay for their work, respondents also requested tax benefits or Social Security credits. Some specifically mentioned expansion of the Earned Income Tax Credit or Child Tax Credit to caregivers. Others wanted to apply tax credits to care-related purchases, such as medications or equipment. Oftentimes, people noted how heavy the financial burden was for those who made too much to qualify for means-tested programs such as Medicaid.

Workplace protections were also raised frequently. Respondents specifically referred to the need to expand the Family and Medical Leave Act – both in terms of the types of employers falling under the law and in terms of the level of financial support it provides. Employer flexibility was also a theme: while some people were grateful for their employers' flexibility, others noted that inflexibility impacted their ability to maintain employment. "Flexibility" included flexible hours as well as the ability to take on part-time positions.

"Federal grants to assist in paying for me or someone else to provide care for my mother. I am losing money taking time off work to care for her. We do not meet Medicaid limits for income and have no assistance from other sources to provide care. I am concerned that I will need to stop working to provide care for her and it will affect our family resources, income, and abilities to provide for our future."



"It would be good if there were policies in place that allowed for caregivers to have time off without being penalized and losing all their vacation and sick leave time when taking time off to take their family member on appointments and medical procedures."

Caregiver Services

In addition to a need for financial supports, respondents reported needs for services that could support them in their role as family caregivers. Although many types of supports were mentioned, the need for respite stands out – that is, services that provide caregivers time off to attend to their own needs and obtain relief from the ongoing demands of care work. In this context, adult day services were frequently mentioned (although often because they were not available).

“Access to respite for family caregivers is very difficult to obtain especially for those caregivers who are providing skilled medical care and/or support for people with high behavioral needs or chronic mental health conditions. [This] could prevent burn-out and many physical and mental health issues that the caregivers eventually get.”



Respondents also mentioned the need for services that would better enable them to provide care. Two types of support were mentioned as critical: caregiver education and training, and a way to access information and advice on caregiving. The first type of support involves gaining expertise in some of the complex tasks associated with providing care, such as how to handle certain medical needs (injecting medications, for example), or how to handle behavioral issues (for individuals with cognitive impairment or mental health issues). The second category – information and advice -- refers to advice about services, insurance coverage, finances, and planning ahead, as well as information about how to identify appropriate services and navigate service systems.

“Educating yourself is hard with so much going on. Trial and error is how I learned but with what I know now, wish I had someone to walk me through the process of navigating the doctors’ appointments, the medications, the insurances - personal, Medicare, etc. Also how to keep all your doctors informed and on the same page.”

“Education is needed for all aspects of caregiving. We caregivers are expected to perform a greater and greater variety of medical procedures that we do not have the training or knowledge to perform. Caregivers are doing everything from changing bandages to administering varying forms of medications as well as bathing and grooming seriously ill people with no training.”



Respondents also reported needs for social and emotional supports, such as mental health services or caregiver support groups. This is tied in with the frequently-mentioned social isolation and psychological burden that often accompanies the caregiving experience.

And lastly, respondents explicitly mentioned the need for caregiver inclusion in the care planning process, both as a critical source of information on the care recipients' needs and as discrete targets for services and interventions. Some respondents tied this explicitly to a need for caregiver assessments, which would systematically assess how caregiving is impacting caregivers themselves and, as a result, provide a basis for service recommendations (for respite, for example), or other types of supports to meet a caregiver's needs.

However, to access supportive services directed at the caregiving population, family caregivers need to identify as such. Thus, increasing public awareness of the caregiving role was seen as an important need.

“Having a support group with resources for sole-caregivers would be most welcomed. A care-giver's cup can become depleted and when it does, the caregiver isn't much good to anyone... Failing to have outlets where you can connect, recharge or share the practical burdens of caregiving results in a surefire recipe for total exhaustion and collapse.”

“When family caregivers are acknowledged as full partners with the professional care team, the patient/family caregiver dyad can be viewed as the unit of care and both members of the dyad can be assessed and receive appropriate care and support.”

“I would [like] to see a national campaign on helping caregivers identify and assisting with connecting them to resources.”

Services for Care Recipients

Many responses addressed the quality, cost, and availability of services for care recipients. In terms of the specific services mentioned, adult/family day services were most frequently discussed. The other category that garnered significant mention was the difficulty of obtaining appropriate mental health services for care recipients. In addition, there was frustration with a lack of affordable, suitable housing.

Because paid services were often cited as unavailable or unaffordable, caregivers frequently stated that they were unable to leave care recipients unattended. However, even where services were available, caregivers were burdened by worries about whether paid caregivers who were brought into the home were appropriate or safe. Respondents noted that direct care workers often lacked appropriate training for the care recipient's specific issues, whether it be dementia, autism, or complex medical needs. Indeed, respondents cited poor quality care as a major reason for their inability to leave care recipients, either to work or to take a break from their caregiving responsibilities.

Thus, concern about the quality of paid caregiving services was frequently cited in the responses. It is notable that caregivers were acutely aware of the link between quality, training and low pay for direct care workers, often explicitly linking these concepts in their responses. Even when discussing highly skilled professionals such as physicians, caregivers frequently talked about a lack of training and understanding of the specific needs of care recipients – around dementia care, for example, or mental health issues, as well as about specific physical health concerns -- or awareness of the need to support the caregiver's role in providing care.

“[Respite] is only possible when a family has reliable and qualified people to take their place when they are unable to be at home. There are agencies that will provide such caregivers, but they are often very poorly paid. This attracts a lower quality of employee and ones that often aren't very good at their jobs. Increased funding for direct support professionals will help families to hire higher quality caregivers to provide care in their absence.”

“We would also like more trained, dedicated direct support staff that are available and not just a pipe dream... This would mean that the Direct Support Professionals need more training, better pay, with good benefits. This is a very important job and the people working need to be valued.”

“A pressing family caregiving need I would like to see addressed is: the lack of education and training regarding dementia among medical providers.”

Conclusion

This report is only a snapshot of the dominant themes in the RFI responses, and yet it reveals the love, warmth, caring, devotion, determination, resourcefulness, and good, old-fashioned grit of the American people. Among the 1,613 responses, however, many other issues were raised, among them calls for further research and investment in caregiving. Overwhelmingly, however, the responses conveyed the financial, physical, and emotional stresses that caregiving creates, and the intense needs that caregivers have for appropriate supports, whether these be financial supports, the ability to have some time off, or help with the everyday tasks of organizing and providing care.

Although the responses were collected before the COVID-19 pandemic hit American shores, it is clear that the issues raised have only become more pressing, given the challenges the pandemic presents. The pandemic has thus meant that caregivers are experiencing even more uncertainty, isolation, and lack of access to support (whether from family or professionals), further highlighting the need to support these hard-working Americans.

Methods

The researchers used grounded theory to analyze the 1,613 responses to the RFI. Grounded theory is an approach to qualitative data analysis that uses inductive reasoning – that is, it groups data using categories that arise out of the data, rather than by applying pre-determined categories. Using a qualitative data analysis software, NVivo, two researchers independently developed codes based on a subset of 200 responses, and then reconciled these codes to develop an initial coding tree. They also checked their coding tree against other research addressing caregiver needs and priorities, to ensure inclusion of all important topics. They then independently applied these codes to the data, compared their application of the codes, reconciled any differences, and adjusted the codes to obtain the final coding tree.

Due to the large number of responses, which precluded detailed hand-coding given the time available, the researchers then utilized the NVivo 12 auto coding feature to code the remaining data. Pattern-based auto coding is designed to speed up the coding process for large volumes of textual content. It relies on coding patterns found in already-coded data – in this case, the subset of 200 responses that had been hand-coded by the researchers. The auto code feature enables NVivo to compare each text passage—for example, sentence or paragraph—to the content already coded to existing nodes. If the content of the text passage is similar in wording to content already coded to a node, then the text passage will be coded to that node. This auto code feature was tested on a different subset of 400 responses. The researchers reviewed the results of the auto coding for that subset, made corrections, and then used that corrected data to apply to the entire dataset. That final coding was then systematically reviewed for accuracy, and the results used to identify the final themes.

Project Team

The research team for this project was led by Pamela Nadash, PhD, Associate Professor of Gerontology at the University of Massachusetts Boston, and part of the LeadingAge LTSS Center @UMass. Dr. Nadash has a long history of policy-focused research on issues around LTSS, both in the US and internationally. She is an experienced quantitative and qualitative researcher and a skilled focus group moderator, with specific expertise in web-based focus groups. Eileen J. Tell, MPH, CEO of ET Consulting is the co-principal investigator. Ms. Tell is an LTSS research expert in both qualitative and quantitative research with consumers, family caregivers and LTSS stakeholders. Since 2000, she has been a subcontractor on numerous LTSS projects for the U.S. Department of Health and Human Services/ASPE/ACL. Marc Cohen, PhD, Co-director of the LeadingAge LTSS Center @UMass Boston and the Research Director of the Center for Consumer Engagement in Health Innovation, provided project oversight and guidance. The project was supported by a research assistant, Taylor Jansen, MS, a PhD student in the Gerontology program at the University of Massachusetts Boston, whose assistance in working with NVivo, the qualitative analysis software employed for the analysis, has been invaluable.

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