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Why We Are Failing Family Caregivers

By Aviv S. Bliwas, JD

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Why We Are Failing Family Caregivers

By Aviv S. Bliwas, JD

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I. Introduction

In October 2009, I joined the ranks of approximately 1 in 5 American adults who serve as informal, unpaid family caregivers.[1] First, I cared for my mother, who was dying of breast cancer. While I was caring for my mother, my father was diagnosed with cancer, complicated by pneumonia and multiple infections to which he eventually succumbed in March 2011. Becoming a caregiver for my parents at age 28 was like learning to swim by being tossed into the deep end of the pool. I spent that 16-month period trying to keep everything going minute by minute. There was absolutely no time to plan a course of action or figure out the next step; I was simply reacting to the next crisis. For both of my parents, caregiving started with a medical emergency that landed each in the hospital.

Caregiving has likely existed for as long as humans have lived together. After all, when we get sick, injured, or old, we need others to feed us and care for us. Yet it is only in the most recent centuries that American society and government have recognized the importance of family caregiving and that written references to a "caregiver burden" have appeared in the literature.[2] A variety of factors likely explain why family caregiving has become more burdensome in recent decades, including the growth of participation of women in the workforce[3] (women being much more likely to serve as primary caregivers[4]), advancements in medicine that have made more serious illnesses and disabilities survivable, decreased birth rates, and changing geographic trends with families living farther apart.[5]

To properly address these factors, it is important to understand why they make family caregiving so much more burdensome. Resources (e.g., programs and services offered by government agencies, nonprofit organizations, and private businesses) focusing on meeting the needs of family caregivers and those making sure that caregivers are supported and prepared to provide complicated medical caregiving would presumably serve to lessen caregiver burdens. But none of these caregivers will have their needs addressed if no one knows they are out there struggling and if those caregivers don't know how to get help or even know that help exists.

In my own caregiving experience, after conferring with the doctors at the hospital, my parents and I discussed the pros and cons of different medical actions. In consultation with these doctors, I made the best decisions I could. I was given referrals for follow-up medical procedures and appointments. When the hospital discharged my parents and sent them home with me, I never met with anyone at the hospital to discuss my parents' care

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[1] Amalavoyal V. Chari, John Engberg, Kristin N. Ray & Ateev Mehrotra, *The Opportunity Costs of Informal Elder-Care in the United States: New Estimates From the American Time Use Survey,* 50(3) Health Servs. Research 871, 871 (June 2015). In real population numbers in 2019, this amounts to approximately 66 million Americans who served as informal caregivers that year. U.S. Census Bureau, *U.S. and World Population Clock,* https://www.census.gov/popclock (accessed Oct. 7, 2020).

[2] Rosemary L. Hoffman & Ann M. Mitchell, *Caregiver Burden: Historical Development,* Nursing Forum 5, 6 (Oct–Dec 1998).

[3] Mitra Toossi, *A Century of Change: The U.S. Labor Force,* 1950–2050, Monthly Lab. Rev. 15, 18 (May 2002).

[4] Gal Wettstein & Alice Zulkarnain, *How Much Long-Term Care Do Adult Children Provide?* 2, Ctr. for Ret. Research at Boston College (June 2017).

[5] *See also id.* at 3.

needs, and I was never told what to expect as far as the progression of their illnesses or the symptoms they might experience. My mother was terminally ill, but no one told me about hospice, neither that it existed nor what it did. During my father's illness, one person asked whether I would be interested in information about a support group. I told the person that yes, I would be interested, but I never saw that person again nor got any information about any support groups that might be available. In short, I was completely on my own.

Caregiving at home was all-encompassing and even more isolating than it was when my parents were in the hospital. There were long periods when I saw no one except my parents, and my duties were pretty much 24 hours a day, 7 days a week. I did everything from administering morphine to my mother, flushing my father's peripherally inserted central catheter (PICC) line,[6] changing my father's ileostomy bag,[7] and helping them both bathe, dress, and go to the bathroom because they were unable to do any of these things without assistance. I managed all doctor appointments (often seeing several doctors every week), transporting my mother or father to appointments because they were too sick to drive, educating myself, and weighing in on various medical procedures recommended by the doctors. I also visited and advocated for my parents when they were in institutional medical settings (e.g., hospitals, rehabilitation facilities). Additionally, I was solely responsible for managing their household, including cleaning, shopping, bill paying, and all the other tasks they had been performing for themselves until then.

During this entire period, I had no idea that there were resources out there that I could pay to help me with all these things I was doing by myself. Even though caring for my parents certainly brought me into regular contact with various medical professionals, no one ever brought these resources up. No one ever asked how things were going. No one ever told me help was available if I needed it.

Many programs and services exist to help vulnerable elders and their caregivers, from those run by nonprofit organizations to those offered by the government. As a caregiver, I was all alone because I simply had no idea that any of these resources existed. Not only that, I was so focused on my caregiving duties that I didn't even have the time, energy, or thought to see whether such programs or services existed. I was busy surviving minute by minute.

The only people I saw who could have made me aware that such programs and services existed were the staff at the hospitals and doctors' offices, places I went to every week. Those are the people who could have asked me whether I was struggling or needed help. This lack of engagement from health care staff is common among caregivers' experiences. Caregivers have been called "an 'invisible, isolated army' carrying out increasingly complicated tasks and experiencing challenges and frustrations without adequate recognition, support, or guidance, and at great

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[6] A PICC line is a long, thin tube inserted into a vein often for the purpose of administering medicine. Mayo Clinic, *Peripherally Inserted Central Catheter (PICC) Line* (Aug. 29, 2019), https://www.mayoclinic.org/tests-procedures/picc-line/about/pac-20468748 (accessed Oct. 7, 2020).

[7] An ostomy is an opening in the abdomen created surgically to allow waste to exit the body after the surgical removal of part of the intestines. MedLinePlus, U.S. Natl. Lib. of Med., *Ostomy* (topic last reviewed July 3, 2014), https://medlineplus.gov/ostomy.html (accessed Oct. 7, 2020).

personal cost."[8] If staff at hospitals and/or doctors' offices were required to counsel family caregivers and give them information on local resources, it's much more likely that the caregivers who need it most would actually know what resources are available and how to access them.

Yet even if those staff at hospitals and doctors' offices had made me aware that programs and services for family caregivers existed, another problem presented itself: these programs and services frequently operate in isolation, with no central clearinghouse where caregivers can receive information on all programs and services available in their area.[9] Even if a central clearinghouse exists (often run by a local area agency on aging), many caregivers as busy and overwhelmed as I was certainly don't have the time to go through endless pages of programs and services and make phone calls, often for programs and services that aren't even applicable to their situation.

The family caregiver support system not only needs to improve its outreach to caregivers to make them aware that such a system exists, it also needs to better educate the health care staff who meet with caregivers and field their questions. Staff need to understand all the programs and services available, including the eligibility requirements and how the resources interact, not just programs and services in their own niche. Moreover, health care staff need to do more than just pass on endless lists of possible resources to family caregivers. They need to engage in real counseling with families to understand their goals and needs and refer them only to programs and services for which they are eligible and that can meet their needs, thus ensuring that the only thing families need to do is determine whether a resource is a good fit for them.

If these improvements are implemented, the use of and access to programs and services for family caregivers would increase. Such improvements not only would make families' lives better but also would make it much more likely for care recipients to receive better care and make fewer hospital or medical emergency visits. Spending more government dollars on programs and services for family caregivers would likely reduce government dollars spent on hospital and doctor visits and on long-term care, expenditures that are typically vastly more expensive than funding to assist family caregivers.

II. Overview of Existing Family Caregiver Support

Family caregiver programs and services, and the government agencies and nonprofit organizations that provide them, have existed for more than 50 years. What follows is an overview of some of the programs, services, and organizations offering them that existed in 2020, thus demonstrating that a lack of programs and services is not why there remains a gap in ensuring that informal family caregivers are supported.

A. Federal Government Programs

Since at least 1965, with the implementation of Medicaid, society has recognized the need for the government to assist in providing funding for caregiving outside the home. However, only in

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[8] Susan C. Reinhard, Lynn Friss Feinberg, Rita Choula & Ari Houser, *Insight on the Issues: Valuing the Invaluable: 2015 Update — Undeniable Progress, but Big Gaps Remain* 5, AARP Pub. Policy Inst. (July 2015).

[9] Lewin Group, *Process Evaluation of the Older Americans Act Title III-E National Family Caregiver Support Program: Final Report* 83, 88 (Mar. 2016).

more recent decades has the federal government paid attention to and allocated funding to support caregiving, including informal family caregiving, in the home. Descriptions of some of the larger federal programs intended to support family caregivers follow.

1. Medicaid

Medicaid is the only federal government program that pays for long-term caregiving. Created under the Social Security Act of 1965,[10] Medicaid provides money to the states to, among other things, pay institutions to care for elderly and disabled people who meet certain income and resource limits.[11] In 1983, Congress amended the Act to allow for a waiver of the Medicaid rules requiring that such care be provided by institutions and to provide Medicaid funding to pay for home and community-based services.[12] Today, approximately 53 percent (more than $80 billion) of all Medicaid long-term care spending is for home and community-based services.[13]

The Medicaid rules allowing for funding of home and community-based services include the option for states to create a program for "self-directed home and community based services."[14] While Medicaid recipients generally are given a choice as to their care provider, the self-directed care option actually allows them to hire private individuals, including their own family members,[15] subject to approval by the state, who are then entitled to be paid by the state through the Medicaid program.[16] In practice, this program is a good way to pay adult children for the otherwise uncompensated care they often provide their parents.

2. Family and Medical Leave Act

Another federal law designed to help families who care for family members is the Family and Medical Leave Act. Enacted in 1993, this law provides that, under certain conditions defined by the Act, employees of covered employers cannot be fired if they need to take unpaid time off work to care for their families.[17]

3. Medicare: Hospice Benefit

In 1982, Congress added a hospice benefit to Medicare coverage as part of the Tax Equity and Fiscal Responsibility Act.[18] Services covered by this benefit include hospice aide and homemaker services, social work services, grief and loss counseling for patients and their families, and short-term respite care for caregivers who need a break.[19]

B. *State and Local Government Programs*

State and local governments are often responsible for implementing federal

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[10] Medicaid.gov, *Program History*, https://www.medicaid.gov/about-us/program-history/index.html (accessed Oct. 7, 2020).

[11] 42 U.S.C. § 1396 et seq. (2018).

[12] Medicaid.gov, *Home & Community Based Services Authorities*, https://www.medicaid.gov/medicaid/hcbs/authorities/index.html (accessed Oct. 7, 2020).

[13] Medicaid.gov, *Home & Community Based Services*, https://www.medicaid.gov/medicaid/hcbs/index.html (accessed Oct. 7, 2020).

[14] 42 U.S.C. § 1396n(i)(1)(G)(iii).

[15] Parents of minor children and spouses are not entitled to participate as the care provider in this program because they are deemed to be legally obligated to provide such care. *Id.*

[16] *Id.*

[17] 29 U.S.C. § 2601 et seq. (2018).

[18] Pub. L. No. 97-248, 96 Stat. 324 (1982); Feather Ann Davis, *Medicare Hospice Benefit: Early Program Experiences,* 9(4) Health Care Financing Rev. 99, 99 (Summer 1988).

[19] Medicare.gov, *Hospice Care*, https://www.medicare.gov/coverage/hospice-care (accessed Oct. 8, 2020).

family caregiver support programs; however, most also fund and operate their own. The 50 states, the District of Columbia, and five U.S. territories have a state unit on aging. Most also have local offices on aging, either an office in each county or offices spread out over certain geographic areas. These local offices on aging are frequently on the front-line of federal and state programs for family caregivers. They provide much-needed information about various government caregiver programs and often administer the programs themselves.

The programs administered by local units on aging vary from state to state. In Pennsylvania, for example, the Cumberland County area agency on aging administers a family caregiver support program that offers various types of assistance, including financial assistance to families, one-time grants for home modifications, a caregiver support group, and some limited legal aid.[20] Additionally, the agency determines the medical eligibility of individuals applying for coverage from the federal Medicaid program.

C. *Nonprofit Organizations*

The number of nonprofit organizations dedicated to family caregiving, or with a family caregiver support component, is dizzying. In a brief internet search, I found websites for the following:

- The Family Caregiver Alliance, which provides state-specific links to local resources[21]
- The National Alliance for Caregiving, which provides links to national caregiving databases as well as links to disease-specific resources[22]
- The Alzheimer's Association, which offers its 24/7 Helpline, local and online support groups, local and online education programs, social engagement programs, and a database of local resources[23]
- The American Cancer Society, which boasts its National Cancer Information Center and offers patient lodging programs, a program that provides patients with rides to treatment, an individual patient navigator, an online support community, free/reduced-cost wigs, free/reduced-cost homemaker/chore services, and financial assistance[24]

These are just a few of the multitude of nonprofit organizations that offer programs and services to support family caregivers. For most major illnesses that lead to a need for caregiving, at least one nonprofit organization exists to try to help the caregivers of individuals with these illnesses. Even if such an organization doesn't exist, many organizations are dedicated to the needs of caregivers generally or older Americans generally. Similar to the federal government, in the nonprofit world, a lack of programs and services to assist family caregivers does not exist.

D. *Private/For-Profit Businesses*

There are many businesses across the

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[20] Cumberland County Pa., *Aging & Community Services,* https://www.ccpa.net/aging (accessed Oct. 8, 2020).

[21] Fam. Caregiver Alliance Natl. Ctr. on Caregiving, *Family Care Navigator*, https://www.caregiver.org/state-list-views?field_state_tid=97 (accessed Oct. 8, 2020).

[22] NAI (Natl. Alliance for Caregiving), *Resources*, https://www.caregiving.org/resources (accessed Oct. 8, 2020).

[23] Alzheimer's Assn., *Programs and Support*, https://www.alz.org/help-support/i-have-alz/programs-support (accessed Oct. 8, 2020).

[24] Am. Cancer Socy., *Find Support Programs and Services in Your Area*, https://www.cancer.org/treatment/support-programs-and-services.html (accessed Oct. 8, 2020).

United States providing caregiver services for a fee. There were approximately 12,200 home health agencies nationwide in 2016, which provide staff to act as caregivers, whether instead of, or as a supplement to, family caregivers.[25] About 80.6 percent of those home health agencies were for-profit.[26] There are companies that provide home modification geared toward individuals who want to stay home but may need grab bars or chair lifts or wheelchair ramps. There are products designed to address any problem that a caregiver might face such as medication management, home monitoring systems, and bed alarms. Just like the services offered by the government and nonprofit organizations, there is no shortage of private services.

III. Current Laws Addressing Family Caregiver Needs and Improvements Needed in Family Caregiver Support

A. Current Laws

As mentioned, societal and government recognition of the importance of family caregivers and how much more complicated and difficult their job has become is a recent phenomenon. Following are descriptions of current laws that address family caregiver needs.

1. National Family Caregiver Support Act

The first piece of legislation specifically enacted to support family caregivers was the National Family Caregiver Support Act in 2000. That year, Congress amended the Older Americans Act to include a new provision creating the National Family Caregiver Support Program (NFCSP).[27] With its enactment, the NFCSP became the first federal program specifically designed to support family caregivers.[28] It accomplishes this by providing federal grants to states to enable them to offer support services to family caregivers.[29] The five core support services that states must offer family caregivers are as follows:

> (1) information to caregivers about available services;
> (2) assistance to caregivers in gaining access to the services;
> (3) individual counseling, organization of support groups, and caregiver training to assist the caregivers in the areas of health, nutrition, and financial literacy, and in making decisions and solving problems relating to their caregiving roles;
> (4) respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
> (5) supplemental services, on a limited basis, to complement the care provided by caregivers.[30]

In 2016, the Administration for Community Living, part of the U.S. Department of Health and Human Services, engaged The Lewin Group to conduct a comprehensive evaluation of the results of the NFCSP. The evaluation included a survey of state units on aging, area agencies on aging, and local service providers. The data makes clear that the NFCSP increased the number of services offered to family caregivers in each of the five core support services.[31] In fact, the study con-

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[25] Centers for Disease Control and Prevention, *National Center for Health Statistics: Home Health Care,* https://www.cdc.gov/nchs/fastats/home-health-care.htm (accessed Dec. 9, 2020).

[26] *Id.*

[27] 42 U.S.C. § 3030s-1(a) (2018).

[28] Lewin Group, *supra* n. 9, at 1.

[29] 42 U.S.C. § 3030s-1(a).

[30] *Id.* at § 3030s-1(b).

[31] Services increased as follows: 247 percent in support group services, 227 percent in training

cluded that the NFCSP "proved to be a catalyst for either providing or formalizing caregiver support services."[32] However, the study did not provide any data on whether the NFCSP actually increased the use of and access to family caregiver support services.

While the study demonstrated that the number of services offered increased, it did not actually quantify how many consumers used those services. Without data on whether the changes wrought by the NFCSP actually impacted the lives of consumers, it seems impossible to state whether the NFCSP has been a success or a failure. Even assuming that the NFCSP has had a positive impact on consumers, the study noted some areas for improvement. One area for improvement, or at least for more research, is efficiency across the long-term care system. The study noted barriers facing state units on aging in working and integrating with other caregiver support programs, barriers that include different eligibility requirements, different target populations, and different reporting requirements. In fact, more than two-thirds of the state units on aging surveyed reported that no effort had been made at the state level to use the same caregiver and care recipient assessment tools across all home and community-based services programs.[33]

Even in cases in which state units on aging reported that such an effort had been made, 75 percent indicated that the programs involved were Medicaid programs, which are limited in scope to the most financially needy families.[34] This means that even if caregivers did manage to find an access point into the family caregiver support system funded in part through the NFCSP, two-thirds were not being made aware of any other services or their requirements. Of those caregivers who were informed of other services, 75 percent were informed about Medicaid-related services only.[35] This further supports the assertion that family caregiver programs, though they exist and even can be called robust, seem to operate in an institutional vacuum, not aware of one another nor working together, making it difficult for family caregivers attempting to navigate the disparate family caregiver support system to find the services they need.

Another limitation of the NFCSP repeatedly reiterated by survey respondents was the program's budget. Total federal funding for the NFCSP is less than $200 million per year.[36] By comparison, the spending projection for the entire Medicare program for 2019 was $636 billion.[37] From the total NFCSP budget, states[38] are allocated a percentage based on their population of individuals who

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and education services, 47 percent in information and referral services, 563 percent increase in caregiver counseling, and 93 percent in respite care services. Lewin Group, *supra* n. 9, at 34.

[32] *Id.* at 92.

[33] *Id.* at 83.

[34] *Id.*

[35] *Id.*

[36] Administration for Community Living, *National Family Caregiver Support Program* (last modified Nov. 12, 2019), https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program (accessed Oct. 8, 2020).

[37] Cong. Budget Off., *Health Care*, https://www.cbo.gov/topics/health-care (accessed Oct. 8, 2020).

[38] The term "states" as used here comprises the 50 states as well as the District of Columbia and the following territories: the U.S. Virgin Islands, Puerto Rico, Guam, American Samoa, and Northern Mariana Islands. 42 U.S.C. § 3002(50).

are 70 years of age or older.[39] Florida, with the second largest number of elderly, 4,358,000,[40] receives not quite $15 million in federal funding, which is projected to serve a little more than 91,000 people.[41] That's about $165 per person per year. Put that in perspective with the average cost in Florida for one person to share a room in a skilled nursing facility, which is approximately $102,565 per year.[42] While there are no direct studies on the effect NFCSP support has on keeping people at home, it seems intuitive to believe that supporting family caregivers helps them remain caregivers and therefore keeps care recipients out of long-term care facilities. Depending on a patient's finances, this could keep down the cost of Medicaid for long-term nursing care.

The survey did not ask how respondents were disseminating information about their family caregiver support programs despite the fact that providing such information to caregivers is the first core support service of the National Family Caregiver Support Act. However, 19 state units on aging provided their statewide caregiver assessment tool as part of the evaluation of the NFCSP and its effectiveness. Of those 19 units, only three tracked how caregivers learned about their programs, a rate of just 15 percent.[43] If one of the NFCSP's goals is to increase the provision of information on family caregiver support programs to family caregivers, one would certainly think it important for such programs to learn how their target audiences are finding or not finding them and to adjust their outreach and marketing accordingly. Perhaps one of the conditions for family caregiver programs' receipt of federal funds from the NFCSP should be that they at least track the effectiveness of their outreach.

2. RAISE Family Caregivers Act

On January 22, 2018, the federal Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017 became law.[44] The purpose of the Act is, essentially, to develop and make public a family caregiving strategy[45] that "shall identify recommended actions that federal (under existing Federal programs), state, and local governments, communities, health care providers, long-term services and supports providers, and others are taking, or may take, to recognize and support family caregivers in a manner that reflects their diverse needs."[46] The Act mandates that the Family Caregiving Strategy address six areas:

> (1) Promoting greater adoption of person- and family-centered care in all health and long-term services and

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[39] *Id.* at § 3030s-1(f).

[40] Christine L. Himes & Lillian Kilduff, *Which U.S. States Have the Oldest Populations?* (Mar. 16, 2019), Population Ref. Bureau (PRB), https://www.prb.org/whichusstatesaretheoldest (accessed Oct. 8, 2020).

[41] St. of Fla. Dept. of Elder Affairs, *2019 Summary of Programs and Services: Section B — Older Americans Act Programs* (Jan. 2019), http://elderaffairs.state.fl.us/doea/pubs/pubs/sops2019/2019_SOPS_B.pdf (accessed Oct. 8, 2020).

[42] Genworth, *Cost of Care Survey* (2019), https://www.genworth.com/aging-and-you/finances/cost-of-care.html (accessed Oct. 8, 2020).

[43] Administration for Community Living, *SUA Resource Library: State Caregiver Assessments,* https://acl.gov/sites/default/files/programs/2016-11/State-Caregiver-Assessment.pdf (accessed Oct. 8, 2020).

[44] Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, Pub. L. No. 115-119, §§ 1–6, 132 Stat. 23 (2018).

[45] *Id.* at § 3(a).

[46] *Id.* at § 3(b).

supports settings, with the person receiving services and supports and the family caregiver (as appropriate) at the center of care teams.

(2) Assessment and service planning (including care transitions and coordination) involving family caregivers and care recipients.

(3) Information, education and training supports, referral, and care coordination, including with respect to hospice care, palliative care, and advance planning services.

(4) Respite options.

(5) Financial security and workplace issues.

(6) Delivering services based on the performance, mission, and purpose of a program while eliminating redundancies.[47]

The Family Caregiving Strategy is to be created and published by the Secretary of Health and Human Services in consultation with other federal agencies and the RAISE Family Caregiving Advisory Council, also created by the RAISE Family Caregivers Act.[48] This advisory council is mandated to meet at least quarterly for the first year (the first year beginning on January 22, 2018) and at least three times a year thereafter.[49] The advisory council is also to issue an annual report each year "concerning the development, maintenance, and updating of the Strategy, including a description of the outcomes of the recommendations and any priorities included in the initial report."[50]

Sadly, these statutory mandates have not been met. The first report was to be issued within a year of January 22, 2018.[51] Then, within 18 months of that date (July 22, 2019), the Secretary of Health and Human Services was to issue the initial Family Caregiving Strategy.[52] Unfortunately, the first Family Caregiving Advisory Council meeting did not take place until late August 2019, a year and a half after meetings were supposed to begin and a month after the strategy was to be issued.[53] Although the advisory council had a disappointingly slow start, the council made up for it in 2020 with several meetings.[54] The council intended to issue its first report to Congress in 2020,[55] however, that has been pushed to sometime in 2021.[56] The council did create and adopt 26 recommendations, which will be incorporated into the report to Congress and "serve as the foundation for the National Caregiving Strategy."[57] Because the initial Family Caregiver Strategy is supposed to incorporate the council's report, no initial strategy has yet been issued by the Secre-

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[47] *Id.*

[48] *Id.* at § 3(a).

[49] *Id.* at § 4(c).

[50] *Id.* at § 4(d)(1).

[51] *Id.*

[52] *Id.*

[53] Administration for Community Living, *RAISE Family Caregiving Advisory Council* (last modified Aug. 21, 2020), https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council (accessed Oct. 8, 2020).

[54] *Id.*

[55] Lauren Bangerter & Kelly O'Malley, *RAISE Family Caregivers Act: Progress Toward a National Strategy to Support Family Caregivers* 6 (Apr. 23, 2020), https://acl.gov/sites/default/files/RAISE_SGRG/RAISE%20Family%20Caregiver%20Act_Progress%20Report_23%20April%202020.pdf (accessed Oct. 8, 2020).

[56] Administration for Community Living, *Family Caregiving Advisory Council Final Recommendations* 1 (Nov. 18, 2020), https://acl.gov/sites/default/files/RAISE_SGRG/RAISE%20RECOMMENDATIONS%20FINAL%20WEB.pdf (accessed December 9, 2020).

[57] *Id.*

tary of Health and Human Services. The strategy is supposed to begin development in 2021.[58]

Despite the lack of tangible progress so far, there is hope for what the council can accomplish. Council members appear to have been chosen extremely carefully, incorporating a variety of experience and viewpoints.[59] The federal members represent 14 federal agencies, offering valuable perspective regarding what recommendations are practical and how those federal agencies would implement such recommendations. Only three of the federal members are specifically required by the statute.[60] The remaining 11 members are optional and appointed by the Secretary of Health and Human Services.[61]

The selection of members and the breadth of federal agencies represented suggests the value the federal government places on the council's work and recommendations. During council meetings, which are open to the public, the thoughtful comments and questions of council members indicate that they are well-informed and passionate about their work, critical ingredients if the council is to have a real impact on the lives of family caregivers.[62]

The RAISE Family Caregivers Act has a sunset provision 3 years from January 22, 2018 (January 22, 2021).[63] Congress recently extended the term by 1 year.[64] Given the very slow rate of progress and the intent that a report be issued annually for the original 3-year term, one hopes Congress will extend the deadline again to allow for the full development of the strategy as well as the intended 3 years to report on progress and fine-tune any needed adjustments.

The lack of quick action on the RAISE Family Caregivers Act indicates several problems in the world of family caregiving. First, this area of American life has been the domain of families and local communities for hundreds of years. Only in the past few decades, with increasing longevity, survival of complicated medical conditions that used to be fatal, smaller families, the number of traditional caregivers (women) increasing in the workforce, and families living farther from one another, has family caregiving become an issue needing solutions from the government.

No comprehensive federal program is in place to deal with the family caregiving issue; programs operated by smaller government agencies and nonprofit organizations, created largely in reaction to local community needs, have sprung up when and where needed. Unfortunately, the existing family caregiver support system does not lend itself to being operated by the federal government, or even state governments.

The federal government has a hodgepodge of programs for family caregivers yet no comprehensive list of them![65] The RAISE Family Caregiving Advisory Coun-

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[58] *Id.*

[59] Administration for Community Living, *supra* n. 53.

[60] 132 Stat. at § 4.

[61] *Id.*

[62] Administration for Community Living, *RAISE Family Caregiving Advisory Council: Past Full Advisory Council Meetings* (livestream recordings), https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council, *click on links under* Past Full Advisory Council Meetings in the top box on the right (accessed Oct. 8, 2020).

[63] 132 Stat. at § 6.

[64] Supporting Older Americans Act of 2020, Public L. No. 116-131, 134 Stat. 240 §122(b).

[65] Bangerter & O'Malley, *supra* n. 55, at 6.

cil is working on compiling a list of these federal programs.[66] The federal government cannot even keep track of its own family caregiver programs; therefore, putting the federal government in charge of state, local, and nonprofit programs seems laughable.

In addition, caregiving is primarily a local issue best addressed on the ground by local communities. The caregiver needs of communities are inherently connected to the demographics and infrastructure of each community. For example, ethnicity, age, transportation, and health care options all play a huge role in addressing caregiver needs. Federal support and funding is important, but the federal government simply is not in the position to create an overall national family caregiving strategy to address such disparate needs. The recommendations issued by the RAISE Family Advisory Council illustrate this point. The recommendations are general and broad, as they must be, given the council's intent that they be applied on a national scale. For example, Recommendation 1.3 is to "Improve outreach efforts to family caregivers to ensure early identification and access to services and supports."[67] The author agrees, this is a critical task; but identifying it is the easy part. Figuring out how to accomplish that task is the hard part that the council likely will not and cannot do; it must be done by the local communities because they are in the best position to know what will work in their particular community.

3. Pennsylvania Caregiver Advise, Record, Enable Act and Revised Federal Regulations for Discharge Planning

Although the Pennsylvania Caregiver Advise, Record, Enable (CARE) Act is a state statute and the regulations regarding discharge planning promulgated by the Centers for Medicare & Medicaid Services (CMS) are federal regulations, both impose requirements for health care providers to follow when discharging a patient.

One major obstacle to assisting family caregivers is the lack of discharge planning. Yet federal regulations as well as the Pennsylvania law supposedly set minimum requirements for that very thing. Some big gaps exist in both the federal regulations and the Pennsylvania law, some of which are filled by the other, but significant gaps remain. Some of the gaps are simply not within the purview of health care providers to fill because they do not have the expertise, personnel, or money to do everything and be everything to every patient coming through their doors. This is why health care providers must be partners within the existing family caregiver support system and not the only resource for caregivers. In addition, although federal and state laws are necessary to provide minimum discharge planning requirements, the oversight requirements of these laws are often extremely cumbersome and sometimes burdensome, which does not further the goal of getting families real help. What it does encourage is a race to the bottom of completing the bare minimum that will pass muster during an eventual audit. The focus becomes the paperwork and meeting the minimum requirements rather than truly helping people.

a. Pennsylvania Caregiver Advise, Record, Enable Act

On April 20, 2016, Pennsylvania passed the CARE Act, which took effect 1 year later (April 20, 2017).[68] The

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[66] *Id.*

[67] Administration for Community Living, *supra* n. 56 at 2.

[68] 35 Pa. Stat. § 447.1 (2017).

CARE Act, or some form of it, has been enacted into law in more than 40 states.[69] This state statute could be classified as a good start, but it certainly does not go far enough nor is it comprehensive enough to address all the issues facing family caregivers.

The Pennsylvania CARE Act requires hospitals to give the patient "an opportunity to designate at least one lay caregiver following the patient's entry into a hospital and prior to the patient's discharge to the residence."[70] Note that the Act specifies a discharge to a residence. There is no requirement for a hospital to give the patient an opportunity to designate a caregiver if the patient is not going straight home but instead is going to a rehabilitation or long-term care facility. In addition, there is no indication that hospitals are voluntarily providing this opportunity to a patient who is being discharged to anywhere but home. Even though this might make sense in a vacuum (Why is a caregiver necessary if a patient is being discharged to a place where there are professional caregivers?), reality is not that simple.

Several problems follow patients, particularly elderly patients with complicated medical issues, into rehabilitation and long-term care facilities. First, medications are frequently transcribed incorrectly or not at all, resulting in incorrect medications being administered or medications not being administered in the correct dosage or at all. Having a designated lay caregiver who is given all this information at the hospital creates a better chance of catching medication mistakes early. Second, while less frequent, patients being transported are sometimes transported to the wrong facility. Again, if a lay caregiver were involved, he or she would likely know where the patient is supposed to be transported to, thus avoiding such a mistake or at least catching it early. Lastly, not all facilities are created equal in terms of communicating with caregivers. Caregivers who serve as advocates for family members in rehabilitation or long-term care facilities can't advocate effectively if no one gives them any information.

Another limitation of the CARE Act is that it only applies to patients being discharged from hospitals. There is no similar requirement for patients being discharged from rehabilitation facilities. Approximately 26 percent of hospitalized Medicare patients are discharged to some sort of rehabilitation facility.[71] Although this is not the majority of Medicare patients, it is still a significant percentage — more than 35 million.[72] Common sense also suggests that it represents the patients who are more likely to need help and have issues that are too complicated for their family caregivers to handle when the patients do eventually make it home.

b. Revised Federal Regulations for Discharge Planning

The recently revised federal regulations governing discharge planning for hospitals, home health agencies, and critical access hospitals promulgated by CMS under the Department of Health and Human Services differ from the requirements in

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[69] AARP, *Download Your Free CARE Act Wallet Card* (Apr. 7, 2016), https://www.aarp.org/caregiving/local/info-2017/care-act-aarp-wallet-card.html?INTCMP=AI-MIM-CAREGIVING-WALLETCARD (accessed Oct. 9, 2020).

[70] 35 Pa. Stat. at § 447.3(a).

[71] Rachel M. Werner & R. Tamara Konetzka, *Trends in Post–Acute Care Use Among Medicare Beneficiaries: 2000 to 2015,* 319(15) JAMA, 1616, 1616 (Apr. 2018).

[72] *Id.*

the CARE Act.[73] The federal regulations apply no matter to where the patient is being discharged, whether to home or to any other medical facility or care setting.[74] The regulations do not specify that a caregiver may be designated, but they do include language that discharge planning must involve the patient and his or her caregiver/support person.[75] However, the regulations lack some of the specificity more helpful to caregivers that are included in the CARE Act.

The Pennsylvania CARE Act requires a discharge plan that includes "[a] description of all after-care assistance tasks necessary to maintain the patient's ability to reside at home."[76] Perhaps more importantly, the Act requires the discharge plan to include "[c]ontact information for any health care, community resources, long-term care services and support services necessary to successfully carry out the patient's discharge plan and contact information for a hospital employee who can respond to questions about the discharge plan … ."[77]

By contrast, the federal regulations, as first proposed, encouraged hospitals to be informed of community resources, but the only proposed requirement was for hospitals to consider the "[p]atient's access to non-health care services and community-based care providers."[78] While the proposed requirement did not seem overly prescriptive or burdensome on its face, many commenters disagreed.[79] In the end, the regulators agreed and decided not to finalize that proposed requirement.

Even if the proposed requirement had made it into the final regulations, the problem with both this requirement and the CARE Act is that for most discharge planners, complying with this requirement means simply handing a list of resources to family caregivers and letting them sort it out for themselves. However, when someone goes to the hospital, it is usually because some health crisis has occurred. This is not the time when family caregivers have the time and energy to sort through a list of resources, make phone calls, and find appropriate resources. Most of the time, a caregiver needs help yesterday. This is not to say that hospitals should give patients and their families only one option nor that hospitals should go over every single option in detail, but there must be a middle ground that still gives families options while saving them some time and frustration.

B. Needed Family Caregiver Support Improvements

Health care providers can improve family caregiver support by doing the following.

1. Keeping Family Caregiver Resource Lists Up to Date

At a minimum, lists of family caregiver resources should be kept up to date[80] and

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[73] 42 C.F.R. §§ 482.43, 484.58, 485.642.

[74] *Id.*

[75] *Id.*

[76] 35 Pa. Stat. at § 447.5(a)(4)(ii).

[77] *Id.* at § 447.5(a)(4)(iii).

[78] Medicare and Medicaid Programs; Revisions to Requirements for Discharge Planning for Hospitals, Critical Access Hospitals, and Home Health Agencies, and Hospital and Critical Access Hospital Changes to Promote Innovation, Flexibility, and Improvement in Patient Care, 80 Fed. Reg. 68125, 68132 (proposed Nov. 3, 2015) (to be codified at 42 C.F.R. pts. 482, 484, 485).

[79] 84 Fed. Reg. 51836, 51852 (Sept. 30, 2019).

[80] Next Step in Care, United Hospital Fund, *Referring Patients and Family Caregivers to Community-Based Services: A Provider's Guide*, https://www.nextstepincare.org/next_step_in_care_guides/294/Community_Based_Services

be as comprehensive as possible. It seems basic, but so many families receive lists with resources no longer operating or with incorrect phone numbers. Many lists draw from only one source, such as the local area agency on aging. But that agency's list might include only resources that contract with the agency, thus excluding others. Also, the features of each resource should be noted, such as the geographic area served, services provided, and medical coverage accepted. Even including basic notes about resources on these lists can eliminate a lot of frustration and wasted time by keeping family caregivers from reaching out to resources that cannot accommodate their needs.

Creating and maintaining such lists, however, should not be the responsibility of health care providers. They already have numerous responsibilities; this should not be another. One commenter noted that "while these services may benefit the patient, hospitals cannot be expected to provide an exhaustive list of services and … the hospital has limited reliable methods to identify non-health care resources in the community."[81] If, however, health care providers do create and maintain such lists, they should pass them on to patients and their families.

2. Consulting With the Patient and Family Caregiver on Patient's Nonmedical Needs

Another critical, but often overlooked, component of discharge planning is consultation with both the patient and family caregiver on nonmedical needs that nevertheless impact the patient's health. Hospitals focus so much on ongoing medical needs that other needs are frequently overlooked. But in the face of increased medical needs, it is often those general needs that become overwhelming or unmet, which adversely affects the patient's care and well-being. For instance, housekeeping and home maintenance might be tasks that were the responsibility of someone who can no longer do them. When carrying out discharge planning, all the needs of the patient's household must be taken into consideration. Health care providers can determine these needs by simply going through a checklist with patients and their families. Then appropriate referrals can be made.

3. Providing Information on Family Caregiver Resources to Caregivers in a Timely Manner

Timely distribution of information on family caregiver resources to family caregivers is another area of failure in discharge planning. There is no requirement directing when this information must be given to patients and their families. Many are given this information only a day or two before discharge and sometimes not until discharge. If families are expected to make informed after-care decisions, they must be given as much time as possible to meet with resources to line up care. This is not something that can be accomplished in 24 hours or less. Understandably, it is sometimes difficult to provide information in advance because patients' needs are usually fluid. However, sometimes it is clear that a patient, particularly an elderly patient, will need more medical care after being discharged from the hospital and that the only delay is getting the patient stable and finding him or her a space somewhere. In such cases, information on resources easily could be given shortly after admission.

(accessed Oct. 9, 2020).

[81] 84 Fed. Reg. 51836, 51852.

IV. A Way Forward

It is clear that there is a multitude of government and nonprofit programs that support family caregivers. Gaps in laws regulating discharge planning always will be likely; however, the fact that many family caregivers do not receive support does not stem from a lack of programs and services. In addition, waitlists for services are not excessive. The Lewin Group study reported that the longest waitlists were for respite care, and approximately 75 percent of families on waitlists were receiving other services.[82] This data appears to indicate that, although further resources are still needed, lack of these resources is not the primary obstacle facing family caregivers.

As I have asserted throughout this article, we are failing caregivers for various reasons. Many have no idea that programs and services to help them exist because we are not reaching them with information on these resources. And even when we do reach them, the programs and services are so disconnected from one another that navigating them is just one more chore family caregivers must undertake in addition to their endless list of caregiving duties.

The essentials for solving this issue are already in place through existing family caregiver programs and services; therefore, we need to capitalize on the unrealized potential existing laws. NFCSP should get more funding. A budget of less than $200 million per year for the entire nation is meaningless, particularly when stacked up against the estimated savings to the government of informal family caregiving.[83] The purpose of this funding would be twofold: to increase public outreach and improve caregivers' access to information through (1) education and training of local partners and (2) creation of a national clearinghouse of information on programs and services.

A. Education and Training of Local Partners

Education and training of local partners would simply involve making presentations to partners likely to assist the target population. Although many area agencies on aging are already doing this, either they are not doing it enough or they are not choosing the correct partners because better access to information on family caregiver resources is still not being provided.

As I noted previously, partnerships with health care providers are critical. Health care providers are on the front lines, where people who need the most help — family caregivers and their family members who need care — are going to be seen. Health care partners should include hospitals, certainly, but also rehabilitation, nursing home, assisted living, and adult day care facilities, even primary care doctors. These partners should make sure that family caregivers are going to get the information they need and are kept from falling through the cracks simply because their family member doesn't go straight home from the hospital, a stipulation that represents a giant gap in the CARE Act at the moment.

Additionally, when a family member leaves the hospital and transitions to a

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[82] Lewin Group, *supra* n. 9, at 62–63.

[83] Estimates of the dollar value of unpaid caregiving vary widely depending on the methodology used to calculate them but range from approximately $150 billion or more to more than $400 billion. Carol V. O'Shaughnessy, *Family Caregivers: The Primary Providers of Assistance to People With Functional Limitations and Chronic Impairments* 10, Natl. Health Policy Forum (Jan. 2013).

rehabilitation or skilled nursing facility, families aren't always ready to start thinking about the next step. Even if information on family caregiver resources is given to caregivers at the hospital, such information could simply be added to their giant stack of paperwork at home that can wait because it's not of immediate concern and is then forgotten about promptly. By making the information available earlier, families receive the information when they are more likely to pay attention to it and act on it. Moreover, providing information early serves as a small, but not overwhelming, reminder to families that when they are prepared to think about what comes next, they will know that resources exist, which is certainly better than the situation in which families don't even know that help exists.

Another consideration in terms of education and training of local partners is to make sure that those partners are aware of all local programs and services and know how to help family caregivers access them. This could be as simple as making sure that local partners can call the local area agency on aging to get a list of programs and services and their eligibility requirements or go to a website to obtain such information.

B. Creation of a National Clearinghouse of Information on Family Caregiver Resources

It is too soon to determine the successes and failures of the RAISE Family Caregivers Act and how it can be improved. However, the task underway to create a comprehensive, up-to-date website to serve as a national clearinghouse of information on family caregiver resources would perhaps be the Act's greatest accomplishment. If this task is successful, additional federal funds for local clearinghouses would be unnecessary.

In order for the website to be a meaningful source of information, it must accomplish several things. First, it must be searchable by local area because family caregivers need information on resources in their area. Resources and their eligibility requirements differ not only across the nation but also county to county. No caregivers are helped by a list of resources outside their geographic area.

Second, the searchability and filter features must be as extensive as possible so that family caregivers are not overwhelmed by a list of resources that don't apply to them. The information must be as detailed and clear as possible to let caregivers determine at a glance whether a resource is worth following up on or does not apply to their situation. Caregivers should not have to click through multiple links before discovering that the resource in question is for men only and the person in need is a woman.

Third, and most importantly, the website must be as expansive as possible to include information on most, if not all, resources, and it must be kept up to date. The website cannot simply list programs and services offered by local area agencies on aging or other government agencies. It must include programs and services offered by nonprofit organizations. It must provide a link to each distinct program or service, not just a link to an agency's or organization's website, thus forcing family caregivers to do all the time-consuming research to locate needed information. The website must do the research for them. Otherwise, the website will be no better than the current family caregiver support system. Moreover, new programs and services must be added and obsolete ones deleted in a timely manner, otherwise, once again, the website will be no better than the current system.

C. What Else Can Be Done?

To summarize, the NFCSP and the RAISE Family Caregivers Act give us, or could give us, the tools family caregivers need. They give us the potential for creating a more comprehensive, usable source of information on family caregiver programs and services across the board along with their eligibility criteria. They give us the funding and structure needed to formulate more directed efforts to help family caregivers at the local level. However, what neither the NFCSP nor the RAISE Family Caregivers Act gives us, and what the CARE Act also fails to provide, is an incentive for health care providers to help family caregivers or a penalty for failing to help these caregivers. Neither the NFCSP nor the RAISE Family Caregivers Act requires tracking of outcomes or follow-up of any kind.

Although health care providers may have no malicious intent when they fail to help family caregivers, the fact is that in the world of family caregiving, there is never enough time, enough staff, or enough money, and things slip through the cracks. Programs and services for family caregivers will not improve if we don't know where the problems and the gaps are. For example, the caregiver assessment tool for Washington, D.C., contains one page that simply asks the interviewer whether he or she thinks the caregiver will take some action.[84] That's it. No requirement to follow up to verify whether the caregiver followed up, just the interviewer's best guess, which tells us nothing.

The data is clear that informal family caregiving serves the public good. It saves our country money,[85] it supplements our health care and caregiving industry with a much-needed labor force, and many families obtain emotional satisfaction from caring for a family member.[86] It is in our national interest, therefore, to promote and support family caregivers. What we have now is not working; we must do something more.

1. Hospital Readmissions Reduction Program as a Blueprint

As part of the Affordable Care Act passed in 2010, the Secretary of Health and Human Services was required to implement the Hospital Readmissions Reduction Program starting October 1, 2012.[87] This program reduces payments to hospitals experiencing excessive patient readmissions.[88] According to CMS, one of the reasons this program is important is that it gives "hospitals an incentive to improve communication and care coordination so patients and caregivers are more involved in post-discharge planning."[89] The program does not seem to have accomplished this goal and instead simply incentivizes hospitals to use observation status. However, by combining the penalties assessed by this program with the structure of the CARE Act, perhaps we can create the perfect vehicle for implementing my proposal for a more robust system for supporting family caregivers

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[84] Administration for Community Living, *supra* n. 43, at 7.

[85] *See* O'Shaughnessy, *supra* n. 83.

[86] Peter S. Arno, Carol Levine & Margaret M. Memmott, *The Economic Value of Informal Caregiving,* Health Affairs, 182, 186 (Mar./Apr. 1999).

[87] Ctrs. for Medicare & Medicaid Servs., *Hospital Readmissions Reduction Program (HRRP)* (last modified Aug. 11, 2020, 9:44 a.m.), https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/HRRP/Hospital-Readmission-Reduction-Program (accessed Oct. 9, 2020).

[88] *Id.*

[89] *Id.*

through hospitals and doctors and tying such support to Medicare payments by funding such support, assessing a penalty for failing to do so, or both.

2. Assistance on the Front Line

Health care facilities are on the front line of informing the public about family caregiver resources for the simple reason that they are most likely to encounter the target population. These facilities should not be responsible for creating or maintaining lists of information on family caregiver resources but simply for getting the information out there.

To help cut down on the amount of legwork imposed on family caregivers, health care staff should help screen patients to ensure that they meet program or service eligibility requirements. For this reason, I propose that hospitals be given funding to pay for at least one dedicated staff person to counsel families and assist with eligibility screening for family caregiver support programs and services. As part of that funding, tracking and follow-up should be required to better understand caregivers' needs and outcomes. If the federal government funds this effort, hospital care coordinators/discharge planners would less likely be subject to the pressures and conflicting directions that plague them (i.e., pressures to get patients out the door but still to a safe and medically appropriate location).

V. Conclusion

Either in conjunction with existing state and federal laws or with a new set of laws, I propose taking the good start made by the CARE Act further and giving the Act teeth. In addition, I propose increasing funding and outreach to build on the foundation created by the NFCSP and the resources created by the RAISE Family Caregivers Act. Family caregivers should be identified not only by hospitals but also by rehabilitation and long-term care facilities, even doctors' offices. This should be done as soon as possible during the patient's stay in a facility, not left until the day before discharge.

Discharge planning should consist of counseling patients and their families to determine their needs and guiding them through the options for meeting those needs. Discharge planning should be individualized and not simply consist of handing over a list every family caregiver resource in the community, whether applicable or not. Multiple follow-ups should take place to make sure families have the support they need. Hospitals and other health care facilities have been absorbing the costs of the extra staff time involved to provide this support, which is perhaps why support is often brief or only consists of providing resource lists instead of having one-on-one discussions with patients and their families and listening to their needs.

Medicare or some other federal or state program should pay for the staff necessary to provide family caregiver support. Regulations should be created to lay out minimum requirements for what discharge planning and family caregiver support should look like, the questions that should be asked, and the follow-up to be done. Health care facilities that do not follow these requirements should have an incentive to do so or be assessed some sort of penalty, either tied to Medicare payments or to some other regulatory mechanism. Only by motivating busy health care providers can we hope to achieve the goals of informing and counseling stressed and overwhelmed family caregivers to enable them to access the support resources they need.