

Spotlight

From *Home Alone* to the CARE Act: Collaboration for Family Caregivers

Susan C. Reinhard
AARP Public Policy Institute

Elaine Ryan,
AARP State Advocacy and Strategy Integration

The 2012 report *Home Alone: Family Caregivers Providing Complex Chronic Care* broke new ground by uncovering the complex medical/nursing tasks that family caregivers are performing with little guidance or support. The Caregiver Advise, Record and Enable (CARE) Act rapidly translated that research into state policies across most of the nation—with 39 states and territories having enacted it thus far, in just three years. The swift speed of this policy adoption signals a recognition by state policymakers of significant unmet family caregiver needs. Now, the Home Alone AllianceSM is focusing on moving policy into practice by identifying innovative practices and creating instructional resources for family caregivers and the professionals who support them.

Introduction

Decades of research document the extensive care and support that family members, neighbors, and friends give to people who have long-term or chronic health needs.^{1,2,3} Most of this research, however, focuses on the personal care and household chores that these family caregivers provide, such as shopping, cooking, bathing, dressing, and many other activities of daily living (ADLs) and instrumental activities of daily living (IADLs) delineated more than half a century ago as falling within the family caregiver's inventory of potential tasks.⁴

Missing from that inventory has been the complex care tasks that family caregivers are expected to do, specifically medical/nursing tasks. Medical/nursing tasks include managing multiple medications,

administering injections, performing wound care, and managing special equipment, among many others. These tasks are the types of duties that nurses and other health care professionals were professionally trained to perform.

In search of a better understanding of the family caregiver's complete job description, the AARP Public Policy Institute (PPI) and the United Hospital Fund (UHF) undertook the first national study of family caregivers to determine what types of medical/nursing tasks they perform and how frequently they perform them. Funded by The John A. Hartford Foundation, *Home Alone: Family Caregivers Providing Complex Chronic Care* (known as *Home Alone*) was a nationally representative population-based online survey that found that almost half (46 percent) of



**Public Policy
Institute**

For more information on this article, please [visit the Public Policy Institute Web site](#). To learn more about the Home Alone AllianceSM, visit www.aarp.org/nolongeralone.

family caregivers perform these tasks.⁵ *Home Alone* brought widespread attention to the huge gap between what family caregivers are expected to perform and the instructions and guidance provided to them. It documented their fears of making a mistake or hurting their family members.⁶ By putting a spotlight on these significant unmet needs, this research tapped into something powerful in the lives of millions of family caregivers across the country.

Translating Research into State Policy across the Nation

Home Alone is a powerful example of research driving policy and ultimately transforming practice. When it was released in October 2012, the reaction from researchers, the media, and advocates was immediate and widespread. The term “medical/nursing tasks” put a name on something that people understood at a personal level. They were either doing these tasks themselves, or they knew someone else who was expected to do them. They had their own stories, their own experiences. And they were relieved to know they were not alone, that there was validation of the complexity of their work, and that their anxieties in doing the clinical work that professionals do was shared by other family caregivers.

This strong reaction to the *Home Alone* report findings from such a broad base of individuals and organizations was a call to action to provide greater supports for family caregivers and those they care for. With repeated input from caregiver organizations and experts at the state and national levels, the AARP State Advocacy and Strategy Integration (SASI) team translated the *Home Alone* findings into model state legislation in the form of the Caregiver Advise, Record, and Enable (CARE) Act. In May 2014, Oklahoma became the first state to make the CARE Act law. Less than three years later, it is law in 39 states and territories as of July 2017. Several other states continue to consider it in 2017 (see Figure 1).

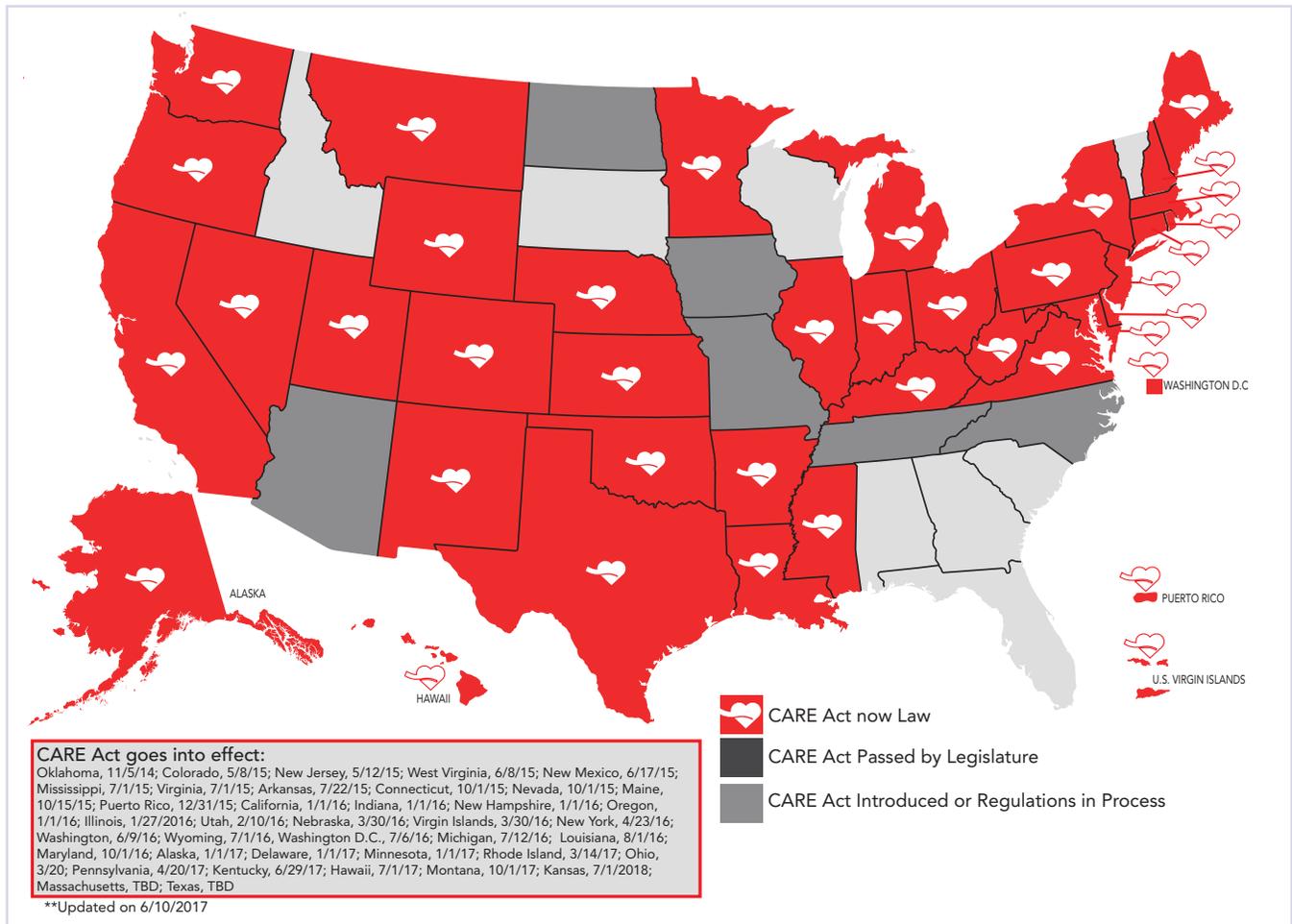
When developing the CARE Act model bill, AARP focused on the need to acknowledge the critical role of family caregivers who are on the front lines of the health care team, yet have little knowledge of how to perform the wide array of complex tasks they are asked to perform in the home. It put in place simple rule changes in hospital

admission and discharge practices. Specifically, AARP targeted three key areas for change. First, caregivers need more visibility, not only during the admission process, but also throughout the family member’s hospital stay. Second, family caregivers need adequate notice prior to the hospital discharge so that they can purchase the necessary medical supplies and food, arrange time off from work or arrange care if needed, and make other home preparations. Third, family caregivers need simple instruction on the medical/nursing tasks they will be performing at home. Family caregivers are often handed paperwork on discharge day with little or no explanation of the actual tasks.

The CARE Act was specifically crafted to address the gap between what professionals expect family caregivers to do and what guidance they receive to get it done. While the specific provisions of the law vary from state to state, the CARE Act generally requires hospitals to provide patients (of any age or diagnosis) an opportunity to identify a family caregiver. If the patient identifies a caregiver, that individual’s name and contact information is recorded in the hospital’s health record. The hospital is required to notify the family caregiver as soon as possible when the individual will be discharged or transferred to a facility (such as a nursing or rehabilitation facility)—and offer consultation about the discharge plan and the caregiver’s role in that plan.

Most important, the hospital must offer the family caregiver instructions on how to perform the medical/nursing tasks that are included in the discharge plan and answer questions about those tasks. A family caregiver can be a relative, neighbor, partner, or friend—anyone the patient identifies as the person(s) who will be assisting with care post-discharge, particularly medical/nursing tasks. Patients are not obligated to identify anyone as their family caregiver, and individuals are not obligated to perform these tasks if designated as the family caregiver. Rather, the CARE Act requires hospitals to make sure patients and families have the opportunity to receive the information and instruction they need to ensure smooth hospital discharges and care transitions.

FIGURE 1
States with the CARE Act Enacted or under Consideration, July 2017



Not surprisingly, the CARE Act’s focus and spirit have resonated with people. In AARP survey research conducted at both national and state levels, the results consistently have shown strong bipartisan support for the CARE Act provisions, and those findings have bolstered efforts to move forward in the states.⁷ The CARE Act became the centerpiece of a multiyear, multistate, and multifaceted Family Caregiving campaign within AARP.

AARP state offices in Oklahoma and New Jersey established the strategic foundation for enacting the CARE Act. Each office secured strong legislative sponsors, engaged members in advocacy, and used the personal stories of volunteers who shared how they could have benefited from the CARE Act. In Oklahoma, the CARE Act was sponsored by a

Republican senator who had a personal experience with family caregiving for his father. Indeed, the majority of the bill sponsors of the CARE Act across the country were moved to introduce the legislation because they considered it to be a common sense solution to provide some basic supports to family caregivers. In New Jersey, the bipartisan group of sponsors included the speaker of the assembly, who made the bill a priority. Because of these strategies, both bills received near unanimous approval by the states’ legislative bodies.

Also indicative of the legislation’s resonance, strong media coverage helped advance the CARE Act in each state as well. The “PBS News Hour” covered the Oklahoma consideration of the bill, featuring family caregivers in Oklahoma who struggled with

providing complex care for their family members.⁸ In New Jersey, state publications repeatedly ran stories about the need for and value of the CARE Act.⁹

The enactments in 2014 sent a strong signal to states around the nation that the CARE Act could bridge the partisan divide to set in statute certain common sense supports for family caregivers. In 2015 advocacy by AARP state office staff and volunteers resulted in the enactment of the CARE Act in an additional 17 states and territories; 16 more states followed in 2016, for a total of 35 states and territories in two years. Thus far in 2017, four more states joined in this state-by-state national movement, bring the count to 39 in three years.

It is rare for research to diffuse into policy across more than two-thirds of America in such a short time. Policy usually moves more slowly. Several factors played into this rapid movement. First, the research made sense to people: “Yes, this is a big problem for me and/or for many people I know.” Second, the simplicity of the legislation to clearly meet the newly revealed, substantiated unmet needs of family caregivers was significant. The common response was “Really, this isn’t already required?” And the honest answer was “No.” Third, the passion of volunteer advocates was unrelenting at a local level, where the policy makers live. And finally, this was never seen as a political or partisan issue. It was seen as an “every person” issue.

It is also important to emphasize that the development of the CARE Act was a collaborative process in every state. AARP state offices sought input from and worked closely with a wide network of stakeholders. Depending on the state, this collaboration involved legislators, disease-specific advocacy groups such as the Alzheimer’s Association, the American Cancer Society’s Cancer Action Network, aging services providers, nursing associations, and state hospital associations. These stakeholders helped to tailor the bill language to fit the state environment. In some states, the hospital association initially opposed the bill and would not join discussions. Typically, they claimed, “we already teach family caregivers, so there is no need for this bill.” But thanks largely to the strong and persistent voices of consumers who were eager to

tell their personal stories to their state legislators, their thinking evolved. And, indeed state legislators themselves drew from their own personal experiences as family caregivers. Moreover, in many other cases, the hospital associations saw an opportunity to recognize the contributions of family caregivers, showcase the promising practices of their member hospitals that were already supporting caregivers, and bring all hospitals in the state up to a new standard of care.

As a result of this close collaboration, each state’s CARE Act is unique. While the core provisions—recognition, notification, and instruction—remain largely intact, each of the resulting laws employs language customized to best meet its own regulatory and political environments. For example, several western states (Oregon, Washington, Hawaii, and Alaska) took a similar approach. They minimized the bill language, set forth clear objectives that hospitals must meet, and gave hospitals the discretion to develop policies to meet those objectives.

In a creative deviation, Utah did not take the legislative route to implement the CARE Act, instead implementing it through administrative action. In doing so, AARP Utah worked closely with officials at a state agency, the state hospital association, and other stakeholders to develop regulatory language. The rule was drafted, opened for comment, and finalized in 2016. Other states are starting to see value in this approach and two (Arizona and Tennessee) are currently developing regulations for promulgation.

Many of the changes to the model bill have been enhancements to the original language. For example, the New Jersey CARE Act provides flexibility for family caregivers to select whether they want to receive a live demonstration or view an instructional video. It also requires the hospital to provide a phone number for the caregiver to call for additional information after they go home. And in Delaware, the bill specifically ties the recording of the caregiver’s name to the patient’s electronic medical record and the state’s Health Information Network.

With additional states continuing to pursue the enactment of the law in 2017, the CARE Act continues to stand as the centerpiece of a multiyear,

multistate family caregiving effort. And in those states that already have the law in place, AARP and other stakeholders are working to ensure that the laws are effectively implemented; that family caregivers, providers, and regulators are aware of the CARE Act; and that they know how to utilize it and ensure the benefits of a transformative new policy that sprang forth from the *Home Alone* report.

Moving from Research and Policy to Practice

Given the rapid translation of research to policy, the Public Policy Institute is moving forward on three fronts to accelerate changes in practice:

- Conducting a national scan of how states, hospitals, and health systems implement the CARE Act to uncover innovative and promising practices
- Developing consumer-friendly, evidence-based resources for family caregivers and the clinicians who support them, particularly instructional videos
- Creating the Home Alone AllianceSM to spark widespread culture change

These three collaborative initiatives are closely intertwined and are intended to leverage the expertise and actions of many family caregiving experts, thought leaders, and organizations. They are also focused on rapid diffusion of innovation at the system and local levels, where family caregivers often both experience their challenges and seek help.

Scanning the States for Innovation

The CARE Act legislation creates an opportunity for hospitals to integrate the support of family caregivers throughout their systems. In many cases, there is a need to change how professionals interact with family caregivers. While the goal is to change practice across settings, the CARE Act focuses on hospitals and health systems.

In the fall of 2016, the Public Policy Institute began a national scan of the implementation of the CARE Act. Based on recommendations from a distinguished group of advisers, research teams led by nurse researchers conducted pilot site visits in several hospitals in New Jersey and New York to

gain a better understanding of how health systems implement the tenets of the CARE Act into hospital policies and change practice. Simultaneously, the AARP SASI team collaborated with AARP's state offices to determine how state governments provide oversight and how consumers learn about their rights under the law.

The goal is to conduct a full national scan focusing on implementation strategies and to identify and rapidly disseminate innovative and promising practices. By conducting on-site interviews with a cross-section of hospital staff and family caregivers, the Public Policy Institute's research teams are developing qualitative information on challenges, learnings, and potential promising practices. There is a strong focus on the need to address multicultural family caregiving and implementation issues in rural and urban settings as well as academic and community hospital environments. Interviews will also be conducted with key state stakeholders (e.g., AARP state offices and other consumer advocacy organizations, professional groups, hospital associations). These conversations will help achieve a clearer and more holistic view of the law's implementation across the state, assess stakeholder awareness of the CARE Act, and potentially identify opportunities for further stakeholder engagement with the law moving forward.

Early learnings from the 2016 pilot site visits include the following:

- Multiple hospital staff and leadership reported that while they initially thought "we already do what the CARE Act requires," the implementation process allowed them to standardize how their respective hospitals interact with family caregivers throughout the discharge process.
- Individual hospitals and health systems have begun certain processes or initiatives that show promise and could scale nationally. One hospital, for example, expanded its call center capacity to create a 24/7 toll-free line for family caregivers to call for support post-discharge. Registered nurses staff the phones and either provide support immediately or forward requests to expert nurses or physicians and follow up with caregivers in short order.

- One hospital provided insight into the training need for hospital registrars who begin the admission process to differentiate among the “next of kin,” “guardian,” or “family caregiver” who may be the same person or two or three different people. The CARE Act is directed to the person who will be giving the actual care.

In addition to publishing and broadly communicating promising practices that could fuel both expedited and high-quality implementation across the nation, this scan seeks to inform interdisciplinary training for health system professionals on identifying, communicating, instructing, and supporting family caregivers throughout a hospital stay and when they are back in the community.

Developing Tools for Family Caregivers

After an extensive search for resources that help guide family caregivers on how to perform a range of complex medical/nursing tasks, the dearth of such help became evident. In collaboration with the Betty Irene Moore School of Nursing at the University of California, Davis, the United Hospital Fund, and the Family Caregiver Alliance (the “founding partners”), we convened experts in the fields of family caregiving, instructional technology, adult learning, and clinical practice. The consensus was that there was a need for a set of guiding principles for developing instructional videos for family caregivers as a starting point.

Focus groups with family caregivers revealed how family caregivers say they learn best through video instruction, providing “dos and don’ts” for how to create video resources.¹⁰ Based on these guidelines, we developed a pilot series of videos focused on helping family caregivers learn how to administer medications, including injections.¹¹ These videos emphasize caregivers seeing themselves learning how to perform a task, rather than seeing only a professional demonstrating it. They capture the sense of anxiety that lay people experience, but emphasize empowerment in learning how to do what they will be doing for their family member. The videos also feature depictions of multicultural caregivers learning in both hospital and home settings. In March 2017 we released a second video series instructing family caregivers on mobility

tasks, in partnership with the US Department of Veterans Affairs.¹² In an effort to provide culturally competent resources, most of the videos are available in Spanish, and these in-language videos reflect Hispanic cultural norms.

Going forward, through the support of the Home Alone AllianceSM discussed below, the goals include the following:

- Collaborating with members of the Home Alone AllianceSM to produce several series of instructional videos to include more on medication administration, wound care, peritoneal dialysis, and other medical/nursing tasks
- Producing videos that feature male caregivers, millennials, and other under-represented caregivers; 40 percent of caregivers are men and one in four are millennials¹³
- Prioritizing a multicultural focus with in-language productions, particularly in Spanish
- Collaborating with schools of nursing and other disciplines to adapt these videos for training professionals to better instruct and support family caregivers providing complex care

Creating the Home Alone AllianceSM to Spark Culture Change

In December 2016 the Public Policy Institute formally launched the Home Alone AllianceSM in collaboration with its founding partners (Figure 2). The HAA brings together collaborators from the public, private, and nonprofit sectors as a catalyst for change in the way health care organizations and professionals interface with family caregivers.

As the hub of research, outreach, convenings, and resource development, the HAA will be a focal point for coordination, idea generation, and collaboration among stakeholders committed to supporting family caregivers engaged in complex care (Figure 3).

Between the initial *Home Alone* report, the success of enacting the CARE Act in more than two-

To learn more about the Home Alone AllianceSM and to access the instructional videos, visit www.aarp.org/nolongeralone.

FIGURE 2
Home Alone AllianceSM Members

American Journal of Nursing
Atlas of Caregiving
Betty Irene Moore School of Nursing at UC-Davis
Center to Advance Palliative Care
Coalition to Transform Advanced Care
Easterseals
Family Caregiver Alliance
Hartford Institute for Geriatric Nursing
Home Instead Senior Care
The John A. Hartford Foundation
National Alliance for Caregiving
National League for Nursing
Nurses Improving Care for Healthsystem Elders (NICHE)
NYU Rory Meyers College of Nursing
Rosalynn Carter Institute for Caregiving
United Hospital Fund
US Department of Veterans Affairs

FIGURE 3
The Home Alone Alliance'sSM Work



thirds of the country in a short period of time, and creating an initial set of resources for family caregivers, AARP and its colleagues have made significant advancements in supporting family caregivers who perform complex medical/nursing tasks. But there is still more work to be done. We need to attain a better understanding of how health systems are implementing the CARE Act, for example, to identify and diffuse promising practices, to inform training of nurses and other clinicians, and to see where gaps remain. In addition, there is still much to learn about the broad range of family caregivers who perform complex medical/nursing tasks. Finally, we need to continue to further develop and refine resources, including instructional content, that directly support family caregivers performing these complex tasks.

By meeting each of these needs, the Home Alone AllianceSM seeks to improve care for individuals supported by family caregivers. Through integrating research and resource development and supplementing these with convenings and outreach, the HAA intends to catalyze sustainable change in how professionals in health systems interact with and support family caregivers, especially those performing complex medical/nursing tasks. The network of the current 15 HAA members runs deep into environments and systems that reach clinicians, providers, educators, family caregiver organizations, faith-based communities, multicultural communities, and policymakers. This alliance is committed to fueling a national culture change in how to better support those who are the very core of health and long-term services and supports—family caregivers.

Acknowledgments: The authors gratefully acknowledge the substantial contributions of many of our colleagues to this Public Policy Institute Spotlight. We are especially grateful to Rita Choula, Brendan Flinn, Jean Accius, Lynn Friss Feinberg, Jordan Green, Julie Alexis, Ilene Henshaw, James McSpadden, and Glen Fewkes.

- 1 Freedman, V. A., and B. C. Spillman, "Disability and Care Needs among Older Americans," *Milbank Quarterly* 92, no. 3 (2014): 509–41.
- 2 Bakas, T., J. K. Austin, S. L. Jessup, L. S. Williams, and M. T. Oberst, "Time and Difficulty of Tasks Provided by Family Caregivers of Stroke Survivors," *Journal of Neuroscience Nursing* 36, no. 2 (2004): 95–106.
- 3 National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America* (Washington, DC: The National Academies Press, 2016). doi: 10.17226/23606.
- 4 Reinhard, S., "The Work of Caregiving: What Do ADLs and IADLs Tell Us?," in *Family Caregivers on the Job: Moving beyond ADLs and IADLs*, edited by Carol A. Levine (New York: United Hospital Fund of New York), 37–65.
- 5 S. Reinhard and C. Levine, *Home Alone: Family Caregivers Providing Complex Chronic Care*, AARP Public Policy Institute, October 2012, <http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>
- 6 S. Reinhard and C. Levine, *Home Alone: Family Caregivers Providing Complex Chronic Care*, AARP Public Policy Institute, October 2012, <http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>
- 7 AARP Research surveyed voters in several states, all of whom expressed strong support for the CARE Act. Recent examples of these surveys include those for Hawaii, Iowa, Massachusetts, Missouri, Nevada, South Dakota, and Washington.
- 8 "Easing the Burden of Long-Term Medical Demands for Family Caregivers," PBS Newshour, April 2014, <http://www.pbs.org/newshour/bb/advocating-care-home-caregivers/>
- 9 Livio, S., "N.J. Legislature Approves Bill Requiring Hospitals to Teach Family How to Care for Discharged Patients," September 2014, http://www.nj.com/politics/index.ssf/2014/09/nj_hospitals_would_have_to_teach_family_how_to_care_for_patient_after_hospital_discharge.html
- 10 S. Reinhard and C. Levine, "It All Falls on Me," AARP Public Policy Institute, September 2016, http://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1078_FamilyCaregiver_SpotlightSep6v5.pdf
- 11 S. Reinhard, et al., "Family Caregiver's Video Guide to Managing Medications," AARP Public Policy Institute, 2016, <http://www.aarp.org/ppi/info-2016/family-caregiver-video-guide-to-managing-medications.html>
- 12 J. Graham, "Video Help Is on Way for Family Caregivers Who Must Draw Blood or Give Injections," Kaiser Health News, 2016, <http://khn.org/news/video-help-is-on-way-for-family-caregivers-who-must-draw-blood-or-give-injections/>
- 13 S. Reinhard and G. Hunt, *Caregiving in the United States 2015*, AARP Public Policy Institute, 2015, <http://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html>

Spotlight 28, August 2017

© AARP PUBLIC POLICY INSTITUTE
601 E Street, NW
Washington DC 20049

[Follow us on Twitter](#)
[Follow us on Facebook](#)
[Visit our Web site](#)

For more reports from the Public Policy Institute, [visit the Public Policy Institute Web site.](#)



**Public Policy
Institute**