

# MEDICAID WORK REQUIREMENTS

The Impact on Family Caregivers and Older Adults

A look at how Medicaid work requirements make it harder for family caregivers to meet their health care needs and a state-by-state survey of work requirements and caregiving exemptions.





ISSUE BRIEF • NOVEMBER 2018

Natalie Kean, Staff Attorney, Justice in Aging

### INTRODUCTION

Millions of Americans help take care of family, friends, and neighbors who are sick, have a disability, or need help at home as they age. Unpaid family caregivers provide the majority of long-term services and supports to older adults and others living in the community who need assistance with activities such as getting out of bed, eating, bathing, dressing, transportation, or going to the doctor. An estimated 40 million Americans provide care to an adult with limitations in daily activities, and nearly one-quarter provide over 40 hours of care per week.<sup>1</sup>

Balancing work and these caregiving responsibilities is difficult, even under the best of circumstances. Many family caregivers who are also employed lack the flexibility in their employment needed to handle emergencies as well as routine caregiving responsibilities. Additionally, many low-wage jobs are seasonal or do not provide stable hours. For those who do not have the option of taking time off with pay, balancing work and family responsibilities can be nearly impossible. In addition, family caregivers are often older adults themselves and may experience additional barriers to employment and burdens from caregiving responsibilities.

Given these challenges, Medicaid is a critical source of support for low-income family caregivers who would otherwise lack insurance coverage and the means to access the health care they need to support their own well-being. However, numerous states are currently implementing or considering restrictions on Medicaid coverage such as requiring eligible individuals to work or participate in "community engagement" activities. This issue brief looks at how imposing work requirements creates additional hurdles that family caregivers must overcome to get and maintain their Medicaid coverage.

### Why Does Medicaid Matter to Family Caregivers?

Medicaid is a lifesaver for individuals who have to cut back their hours or leave the workforce to care for an older family member or friend. Family caregivers are less likely than non-caregivers to have access to

health insurance through a job or spouse because they are more likely to be out of the workforce or working in part-time, lowwage jobs that do not offer benefits.<sup>2</sup> In fact, for those Medicaid enrollees under 65 who are not working, having caregiving responsibilities is a primary reason why they don't work outside the home.<sup>3</sup> Furthermore, more than 4 in 5 family caregivers are under age 654 and are therefore not likely eligible for Medicare. Thus, Medicaid is an important source of health insurance coverage for many family caregivers who do not have access to other affordable coverage options.



have a health condition or limitation affecting their daily life

Medicaid is critical to helping low-income caregivers take care of their own health while they care for loved ones. A recent poll shows that almost 40% of family caregivers have a physical or mental health condition or a physical limitation that affects their daily life and activities.<sup>5</sup> Moreover, a third of family caregivers report that they have neglected their own health care due to their caregiving responsibilities.<sup>6</sup>

### Who Are Family Caregivers?

Family caregivers are broadly defined as any relative, partner, friend, or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic, disabling or serious health condition. Most family caregivers provide this care in response to the needs of the people they care for and are close to; and most are providing this assistance without



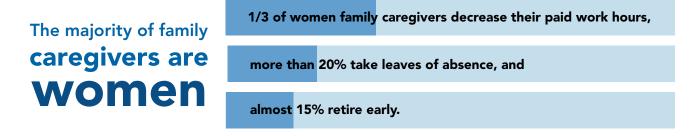
provide care for an older adult relative.

training.8 They may not even consider themselves caregivers, much less keep track of how much time they spend each week providing this care.

Only a third of care recipients live in their family caregiver's home; almost half of persons receiving care live in their own homes. More than 3 of 4 family caregivers incur an average of about \$7,000 in out-ofpocket costs related to their caregiving. 10 About 6 in 10 family caregivers also work at paid jobs; 11 and nearly two-thirds of U.S. workers ages 45 to 74 provide care for an older adult relative. 12

While some of this care is provided to those with steady and relatively predictable care needs, sometimes a loved one experiences a sudden illness or accident that changes their care needs, and takes the family caregivers away from their jobs and other responsibilities. Over time, many family caregivers have to quit their jobs or reduce their hours due to caregiving responsibilities or the stress and health effects of caregiving.

Family caregiving cuts across gender and generation. About 40% of family caregivers are men and close to 1 in 4 is a Millennial.<sup>13</sup> However, the majority of family caregivers are women, and over a third are between the ages of 50 and 64.<sup>14</sup>



Moreover, the challenges of family care are disproportionately borne by women, people of color, and individuals who are low-income. For example, lower income family caregivers are more likely to be the sole unpaid caregiver and less likely to be caring for someone who also receives paid help.<sup>15</sup> Over half of women caregivers with incomes of \$35,000 or less spend more than 20 hours per week providing care.<sup>16</sup>

A third of women caregivers decrease their paid work hours, more than 20% take leaves of absence, and almost 15% retire early.<sup>17</sup> Women who are family caregivers are more than twice as likely as non-caregivers to live in poverty.<sup>18</sup> And more than half of women caregivers have a chronic condition of their own and a quarter experience health problems as a result of their caregiving.<sup>19</sup>

## What Are State Medicaid Programs Requiring Family Caregivers to Do?

In January 2018, the Centers for Medicare & Medicaid Services (CMS) announced a new policy regarding states' ability to condition Medicaid eligibility and enrollment on fulfilling work requirements. In a letter to all state Medicaid directors, CMS explained that it would "support state efforts to test incentives that make participation in work or other community engagement a requirement for continued Medicaid eligibility or coverage for certain adult Medicaid beneficiaries in demonstration projects." CMS outlined parameters for states to consider in designing demonstration projects ("waivers") that include work

requirements, including exempting certain populations from such requirements and allowing "a variety of activities" to count as work. Although the guidance suggested that states consider exempting "primary caregivers of dependents" and allowing caregiving for "elderly family members" to count as work, CMS does not require states to do either.

### Which States Are Imposing Work Requirements?

As of November 2018, 17 states are either implementing or have a written plan to impose work requirements as a condition of Medicaid eligibility. Only 8 of these states have expanded their Medicaid programs under the Affordable Care Act (ACA) to cover childless adults under age 65 with income below 138% of the federal poverty level (FPL). These states are primarily targeting work requirements to the Medicaid expansion population, though some also include other adults under age 65 such as individuals eligible for transitional medical assistance or family planning services. The other 9 states that have not expanded Medicaid are primarily targeting very low-income parents, "caretaker relatives" of dependent children, and other adults under age 65 who are eligible for Medicaid through a non-disability pathway.

A state applies to CMS for a waiver in order to impose work requirements as a "demonstration." As of November 1, 2018, CMS has approved four of those applications, three in states that have expanded Medicaid under the ACA (Arkansas, Indiana, New Hampshire), and in Wisconsin, a non-expansion state. However, the work requirements are currently effective only in Arkansas. Work requirements in Indiana, New Hampshire, Kentucky<sup>21</sup> (if reapproved), and Wisconsin are set to take effect in 2019.

## How Do States Apply These Requirements to Family Caregivers?

States that are pursuing work requirements as part of a demonstration proposal can (but are not required to) exempt family caregivers from work requirements or count caregiving hours as meeting the work requirements. However, implementing these options is complicated, since there is not a single Medicaid eligibility category for low-income family caregivers. Rather, an individual who serves as a family caregiver may be eligible based solely on their income in states that have expanded Medicaid, or they may qualify for "traditional" Medicaid through the "aged/blind/disabled" pathway or because they are a parent or "caretaker relative" of a dependent child, for example.

As shown in the table in the appendix, all states that have submitted applications to CMS for work requirement waivers do provide some exemptions for family caregivers. However, who would be eligible for these "caregiver" exemptions varies widely from state to state and is often unclear.

### The 17 states that are considering or implementing

## work requirements

provide varying exemptions for caregivers



- Formulating waiver proposal states (3): Oklahoma, Tennessee, Virginia
- Pending CMS approval states (10): Alabama, Arizona, Kansas, Kentucky, Maine, Mississippi, Michigan, Ohio, South Dakota, Utah
- Approved states (4):
  Arkansas, Indiana, New Hampshire,
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- Caregiving hours counted towards work requirement: Indiana, Kentucky, New Hampshire, South Dakota, Virginia
- Exemption from work requirement applies to adults caring for persons who are not dependents/relatives or living in the same household: Alabama, Arkansas, Michigan, Maine, Oklahoma, Utah, Wisconsin
- Not currently expanding Medicaid under ACA
- Kareas and Arisona limit the caregiver exemption to caring for another Medicaid envolve who is also a relative or household member.
- Kentucky's waiver was invalidated by a court and is pending CMS re-approval

In all states, family caregivers for at least a subset of adult "dependents" or family members would be exempt from the work requirements. Wisconsin's exemption language is the broadest: "primary caregiver for a person who cannot care for himself or herself." Several other states exempt individuals "caring for an incapacitated person" but do not define "incapacitated" (Arkansas, Michigan, Maine, Oklahoma, Utah). The majority of states limit the exemption to care for a dependent (Indiana, Kentucky), a relative/family member (Arizona, Virginia, Mississippi), or a household member (Ohio, Kansas, Tennessee, South Dakota). A few states impose additional limitations such as requiring a physician determination that the care is necessary (e.g., New Hampshire) or that the care recipient have certain conditions (e.g., a disability or mental illness).

Of the 17 states reviewed, 12 would either clearly exempt individuals who are providing care for someone who is not a household member, dependent, or relative, or credit the caregiving hours performed by these individuals towards meeting the state's work requirement.<sup>22</sup> Two states, Arizona and Kansas, would limit the caregiver exemption to individuals providing care for another Medicaid enrollee. In Arizona, the person receiving care must be both a family member and enrolled in the state's LTSS (long-term services and supports) system.

# eligible for "caregiver" exemptions

varies widely from state to state and is often unclear. Only five states explicitly count caregiving hours towards meeting the work requirement (Indiana, Kentucky, New Hampshire, South Dakota, Virginia). In these states, caregiving for a non-dependent would generally count as work while individuals who provide caregiving for dependents, household members, or non-dependent relatives (depending on the state) would be eligible for an exemption. For example, Virginia proposes exempting primary caregivers for an adult dependent with a disability or a non-dependent relative, and counting "caregiving services for a non-dependent relative or

other person with a chronic, disabling health condition" as work. Indiana exempts primary caregivers of a "disabled dependent" from the work requirement and counts "caregiving services for a non-dependent relative or other person with a chronic, disabling health condition" as work. Indiana also specifies that employed family caregivers receiving unpaid leave benefits to provide family care under the federal Family and Medical Leave Act (FMLA) can count those hours towards the requirement.

Several states also outline a "good cause" exemption for individuals who have "an immediate family member in the home with a disability under federal disability rights laws and [were] unable to meet

the requirement for reasons related to the disability of that family member; or for individuals whose immediate family member who was living in the home with the individual experiences a hospitalization or serious illness."<sup>23</sup> This exemption appears to be aligned with exemptions for work requirements in the Supplemental Nutrition Assistance Program (SNAP) or Temporary Assistance for Needy Families (TANF) program.

Finally, some states exempt individuals based on age, including those under 65. This age-based exemption means that some family caregivers who are between 50 and 64 will not have to apply for the caregiver exemption or report their caregiving hours as work. However, these age exemptions vary by state, and therefore add another layer of complexity that those who are trying to understand the requirements must navigate.

### Age-based exemptions by state

EXEMPT	STATE
Age 50 and older	Arkansas, Ohio, and Wisconsin
Age 51 and older	Oklahoma
Age 55 and older	Arizona
Age 60 and older	Alabama, Indiana, South Dakota, and Utah
Age 63 and older	Michigan
No exemption under 65	Kansas, Kentucky, New Hampshire, Maine, Mississippi, Tennessee, Virginia

# How does the Burden of Paperwork & Reporting Affect Family Caregivers?

Work requirements are extremely burdensome for beneficiaries to navigate and for states to administer. Requiring people to verify that they are either working or exempt from the requirement will inevitably lead to Medicaid-eligible individuals falling through the cracks simply because the process is too complicated, onerous or doesn't work correctly. The caregiver-specific exemptions states have outlined will require the family caregiver to apply for an exemption and provide documentation; and in most cases, the exemption's vague language and undefined terminology, such as "incapacitated" and "dependent," leaves

uncertainty about who is eligible, what they must show to be approved, and how often they must apply or verify their exempt status. And, although a few exemptions that some family caregivers may qualify for, such as those based on age or Medicaid-eligibility category, are likely to be easily verified through data sources and may not even require the individual to apply for the exemption, they are still subject to error if data is missing or entered incorrectly.

Even more burdensome for family caregivers is a requirement to report caregiving hours in order to remain enrolled in Medicaid. Most unpaid care is provided based on a broad range of day-to-day help needed by people with longer-term illnesses, disabilities, frailty, or other extended health conditions. As a result, the burden is going to be greatest for those who already face the most stressful situations of caring for a loved one with

significant and complex care needs. These individuals are often providing round-the-clock care and do not have the time or energy to keep track and report their hours. Moreover, family caregivers

# Despite being eligible for Medicaid, some family caregivers are going to lose their coverage because of the burdens of navigating and reporting under the work requirements.

generally are unaccustomed to tracking their hours and are unlikely to have a system in place to do so. Someone working at a paid job likely has access to documents such as pay stubs showing the number of hours they worked, whereas family caregivers do not have built-in record keeping and the burden would be on them to find a way to record their hours spent providing care.

Finally, many family caregivers are likely to be unaware that they are required to or unable to apply for an exemption or report their work. A recent Kaiser Family Foundation analysis of work requirement implementation in Arkansas showed that most of the thousands of people who lost Medicaid coverage did not know or understand the requirements.<sup>24</sup> And even if they were aware of the requirements, a third do not have access to the internet to report their compliance; many Arkansans who lost coverage or are at risk of losing coverage also lack transportation to find or get to work. These are all barriers to maintaining coverage for family caregivers in other states imposing work requirements as well. Therefore, despite being technically eligible for Medicaid, at least some family caregivers are going to lose their coverage because of the burdens of navigating and reporting under the work requirements.

# WHAT ARE THE CONSEQUENCES?

### Family Caregivers Could Lose Coverage

Due to the complexity of these work requirements, some family caregivers who are eligible for Medicaid will lose coverage. They may not fit the state-specific definitions of caregiver exemptions, or they may not "work" the requisite number of hours on a regular basis. And as we have seen in Arkansas, work requirements will cause many to lose coverage because they are unaware of their obligations to report or the reporting systems will not function properly or adequately. Less than 15% of the beneficiaries whom Arkansas required to report work activities or apply for an exemption had successfully done so, indicating the vast majority were either unaware of this reporting requirement or unable to navigate it.<sup>25</sup>

### Older Adults' Care Could Be Compromised

Without Medicaid coverage, family caregivers will have greater difficulty maintaining their own health, thus compromising their ability to provide care to others. Nearly 1 in 5 family caregivers report that their general health is worsened by their caregiving responsibilities, <sup>26</sup> so having health coverage like Medicaid is especially critical to ensuring they can get treatment for their own health needs as well as prevent deterioration. Similarly, if individuals who provide occasional care are required to work a certain number of hours, they may be unable to devote the same amount of time to caregiving. Many family caregivers do not live with the person they are caring for, so having even just one or two fewer hours in the day to get to the person in need of care can be a barrier.

Taking away coverage from family caregivers also puts more older adults at risk of being institutionalized because their family or friends can no longer care for them. A recent study showed that caregiver factors, including age and strain, contribute to risk of long-term nursing home stays, and suggested that investing in better support for family caregivers could reduce long-stay nursing home use.<sup>27</sup> Medicaid is one such vital support to ensure that caregivers are able to get the healthcare they need.



### **Increased Health Disparities**

Because family caregivers are more likely to be low-income, older, women, and people of color, compromising Medicaid coverage for this population will increase the health disparities they already face. For example, diabetes disproportionately affects people with low-incomes, older adults, and racial and ethnic minorities. Almost 25% of black adults and Hispanic adults ages 50-64 have diabetes, versus 12% of white adults in the same age group. However, Medicaid has provided access to treatment to a large portion of the population living with diabetes, especially in expansion states. 30

Given this overlap between characteristics of caregivers who are most likely eligible for Medicaid themselves and populations experiencing the greatest health disparities, taking away Medicaid coverage from this population by imposing work requirements will only exacerbate health disparities.



## CONCLUSION

Taking away Medicaid coverage by imposing work requirements on family caregivers will harm both the caregivers and the persons they care for, increasing health disparities and jeopardizing the ability of older adults to continue living at home and in their communities. While states are recognizing some types of family caregiving as either work or qualifying an individual for an exemption, the parameters are vague and in some cases narrow. The likely result is that some family caregivers who are eligible for Medicaid will nonetheless lose their coverage because their caregiving work does not meet the state's definitions or qualify them for an exemption. Even more are at risk of losing coverage because they will not know about or understand the requirements, or be able to navigate them.

## States that have expanded Medicaid (8)

STATE Waiver Status	WORK REQUIREMENT (4 states count caregiving hours)	Exemption: CAREGIVER	Exemption: AGE
Arkansas in effect	80 hours/month	"Caring for an incapacitated person"	50+
Arizona awaiting CMS approval	20 hours/week	"Caregivers of a family member who is enrolled in the Arizona Long Term Care System"	55+
Indiana approved	0-20 hours/week (phased in over 18 months) Including "caregiving services for a non-dependent relative or other person with a chronic, disabling health condition, including individuals receiving FMLA to provide caregiving"	"Beneficiaries who are a primary caregiver of a disabled dependent"	60+
Kentucky invalidated by court; awaiting new CMS decision <sup>20</sup>	80 hours/month Including "caregiving services for a non-dependent relative or other person with a chronic, disabling health condition"	"Primary caregivers of a dependent, including either a dependent minor child or disabled adult dependent (limited to only one exemption per household)"	65+
Michigan awaiting CMS approval	80 hours/month	"A caretaker of a dependent with a disability who needs full-time care based on a licensed medical professional's order (this exemption is allowed one time per household); A caretaker of an incapacitated individual even if the incapacitated individual is not a dependent of the caretaker"	63+
New Hampshire approved	100 hours/month Including "Caregiver services for a nondependent relative or other person with a disabling medical or developmental condition."	"A parent or caretaker as identified in RSA 167:82, II(g) where the required care is considered necessary by a licensed physician, APRN, board-certified psychologist, physician assistant, or licensed behavioral health professional who shall certify the duration that such care is required."	65+
Ohio awaiting CMS approval	80 hours/month	"Caring for a disabled/incapacitated household member"	50+
Virginia (expansion takes effect Jan. 2019) not yet submitted to CMS	20-80 hours/month (increases over time); Including "Caregiving services for a non- dependent relative or other person with a chronic, disabling health condition"	"Primary caregiver for an adult dependent with a disability or a non-dependent relative"	65+

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### **APPENDIX**

### States that have not expanded Medicaid (9)

STATE Waiver Status	WORK REQUIREMENT (1 state counts caregiving hours)	Exemption: CAREGIVER	Exemption: AGE
Alabama awaiting CMS approval	35 hours/week 20 a week for parents / caretakers with a child under six	"Anyone required to care for a disabled child or adult"	60+
Kansas awaiting CMS approval	<b>20-30 hours/week</b> depending on number of adults and whether children under six in household	"Caretakers for dependent children under six years or those caring for a household member who has a disability" "Certain caretakers of KanCare members 65 years and older who meet criteria specified by the State."	65+
Maine awaiting CMS approval	20 hours/week	"Providing caregiver services for an incapacitated adult"	65+
Mississippi awaiting CMS approval	20 hours/week	"primary caregiver" for: "a person diagnosed with a mental illness" "a disabled family member"	65+
Oklahoma not yet a formal application	80 hours/month	"A parent or caretaker personally responsible for the care of an incapacitated person"	51+
South Dakota (LIMITED TO 2 COUNTIES) awaiting CMS approval	80 hours/month or achieve monthly milestones in individualized employment and training plan, which may include "Caregiving for an elderly or disabled individual"	"Nonparent caretaker relatives" and "Primary caregivers of elderly or disabled individuals living in the caretaker's residence"	60+
Utah awaiting CMS approval	<b>30 hours/week</b> Or job search/training if not working	"Responsible for the care of an incapacitated person"	60+
Tennessee not yet submitted to CMS	20 hours/week	"Individuals who are providing caregiver services for a household member (child or adult) with a disability or incapacitation"	65+
Wisconsin approved	80 hours/month	"primary caregiver for a person who cannot care for himself or herself"	50+

**BACK TO MAP** 

### **ENDNOTES**

- 1 AARP Public Policy Institute & Nat'l Alliance for Caregiving, Caregiving in the U.S. 2015 (June 2015), available at <a href="https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf">www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf</a>
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- 5 AP-NORC, Long-Term Caregiving: The True Costs of Caring For Aging Adults (Oct. 2018), available at <a href="https://www.longtermcarepoll.org/wp-content/uploads/2018/10/Long-Term-Caregiving-2018-Report.pdf">www.longtermcarepoll.org/wp-content/uploads/2018/10/Long-Term-Caregiving-2018-Report.pdf</a>
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- 10 AARP Family Caregiving and Out-of-Pocket Costs: 2016 Report (Nov. 2016), available at <a href="mailto:aarp.org/content/dam/aarp/research/surveys">aarp.org/content/dam/aarp/research/surveys</a> statistics/ltc/2016/family-caregiving-costs.doi.10.26419%252Fres.00138.001.pdf
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- 12 Lynn Feinberg, AARP Public Policy Institute, Keeping Up with the Times: Supporting Family Caregivers with Workplace Leave Policies Feinberg (2013), available at <a href="https://www.aarp.org/content/dam/aarp/research/public\_policy\_institute/ltc/2013/fmla-insight-keeping-up-with-time-AARP-ppi-ltc.pdf">www.aarp.org/content/dam/aarp/research/public\_policy\_institute/ltc/2013/fmla-insight-keeping-up-with-time-AARP-ppi-ltc.pdf</a>
- 13 Brendan Flinn, AARP Public Policy Institute, Millennials: The Emerging Generation of Family Caregivers (May 2018), available at <a href="https://www.aarp.org/content/dam/aarp/ppi/2018/05/millennial-family-caregivers.pdf">https://www.aarp.org/content/dam/aarp/ppi/2018/05/millennial-family-caregivers.pdf</a>.
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- 19 Family Caregiver Alliance, supra note 16.
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- 21 In late June 2018, a federal court invalidated CMS' approval of Kentucky's waiver. Memorandum Opinion, Stewart v. Azar, Civil Action No. 1:18-cv-152 (JEB), filed June 29, 2018. As of early November, CMS is still in the process of reconsidering the application.
- 22 These 12 states are: Alabama, Arkansas, Maine, Mississippi, Oklahoma, Utah, and Wisconsin, which exempt individuals who are providing care for a nondependent/nonrelative/non household member; and Indiana, Kentucky, New Hampshire, South Dakota, and Virginia, which count caregiving hours for a nondependent towards meeting the work requirement.
- 23 The 7 states that have a "good cause" exemption for individuals who have "an immediate family member in the home with a disability under federal disability rights laws and [were] unable to meet the requirement for reasons related to the disability of that family member; or for individuals whose immediate family member who was living in the home with the individual experiences a hospitalization or serious illness" are: Arkansas, Indiana, Kentucky, Michigan, New Hampshire, Utah, and Tennessee. Three additional states have similar "good cause" exemptions: Alabama (good cause exemptions along the lines of those for TANF), Ohio (for "illness of another requiring presence of the member"), and Virginia (for individuals "who reside with an immediate family member who experiences a hospitalization or serious illness").
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- 29 Catherine W. Gillespie, AARP Public Policy Institute, *Disparities in Diabetes Prevalence among Older Adults* (Nov. 2016), available at <a href="https://www.aarp.org/content/dam/aarp/ppi/2016-11/AARP\_Diabetes\_Nov29v2.pdf">www.aarp.org/content/dam/aarp/ppi/2016-11/AARP\_Diabetes\_Nov29v2.pdf</a>
- 30 Kaiser Family Foundation, supra note 28.