

# **Putting a Price on Informal Caregiving in Colorado: Research for the Strategic Action Planning Group on Aging**

## Introduction

Informal caregiving can take many forms, from unpaid family members or friends managing medications to helping with yardwork to bathing and feeding loved ones. Nearly one of 10 Coloradans, or 500,000 residents, is acting as an unpaid caregiver to someone aged 50 or older.<sup>1,2</sup>

Informal caregiving helps older adults age within their community, surrounded by a network of supports. It may also be a cost-effective alternative to paying for outside care; without informal supports, many individuals and their families, as well as the state, would be paying a steep price for paid care. But the financial, physical and emotional pressures associated with informal caregiving also come at a high cost.

A new model developed by the Colorado Health Institute (CHI) estimates that the cost to individuals providing informal care for older adults in 2015 was \$3.7 billion, or \$7,400 per caregiver.

The physical and emotional toll of informal caregiving is taxing on the body as well as the wallet.

Informal caregivers typically see their health deteriorate, with a heightened prevalence of major conditions such as hypertension, diabetes and depression.<sup>3</sup> Strained family relations can contribute to the emotional toll. Informal caregivers are also more likely to take part in negative health behaviors such as smoking or drinking.<sup>4,5</sup>

All of these health impacts translate to higher health care costs for the caregivers themselves.

Many informal caregivers also pay for their loved ones' expenses — picking up pharmaceutical tabs, provider copays, transportation or even things like home modifications — depleting their own resources for the day when they too may need care.

The effects of informal caregiving are even more pronounced for those caring for people with complex health needs, particularly dementia or Alzheimer's disease. Nearly three of four people caring for an individual with dementia or Alzheimer's say they are concerned about their own health and, compared with other caregivers, they report more mental and physical health problems, family strain and employment challenges.<sup>6,7</sup>

The average age of an informal caregiver providing support to an older adult is about 50, so most are still working as they juggle this responsibility.<sup>8</sup> Fewer work hours, forgone wages, sacrificed promotions and lost benefits are some of the costs incurred by informal caregivers who are employed.

The fact that so many informal caregivers are still in the workforce puts employers front and center in the discussion about the costs of caregiving. Their bottom lines can be hurt by absenteeism, presenteeism (productivity loss on the job by preoccupied employees), turnover and more.

The price tag of informal caregiving to employers was \$564 million in 2015, according to CHI's model. That amounts to employers paying \$1,100 per caregiver in 2015.

The bottom line: informal caregivers and their employers are paying a steep price.

Many older adults would struggle to pay for ongoing services and be forced to give up their independence if it weren't for the informal support they receive from friends and family. Many families and friends would rather provide this care, unpaid, than have their loved ones move into institutional settings. But these caregivers are rapidly approaching an age when they, too, will need support.

Colorado's demographic shift means that in a decade or two, the ratio of informal caregivers to older adults is expected to shrink dramatically as the overall population becomes older. The caregiver support ratio, a measure of the number of potential caregivers ages 45-64 to older adults aged 80-plus, was more than nine-to-one in 2010 and is expected to drop below five-to-one by 2030.<sup>9</sup> Filling this care gap with formal caregivers would be costly to families and the state, and it would mean that fewer older adults have a familiar face helping them out.

It will be important to identify effective strategies for supporting the 500,000 informal caregivers of older adults in Colorado.<sup>10</sup> There are six approaches to supporting informal caregivers outlined in this research report:

1. Build Awareness and Identify Informal Caregivers in Need
2. Create Flexibility in the Workplace
3. Reduce the Financial Burden for Informal Caregivers
4. Engage the Health Care System
5. Provide Education, Training and Other Support for Informal Caregivers
6. Support Connectivity, Affordability and User-Friendliness Within Caregiver Technologies

The political momentum to address caregiver concerns is strong within all six domains. But meeting the needs of informal caregivers will require cross-sector commitments that includes the involvement of several non-traditional partners. This report identifies actionable levers, at the state and local level, for supporting the backbone of Colorado's long-term services and supports workforce: informal caregivers.

## Fast Facts

### Who is Providing Informal Care for Older Adults in the United States?<sup>11</sup>

- The average age of an informal caregiver is about 50 years old.
- Most informal caregivers (86 percent) are caring for a relative.
- 60 percent of informal caregivers are women. Female caregivers tend to provide more hours of care than men.<sup>12,13</sup>
- Six of ten informal caregivers are employed.
- Informal caregivers' median household income is \$55,000, slightly higher than the average U.S. median household income.
- Hispanic caregivers spend an average of 32 hours per week providing support, compared with 21 hours among white non-Hispanic caregivers.

### What Types of Care Do Informal Caregivers Provide?<sup>14</sup>

- 60 percent of informal caregivers in the United States help with one or more Activity of Daily Living, which can include eating, bathing, dressing and getting out of bed.

Informing Policy. Advancing Health.

- Six of ten informal caregivers help with medical or nursing tasks, most without receiving any formal training or preparation.
- Six of ten caregivers (63 percent) are providing care for someone with a physical condition, and 30 percent are supporting an individual with a memory problem.
- Informal caregivers provide an average of 3.7 years of care.<sup>15</sup> However, that figure varies greatly. For example, caregivers of individuals with dementia or Alzheimer's disease tend to provide care for longer durations than other caregivers, with 38 percent providing care for over six years.<sup>16</sup>

## The Cost of Informal Caregiving

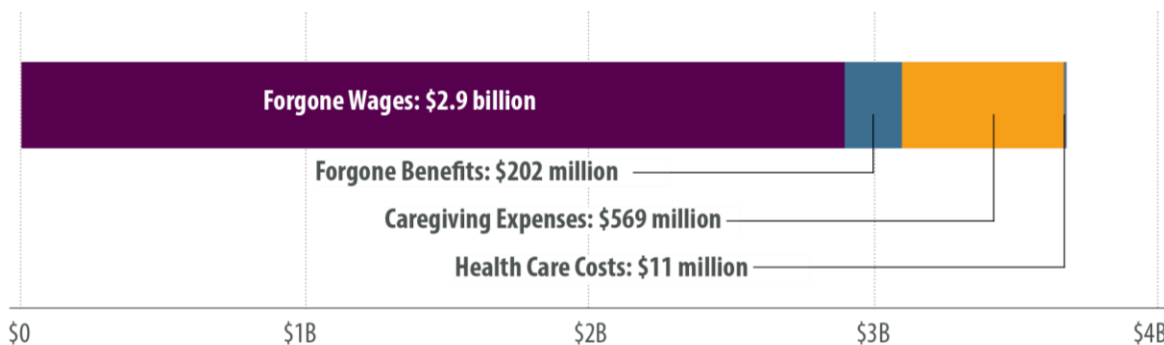
CHI developed a statistical model that estimates the quantifiable costs of informal caregiving to individuals and businesses in Colorado. The model quantifies the opportunity costs to the unpaid caregiver workforce in Colorado for the first time. A wealth of national research on the financial impacts of informal caregiving, both from the individual and employer perspective, was incorporated into the model and adjusted to reflect the characteristics of Colorado’s informal caregiver population. In particular, research by AARP, the National Alliance for Caregiving and MetLife Mature Market Institute were invaluable resources.

### The Cost to Informal Caregivers

The cost of informal caregiving to individuals in Colorado was \$3.7 billion in 2015 or \$7,400 per caregiver, an estimate that includes forgone wages, forgone benefits, caregiving expenses and increased health care costs for caregivers (see Figure 1).<sup>17, 18, 19, 20, 21, 22</sup> By 2030, it’s projected to climb to \$6.6 billion (in 2015 dollars).<sup>23, 24</sup>

The model used quantifiable costs of caregiving. Excluded from this model, but no less important, are other potential costs that are more difficult to measure, including forgone promotions, professional development opportunities and raises.

**Figure 1. Cost of Informal Caregiving to Individuals in Colorado, 2015.**



The \$3.7 billion in costs are made up of the following:

**Forgone Wages:** Responsibilities associated with informal caregiving often make it difficult to hold a job, particularly a full-time job. Becoming an informal caregiver increases the likelihood workers will cut back on their hours. Some informal caregivers are even forced to quit or retire early.

- **Total cost in 2015: \$2.9 billion.**

**Forgone Benefits:** Fewer hours worked or departing from the labor force may result in lower retirement benefits and fewer health insurance benefits.

- **Total cost in 2015: \$202 million.**

**Caregiving Expenses:** Unpaid caregivers will often share or even pay for expenses associated with providing care, such as travel costs or home modifications.

- **Total cost in 2015: \$569 million.**

**Increased Caregiver Health Care Costs:** The role of an unpaid caregiver can strain both physical and mental health. Informal caregivers, for example, are twice as likely to experience chronic conditions (45 percent) compared with non-caregivers (24 percent). Often, caregivers neglect their own health needs — skipping preventive visits or putting off needed care, for example.<sup>25,26</sup>

- **Total cost in 2015: \$11 million.**

***Value Versus Cost: Interpreting CHI's Estimates***

*An AARP analysis in 2015 estimated the value of informal caregiving in Colorado at \$7.4 billion. These estimates are different from CHI's analysis in several ways. The AARP analysis estimates the value of informal caregiving by multiplying the hours that Coloradans spent providing informal care by the average price of formal caregiving services. CHI looks at the issue in a different way, estimating the costs associated with informal caregiving. Interpreted together, the two analyses show that informal caregiving is costing individuals \$3.7 billion for services that are valued at \$7.4 billion.<sup>27,28</sup>*

## The Cost to Employers

The cost of informal caregiving to employers in Colorado was \$564 million in 2015 from turnover, absenteeism and presenteeism (see Figure 2). The cost to employers per informal caregiver was about \$1,100 in 2015.<sup>29, 30, 31, 32, 33</sup>

By 2030, the overall cost to employers is projected to nearly double to \$1.0 billion (in 2015 dollars).<sup>34, 35</sup> This estimate, the first of its kind in Colorado, reinforces that caregiving is not just a personal household issue. Employers shoulder these costs too, highlighting the need to explore workplace policies that support their employees providing informal care.

**Figure 2. Cost of Informal Caregiving to Colorado Employers, 2015.**



The \$564 million in costs to Colorado employers is made up of the following:

**Turnover:** The demands of informal caregiving on top of employment can be too much to handle. It is not uncommon for unpaid caregivers to quit their jobs or retire early. The cost of turnover takes into account expenses such as training replacements.

- **Total cost in 2015: \$427 million.**

**Absenteeism:** Employees with caregiving responsibilities are more likely than non-caregivers to miss days of work. Sixty percent of informal caregivers who have jobs report a negative impact on their jobs, such as working fewer hours or taking additional time off of work.<sup>36</sup> The absenteeism estimates includes those who took paid time off that they would not otherwise use. CHI's analysis also includes estimated costs of partial absenteeism — coming in late or leaving early due to caregiving responsibilities.

- **Total cost in 2015: \$72 million.**

**Presenteeism:** The responsibilities that come with caregiving, as well the stress, can make it tough for employees to focus on work. This effect, often referred to as presenteeism, is difficult but important to measure. CHI assessed the cost of presenteeism by using the number of hours lost due to workday interruptions.

- **Total cost in 2015: \$65 million.**

## Creating a Supportive System for Informal Caregivers in Colorado

Informal caregivers make sacrifices that place them — Colorado’s future generations of older adults — at risk for financial hardship as they age.

But informal caregivers also provide essential services not only for their loved ones but also for Colorado’s budget. Without them, many seniors would spend down their resources to pay for formal caregiving and eventually qualify for Medicaid, with financial impacts for both individuals and the state.

CHI has identified six levers — policy options, promising programs and other strategies — which could help to ensure that informal caregivers are well-supported as they continue to provide important services for older adults in Colorado. In each section, CHI also provides context by highlighting efforts that have laid the groundwork for informal caregivers in our state.

### **Lever 1: Build Awareness and Identify Informal Caregivers in Need**

“Caregivers are really good at suffering silently,” said Meghan Baskett, program manager of the Colorado Respite Care Program in a key informant interview for this research. One of 10 Coloradans is an informal caregiver, but their peers and colleagues are often unaware they are providing these important services.

Some informal caregivers don’t always self-identify. One study found that only about 19 percent of caregivers considered themselves in this role.<sup>37</sup>

Building awareness and dispelling caregiving stereotypes are important steps in making sure that informal caregivers have access to needed supports. But a successful awareness campaign could mean a surge of informal caregivers seeking support, so it’s also important to consider whether programs and funding can accommodate those needs.

#### *What’s Been Done*

- At the federal level, the bipartisan [Assisting Caregivers Today \(ACT\) Caucus](#) launched in the spring of 2015 to inform members of Congress about the valuable contributions of unpaid caregivers, the daily challenges they face and strategies for supporting them. The caucus, which is co-chaired by Colorado Senator Michael Bennet, serves as a forum to exchange ideas and strategize about these issues across party lines. In addition to working with traditional stakeholders such as caregivers, older adults and service providers, the caucus engaged many nontraditional stakeholders, including employers, private and public payers and technology innovators.<sup>38</sup>
- Colorado received a three-year grant from the Administration for Community Living to strengthen the sustainability of the [Colorado Respite Care Project](#). One of the four key objectives of this work is to enhance community understanding and education activities about respite care.<sup>39</sup> The program, funded by Lifespan Respite grants since 2011, is working toward a



coordinated statewide respite care system that meets the needs of Colorado's family caregivers. These grants are used to coordinate existing respite resources, increase the availability of respite workers and volunteers and boost awareness about respite services.<sup>40</sup>

### *Opportunities for Colorado*

The federal [Recognize, Assist, Include, Support and Engage \(RAISE\) Family Caregivers Act](#) was introduced in July 2015 to develop a national strategy for identifying ways to support family caregivers. The bipartisan bill, which passed in the Senate in December 2015 but hasn't made it through the House, was introduced by Senator Michael Bennet.

- The SAPGA may want to consider voicing support for this legislation, though Congress does not have much time left before the November election. Given Senator Bennet's leadership role with this legislation and the ACT Caucus, the SAPGA may want to discuss opportunities for leveraging his expertise and interest in the issue to support state-level efforts.

It's not always easy to identify whether an unpaid family caregiver needs support. Some provider offices and other community-based organizations offer caregiver assessments that triage informal caregivers and identify those who could benefit the most from additional support. The SAPGA could consider supporting the implementation of assessments like the [Tailored Caregiver Assessment and Referral \(TCARE\)](#), an evidence-based triage and care management program that has been implemented in 12 other states. TCARE has demonstrated positive health outcomes for informal caregivers.<sup>41</sup> To administer the assessment, professionals must undergo an intensive two-day training and some additional continuing education.

- If the SAPGA chooses to recommend the implementation of TCARE or similar assessments, one strategy would be to recommend the value of subsidizing some of the upfront training costs for professionals. To cover the operational costs of TCARE, the Planning Group might consider partnerships with public and private payers that benefit from unpaid caregivers.

Some states include a family caregiver assessment as part of their Medicaid home and community-based client (HCBS) assessment tool to identify caregivers in need of support. These assessments, which occur at the same time as the client assessment, help care planners understand caregivers' contributions, their training and preparedness, stress levels, physical strain and support needs. These needs are then built into the care plan for HCBS clients to ensure that caregivers are not overburdened and that they receive needed support.

- The Colorado Department of Health Care Policy and Financing is currently transitioning to a new eligibility assessment tool, so it would be an opportune time for the SAPGA to consider recommending that the Department embed a family caregiver component into that assessment.

In Minnesota, a [caregiving awareness campaign](#) launched in 2012 — the first of its kind. Relatable ads were spread throughout Minnesota with messages like the one below, "You call it helping my brother with home repairs. We call it caregiving." The messages directed caregivers to a landing page with

informational materials, including a Minnesota Caregiver Resource Guide, a search-by-location feature to locate convenient supportive services and a 1-800 number for help in finding community services. Given Minnesota's success, there may be an appetite for something similar in Colorado.

- A program manager at the Amherst H. Wilder Foundation, a Minnesota-based group that spearheaded that campaign, told CHI that there would be an opportunity for Colorado to partner with Minnesota.<sup>42</sup> This would eliminate the upfront cost of creating the artwork for a campaign, allowing investments to be used primarily for developing information and referral materials, customizing the message and disseminating the campaign.<sup>43</sup> That first step — developing informational materials — is crucial; an awareness campaign's success hinges on the availability of community services and supports for informal caregivers.



Questions were included on the 2016 Colorado Behavioral Risk Factor Surveillance System (BRFSS), a state-level health behavior survey, to better understand the prevalence and scope of informal caregiving activities at a statewide level. Supplemental state modules are considered each year for inclusion on the BRFSS. According to the Colorado Department of Public Health and Environment, the caregiver module was not included on the 2017 survey because no groups proposed that it remain on the survey.

- The SAPGA could recommend that this module be included on future iterations of the survey — which would require funding and stakeholder interest — to track this information over time and to stay abreast of changes to the informal caregiver workforce and its needs. The Colorado Opportunity Project, a collaboration between the Colorado Department of Human Services, Colorado Department of Public Health and the Environment and Health Care Policy and Financing, also identified a need for tracking access to informal caregiving, so the SAPGA may be interested in partnering with their group in support of data collection.

### **Lever 2: Create Flexibility in the Workplace**

The federal government, state government and Colorado-based employers have implemented some policies to support their employees who are caring for family members. State aging plans, such as Colorado's Aging Framework, have proposed workplace flexibility for caregivers as a strategy for achieving one of its core goals: promoting support for family caregivers.<sup>44</sup>

There are additional levers that could be considered at the employer and state levels to strengthen the support system for working caregivers. Some of those policy options are explored below.

#### *What's Been Done*

- The federal Family and Medical Leave Act (FMLA) requires certain employers to provide up to 12 weeks of unpaid family leave within a year for employees who are sick or need to care for an ill family member. Employees must work for a covered employer to be eligible for these

benefits. Government agencies, elementary and secondary schools and private employers with 50 or more employees within 75 miles of each other are typically covered. It is up to states whether they pursue family and medical leave laws for employees of small businesses.<sup>45</sup> Interestingly, a national study found no difference in the proportion of small and large employers offering FMLA compliant leave, suggesting that policies are becoming more of a norm among employers.<sup>46</sup> In addition to being employed at a covered entity, individuals must have worked for their employer at least one year (and a minimum of 24 hours per week). People caring for a parent or spouse are among those eligible.

- In 2013 Colorado implemented the Colorado Family Care Act, which extends FMLA coverage to some people who were not covered by the federal policy, such as those in civil unions or committed relationships (though the state policy is still limited to large employers). In 2015, the United States Department of Labor took a similar step, updating the definition of spouse to cover those in legal same-sex marriages.<sup>47</sup>

### *Opportunities for Colorado*

FMLA lays the groundwork for caregiver-friendly workplaces, but a national study still found that about one of five large employers were out of compliance with FMLA despite being covered.<sup>48</sup>

- While the U.S. Department of Labor's Employment Standards Division is charged with enforcing FMLA, the SAPGA could consider strategies for enhancing compliance in Colorado.

FMLA requires certain employers to offer unpaid leave, leaving many unpaid caregivers and their families in difficult financial circumstances. State family leave policies can set standards for compensating employees who are caring for an aging family member. Coverage is also more inclusive under these state policies, covering more part-time workers and those at small businesses. Three states have adopted paid family leave insurance policies — Rhode Island, California and New Jersey. All three have implemented a Temporary Caregiver Insurance program, which is funded by employee payroll deductions.<sup>49</sup> The programs, which range from four to six weeks of paid leave, provide eligible workers with a portion of their wages — roughly half to two thirds — while they care for a family member. Rhode Island's program also offers job protection to employees who are on leave, creating a safeguard against job loss and retaliation for taking paid family leave. Washington and New York have also developed plans to implement a family leave policy. New York's plan stands to be the most comprehensive in the country, mandating that employers offer up to 12 weeks of paid time off.<sup>50,51,52</sup>

- The SAPGA could explore whether there is an opportunity to model legislation based on one or more of these state family leave policies.<sup>53</sup>

Similarly, legislation requiring paid sick leave has passed in six states (California, Connecticut, Massachusetts, Oregon, Vermont and Illinois) as well as the District of Columbia and more than 19 cities.<sup>54,55</sup> It can help informal caregivers whose health declines as a result of their caregiving responsibilities.<sup>56</sup> Overall, unpaid caregivers are more likely to report fair or poor health than non-caregivers, and the longer people remain in an informal caregiver role, the worse their health becomes.<sup>57</sup>

- In recent legislative sessions, Democratic lawmakers in Colorado have unsuccessfully attempted to pass paid sick leave legislation.<sup>58</sup> The SAPGA could propose revising and

revisiting paid sick leave policies proposed during past sessions. The SAPGA could also encourage Colorado cities to pursue a paid sick leave policy.

Historically, flexibility in the workplace referred to arrival and departure times or working remotely. Times, though, are changing. There are now many dimensions of workplace flexibility that employers can consider that will make their companies more attractive to prospective and current employees. These policies can also make it easier for informal caregivers to juggle their responsibilities. A national study of employer policies<sup>59</sup> breaks this down into some key categories:

- Flexibility with time and place** (e.g., telecommuting or flex time)
- Managing time** (e.g., allowing for breaks and the ability to make up hours)
- Reduced time** (e.g., access to part time schedules)
- Time off** (e.g., policies for sick days and unplanned events)
- Caregiver leave** (e.g., policies allowing for extended leave due to caregiving)
- Flex careers** (e.g., enabling employees to rejoin employment when caregiving responsibilities subside)
- Job sharing** (e.g., sharing work responsibilities allowing flexibility during a crisis)
- Culture of flexibility** (e.g., workplace policies are promoted and communicated clearly)

These workplace accommodations can translate to employer savings. One study found that a results-oriented work environment with flexible hours yielded a 45 percent decrease in employee turnover, which is the primary cost of caregiving to employers.<sup>60,61</sup> A 2014 study also made the cost case for flexibility in the workplace, demonstrating that for every dollar invested in flex time, businesses can expect a return on investment of between \$1.70 and \$4.34. The study takes into account the lower rates of absenteeism, increased retention and stronger recruitment that result from these flexible policies. The return on investment for offering telecommuting options was between \$2.46 and \$4.45 for each dollar.<sup>62</sup> Flexible workplace policies like telecommuting can be unrealistic for certain professions such as teachers and service workers. Encouraging companies to offer alternative options for flexibility, such as caregiver leave policies, will help to ensure that all workers have access to caregiver benefits.

- The SAPGA could recommend trainings or other educational resources for employers about the mutual benefits of flexible work environments, including the return on investment to employers. There may be value in offering educational opportunities targeted toward large employers. The research shows that, nationally, small employers are more likely to provide flexibility at work in general and specifically for important family needs.<sup>63</sup> Partnering with employer groups, such as local chambers of commerce, may be an effective way to disseminate this information.

The Colorado Respite Care Project is piloting a self-care training program for informal caregivers in the workplace. Initially, the group had planned to collaborate with a national coalition known as [ReACT \(Respect a Caregiver's Time\)](#), which is working to provide employers with the tools they need to support employed informal caregivers. While the Colorado Respite Care Project did end up utilizing some of ReACT's employer-engagement materials, there has been so much demand for the coalition's work the Respite Care Project decided it was unrealistic to partner with ReACT in a larger capacity at this time. Instead, it is collaborating with the Colorado Department of Human Services and

the Colorado Department of Public Health and Environment to administer these trainings on self-care for working informal caregivers. So far, it has piloted the trainings in Denver and Pueblo.<sup>64, 65</sup>

- Depending on the success of the pilot, the SAPGA may choose to recommend statewide implementation of this effort.

Another way that employers can make sure their workers have access to caregiver support resources is by offering an Employee Assistance Program (EAP). EAPs provide short-term counseling, referrals and other services to employees who face personal challenges, including but not limited to the stress that comes with juggling caregiving and professional responsibilities. The State of Colorado offers an EAP benefit to state workers that has demonstrated a significant reduction in depression, anxiety, absenteeism and presenteeism.<sup>66, 67</sup>

- Colorado businesses may be interested in offering an Employee Assistance Program modeled off of the State of Colorado's program. The SAPGA could explore the possibility of partnering with the State of Colorado's human resources department to create an EAP implementation framework to share with businesses. However, creating an EAP may be too resource intensive for some small companies and nonprofits. The SAPGA could investigate the feasibility of a shared-EAP model for smaller organizations.

Workplace wellness has gained popularity among many employers but caregiver support is often not included in these programs. [Health Links](#), a workplace wellness group based out of the Center for Health, Work and Environment within the University of Colorado's School of Public Health, is a leader in promoting workplace wellness. The group considers informal caregiving to be an important factor when considering workplace wellness, and has recently collaborated with the Colorado Department of Public Health and Environment to create a [Family-Friendly toolkit](#) for employers and also developed an assessment as an addendum to their employer certification that includes caregiver policies.

- Family-friendly workplace policies are often tailored to new parents and caregivers of children.<sup>68</sup> The new assessment and toolkit referenced above help to redefine 'family' and encourage employers to think broadly about how they can support their employees outside of work, but there is still a youth focus and much work needed to educate employers about what they can do to support caregivers of older adults. The SAPGA could explore opportunities to partner with Health Links and the Colorado Department of Public Health and Environment to disseminate those resources and increase employer awareness of the unique needs of caregivers of older adults.

### **Lever 3: Reduce the Financial Burden for Caregivers**

"In many cases, people will be spending more time and resources caring for their aging parents than they did raising their own children," said Jo Ann Jenkins, the CEO of AARP, at a recent conference.<sup>69</sup> Employer flexibility and other caregiver support programs undoubtedly will help informal caregivers. But what financial supports are in place in Colorado or other states to directly alleviate the financial burden? Some of the more obvious policy levers involve the state's Medicaid population and their caregivers, but informal caregivers who don't serve Medicaid clients are often those most in need.

### *What's Been Done*

- Colorado is among the states that offer the federal Child and Dependent Care Credit, also known as the Elderly Dependent Care Credit, to offset the cost of things like home care or adult day care to allow caregivers to maintain their employment.
- In an effort to offer flexible and comfortable home care options for its clients, Medicaid offers Consumer-Directed Attendant Support Services (CDASS), which allows many of their long-term services clients to hire and manage their caretakers, including family and friends. Medicaid also offers short-term respite care to informal caregivers of clients on most of the long-term services and supports waivers, including the waiver for the elderly, blind and disabled.<sup>70</sup> By compensating caregivers who are otherwise unpaid, CDASS formalizes caregiving in an effort to reduce the financial burden on families and increase satisfaction among their clients.
- In addition to covering home care and other non-medical care, Colorado's Home Care Allowance (HCA) — a financial assistance program for elderly, low-income and disabled residents — provides small payments to cover the cost of certain services like respite care and other forms of caregiver support. HCA does not provide around-the-clock care, and the services it covers are less intensive than Medicaid's home and community-based services waiver.
- Colorado followed in the footsteps of other states in November 2015 when it launched a respite care voucher program for informal caregivers. The program, which is funded through a federal grant and the state general fund, served 73 caregivers during its first phase. The Colorado Respite Care Project is spearheading this effort.<sup>71</sup>

### *Opportunities for Colorado*

The [Credit for Caring Act](#) was introduced by Congress in early 2016. The bipartisan measure would offer a federal tax credit to working caregivers for qualified out-of-pocket expenses above \$2,000 and up to \$3,000. Eligible expenses include respite care and adult day care, helping to offset the cost of for caregivers and providing opportunities for them to continue their employment. Senator Bennet is a co-sponsor of the bill.

- The SAPGA could propose supporting this piece of federal legislation, which is still being considered by Congress.<sup>72</sup> Alternatively, the SAPGA could recommend modeling a state tax credit based on the Credit for Caring Act.

People often underestimate the savings needed during retirement, in part due to misconceptions around what Medicare will cover when it comes to long-term services and supports.

- The SAPGA could recommend funding educational resources or subsidized financial planning services targeted toward working-age adults, since financial saving takes time.

#### **Lever 4: Engage the Health Care System**

People who are being cared for informally at home are most likely interfacing with the health care system as well. This makes provider's offices uniquely positioned to identify informal caregivers, offer them information about supportive resources and coach them through the patient's care needs as well as their own. Yet only one of three informal caregivers say that a health care provider asked them about the care recipient's needs and 16 percent say that a provider broached the topic of self-care.<sup>73</sup> Many providers lack the training and tools necessary to do this. Ensuring that payment and reimbursement structures are supporting caregivers will also go a long way.

##### *What's Been Done*

- [The Caregiver Advice, Record, Enable \(CARE\) Act](#) has been implemented in 18 states (including Colorado) to ensure that hospital discharge processes include caregivers. On May 8, 2015, Governor John Hickenlooper signed House Bill 15-1242, a bipartisan bill that requires hospitals to include family caregivers as part of the care team. Prior to this, caregivers often were not included in health care conversations, such as instructions on medication management or dietary guidelines, hindering their ability to support the person in their care.<sup>74</sup>
- Medicare has updated its benefits to be more inclusive of family caregivers. The federal insurance program began compensating for transitional care management, including communication with caregivers and caregiver education, for inpatient beneficiaries. Medicare also began covering some telehealth services for caregivers in 2015.
- A new program was introduced at the University of Colorado at Colorado Springs (UCCS) Aging Center that leverages the expertise of trained therapists as they work with families to develop plans for providing informal care. The program, called Caregiver Family Therapy, helps to coordinate informal care and assign caregivers roles that are best suited to their skillset.<sup>75</sup>

##### *Opportunities for Colorado*

More than half of informal caregivers nationally assist with medical and nursing tasks at home, such as managing medications and administering IVs and injections. Despite being on the front lines of care delivery, when they step into the health care setting they are often still on the sidelines. The CARE Act, a federal requirement that caregivers be included as part of the care team during hospital discharge, is only a first step in incorporating them in health care decision-making and care instructions.

- The SAPGA may choose to recommend that the state legislature consider requiring inclusion of informal caregivers during health care visits, rather than just at the time of hospital discharge.

Health care providers frequently interact with informal caregivers, but many are not aware of all that is happening behind the scenes. It is important that providers are informed about the prevalence of family caregiving and its impact on the individuals providing care.

- Training sessions for providers and their staff can boost awareness about these issues and discuss next steps for connecting informal caregivers to available resources.

Training the future health care workforce about these issues is equally important, particularly as Colorado's population continues to age. Ensuring that Colorado health professional schools are building this into their curriculum is one way to support the next generation of caregivers. All health professionals, from certified nurse assistants to oncologists, should be aware of the issues associated with caregiving as well as red flags.

- The SAPGA could support the development of trainings or certificate programs for students who do not plan to specialize in geriatrics but will interact with many older adults is particularly important.

Creating a strong referral system between health care providers and community supports can connect many informal caregivers to help at a relatively low cost. The Alzheimer's Association of Colorado is one organization that has built a strong rapid referral program for the people it serves. Once patients and caregivers give their permission, the referral program opens a line of communication between the family, social worker and provider's office with a built-in feedback loop. The initiative's integration with some health systems' electronic health records has made the referral process particularly successful.<sup>76</sup> But this specific program only serves one group within the older adult demographic.

- The SAPGA could consider recommending investments to build stronger referral partnerships with the health care system so that informal caregivers are part of the conversation from the start, before their health deteriorates or a crisis hits.

### **Lever 5: Provide Education, Training and Other Support for Informal Caregivers**

The state plays an important part in supporting caregivers, but there is no silver bullet to solve these issues statewide. Local communities and community-based organizations play an important role in this effort. The good news is that there are many programs already being offered to support caregivers. The challenge: spreading the word to those who could benefit from these programs, securing sustainable funding and ensuring that the right programs are being implemented equitably and where they are needed the most.

#### *What's Been Done*

- The [National Family Caregiver Support Program](#), funded through the Older Americans Act, offers a range of services to caregivers, including information about available services, support accessing services, counseling, trainings and respite care. The program has a reputation for being fairly flexible so that states and service providers can shape the program to fit the needs of their community.<sup>77</sup>
- [Powerful Tools for Caregivers](#) is an evidence-based self-care education program for informal caregivers that's being implemented by Area Agencies on Aging (AAA) across the country, including those in Boulder, Larimer and Montrose. The six-week program has been shown to improve management of emotions, self-efficacy, healthy behaviors such as exercise and preventive health care visits, and awareness of supportive resources.<sup>78</sup>
- The [Savvy Caregiver](#) training program has been implemented in Colorado with funding from the Administration on Aging and the Alzheimer's Disease Demonstration Grants to States program. The evidence-based program, which was developed with rural caregivers in mind,



has been shown to decrease depression and increase the use of support groups by informal caregivers in rural communities. Variations of the training are available for caregivers of different ages, ethnicities, and those caring for people with specific conditions or diseases.

### *Opportunities for Colorado*

Securing ongoing and diverse funding for these caregiver support programs will help ensure that Colorado's unpaid caregiver workforce can continue to receive needed services. Today, a substantial portion of caregiver program funding comes from the Older Americans Act and federal grants from the Administration for Community Living.

- The SAPGA could make recommendations to explore new funding streams to ensure the longevity of these vital programs.

Garnering political support will be critically important to the ongoing implementation of caregiver support programs in our state, particularly as the older adult population swells over the coming years. Some advocacy leaders, such as the national organization Caring Across Generations, are working at a grassroots level to engage elected officials and political candidates on this issue. Recently, the group launched a petition encouraging moderators of the Presidential debates to include a question on family caregiving policy.

- The SAPGA might choose to recommend strategies like this for engaging state and local elected officials in this discussion.

One caregiver support program in a community is not enough. Informal caregivers have distinct needs and preferences. For example, a spousal caregiver may seek out very different supports than one caring for a parent; an 85 year-old caregiver will be looking for something different than a middle-aged adult with children; a caregiver of an individual with dementia will need different information than someone who is caring for a person with a physical disability. It's important that a variety of educational and supportive services are available to meet the needs of all individuals providing informal care.

- The SAPGA could support an effort to map existing resources for informal caregivers across the state in order to identify gaps.

Respite care is one of the most frequently requested caregiver services, and the unmet need is high. But it is unlikely that significant investments will be made to provide this service until the return on investment is demonstrated to the state legislature, a recommendation that emerged from the Respite Care Task Force.

- The SAPGA may want to consider reinforcing the recommendations from Colorado's Respite Care Taskforce to pursue a comprehensive [study of the return on investment of respite care](#). It is likely that this work will proceed because of House Bill 1398, which requires the Colorado Department of Human Services to execute the recommendations of the Respite Care Taskforce.

The success of any respite program depends upon the availability of providers to meet caregivers' needs. And today's shortage of respite providers — particularly those trained to accommodate the needs of underserved populations — threatens the success of current and future respite programs. In some cases, funding for respite is available but underutilized due to provider availability. Low wages,

the high emotional toll and, subsequently, the frequency of burnout and turnover are some of the factors curbing growth in the respite provider workforce.

- The SAPGA could recommend scaling respite resources like the voucher program. But given the limited number of providers, it would be equally if not more important to expand the respite provider workforce. Many groups, particularly faith-based organizations, provide critical informal respite for members in the community. Supporting informal providers could have a large impact on access to respite care.
- Additionally, the SAPGA could recommend creating an inventory of approved respite provider training programs as well as standardized licensure and certification requirements to create consistency across providers. This has been implemented in other states but not in Colorado.

### **Lever 6: Support Connectivity, Affordability and User-Friendliness within Caregiver Technologies**

The promise of technology to support older adults and caregivers permeates all five of the areas discussed above.

Technology supports awareness campaigns through targeted marketing and advanced data collection. It facilitates alternative work arrangements, so that an informal caregiver is able to work from home or video conference with a loved one at home. It opens doors in the medical field, through telehealth, assistive technologies and other health innovations. Personal bot assistants and other at-home devices are emerging on the market and have the potential to assume responsibility for several caregiver tasks. And technology has improved information and referral systems for informal caregivers, helped to coordinate efforts across caregivers and service providers and connected those in need with a wealth of online resources and support groups.

But while more than 70 percent of caregivers say they are interested in using technological supports, only seven percent are currently using them to assist with their informal caregiving responsibilities. When asked whether they would use a technology that was provided to them, only 59 percent said they would be likely use it. That's lower than the percentage who say they are interested in using technology, suggesting that the market is coming up short when it comes to meeting caregivers' needs.<sup>79</sup>

High prices, limited broadband connectivity, low user-friendliness and lack of awareness thwart widespread adoption of many of these technologies. Time limitations and a lack of confidence that these supports will really make a difference also contribute to low uptake.<sup>80</sup>

These aren't insurmountable hurdles, but it will take a concerted effort from state and local leaders across the public and private sectors in order to make technologies accessible and affordable for informal caregivers in Colorado. Below are key strategies for overcoming these challenges:

Understand the market. Much is unknown about the needs and preferences of informal caregivers. A caregiver study could help innovators and state leaders better understand caregivers' diverse needs – an older adult providing care for a spouse will have very different preferences from a millennial caring for a parent. It is essential to include many different caregivers throughout the development of technologies intended to support them.

Offer technology trainings. Educating informal caregivers on how to use gerontechnologies, such as sensors or other tracking systems, could alleviate some of their time and stress burden. Similarly, helping older adults become more comfortable using computers and smart technology may increase their autonomy and reduce the demand for certain caregiver supports.

Expand affordable access to broadband. Efforts are already underway to expand broadband connectivity, but there is more that could be done to ensure that older adults and their informal caregivers have access to needed technologies. For example, the use of remote monitoring devices, a category of gerontechnology often cited for its potential to support for caregivers, is limited in communities where access to broadband is low. The positive impacts of improvements to broadband connectivity extend well beyond informal caregiving or even aging issues.<sup>81</sup>

Leverage technologies aimed to support broader audiences. While some products are specifically designed for caregivers, others are designed to appeal to a broad range of users but still have great potential to support informal caregivers. Because informal caregivers often do not self-identify as caregivers, programs that are marketed to a larger audience can be particularly successful. Examples include things like google docs for coordination, Uber, Lyft and other ridesharing applications for transportation or applications like MedHelp for health information and referrals.

Explore options for reimbursing the purchase and/or use of gerontechnology. Legislation involving the reimbursement of telehealth services has emerged several times over the past few years. Looking ahead, there may be interest in expanding reimbursement options for a broader set of supportive technologies than what is currently covered. Demonstrating a return on investment to private and public payers will be crucial.

## Opportunities for the SAPGA

This research yielded the following opportunities as having potential for alleviating financial, health and social burdens on Colorado’s informal caregivers. The Colorado Health Institute does not endorse these strategies or policies.

<b>Build Awareness and Identify Informal Caregivers in Need</b>
1. Leverage Senator Bennet's interest and experience in informal caregiving at the state level.
2. Support the RAISE Family Caregiver Act at the federal level.
3. Implement the Tailored Caregiver Assessment and Referral (TCARE) in Colorado.
4. Support funding to train professionals to implement TCARE, including opportunities for reimbursement from payers.
5. Add a caregiver assessment to the Medicaid Home and Community Based Services assessment.
6. Conduct an awareness campaign and consider partnering with Minnesota's Amherst H. Wilder Foundation to reduce costs.
7. Propose the ongoing inclusion of caregiving questions on the Behavioral Risk Factor Surveillance System.

<b>Create Flexibility in the Workplace</b>
1. Enhance compliance of the Family Medical Leave Act through incentives or other mechanisms.
2. Propose a state family leave policy, also known as Temporary Caregiver Insurance, to provide short-term paid leave funded by employee payroll deductions.
3. Revisit paid sick leave policies at the state-level and encourage cities to consider local policies.
4. Recommend trainings or other educational resources about the benefits of implementing flexible work policies.
5. Consider expanding the Colorado Respite Care Project's collaborative pilot, which provides self-care trainings to working caregivers.
6. Create a framework for businesses interested in implementing an Employee Assistance Program and consider the feasibility of a shared model for smaller organizations.
7. Develop a strategy for expanding workplace wellness initiatives to include informal caregiving support. Consider partnering with Health Links and the Colorado Department of Public Health and Environment to disseminate their resources and educate employers about the unique needs of those caring for older adults.

<b>Reduce the Financial Burden for Caregivers</b>
1. Support the federal Credit for Caring Act or consider modeling a state tax credit after that legislation.
2. Fund educational resources or subsidized financial planning resources for working-age adults to prepare for the future.

**Engage the Health Care System**

1. Propose legislation requiring health care providers to include informal caregivers during health care visits.
2. Educate health care providers and staff about prevalence and impact of caregiving issues and inform them about community resources.
3. Develop trainings or certificate programs for health professions students not specializing in geriatrics but who will interface with older adults and their caregivers often.
4. Build referral networks between health care providers and community caregiver support programs.

**Provide Education, Training and Other Support for Informal Caregivers**

1. Secure ongoing and diverse funding for caregiver support programs.
2. Engage elected officials and political candidates at the local and state levels.
3. Map existing resources for informal caregivers to identify service gaps.
4. Reinforce recommendations from Colorado's Respite Care Taskforce, particularly the proposed study on the return of investment for respite services.
5. Identify opportunities to support informal providers of respite services, including faith-based organizations.
6. Standardize training, licensure and certification requirements for respite providers.
7. Conduct an inventory of approved respite provider training programs.

**Support Connectivity, Affordability & User Friendliness / Technology Support**

1. Develop a resource guide for gerontechnology innovators that describes the needs and preferences of informal caregivers.
2. Offer technology trainings to informal caregivers and older adult care recipients.
3. Expand affordable access to broadband.
4. Leverage technologies aimed to support broader audiences.
5. Study the return on investment of gerontechnology.
6. Explore options for reimbursing the purchase and/or use of gerontechnology.

## Conclusion

Colorado's population is getting older fast. The majority of older adults will need some supportive services after they turn 65. And most will want to receive those services within the community.

Informal caregivers will continue to support older adults who choose to age in place. But the people providing informal care are not adequately supported and bear a high financial, physical and emotional cost. Those costs are projected to increase sharply as demand for informal caregiving grows.

This report delves into six approaches to supporting informal caregivers, which align closely with caregivers' unmet needs. Specific strategies and policy options that align with those needs and have the potential to alleviate the burden to informal caregivers in Colorado are identified throughout the report. The SAPGA can consider these opportunities during the development of its recommendations to the Colorado legislature.

The SAPGA can contact Natalie Triedman, policy analyst, with any questions about this research. She can be reached at [triedmann@coloradohealthinstitute.org](mailto:triedmann@coloradohealthinstitute.org) or 720-382-7077.

- 
- <sup>1</sup> Susan Reinhard, Lynn Friss Feinberg, Rita Choula and Ari Houser. AARP Public Policy Institute. Valuing the Invaluable, July 2015. <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>.
- <sup>2</sup> Colorado State Demography Office. Population by Age and Gender.
- <sup>3</sup> MetLife Mature Market Institute, National Alliance for Caregiving, University of Pittsburgh Institute on Aging. New Insights and Innovations for Reducing Health Care Costs for Employers, February 2010. <https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-working-caregivers-employers-health-care-costs.pdf>.
- <sup>4</sup> New Insights and Innovations for Reducing Health Care Costs for Employers. February 2010.
- <sup>5</sup> Natalie McGill. In US, Caregivers Being Called on to Play Greater Role: Rise in Older Population Fuels Growth. The Nation's Health (vol. 46 no 5. 1-22). <http://thenationshealth.aphapublications.org/content/46/5/1.4.full>.
- <sup>6</sup> Alzheimer's Association. 2016 Alzheimer's Facts and Figures. <http://www.alz.org/facts/>.
- <sup>7</sup> Marcia G. Ory, Richard R. Hoffman III, Jennifer L. Yee, Sharon Tennstedt and Richard Schulz. Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. 1999. The Gerontologist Vol 39 No 2. [http://www.caregiving.org/pdf/research/Ory\\_Schulz\\_NAC\\_survey.pdf](http://www.caregiving.org/pdf/research/Ory_Schulz_NAC_survey.pdf).
- <sup>8</sup> AARP Public Policy Institute and the National Alliance on Caregiving. Caregiving of Older Adults: A Focused Look at Those Caring for Someone Age 50+, June 2015. <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>.
- <sup>9</sup> CHI analysis of population data from the Colorado State Demography Office.
- <sup>10</sup> CHI estimate based on AARP data of the number of informal caregivers in Colorado and the percentage of informal caregivers who provide care for individuals ages 50 and older. The total number of Colorado caregivers based on the AARP analysis is 584,000.
- <sup>11</sup> Caregiving of Older Adults, 2015.
- <sup>12</sup> Note: The difference in hours spent caregiving by gender is among all caregivers, not just those providing services for older adults.
- <sup>13</sup> National Alliance for Caregiving in collaboration with AARP. Caregiving in the U.S. 2009. [http://www.caregiving.org/data/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf).
- <sup>14</sup> Caregiving of Older Adults, 2015.
- <sup>15</sup> Caregiving of Older Adults, 2015.
- <sup>16</sup> Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia 2016;12(4).
- <sup>17</sup> Bureau of Labor Statistics.
- <sup>18</sup> Caregiving of Older Adults, 2015.
- <sup>19</sup> National Alliance for Caregiving, University of Pittsburgh Institute on Aging, and MetLife Mature Market Institute. Working Caregivers and Employer Health Care Costs: New Insights and Innovations for Reducing Health Care Costs for Employers. February 2010. <https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-working-caregivers-employers-health-care-costs.pdf>.
- <sup>20</sup> Valuing the Invaluable, 2015
- <sup>21</sup> Colorado State Demography Office.
- <sup>22</sup> National Alliance for Caregiving and Evercare. Family Caregivers – What They Spend, What They Sacrifice: The Personal Financial Toll of Caring for a Loved One. November 2007.
- <sup>23</sup> Congress of the United States Congressional Budget Office. Rising Demand for Long-Term Services and Supports for Elderly People. June 2013.
- <sup>24</sup> The Retirement Project. Meeting the Long-Term Needs of the Baby Boomers: How Changing Families Will Affect Paid Helpers and Institutions. May 2007.
- <sup>25</sup> Working Caregivers and Employer Health Care Costs: New Insights and Innovations for Reducing Health Care Costs for Employers. February 2010.
- <sup>26</sup> Alice Ho, Sara R. Collins, Karen Davis and Michelle M. Doty. A Look at Working Age Caregivers' Roles, Health Concerns, and Need for Support. August 2005. [http://www.commonwealthfund.org/~media/files/publications/issue-brief/2005/aug/a-look-at-working-age-caregivers-roles--health-concerns--and-need-for-support/854\\_ho\\_lookatworkingcaregiversroles\\_ib-pdf.pdf](http://www.commonwealthfund.org/~media/files/publications/issue-brief/2005/aug/a-look-at-working-age-caregivers-roles--health-concerns--and-need-for-support/854_ho_lookatworkingcaregiversroles_ib-pdf.pdf)
- <sup>27</sup> The AARP study estimated that, in Colorado, there were 584,000 informal caregivers in 2013 (11 percent of the state's population). Using survey data, AARP estimated that 543 million hours were spent caregiving and then applied that to the economic value of per hour in Colorado (\$13.68). The total estimated economic value was \$7.43 billion.
- <sup>28</sup> Working Caregivers and Employer Health Care Costs, 2010.
- <sup>29</sup> Bureau of Labor Statistics.

- <sup>30</sup> Caregiving of Older Adults, 2015.
- <sup>31</sup> Valuing the Invaluable, 2015
- <sup>32</sup> Colorado State Demography Office.
- <sup>33</sup> MetLife Mature Market Institute, National Alliance for Caregiving, Center for Long Term Care Research and Policy at New York Medical College. Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents. June 2011. <https://www.metlife.com/mmi/research/caregiving-cost-working-caregivers.html#key findings>.
- <sup>34</sup> Congress of the United States Congressional Budget Office. Rising Demand for Long-Term Services and Supports for Elderly People. June 2013.
- <sup>35</sup> The Retirement Project. Meeting the Long-Term Needs of the Baby Boomers: How Changing Families Will Affect Paid Helpers and Institutions. May 2007.
- <sup>36</sup> Caregiving of Older Adults, 2015.
- <sup>37</sup> The Family Caregiver Alliance. The Rosalinde and Arthur Gilbert Foundation Awards Ceremony and 5<sup>th</sup> Year Celebration. April 11, 2013. <https://www.caregiver.org/rosalinde-and-arthur-gilbert-foundation-awards-ceremony-and-5th-year-celebration>.
- <sup>38</sup> AARP. Bipartisan Congressional Assisting Caregivers Today (ACT) Caucus. August 2015. <http://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2015/bipartisan-congressional-caregivers-caucus.html>.
- <sup>39</sup> Building Long-Term Sustainability in State Lifespan Respite Programs: Colorado Respite Care Project Grant Summary and Outcomes. <http://www.ucdenver.edu/academics/colleges/medicalschooll/programs/JFKPartners/educationtraining/Documents/Grant%20Activity%20Summary%20and%20Outcomes.pdf>
- <sup>40</sup> Colorado Respite Coalition. Colorado Respite Care Project. <http://coloradorespitecoalition.org/about/care-project.php>.
- <sup>41</sup> Rhonda J. V. Montgomery, Ph.D., Administration for Community Living. Tailored Caregiver Assessment and Referral (TCARE).
- <sup>42</sup> The SAPGA can reach Maureen Kenney, program manager of the Wilder Foundation, at 651-280-2509.
- <sup>43</sup> Key informant interview with Maureen Kenney, Caregiver Services Program Manager, Wilder Foundation. July 20, 2016.
- <sup>44</sup> Colorado Department of Human Services and the Colorado Commission on Aging. Colorado Aging Framework: A Guide for Policymakers, Providers, and others for Aging Well in Colorado. July 2015. <https://www.colorado.gov/pacific/sites/default/files/Colorado%20Aging%20Framework%20FINAL%20-%20July%202015.pdf>.
- <sup>45</sup> Kenneth Matos and Ellen Galinsky. Families and Work Institute. 2012 National Study of Employers. Alfred P. Sloan Foundation. 2012. [http://familiesandwork.org/site/research/reports/NSE\\_2012.pdf](http://familiesandwork.org/site/research/reports/NSE_2012.pdf)
- <sup>46</sup> 2012 National Study of Employers. 2012.
- <sup>47</sup> United States Department of Labor. The Employee's Guide to the Family and Medical Leave Act. <https://www.dol.gov/whd/fmla/employeeeguide.pdf>
- <sup>48</sup> 2014 National Study of Employers. 2014.
- <sup>49</sup> State of New Jersey Department of Labor and Workforce Development. Family Leave Insurance: Cost to the Worker. <http://lwd.dol.state.nj.us/labor/fli/content/cost.html>.
- <sup>50</sup> Valuing the Invaluable, 2015.
- <sup>51</sup> Montana Department of Labor and the Montana Budget and Policy Center. Paid Leave in Four States: Lessons for Montana Policymakers and Advocates. December 2015. <https://www.dol.gov/wb/media/Paid%20Family%20Medical%20Leave%20in%20Four%20States%20FINAL.pdf>
- <sup>52</sup> New York State. Paid Family Leave: Strong Families, Strong NY: New York Passes Nation's Strongest Paid Family Leave Program. <https://www.ny.gov/programs/paid-family-leave-strong-families-strong-ny>
- <sup>53</sup> National Conference of State Legislatures. State Family and Medical Leave Laws. July 19, 2016. <http://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx>.
- <sup>54</sup> Vicki Shabo. Advances in Workplace Protections for Family Caregivers. American Society on Aging. January 11, 2016. <http://www.asaging.org/blog/advances-workplace-protections-family-caregivers>
- <sup>55</sup> PR Newswire. Workplace Flexibility for Family Caregivers New State Law. August 22, 2016. <http://www.prnewswire.com/news-releases/workplace-flexibility-for-family-caregivers-new-state-law-300316527.html>
- <sup>56</sup> National Conference of State Legislatures. Paid Sick Leave. July 9, 2016. <http://www.ncsl.org/research/labor-and-employment/paid-sick-leave.aspx>
- <sup>57</sup> Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents. June 2011.



- <sup>58</sup> Legispeak: Colorado General Assembly Tracking. SB16-114- Employee-Earned Paid Sick Leave. <http://www.legispeak.com/bill/2016/sb16-114>.
- <sup>59</sup> 2012 National Study of Employers. 2012.
- <sup>60</sup> Moen, Phyllis, Erin L. Kelly, and Rachele Hill. "Does Enhancing Work-Time Control and Flexibility Reduce Turnover? A Naturally Occurring Experiment." *Social problems* 58.1 (2011): 69–98. Print. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3084004/>
- <sup>61</sup> Stephen Miller. Study: Flexible Schedule Reduce Conflict, Lower Turnover. April 11, 2011. <https://www.shrm.org/resourcesandtools/hr-topics/benefits/pages/flexschedules.aspx>
- <sup>62</sup> AARP and ReACT. Determining the Return on Investment: Supportive Policies for Employee Caregivers.
- <sup>63</sup> 2014 National Study of Employers. 2014.
- <sup>64</sup> Building Long-Term Sustainability in State Lifespan Respite Programs.
- <sup>65</sup> Key informant interview with Meghan Baskett, Program Manager, Colorado Respite Care Project. 7/18/2016.
- <sup>66</sup> Colorado Department of Public Health and Environment. Family-Friendly Workplace Toolkit. <https://drive.google.com/file/d/0B4u1qfqmSaHjd251djFoR2VoOW8/view>
- <sup>67</sup> Colorado State Employee Assistance Program. <https://www.colorado.gov/c-seap>
- <sup>68</sup> Key informant interview with Michelle Haan, Program Manager, Health Links. 8/26/2016.
- <sup>69</sup> Harris, Richard. Caregivers Say: Pay Attention to Us: Calls for Better Support Resound at a National Caregiving Conference. *Next Avenue*. (June 29, 2016). <http://www.nextavenue.org/caregivers-tell-country-need-us-pay-attention-us/>.
- <sup>70</sup> Colorado Department of Health Care Policy and Financing. Long Term Services and Supports – Benefits and Services. [https://www.colorado.gov/pacific/hcpf/long-term-services-supports-benefits-services-glossary#Respite\\_Care](https://www.colorado.gov/pacific/hcpf/long-term-services-supports-benefits-services-glossary#Respite_Care)
- <sup>71</sup> Key informant interview with Meghan Baskett, Colorado Respite Care Project. July 18, 2016.
- <sup>72</sup> Govtrack US. S. 2759: Credit for Caring Act of 2016. April 7, 2016. <https://www.govtrack.us/congress/bills/114/s2759/text/is>
- <sup>73</sup> Caregiving of Older Adults, 2015.
- <sup>74</sup> Valuing the Invaluable, 2015.
- <sup>75</sup> Zak Stambor. Caring for Caregivers. *Monitor Staff*. November 2006 (Vol 37) No. 10. <http://www.apa.org/monitor/nov06/caregivers.aspx>
- <sup>76</sup> Key informant interview with Amelia Schafer, Vice President of Programs, Alzheimer’s Association of Colorado. July 15, 2016.
- <sup>77</sup> Key informant interview with Todd Coffey, State Unit on Aging.
- <sup>78</sup> Powerful Tools for Caregivers. <http://www.powerfultoolsforcaregivers.org/>
- <sup>79</sup> AARP Project Catalyst. Caregivers & Technology: What They Want and Need. April 2016. <http://www.aarp.org/content/dam/aarp/home-and-family/personal-technology/2016/04/Caregivers-and-Technology-AARP.pdf>
- <sup>80</sup> Caregivers & Technology: What They Want and Need, April 2016.
- <sup>81</sup> Northwest Colorado Council of Governments. Regional Broadband Strategic Plan. December 13, 2013. <https://drive.google.com/file/d/0B-vz6H4k4SESU05hem5XYXRwQWc/view>.