

MEMORANDUM

To: Colorado's Strategic Action Planning Group on Aging
From: Natalie Triedman, Policy Analyst, Emily Johnson, Senior Policy and Statistical Analyst, and Amy Downs, Vice President, Colorado Health Institute
Re: DRAFT Caregiving Research
Date: July 20, 2016

This memo summarizes findings from the first phase of research and analysis by the Colorado Health Institute (CHI) for the Strategic Action Planning Group on Aging (SAPGA). This phase focuses on the cost of informal caregiving in Colorado. Member feedback from the July 25 meeting will be included in the final research report.

CHI is answering this question posed by the SAPGA:

What is the financial impact of informal caregiving on Colorado families, Colorado businesses and the economy?

Informal caregiving became a top research priority because it is an essential system of support for so many older adults in Colorado. It 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 is acting as an unpaid caregiver to someone aged 50 or older.^{i, ii}

Informal caregiving benefits seniors by allowing them to age within their community, surrounded by a strong network of supports. It is also a cost-effective alternative to paying for outside care. But it can place immense financial, physical and emotional pressures on people and families.

A new model developed by CHI for this research estimates that the cost to individuals in 2015 was \$3.7 billion.

The physical and emotional toll of informal caregiving is taxing on the body as well as the wallet. Research shows that informal caregivers typically see their health deteriorate, with a heightened prevalence of major conditions such as depression, hypertension and diabetes. The informal caregivers also report lower general health status than non-caregivers and are more likely to take part in negative health behaviors such as smoking or drinking.^{iii, iv} All of these factors translate to higher health care costs for the caregivers themselves.

While taking care of a loved one, many informal caregivers will pay the costs associated with caregiving — 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 average age of an informal caregiver is 49, so most are still working as they juggle this part- or full-time responsibility.^v CHI's analysis shows that time spent away from work can be costly. Fewer work



Informing Policy. Advancing Health.

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 is jarring at \$564 million in 2015, according to CHI's model.

Informal caregiving also affects Colorado's economy. Unpaid caregivers earn lower wages, and their time is tied up in caregiving, which drives down statewide tax revenue on income as well as leisure-time expenditures.

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

But unpaid caregiving helps seniors age in place at a low upfront cost. It provides a comfortable and familiar environment that allows older adults to maintain their independence. It's also cheaper than professional caregiving services. For many, it is the only affordable option.

Many seniors 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. So rather than pay for a home health worker or concierge service, family members and friends chip in their time. Without informal caregivers, many older adults would be unable to remain at home.

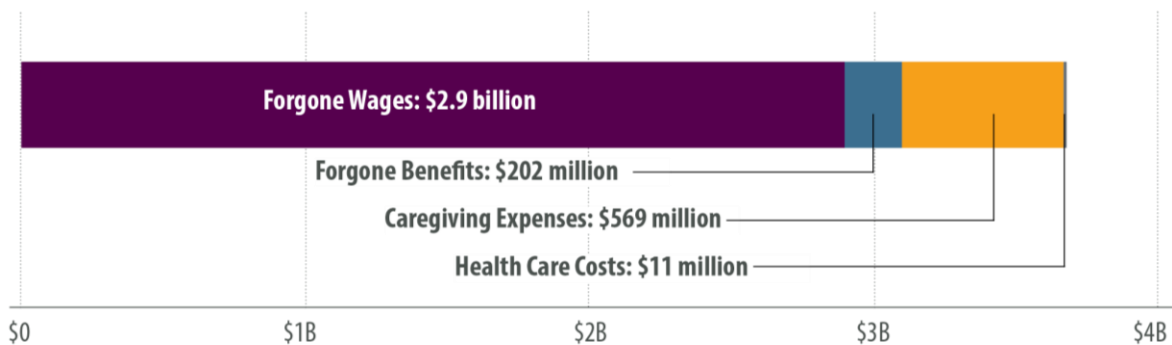
Colorado's demographic shift underscores the essential role that informal caregivers will continue to play as the state's Baby Boomers age. But in a decade or two, the ratio of informal caregivers to older adults is expected to shrink dramatically as the age demographic skews older. Filling this care gap with formal caregivers would be costly to families, and it would mean that fewer older adults have a familiar face helping them out.

Rather than rely exclusively on increasing the pipeline for professional caregivers, it will be important to identify effective strategies for supporting the 500,000 informal caregivers Colorado.^{vi}

Key Findings

CHI developed our own a statistical model to estimate the quantifiable costs of informal caregiving to individuals and businesses in Colorado. 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. These findings delineate the specific opportunity costs to the unpaid caregiver workforce in a way that hasn't been done before in Colorado.

- **The cost of informal caregiving to individuals in Colorado was \$3.7 billion in 2015 in terms of forgone wages, forgone benefits, caregiving expenses and increased health care costs for caregivers.**
- **By 2030, it's projected to climb to \$6.6 billion (in 2015 dollars).**



- **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:** Often, unpaid caregivers will 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. ^{vii,viii} **Total cost in 2015: \$11 million.**

Note: 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 values the hours spent on 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: the costs associated with informal caregiving.^{ixx}

- **The cost of informal caregiving to employers in Colorado was \$564 million in 2015 from turnover, absenteeism and presenteeism.**
- **By 2030, it's projected to nearly double to \$1.0 billion (in 2015 dollars).**



- **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.^{xi} CHI's analysis 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.**

These financial losses to individuals and businesses have implications for the state's economy. Forgone wages, extended leave and early retirement translate to lost income tax revenue to the state. And with less disposable income, caregivers typically spend less recreationally on things like vacations or eating out. These forgone tax revenues are an important consideration when viewing the impact of caregiving in the context of the state economy.

Creating a Supportive System for Informal Caregivers in Colorado

The costs associated with informal caregiving illuminate one of many challenges for these unpaid workers. 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 for many seniors. Without them, many high-need seniors would otherwise 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 SAPGA research. One of 10 Coloradans is an informal caregiver, but their peers and colleagues are often unaware of this. Even informal caregivers themselves don’t always self-identify. In fact, one study found that only about 19 percent of caregivers self-identified.^{xii} 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 important to consider whether there are programs and funding to 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 was co-chaired by Colorado Senator Michael Bennet, served 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, technology innovators and others.^{xiii}
- In Colorado, political momentum and increased funding opportunities around educating residents about respite care have elevated awareness of caregiving in general. For example, 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.^{xiv} 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.^{xv}

Opportunities for Colorado

- The federal **Recognized, 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 Bennett. 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 Bennett'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.^{xvi} To administer the assessment, professionals must undergo an intensive two-day training and some additional continuing education opportunities. 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 and might be interested in reimbursing for the assessment delivery.
- 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 over-burdened 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 year-long 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. When CHI spoke with a program manager at the Amherst H. Wilder Foundation, a Minnesota-based group that spearheaded that campaign, they shared that there would be an opportunity for Colorado to partner with them. 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.^{xvii} 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 recently added to the 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. The SAPGA could recommend that this module remain on 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.

Lever 2: Create Flexibility in the Workplace

The federal government, state government and Colorado-based employers have implemented some policies to support family caregivers. 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.^{xviii} But the opportunity costs of caregiving are still weighing on many Coloradans. 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 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.^{xix} 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. 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.^{xx} 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 2015, the United States Department of Labor updated the definition of spouse, extending benefits to those in legal same-sex marriages.^{xxi}

Opportunities for Colorado

- While FMLA lays the groundwork for caregiver-friendly workplaces, a national study found that about one of five large employers were out of compliance with FMLA despite being covered. The SAPGA could consider recommending strategies for **enhancing compliance of FMLA** in Colorado.^{xxii}
- Unlike FMLA, which requires employers to offer unpaid leave, **state-level family leave policies** 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 successfully implemented these policies, but Colorado is not one of them. Rhode Island, California and New Jersey have enacted a paid family leave insurance program, or **Temporary Caregiver Insurance**, which is funded by employee payroll deductions.^{xxiii} 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.^{xxiv, xxv} The SAPGA could explore the different approaches of these three states, as well as others like New York that will soon be implementing a family leave policy, and recommend that the legislature consider modeling legislation based on these states’ experiences.^{xxvi}

- Similarly, legislation requiring **paid sick leave** for individuals has passed in five states and many cities. It can help informal caregivers whose health declines as a result of their caregiving responsibilities.^{xxvii} 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.^{xxviii} In recent legislative sessions, Democratic lawmakers in Colorado have unsuccessfully attempted to pass paid sick leave legislation.^{xxix}
- 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 making it easier for informal caregivers to juggle their responsibilities. A national study of employer policies breaks this down into some key categories^{xxx}:
 - **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)
 - **Culture of flexibility** (e.g., workplace flexibility policies are promoted and communicated clearly)

Some studies show that these workplace accommodations can translate to employer savings. A 2014 study found 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.^{xxxi}

- The Colorado Respite Care Project is piloting a self-care training program to 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 here 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, they are 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, they have piloted the trainings in Denver and Pueblo. Depending on the success of the pilot, the SAPGA may choose recommend statewide implementation of this effort.^{xxxii, xxxiii}

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.^{xxxiv} 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 involved 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.^{xxxv} 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.^{xxxvi}

Opportunities for Colorado

- 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. 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. While the SAPGA might be interested in offering a recommendation to scale respite resources like the voucher program, it may be more effective to offer recommendations for **expanding the respite provider workforce**.

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. Yet 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 they are caring for.^{xxxvii}
- 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.

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 ongoing **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 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. Offering trainings or certificates 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 individuals that they serve. 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.^{xxxviii} 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 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.^{xxxix}
- **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.^{xl}
- 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 on 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 debate 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.

- 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.

Lever 6: Connectivity, Affordability & User-Friendliness are Critical Components of 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. 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.^{xii}

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.^{xiii}

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. Including many different caregivers throughout the development of technologies intended to support them is essential.

- 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, uptake 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.^{xliii}
- Leverage technologies aimed to support broader audiences. While some products are specifically designed for caregivers, others have 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, these 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.

Questions for the SAPGA

After presenting this work to the SAPGA at the meeting on July 25, CHI will lead a discussion around the following questions:

- What topic areas in this memo resonate the most with you?
- What policy options or programs outlined in this memo do you think are most realistic and promising for Colorado?
- What visual(s) would be most helpful for disseminating this research?
- Are you equally interested in research on policy/programmatic successes and opportunities at the federal, state, employer, provider or community level? Should CHI prioritize any of these policy levels?

CHI looks forward to discussing this research with the SAPGA on July 25. We encourage the SAPGA to send any questions or suggestions to Natalie Triedman prior to the meeting so that we can use those ideas as a launching pad for the facilitated discussion. You can reach her at triedmann@coloradohealthinstitute.org or 720-382-7077.

ⁱ 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>

ⁱⁱ Colorado State Demography Office. Population by Age and Gender. Accessed July 2016. https://dola.colorado.gov/demog_webapps/pagCategory.jsf.

-
- iii 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>.
- iv 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>
- v AARP Public Policy Institute and the National Alliance on Caregiving. Caregiving in the U.S., June 2015. <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- vi 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.
- vii 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>.
- viii 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
- ix 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.
- x Working Caregivers and Employer Health Care Costs, 2010.
- xi Caregiving in the U.S., 2015.
- xii The Family Caregiver Alliance. The Rosalinde and Arthur Gilbert Foundation Awards Ceremony and 5th Year Celebration. April 11, 2013. <https://www.caregiver.org/rosalinde-and-arthur-gilbert-foundation-awards-ceremony-and-5th-year-celebration>.
- xiii 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>.
- xiv Building Long-Term Sustainability in State Lifespan Respite Programs: Colorado Respite Care Project Grant Summary and Outcomes. <http://www.ucdenver.edu/academics/colleges/medicalschoo/programs/JFKPartners/educationtraining/Documents/Grant%20Activity%20Summary%20and%20Outcomes.pdf>
- xv Colorado Respite Coalition. Colorado Respite Care Project. <http://coloradospitecoalition.org/about/care-project.php>.
- xvi Rhonda J. V. Montgomery, Ph.D., Administration for Community Living. Tailored Caregiver Assessment and Referral (TCARE).
- xvii Key informant interview with Maureen Kenney, Caregiver Services Program Manager, Wilder Foundation. July 20, 2016.
- xviii 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>.
- xix 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
- xx 2012 National Study of Employers. 2012.
- xxi United States Department of Labor. The Employee's Guide to the Family and Medical Leave Act. <https://www.dol.gov/whd/fmla/employeeguide.pdf>
- xxii 2012 National Study of Employers. 2012.

-
- ^{xxiii} 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>.
- ^{xxiv} Valuing the Invaluable, 2015.
- ^{xxv} 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>
- ^{xxvi} 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>.
- ^{xxvii} National Conference of State Legislatures. Paid Sick Leave. July 9, 2016. <http://www.ncsl.org/research/labor-and-employment/paid-sick-leave.aspx>
- ^{xxviii} 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](https://www.metlife.com/mmi/research/caregiving-cost-working-caregivers.html#key%20findings).
- ^{xxix} Legispeak: Colorado General Assembly Tracking. SB16-114- Employee-Earned Paid Sick Leave. <http://www.legispeak.com/bill/2016/sb16-114>.
- ^{xxx} 2012 National Study of Employers. 2012.
- ^{xxxi} AARP and ReACT. Determining the Return on Investment: Supportive Policies for Employee Caregivers.
- ^{xxxii} Building Long-Term Sustainability in State Lifespan Respite Programs.
- ^{xxxiii} Key informant interview with Meghan Baskett, Program Manager, Colorado Respite Care Project. 7/18/2016.
- ^{xxxiv} 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/>.
- ^{xxxv} 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
- ^{xxxvi} Key informant interview with Meghan Baskett, Colorado Respite Care Project. July 18, 2016.
- ^{xxxvii} Valuing the Invaluable, 2015.
- ^{xxxviii} Key informant interview with Amelia Schafer, Vice President of Programs, Alzheimer’s Association of Colorado. July 15, 2016.
- ^{xxxix} Key informant interview with Todd Coffey, State Unit on Aging.
- ^{xl} Powerful Tools for Caregivers. <http://www.powerfultoolsforcaregivers.org/>
- ^{xli} 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>
- ^{xlii} Caregivers & Technology: What They Want and Need, April 2016.
- ^{xliii} Northwest Colorado Council of Governments. Regional Broadband Strategic Plan. December 13, 2013. <https://drive.google.com/file/d/0B-vz6H4k4SESU05hem5XYXRwQWc/view>.