

Senate Committee on Human Services
Informational Hearing

**Caring for Caregivers of Older Adults:
Recognizing the Benefits and Needs of Family Caregivers**

February 25, 2019, 3:00 p.m.
Capitol, Room 2040

BACKGROUND PAPER

Introduction

Americans are living longer than ever. In California, the senior population is projected to increase by 4 million in the next ten years. In 40 years, California's Department of Finance projects California's senior population will continue to grow to approximately 13.5 million. Seventy percent of people over 65 will need assistance with performing daily activities of living in order to continue living in their homes.¹ This assistance is very often provided by unpaid family caregivers.

Caregiving can be defined as family or friends helping older adults or persons with a disability with personal care and other activities of daily living. Caregiving is an issue that has touched or will touch the vast majority of Californians - either due to their own need for in-home care or because a loved one needs care in order to avoid costly stays in nursing homes and hospitals. With 4.5 million caregivers, California has the highest number of family caregivers in the US.

The majority of California's caregivers are balancing their caregiving responsibilities with those of their full-time employment. Nationally, the AARP found that 60 percent of family caregivers were also working paying jobs at some point during their caregiving journey.²

Caregiving, while often very rewarding, can strain the caregivers' finances, physical and mental health. While there are quite a few programs offering services, accessing the right services at the right time can be difficult. Studies have shown that coordinated supports and services can reduce caregiver depression, anxiety, and stress, and enable them to continue providing care, thereby avoiding or delaying the need for costly institutional care.

Unpaid caregivers can be anyone, but they are most likely to be the spouse or child of the care recipient. Adults of any age can be caregivers, regardless of income level; educational achievement; whether residing in rural or urban settings; race; ethnicity; language spoken; or gender identity. Millennials are a fast-growing age group of family caregivers, but octogenarians are also performing caregiving.

Often, people providing care do not self-identify as caregivers. Family caregivers often state they are simply fulfilling familial or community duties. By providing care that allows care

recipients to stay in home and avoid or delay costly nursing home care and hospitalization, caregivers play a vital, yet sometimes unrecognized, role in the system of Long Term Services and Supports (LTSS).

Caregiving typically includes a wide array of activities. Most caregivers help with personal care and other activities of daily living (i.e., bathing, dressing, shopping, managing household finances, meal preparation and transportation). Many caregivers also address certain medical needs of their care recipient. This can include conducting medical/nursing tasks (such as tube feedings or wound care); locating, arranging, and coordinating services and supports; serving as the advocate for the care recipient during medical appointments or hospitalizations; communicating with health and social service providers; and implementing care plans.

Recognizing the need to address the needs of family caregivers, Assembly Concurrent Resolution 38 (Brown, Chapter 200, Statutes of 2015) created the California Task Force on Family Caregiving to examine issues relative to the challenges faced by family caregivers and opportunities to improve caregiver support, review current network and the services and support available to caregivers, and make policy recommendations to the Legislature. The Task Force final report was issued in 2018 and contains recommendations in seven categories, some of those recommendations are discussed herein and others are currently under consideration via the legislative and budgetary processes.

Need for Family Caregivers

As the state's older population increases, it is expected that the demand for caregivers will increase as well. Causes of the projected rapid growth include aging baby boomers, increasing longevity, a higher number of individuals with chronic conditions associated with aging, and the increasing cost of LTSS.³ With longevity comes increased need for care. After reaching the age of 65, most people will require LTSS for an average of three years.⁴

LTSS are the services and supports used by individuals of all ages with functional limitations and chronic illnesses who need assistance to perform routine daily activities such as bathing, dressing, preparing meals, and administering medications. LTSS include the wide array of medical and non-medical services provided to people of all ages with impaired mobility, impaired cognitive function, physical or mental disabilities, complex medical needs or chronic disease. Individuals may need these services on a regular or occasional basis, for a few months or a lifetime.

The out of pocket expense to provide LTSS for older adults is often unaffordable for seniors on a fixed income. As the level of care increases, so does the cost. Paid in-home care costs about \$26 per hour, which means 20 hours of weekly care would cost about \$2,250 per month. The average cost of assisted living in California in 2018 was \$4,070 per month. However, that price ranges from \$1,020 to \$10,720, depending on the geographic region.⁵ According to the Public Policy Institute, nursing home care in 2014 averaged \$7,500 a month for a semi-private room and \$8,666 a month for a private room.⁶

Long-term care (LTC) insurance has not met its promise of an affordable option to help meet LTSS needs. Such policies require an annual premium in return for financial assistance if/when policy holders need help with activities of daily living or nursing home care as they age. These policies can be cost prohibitive and recent reports indicate that the cost will increase over time. Additionally, insurance companies are dropping LTC coverage from their menu of optional coverage. According to AARP, more than 100 insurers sold such policies in the 1990s and fewer than 15 were offering LTC policies in 2018.⁷

There are government healthcare programs that cover LTSS. Medicaid (Medi-Cal in California) is available for people who meet income eligibility and Medicare is available for those who meet age requirements. However, neither program adequately covers LTSS (even for people who are eligible for both). Medicare only pays for short-term rehabilitative care. Medicaid pays for personal care and supportive services, but income/asset limits can force older adults to spend down their assets in order to qualify for help through Medicaid. This scenario forces people into poverty in their later years in order to access the care they need.

Lack of affordable LTSS is a contributing factor to why many family members find it necessary to provide in-home unpaid care for their loved ones. According to The SCAN Foundation, nearly two-thirds of older adults with LTSS needs who are living at home receive all help from unpaid family caregivers.

Aside from financial reasons, family caregiving allows older adults to remain in their homes, when this is their desired arrangement. It also promotes aging with dignity and is consistent with person-centered care.

Person-centered care, an increasingly popular approach to care for older adults, enables patients to actively participate in their own medical treatment in close cooperation with health professionals. The federal Centers for Medicare and Medicaid Services is promoting person centered care in a number of LTSS programs, including Home and Community Based Services waivers, which allow beneficiaries to receive treatment at home or in a community setting, rather than being required to enter an institution. When given the option, most older adults desire to “age in place,” which the Centers for Disease Control and Prevention defines as “the ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level.” These policy concepts are bolstered by family caregivers who work to keep their care recipients living safely in their own homes.

Profile of Family Caregivers

California’s 4.5 million unpaid caregivers are the spouses, partners, adult children, relatives, friends, or neighbors who provide care and support to older adults and/or adults with developmental disabilities. They provide care in a wide variety of circumstances and for varying lengths of time. For example, they may provide care for a parent with a chronic degenerative disease; spouse who is rehabilitating after surgery; a grandparent who needs help with household chores and running errands; and a child with developmental disabilities.

Family caregivers also provide lifelong care to children, siblings, or other loved ones with intellectual or developmental disabilities (IDD). These caregivers play an important role within

the system of services and supports available to California’s IDD community. They face many of the same challenges as those caring for their aging loved ones and often also have to navigate various systems in order to access different aids, services, or types of care. These caregivers may benefit from some of the same supports and services needed by those caring for aging loved ones and may be caring for loved ones enrolled in the same or similar programming. However, this background paper is on the needs of caregivers for older adults, will thus be focusing on caregiving through that lens.

According to AARP and the National Alliance on Caregiving’s report “Caregiving in the U.S.:

- 60 percent of caregivers are female;
- On average, caregivers are 49 years old, although they are often much younger and much older;
- 19 percent of caregivers are 65 years of age and older;
- Approximately 20 percent of caregivers are taking care of more than one person, while 10 percent have provided care to three or more individuals; and
- In the US, 62 percent of caregivers are white; 13 percent are African American; 17 percent are Latinx¹ and 6 percent are Asian-American.

Many caregivers are “sandwiched” between caring for aging parents and their own children. Nearly half of adults in their 40s and 50s have a parent age 65 or older and are either raising a young child or financially supporting a grown child. About 15 percent of middle-aged adults are providing financial support to both an aging parent and a child.⁸

Many millennials are acting as caregivers. Over one-third of Americans age 18 to 39 have provided care to an older family member or friend. An additional 34 percent think it is likely they will become a caregiver within the next five years and more than half of respondents say they are ill prepared for that role. Millennial family caregivers provide more than 20 hours per week in care, on average. One in three millennial caregivers support someone with a mental health or emotional problem.⁹

Profile of Care Recipients

Care recipients are most often the parent or parent in-law of their caregivers. The second most common care recipients are caregivers’ spouses. Recipients are less frequently, grandparents, extended family members, siblings or children of the caregiver. Forty eight percent of care recipients reside in their own home and 35 percent reside in their caregiver’s home.¹⁰

The average age for a care recipient is 69.4 years old, with just under half of all care recipients being age 75 and older.¹¹ Moreover, the reason for care breaks down as follows:

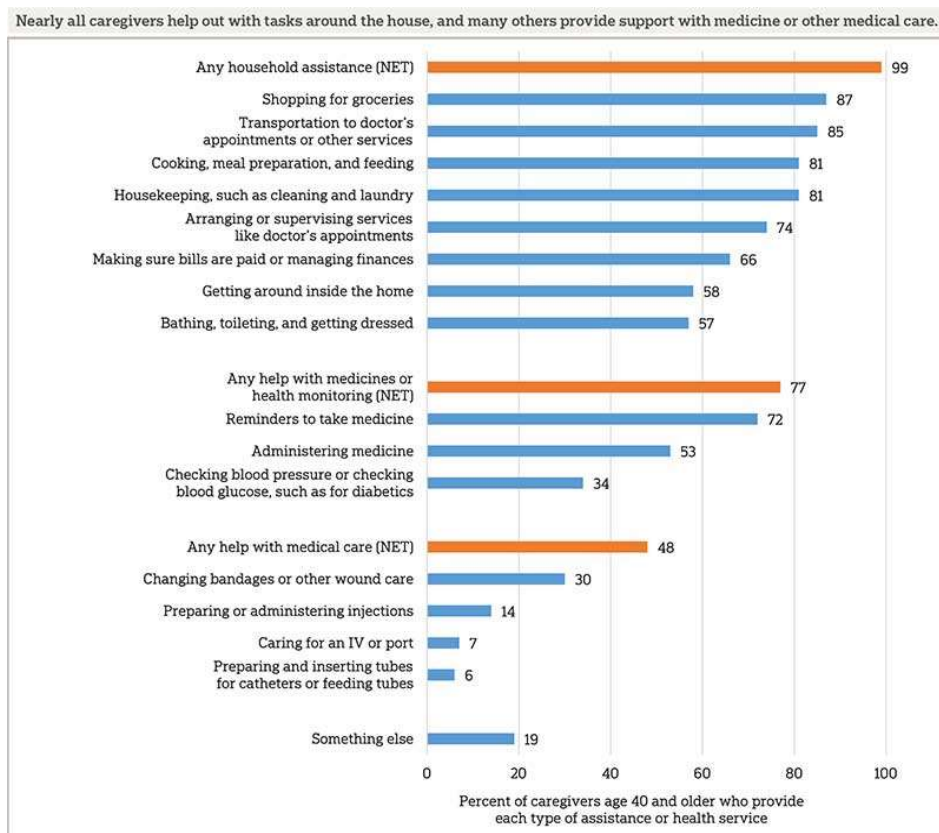
- 64 percent have a long-term physical condition, such as loss of vision or mobility;
- 40 percent have a short-term physical condition, such as pneumonia or a fall; and
- 12 percent have memory loss, such as Alzheimer’s disease or dementia.¹²

¹ Latinx” is an inclusive, gender neutral label for Latino/Latina

What Services do Caregivers Provide?

Caregivers provide assistance with personal care that is associated with the care recipients' everyday life: such service ranges from trips to the grocery store to inserting a catheter or feeding tubes. They help with daily tasks around the house, referred to as Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs are basic everyday activities related to personal care. They include bathing or showering, dressing, getting in and out of bed or a chair, walking, using the toilet, and eating. IADLs refers to activities related to living independently in the community, including but not limited to, meal planning and preparation, managing finances, shopping for food, clothing, and other essential items, performing essential household chores, communicating by phone or other media, and traveling around and participating in the community. If a person has any difficulty performing an ADL or an IADL on their own, or does not perform the activity at all due to health problems, that person is deemed to have a limitation in that activity, such limitation may be temporary or chronic.

As shown in the chart below, about three quarters of caregivers over 40 also help with medicines or health monitoring. About half of family caregivers over 40 assist with medical care such as wound care, tube feedings, catheter and colostomy care, and preparing or administering injections.¹³



Question: [Do/did] you provide any of the following types of ongoing living assistance or home health services?

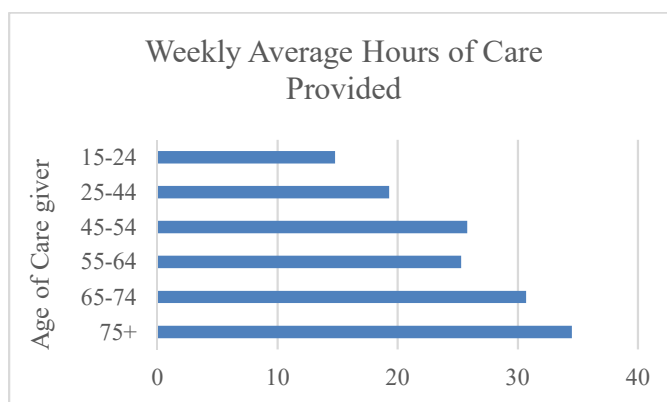
Source: AP-NORC Long-Term Caregiving Poll conducted June 27-July 31, 2017, with 1,004 adults nationwide age 40 and older with caregiving experience

Caregivers also act as healthcare advocates by communicating with healthcare providers about care recipients' needs. Those caring for recipients with Alzheimer's, dementia or other memory

loss are particularly likely to communicate on behalf of their recipient and to advocate and navigate within the healthcare system.

Performing the tasks associated with caregiving can be difficult for caregivers. For example, 25 percent of those performing ADLs report finding such care difficult, with higher-hour caregivers more likely to report experiencing difficulty. The most difficult individual ADLs involve personal care activities, like dealing with incontinence or diapers, helping the recipient to and from the toilet, and bathing/showering assistance.¹⁴

As caregivers age, they are more likely to spend increasing hours providing care.



Caregiving Resources and Services

There are a variety of services and supports available to older Californians. However, each of these programs come with separate eligibility requirements. Some support the needs of caregivers, offering a safe place to loved ones who need care so that primary caregivers may spend time away from caregiving responsibilities and go to work or other activities. Others offer paid caregivers who can provide short term care, information, training, and nutrition services. The following is a brief summary of the variety of programming available, as well as the resources that help older Californians and their loved ones navigate these programs. This overview is focused through the lens of caregiving and is not intended to be an overview of the entirety of California’s long-term care supports and services or other programming available for California’s aging population.

Area Agencies on Aging (AAA)

An AAA is a public or private nonprofit agency designated by the state to address the needs and concerns of all older persons at the regional and local level. Each AAA typically operates in a specific geographic area, known as a planning or service area or PSA. They were established by the Older Americans Act in 1965 and either directly provide or contract with local organizations for the provision of services to seniors and adults with disabilities. The California Department of Aging has designated 33 AAAs, representing 33 PSAs that vary in size and provide services to the entire state.

AAAs implement the services and intent found within the Older Americans Act, which translates into the coordination and provision of services that help older adults stay in their homes aided by the supports needed to make independent living possible. Services provided by AAAs, or through their contracts with community providers, include: home adaptation funding; provision of assistive devices; support groups; nutrition programs, including congregate nutrition programs and home delivered meal programs; disease prevention and health promotion programs; family caregiver support programs, including training and education; and supportive services programs. These programs receive funding from a variety of sources, including federal funding, small amounts of California General Fund dollars, and local funding.¹⁵

AAAs also administer the following programs that directly and indirectly support caregivers:

Nutrition Services: Nutrition services are offered in two types of settings: congregate and home delivered meals. Congregate nutrition services provide meals in group settings. The services offered include nutrition and health promotion education along with opportunities for socialization. Both programs have eligibility requirements. To be eligible for congregate nutrition services one must be: 60 years of age or older; an individual with a handicap or disability; a spouse of an eligible participant regardless of their own age; or a volunteer who provides needed services during the meal hours. Home delivered meal services are available to people, age 60 or older, who are homebound by reason of illness, incapacity, or disability, or who are otherwise isolated. Most home-delivered meal programs provide clients with a hot meal five days a week delivered by staff or volunteer drivers.

Both congregate nutrition and home delivered meals serve a broad population, with preference given to those in the greatest economic or social need. They are both administered by the California Department of Aging through California's network of AAAs and their service providers. Nutrition services are funded by the federal funds provided through Title III of the Older Americans Act and state General Fund dollars.

Family Caregiver Support Program (FCSP): The FCSP was established under Title III of the federal Older Americans Act Amendments of 2000. Federally, FCSP services are available to family and other unpaid caregivers supporting older individuals, as well as grandparents and older relatives caring for children. Each AAA determines their specific array of services depending on the unique needs of their community, but services may include: caregiver information; assistance in gaining access to services; counseling and training support; temporary respite; and limited supplemental services to complement the care provided by unpaid caregivers. These services may be provided directly by the AAAs or through their partnerships with other public or private agencies.

Caregiver Information and Assistance Program: Run by the AAAs, the Information and Assistance Program provides up-to-date information about caregiver support programs and services available within a local community. The California Department of Aging provides a statewide toll-free information line that connects callers with the local Information and Assistance Program service provider. If calling on behalf of a loved one residing in a different area, the caller can be referred to service providers in those regions.

Aging and Disability Resource Centers (ADRCs)

ADRCs were created at the federal level through a collaborative effort led by the Administration for Community Living and Centers for Medicare and Medicaid Services. The goal of ADRCs is to streamline access to LTSS for older adults, all persons with disabilities, family caregivers, veterans, and LTSS providers. Due to these goals, each ADRC is also an Independent Living Center (ILC) and an AAA. Since many communities currently have multiple agencies administering LTSS and have complex, fragmented, and often duplicative intake, assessment, and eligibility functions, ADRCs are intended to act as a single more coordinated system of information and access for persons seeking LTSS.¹⁶

ADRC's are intended to act as a No Wrong Door system. This means when a person contacts an ADRC they are connected with what they need regardless of their age, income, or disability.¹⁷ ADRCs do this by building upon the strengths of existing community service providers and removing the multiple intake and assessment processes. Additionally, any individual within the ADRC's geographical area may contact the ADRC for services. There are no eligibility requirements for contacting the ADRC, although access to services will be dependent upon a program's eligibility requirements.

There are currently seven ADRCs in California, with each representing a different county. The following counties are currently represented by an ADRC: Alameda; Nevada; Orange; Riverside; San Diego; San Francisco; and Ventura. ADRCs only serve residents within their county. However, caregivers from outside of the county may obtain assistance from ADRCs if the care recipient is a county resident. They provide these consumers with: benefits counseling; assessments to determine what services they might need; referrals to resources that provide housing, transportation, day care services, in home services, assisted living, skilled nursing centers, and assistive technologies; and other resources to help individuals stay in the community.

Federally, ADRCs are supported by the Administration on Aging, the Administration for Community Living, the Centers for Medicare and Medicaid Services, and the Veterans Administration. However, federal grant funding for starting an ADRC is no longer available and there is no dedicated state funding source for ADRCs. Rather, the state's seven ADRCs stitch together a combination of county, state and federal funding that is available due to their status as ILCs and AAAs.¹⁸

Caregiver Resource Centers (CRCs)

Statewide, 11 CRCs provide services and support to the families and caregivers of older adults with chronic health conditions, including frail adults over the age of 60, adults with cerebrovascular diseases, and those with brain impairing conditions. Each of the 11 CRCs provides services to a specific geographic area, allowing all Californians to have access to the CRC serving their region. CRCs, under the purview of the California Department of Health Care Services, are intended to act as an entry to services available to informal caregivers in their own communities. As such, each CRC tailors the services offered to the needs of their geographic area and provide these services at low or no cost. The core services provided by CRCs include:

information and referral; short-term counseling; respite care; education; and, training and support to families and caregivers of persons with Alzheimer's disease, stroke, Parkinson's disease, and other disorders. Any caregiver within the CRC's geographic area can contact the CRC for services and supports. The services available to them may vary based on the eligibility requirements for each individual program.¹⁹

Through Fiscal Year 2007-08, CRCs received funding through contracts with the Department of Health Care Services totaling \$11,747,013. According to the California Task Force on Family Caregiving, in 2009, CRC funding was cut by 74 percent, from 10.5 million. A \$2 million investment in 2015 restored some of the CRC's funding, but their current funding levels remain far below what they were in 2008. In the meantime, the need for CRC services has continued to grow.²⁰

Community-Based Adult Services (CBAS)

CBAS programs are day care programs providing a variety of health, therapeutic and social services to older adults and people with disabilities that meet Medi-Cal program and waiver requirements. This program was formerly known as the Adult Day Health Care program, but that program ended as a Medi-Cal benefit as of March 31, 2012. CBAS programs focus on providing services to older adults with chronic medical, cognitive, or mental health conditions who are at risk of needing institutional care, with the purpose being to delay or prevent their institutionalization through a variety of community-based services.

Each CBAS center has a multidisciplinary team of health professionals who conduct a comprehensive assessment of each potential participant to determine and plan services needed to meet the individual's health and social needs. Services provided include professional nursing services; physical, occupational and speech therapies; mental health services; therapeutic activities; social services; personal care; hot meals and nutritional counseling; and transportation to and from the participant's residence. CBAS is offered as a Medi-Cal managed care benefit, thus to be eligible for CBAS services an individual must be eligible for Medi-Cal and be 18 years of age or older while meeting specific medical necessity and eligibility criteria. Additionally, CBAS centers are currently only operating in approximately 30 of California's 58 counties.

Multipurpose Senior Services Program (MSSP)

MSSPs provide social and health care management for frail elderly clients who are certifiable for placement in a nursing facility but who wish to remain in their communities. MSSP's goal is to arrange for the provision of community services so that placement of these clients into an institutional placement can be prevented or delayed. To be eligible for MSSP, the cost of services provided on behalf of the MSSP must be less than that of nursing facility care. To be eligible, an individual must: be 65 years of age or older; live within a site's service area; be appropriate for care management services; eligible for Medicaid; and certified or certifiable for placement in a nursing facility. MSSP funds may be used to provide the following services: adult day care; housing assistance; chore and personal care assistance; protective supervision; care

management; respite; transportation; meal services; social services; and communications services.²¹

Central to the MSSP mission is that a registered nurse and social worker conduct a joint, comprehensive assessment to develop a living care plan linking medical and social services to the client. Staff identify appropriate services, arrange transportation, ensure doctor's appointments are attended, assist with medication compliance and may provide additional necessary items to facilitate independent living, such as a small refrigerator for perishable medications. While CBAS care and services are provided at the CBAS site, MSSP services may occur in an individual's home, through an adult day program, or through a combination of the two.

MSSP sites are operated in only 38 counties and collectively can serve up to 11,789 clients per a month. The MSSP Association reports a wait list of approximately 1,500 people statewide in any given month. MSSP sites are operated under a federal Medicaid Home and Community-Based, Long-Term Care Services waiver, which caps participation. MSSP sites are therefore funded through federal funding related to Medicaid dollars with a 50 percent state matching requirement that is covered by the California's General Fund.²²

Adult Day Services

Adult Day Services programs provide a community alternative to nursing home care for those who do not need 24-hour skilled nursing. Adult Day Services programs are designed to help people stay mentally and physically active, reduce isolation, improve their health, and prevent decline of their abilities at sites located within the older adult's community. Most clients attend an adult day services program two to five days per a week, based on their individual need and program hours range from four to eight hours per a day. All programs provide or assist with transportation and some offer extended hours to help accommodate working caregivers. Some programs also offer support groups, training, and other services to caregivers.

Programs typically fall into the Adult Day Program Centers or Adult Day Health Care categories. Adult Day Health Care, now rebranded as CBAS programs as discussed above, provide a medical model of care through an out-patient day program. Adult Day Program Centers are not funded by Medi-Cal and often have an out of pocket cost associated with participation in the program. The services offered by both programs vary from center to center but all are required to include an individual plan of care, activity programs, dietary services, meals and snacks, personal care and supervision, assistance with the self-administration of medication, and transportation services. Additionally, there is an Alzheimer's Day Care Resource Center Designation for adult day care programs or CBAS centers that offer specialized Alzheimer's care for moderate to late stage Alzheimer's patients or person with similar conditions. These programs provide staff highly trained on caring for individuals with Alzheimer's and programing according to each patient's level of functioning. They also provide caregiver respite and support.²³

In-Home Supportive Services Program (IHSS)

The IHSS program assists eligible low-income individuals in California who are at least 65 years old, living with disabilities, or blind by providing for services that enable them to remain in their homes. The program pays care providers to assist with personal care services (such as bathing, toileting, and grooming), domestic and related services (such as meal preparation, housecleaning, and the like), specified paramedical services, and protective supervision. Eligible individuals are authorized for certain services and a specific number of hours of care.

The growth of the IHSS program in recent years has been significant. In Fiscal Year 2007/08, there were about 400,000 IHSS recipients. The most recent data shows there are 593,461 recipients and the program will likely exceed 600,000 recipients by 2020. Typically, about 98 percent of these individuals receive IHSS services as a Medicaid benefit. Currently, there are about 506,882 IHSS providers in California; 72 percent of these providers are relatives and 53 percent of these providers live in the same residence as the recipient.

IHSS offers family caregivers the possibility of receiving compensation for some of the care they provide, if the loved one they care for is determined to be eligible for IHSS. While it is an option for some caregivers, the IHSS program is only available to people who meet income eligibility requirements.

Fiscal Impact of Caregiving

As of 2013, California's family caregivers were providing an estimated 4.14 billion hours of care annually to their parents, grandparents, spouses, partners, close friends and other adult family members. These hours of uncompensated work are worth an estimated \$57 billion in care services.²⁴ Nationwide, the AARP found that the economic value of unpaid caregiving was approximately \$470 billion in 2013.²⁵ The AARP further found that the nationwide economic value of this unpaid care surpassed the "total Medicaid spending (\$449 billion) and nearly equaled the annual sales (\$469 billion) of the four largest U.S. technology companies combined (Apple, Hewlett-Packard, IBM, and Microsoft) in 2013."²⁶ With an aging population, the number of Californian's providing unpaid care is on track to rise, as is the economic value of this informal care.

Although these family caregivers are saving California's long term care system billions of dollars, unpaid caregiving is by no means free. Caregivers face various forms of economic pressure as a result of providing care to a loved one. It is estimated that family caregivers spend an average of \$7,000 per a year on out of pocket caregiving costs.²⁷ For most caregivers, it was estimated that almost 20 percent of their income went towards caregiving costs. For low-income and Black and Latinx caregivers the economic impact was greater, with as much as 40 percent of their income estimated to be spent on caregiving costs.²⁸ Furthermore, 67 percent reported reducing their own living expenses in order to accommodate the expenses they incurred as a result of caregiving and 63 percent reported having withdrawn money from savings or having cashed in or sold assets in order to provide care.²⁹ Additionally, there are a multitude of long term financial implications stemming from the overlapping responsibilities of caregiving and employment.

As previously noted, the AARP found that 60 percent of family caregivers were also working paying jobs at some point while caregiving.³⁰ Many employed caregivers were also found to be balancing the responsibilities of their employment with high care needs, as one in four employed caregivers reported helping their loved one with three or more activities of daily living and over half reported performing complex medical tasks, such as providing wound care or administering multiple medications.³¹ Millennial caregivers were found to be especially impacted by the dual responsibilities of caregiving and employment. The AARP found that 73 percent of caregivers aged 18 to 34 were also employed while caregiving for an ill or aging family member. Fifty three percent were employed fulltime.³² Younger caregivers also report increased concerns about their job security due to missing work in order to provide care.³³

Many caregivers balancing employment and caregiving report experiencing stress from trying to juggle these often competing demands. If employed caregivers are unable to access supports, both in terms of supportive services for their loved one and for themselves, as well as supports in the workplace, they often end up giving up on employment.³⁴ Caregivers report quitting their employment or retiring prematurely when the dual responsibilities become too much.³⁵ Additionally, a study completed by Northwestern Mutual found that:

- 41 percent of caregivers have reduced their work hours or changed their schedule/shift to provide care;
- 13 percent have resigned their jobs to provide care; and
- 9 percent have changed jobs or careers to provide care.³⁶

Quitting employment, retiring prematurely, and even reducing work hours further risks caregivers' financial security by discontinuing their access to stable income, healthcare benefits, retirement plans, and Social Security. Over the course of their lifetime, caregivers are estimated to lose \$659,139 as a result of reduced salary and reduced retirement benefits.³⁷

Women are found to be the most financially harmed since they are more likely to act as caregivers, make disproportionately less income, are more likely to leave the workforce as a result of caregiving and thus more likely to enter poverty as a result of their caregiving responsibilities.³⁸ Furthermore, according to the Social Security Administration, women average 13 years with no earnings due to caregiving responsibilities.

For some caregivers, it did not feel like their choice to leave the workforce or find alternative employment. One study completed by NORC, an objective non-partisan research institution at the University of Chicago, found that:

- 10 percent of caregivers reported being treated differently by management or coworkers as a result of their needing to provide care;
- 8 percent reported being excluded from further job growth opportunities; and
- 7 percent reported having had their roles or responsibilities changed due to caregiving obligations.³⁹

Additionally, NORC found through their polling that a small number of caregivers reported being fired or asked to resign as a result of their caregiving responsibilities.

Employers and certain workplace policies can improve caregiver burdens rather than act as a further stressor. Studies have shown that employers and management who understand the responsibilities of caregiving and the stress it puts on employees can take proactive steps to reduce employee burdens in a way that is ultimately beneficial to the employer.⁴⁰ This often begins with a company culture where an employee feels comfortable sharing their role as a caregiver, one where they do not feel at risk of being treated differently or at risk of being excluded from future opportunities because of their dual responsibilities. Knowing there are caregivers within their workforce allows employers to better understand the needs of their employees and work to support them in a way that is beneficial to all.⁴¹ Research has shown that some workplace policies provide a significant impact on the needs of caregivers, or at least have the potential to do so. These workplace policies are: family leave policies; paid sick days; and flexible schedules/accommodating workplace policies.⁴²

Workplace Family Leave Policies

Three workplace family leave laws may be available to California’s family caregivers. They are the California Family Rights Act (CFRA), the Federal Family and Medical Leave Act (FMLA) and California Paid Family Leave (PFL). Of these, only the PFL provides any form of payment to employees while on leave. However, PFL only offers partial wage replacement. Under PFL, employees may receive 60 percent or 70 percent of their normal wages for a maximum of \$1,216 weekly. The PFL provides six weeks of leave, but it is available only to employees who have accrued at least 300 dollars in State Disability Insurance through payroll taxes. Both CFRA and FMLA provide 12 weeks of leave to employees in workplaces with 50 or more employees. Additionally, each of these policies provide the employee on leave with job protection and permits employees to maintain their health benefits.⁴³

Each of these policies has slightly different eligibility conditions, with PFL covering the most types of caregiver relationships. The programs’ eligibility requirements are summarized as follows:

| Federal Family and Medical Leave Act (FMLA) | California Family Rights Act (CFRA) | California Paid Family Leave (PFL) |
|---|--|--|
| Must be employed at least 12 months with 1,250+ hours worked with current employer. | Must be employed at least 12 months with 1,250+ hours worked with current employer. | Must have accrued \$300+ in State Disability Insurance (SDI) on payroll taxes. |
| Document need of care for: <ul style="list-style-type: none"> • Parent; • Child; or • Spouse | Documented need of care for: <ul style="list-style-type: none"> • Parent; • Child; • Spouse; or • Registered domestic partner. | Documented need of care for: <ul style="list-style-type: none"> • Parent; • Parent in law; • Spouse; • Registered domestic partner; • Grandparent; • Child; or • Sibling⁴⁴ |

Although family leave policies have been found to be very helpful for the caregivers who are able to use them, researchers have found that these policies are not equitable. For example, the FMLA does not apply to 40 percent of the United States workforce because it does not cover those employed at small establishments, those who work part-time, or those who have not worked at their job for long enough. This means these policies frequently do not apply to those sectors of work where employees may need these protections the most, such as retail and service industry jobs.⁴⁵

PFL has its own challenges. Though more widely available, it does not cover all of California's employees because it excludes those who do not pay into California's SDI tax. This requirement is due to PFL being self-funded through employee contributions through the SDI tax. Thus, ineligible workers include contractors, the self-employed, and many public sector employees, though in some instances they may be able to choose to opt in.⁴⁶

Additionally, PFL was found to be underutilized by those caring for older adults. Sixty percent of eligible caregivers were found to not know about the program, and many of those who were aware of the program were unaware of whether they were eligible – only 31 percent of those aware of the program reported understanding it. Moreover, Latinx and immigrants were found to be about half as likely to be aware of PFL than other groups. Workers from low-wage, low household income, and low education backgrounds were almost one third less likely to be aware of the policy.⁴⁷ For those who did know about PFL, many reported not utilizing the policy because of: low wage replacement; fear of job instability; employer perception; complicated application process; lack of culturally relevant materials; and stigma against using government assistance.⁴⁸ PFL is sometimes incorrectly perceived to be designed or limited to bonding time for new parents, which can unnecessarily create barriers for caregivers of older adults from using the program.

Advocates recommend a variety of changes to increase utilization by caregivers for older adults. Their recommendations include making PFL more comprehensive, by including job protection, increasing the length of time during which PFL can be used, and increasing the relationships covered. They also suggest increasing awareness, understanding, and support with the application process by ensuring information about PFL and how to apply is widely available through a variety of channels and culturally diverse mediums to increase use of this policy.⁴⁹ Moreover, the California Task Force on Family Caregiving suggests, in its final report, that improvements to existing leave policies should be made through legislation that expands the eligibility criteria so that these policies apply to more family caregivers.

Paid Sick Days

In 2014 California passed the Healthy Workplaces, Healthy Families Act, which provides for paid sick leave for employees who work with the same employer for 30 or more days. Under this state law, employees earn at least one hour of paid sick leave for every 30 hours they work. The paid sick leave can then be taken for their own health or for a family member's health. Employers may limit employees' use of paid sick leave to 24 hours or three days per a year. Paid

sick leave applies to full time, part-time, and temporary employees, but employees covered by qualifying collective bargaining agreements are excluded.⁵⁰

Since paid sick leave allows employees to take paid time off for the health of a family member, most caregivers can utilize paid sick leave to take short periods of paid time off as needed for caregiving or doctor's appointments. Additionally, paid sick leave does not have to be taken in whole day increments, rather a caregiver may utilize this policy to take an hour or two here or there as needed.⁵¹

Due to this wider availability and flexibility, paid sick leave seems to be higher utilized by caregivers than PFL. A survey of California's caregivers found that more than 40 percent of caregivers who are eligible for and aware of PFL resorted to other workplace supports instead of utilizing PFL. The survey found that approximately 32 percent of working family caregivers used paid time off, including paid sick leave, and/or took advantage of employer-provided flexible workplace options, including shifting hours, working from home or working part time, which is discussed below. The survey found that in general, many more working caregivers, 84 percent, utilized paid time off, such as vacation or sick time, or changing their schedule in order to take time off for caregiving responsibilities.⁵²

Scheduling and Other Policies

Caregivers rely on schedule predictability, consistency, and flexibility when balancing the needs of caregiving and work. These policies are at the discretion of employers, but are very much relied on by employees to meet their caregiving responsibilities. For example, schedule predictability and consistency allows employees to know when they should schedule doctor's appointments and the like even weeks in advance. It provides them with a sense of security in knowing that they will be available to meet certain needs of the individual they are caring for. While schedule flexibility, such as working from home or being able to shift hours, allows caregivers to deal with the responsibilities of caregiving that are less predictable.⁵³ Millennial caregivers in particular have reported that flexible work arrangements significantly ease the burden of caregiving.⁵⁴

Research has shown that these policies are not just beneficial to employees, but also improve outcomes for the employer. For example, research shows that greater supports, such as flexibility and the ability to work remotely, can lead to greater productivity and greater job satisfaction.⁵⁵ These in turn are thought to reduce employee turnover which reduces employer costs associated with turnover, lost institutional knowledge, and the need for temporary hiring or paying for overtime. Therefore, research suggests that creating a company culture and workplace policies that acknowledge and accommodate the needs of caregivers does not just improve the outcomes for caregivers, but also outcomes for employers.⁵⁶

Health and Wellbeing of Caregivers

Caregivers have been shown to be vulnerable to deteriorating health and wellbeing. This is often due to the physical and emotional strain of caregiving. Studies consistently show higher levels of stress, anxiety, depression and other mental health problems among caregivers than non-

caregivers. These conditions can comprise caregiver's physical and psychological health. For example, caregivers often have higher rates of cardiovascular risk factor and poor immune functioning. Furthering their vulnerability, caregivers often neglect their own health and wellbeing.

Mental Health Consequences

While rewarding, caregiving can be stressful and anxiety-inducing. The sense of responsibility for the wellbeing of a loved one, the time commitment, and the physical demands of caregiving can be overwhelming. This is especially true for those who are caring for loved ones with chronic or worsening conditions, such as those who have Alzheimer's, dementia or other memory loss.

According to the AARP's 2015 report "Caregiving in the U.S.:"

- 38 percent of family caregivers find their situation highly stressful, 25 percent report moderate stress, and 36 percent report little to no stress.
- Caregivers whose care recipient has emotional or mental health problems are more likely than others to report a decline in their own health (25 percent versus 14 percent).⁵⁷

The following statistics were pulled from reports published by the Family Caregiver Alliance:

- Up to 70 percent of caregivers have clinically significant symptoms of depression. About a quarter to half of these caregivers meet the diagnostic criteria for major depression.
- Caregivers who experience chronic stress may be at greater risk for cognitive decline including loss in short-term memory, attention and verbal IQ.
- Caregivers describe feeling frustrated, angry, drained, guilty or helpless as a result of providing care.
- In response to increased stress, caregivers are shown to have increased alcohol and other substance use. Several studies have shown that caregivers use prescription and psychotropic drugs more than non-caregivers.
- Family caregivers are at greater risk for higher levels of hostility than non-caregivers.
- Spousal caregivers who are at risk of clinical depression and are caring for a spouse with significant cognitive impairment and/or physical care needs are more likely to engage in harmful behavior toward their loved one.⁵⁸

Caregivers whose care recipient has emotional or mental health problems are more likely than others to report a decline in their own health. The physical and emotional impact of dementia caregiving resulted in an estimated \$9.7 billion in health care costs in 2014. Those caring for someone with a loss of memory or mental abilities are more likely than those caring for someone without these conditions to say caregiving is stressful, time consuming, frustrating, and makes them feel overwhelmed and sad. About 40 percent of family caregivers of people with dementia suffer from depression and caregivers' rates of depression increase with the severity of cognitive impairment of the person with dementia. For millennial caregivers, 79 percent of those caring for dementia reported emotional distress as a major caregiver burden and want more help to deal with this hardship.⁵⁹

Physical Health Consequences

The harmful mental health effects on caregivers compounded with the physical strain of caregiving put many caregivers at risk for poor physical health. Additionally, nearly half of all caregivers are 50 years of age and older, making them vulnerable to a decline in their own health.

According to a Caregiver Health report prepared by the Family Caregiver Alliance, 45 percent of caregivers surveyed reported chronic conditions, such as heart attack, heart disease, cancer, diabetes and arthritis, which is nearly twice the rate of non-caregivers. Caregivers also suffer from increased rates of physical ailments, such as acid reflux, headaches, and have high levels of obesity and body pain. Additionally, caregivers have diminished immune response, which can lead to frequent infection and increased risk of cancers. For example, caregivers have a 23 percent higher level of stress hormones and a 15 percent lower level of antibody responses. Caregivers also suffer from slower wound healing. Elderly spousal caregivers (ages 66-96) who experience caregiving-related stress have a 63 percent higher mortality rate than non-caregivers of the same age.⁶⁰

The same Caregiver Health report indicates that the overall health of female caregivers is worse than their male counterparts. Female caregivers report higher levels of depressive and anxiety symptoms and lower levels of subjective well-being, life satisfaction, and physical health than male caregivers. Women who spend nine or more hours a week providing care for a spouse have an increased risk of heart disease by two-fold and are more likely to have a history of high blood pressure, diabetes and higher levels of cholesterol. There is an increased risk of mental health consequences among women who provide 36 or more hours per week of care to a spouse.⁶¹

Additionally, 20 percent of employed female caregivers age 50 and older report symptoms of depression compared to 8 percent of their non-caregiving peers.⁶²

The Family Caregiver Alliance report on Caregiver Health also indicates that caregivers are less likely to engage in preventive health behaviors, including seeing their own physician, filling prescriptions, choosing a healthy diet and getting regular exercise. Often, caregivers' self-care suffers because they lack the time and energy to take care of their own health and wellbeing needs.

Still another report, issued by NORC, found that 35 percent of caregivers have skipped routine physical or dental care, 33 percent skipped recommended treatment, and 31 percent didn't go to the doctor at all when sick or injured as a result of their caregiving responsibilities.⁶³

Training

The overall condition of the care recipient is directly related to the types of assistance provided by the caregiver. Those providing care to a person who needs assistance with a few ADLs and/or IADLs might be driving care recipients to appointments and assisting with meals and dressing. Caregivers providing short-term care for a surgical or illness recovery are more likely

to help with more complex tasks (medical/nursing tasks) like changing bandages. A person caregiving for someone with loss of memory or other similar condition is more likely to provide help with medication management and health monitoring.⁶⁴

A report by NORC⁶⁵ (based on a survey of caregivers over 40 years of age) found that few caregivers have received formal training on how to provide ongoing living assistance. For example, 37 percent of caregivers who help with bathing, toileting and getting around the house had received formal training. Less than half of caregivers who perform medical/nursing tasks have received formal training. Overall, more than half of caregivers surveyed reported feeling undertrained, and 28 percent say they received hardly any or none of the training they needed to provide care. As the table below shows, the survey found the vast majority of caregivers are self-taught and only 24 percent received formal training from a doctor or other healthcare professional.

| Caregivers Age 40 and Older Who Learned how to Provide Ongoing Living Assistance | |
|---|------|
| Learned on the job or self-taught | 87 % |
| Talked to a healthcare professional | 61 % |
| Talked to friends or family with caregiver experience | 34 % |
| Online searching | 26 % |
| Formal training from doctor or other healthcare professional | 24 % |
| Read newspaper, magazine or book | 19 % |
| Took a class | 12 % |
| Professional/educational experience | 6 % |

A different survey conducted by AARP and the National Alliance for Caregiving⁶⁶ found that 84 percent of caregivers indicated a need for more help and information related to caregiving. The top three topics of concern to caregivers were keeping their loved one safe, managing their own stress and making end-of-life decisions. Higher-hour caregivers are especially interested in training on how to manage their own stress, managing the challenging behaviors of care recipients, and dealing with incontinence or toileting problems.

More than 5 million Americans are living with Alzheimer’s disease and 1 in 10 Americans over the age of 65 has Alzheimer’s. When the first wave of baby boomers reaches age 85 in 2031, it is projected that more than 3 million people age 85 and older will have Alzheimer’s.⁶⁷ Caring for someone with dementia can be very demanding and has been associated with depression and negative health outcomes. According to Youth Against Alzheimer’s, one in two millennials caring for someone with Alzheimer’s expressed a need for more information on how to deal with their own emotional and physical distress. Given the prevalence of Alzheimer’s disease and dementia, training on how to care for people with these diagnoses is particularly desired.

Training can be provided in-home, in congregate settings, via written materials, and via videos. Many programs offer support groups and workshops for caregivers. Online training, including videos, is an emerging tool for caregivers. For example, AARP has posted training videos on wound care, mobility and managing medications. The Family Caregiver Alliance also has training videos on topics such as bathing and dressing, transferring, and dental care. They

also offer an online support groups for caregivers. The Alzheimer’s Association has information targeted for caregivers on its website; including types of in-home services, finding in-home services, how to choose a providers and cost of care. Caregiver Resource Centers provide over 200 consumer educational materials in multiple languages. This is just a sampling of information that is available by programs that serve older adults and their caregivers.

While there are training materials and programs available, many caregivers are not accessing those resources. According to the Dignity Fund Community Needs Assessment, a survey that was conducted in San Francisco and published in January 2019, “there is a perception that services are not available them, which indicates that many caregivers have limited understanding of what services are available to them and how they can access support services.”⁶⁸

Respite

Caregivers’ need for respite, which provides temporary relief for primary caregivers, is well documented in numerous studies and surveys. Respite services are especially appealing to higher-hour caregivers who live with their care recipient, those caring for someone with Alzheimer’s or dementia and those caring for someone with a mental health issue.⁶⁹ The need for respite becomes more intense as the caregiver ages and as the level of care provided increases, the physical and emotional toll intensifies.

Respite can be provided by paid or unpaid caregivers in the home of the care recipient, or in a social day program like Adult Day Programs, MSSPs and CBAS, if the care recipient meets eligibility requirements. As discussed above, recipients attending these programs can interact and/or have meals with peers and others in a safe and stimulating environment while the care providers is free to conduct their own activities.

Whether provided by paid or unpaid caregivers, in-home respite caregivers come to the care recipients’ home and take care of recipients while family caregivers are free to address of personal business, run errands, take appointments, chores, etc. Seventy-seven percent of caregivers say there is another family member or friend who can temporarily take on caregiving responsibilities to provide a break, but few have access to formal respite care options for their loved one.⁷⁰ A paid caregiver cannot perform many of medical/nursing tasks provided by unpaid caregivers unless they are appropriately certified or licensed to do so.

The California Task Force on Family Caregiving discussed the need for respite in its final report, which includes recommendations to expand access to affordable respite services to family caregivers. Specifically, the Task Force recommended increased respite funding for Caregiver Resource Centers, Area Agencies on Aging, and other organizations that currently distribute state funds for respite to family caregivers; expanded opportunities to obtain respite for caregivers seeking to participate in caregiver services such as educational events, counseling, and support groups; development of infrastructure and standardized training for volunteer respite provider programs; and provide respite to caregivers on sliding scale basis.

Culturally Appropriate Options for Caregivers and Care Recipients

According to the Public Policy Institute of California, the number of seniors in every major racial/ethnic group will increase significantly by 2030. The fastest rates of growth will occur among nonwhite populations, especially Latinx (170 percent or 1.4 million people) and Asians (118 percent or 765,000). The African American senior population will increase by 95 percent, or 230,000 people.⁷¹

The LTSS system may not be prepared to meet the diverse needs of its aging population. According to the final report of the Task Force on Family Caregiving, “services and supports available to ethnic minority populations may not be adequately relevant to care receivers’ needs and preferences, and in some cases are not delivered in a manner that is culturally competent. As one Task Force member pointed out, family caregivers are likely reluctant to send a recipient to an adult day center if it does not provide culturally relevant programming, thereby undermining an opportunity for respite.”

One national survey found that 22 percent of Latinx caregivers and 19 percent of Asian caregivers expressed a need for non-English information materials. Caregivers from racial/ethnic minority groups often assume that the services do not provide culturally relevant programming and, therefore, they may miss out on resources that are available to them.⁷²

Perhaps further impeding caregivers’ access to existing services and supports is cultural tendency to believe that caregiving is a family obligation, therefore, turning to community for LTSS is not viewed as a viable option.

One study found that 84 percent of Latinx caregivers believe that caregiving is expected of them and 70 percent think it would bring shame on their families if they were to not accept their caregiving role. About three fourths of Latinx caregivers feel that delivery of services, information, and materials in Spanish is important. Eighty percent of Latinx caregivers feel that a training class on caregiving duties would be helpful. Per Evercare’s study, Latinx caregivers want and need culturally sensitive materials that are in Spanish.⁷³

Other studies show that caregiving of elderly persons is highly valued and encouraged in the African American community and these cultural expectations may “obscure the negative consequences that befall the caregiver (eg, lost income, worsening health).”⁷⁴

Similar findings have been reported in the Asian community. According to the National Asian Pacific Center on Aging (NAPCA), 17 percent of Asian American and Pacific Islanders live in multigenerational households and 73 percent of Asian American and Pacific Islanders feel a sense of responsibility to care for their parents. However, NAPCA reports that cultural issues, such as family shame, create barriers that can keep Asian American and Pacific Islanders and their caregivers from accessing services and supports. Further, existing services and supports often lack the cultural and linguistic capabilities required to effectively engage and serve older Asian American and Pacific Islanders and their family caregivers.⁷⁵

In order to ensure caregivers and their care recipients are receiving the full array of supports and services available to them, there is a need to provide those services and supports in a manner that is culturally and linguistically appropriate.

Conclusion

There is an understandable tendency to focus on the immediate needs of older adults who need assistance with ADLs and IADLs and medical/nursing tasks, but caregivers also need help so they can continue to provide assistance while maintaining their own health and wellbeing. Often, caregivers are not prepared for the role of caregiver and the responsibilities of caregiving can evolve and expand quickly. This, coupled with the previously discussed strains on caregiver physical and emotional wellbeing, make it necessary to provide an array of affordable services and supports for caregivers.

Multiple studies and advocates in the caregiver community report need for training that is culturally and linguistically culturally appropriate, expanded access to respite, and employment flexibility/workplace protection. As discussed above, a wide variety of such services are provided via a myriad of centers and programs like AAAs, ADRCs, CRCs and Adult Day Programs. Because the system of LTSS is somewhat fragmented, it can be difficult for individual caregivers to connect to the center or program that can meet their specific needs. As the research shows, the impact of failure to obtain LTSS can be profound on both care recipients and their caregivers.

This issue of LTC and other needs of the surging aging population has recently elevated in profile. Governor Newsom announced plans to create a statewide Master Plan on Aging and an Alzheimer's Prevention and Preparedness Task Force. This committee will continue to explore opportunities to improve the services and supports available to older adults, and their caregivers, residing in California.

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