Access to Affordable and Accessible Services and Supports
DRAFT October 13, 2017

“Long-term services and supports,” or LTSS, is a term that most often denotes services and supports such as in-home assistance, transportation services, or housing options (e.g., assisted living) provided to or purchased by an older adult. However, caregivers need their own kinds of “LTSS” to help them while they support older family members and friends.

Caregiver services and supports include benefits like providing a break from caregiving to address one’s own needs, opportunities for peer support from other caregivers, and other services like training and counseling. However, such services and supports are often not available to family caregivers when they need them. The costs for some services and supports, like respite care and housing modifications, are prohibitively expensive. Access is another barrier to utilization, including difficulty identifying services and limited opportunities for attendance given caregiving responsibilities. The quality of available services can also undermine their value to caregivers.

This review focuses on Access to Affordable and Accessible Services and Supports to family caregivers, as defined by the California Task Force on Family Caregiving at their inaugural meeting.¹ Based on policy priorities identified at the first meeting, special consideration is given to respite care, support groups, and housing, as well as access to the many evidence-based caregiver interventions which have been developed over the past several decades. For each of these areas, the benefits of these supports are reviewed, as well as barriers to access and potential policy solutions to overcome barriers to access and improve affordability.

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Accessing and Paying for Respite Care

Respite care services provide caregivers with a break from caregiving, and may be either planned or provided in an emergency. Caregivers use respite services so they can go to work or for recreation, or even to take a rest from caregiving while remaining in the home. Respite often occurs in the care receiver’s home, but can be provided in an institution or with a host family. Generally, “respite” refers to paid services, but family and friends can be considered “informal” sources of respite. This section pertains to “formal” or paid respite, as well as specialized volunteer programs.

Respite is among the most sought out service for caregivers, but just 15% of caregivers reported ever using respite services. Not all caregivers need to or want to use respite care. Respite services are more important to certain subsets of caregivers than others. Burden plays a considerable role in caregivers’ reported need for respite: 42% of highly burdened caregivers express an interest in respite care compared to 24% of caregivers with low levels of burden. Those who live with the person they care for, attend to a person with Alzheimer’s Disease, and those caring for someone with a mental health issue also show higher levels of interest in respite services. Key reasons caregivers give for desiring respite include 1) peace of mind while attending to other practical and social needs and 2) need for assistance with physically-straining or socioculturally-inappropriate caregiving activities (e.g., in some cultures, it would be inappropriate for caregivers from a gender different than the care recipient’s to provide personal care).

Benefits of Respite for Caregivers

Respite services positively impact caregivers’ health and wellbeing. Early evidence showed only a weak effect of respite services on caregiver health. Recently, however, the National Academies of Sciences, Engineering & Medicine concluded there is now enough evidence supporting a robust effect of respite on caregiver health and wellbeing. Unfortunately, evaluations of respite still only pertain to certain types of respite, while others remain understudied; high quality evidence evaluating the effect in-home respite is lacking, but there has been considerable work on adult day services (ADS).

In addition to the practical value of respite reported by caregivers (e.g., being able to address other tasks), evaluations show that ADS use lower stress and can improve caregiver health. ADS use lowers exposure to stress for caregivers by approximately an hour per day and dampens reactivity to problem behaviors by the care recipient. "Biomarker" data is being used to capture the objective impact of ADS services on caregiver health. Biomarkers are objective measures of physiological

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functioning and are often attained from blood, saliva and other tissue samples. Cortisol is a hormone that is often used to measure of stress and are thus considered useful biomarker. Cortisol levels change throughout the day in healthy adults, but can become dysregulated and cause health problems under conditions of chronic stress. Recent findings suggest that dysregulated cortisol levels can be restored in family caregivers to persons with dementia who use an adult day service, even on days when this service is not being provided.\(^8\) This can reduce risk of illness and poor mental health. Additional evaluation of different kinds of respite services that uses objective measures would improve understanding on who among caregiver could most benefit from respite.

Barriers to Using respite

Although respite services are highly desired by caregivers and demonstrate measurable benefits, few caregivers use formal respite services. Caregivers contend with several barriers to using respite, including: finding services, the availability of flexible scheduling, finding providers with an adequate skill level, alignment with cultural beliefs, and—described in the next section—high costs.

Challenges with finding services. Many caregivers struggle to find respite services. Even information resources meant to assist caregivers with accessing services are often inadequate. In one interview study, a caregiver looking for respite described how the operator at an information line completed the same Google search he completed prior to calling.\(^9\) There was no “value added” to help with identifying a provider. In another study occurring at an Area Agency on Aging, researchers found that previous use of respite services was the greatest predictor for respite utilization.\(^10\) This suggests that, rather than need for services, the caregivers who are most likely to use respite are those who already know how to access this service.

Lack of flexible scheduling options and available providers. Even when respite services are identified by caregivers, they are not always flexible enough to meet caregivers’ scheduling needs. For example, some caregivers would like respite care during evenings and at night to engage in social activities or even to help them sleep better, but cannot find services to meet this need.\(^6, 9, 11\) Last-minute services such as those required during emergencies can also be hard to attain.\(^6\)

Some of the difficulty caregivers face in scheduling services is due to shortages in the number of qualified respite providers.\(^2\) In 2012, the National Research Council reported home health and home care aids, who often provide respite services, had the second and third largest occupational growth projections, even as the supply of workers dwindles.\(^12\) Those in rural areas are particularly likely to struggle with accessing a provider. Job advancement opportunities, including additional training as

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recommended by California’s Senate Select Committee on Aging and Long-Term Care, could help to address this shortage.\textsuperscript{13}

For caregivers to persons with complex medical conditions, finding providers for respite care can be even more challenging. In addition to training on medical tasks, legislative action enabling nurse delegation of medical tasks to home health aides—a quality criteria highlighted in the Long-Term Supports and Services Scorecard—could also improve respite access by allowing more providers to complete these tasks.\textsuperscript{14} California currently ranks 45\textsuperscript{th} amongst states on this quality criteria on the Scorecard.

**Training among providers.** Additional training of the home care and respite provider workforce could also address concerns caregivers have regarding the quality of respite services. Reluctance to schedule respite is sometimes due to perceptions about the skill level of providers. In interviews, caregivers said they wished providers would engage more with the care receiver; such engagement often demands certain skills and knowledge, particularly when attending to a person with dementia or other cognitive impairments. Other caregivers wanted a provider who could give advice, and share their expertise on how to complete tasks which caregivers did not yet feel comfortable doing. Caregivers also voice concern about the risk of harm at the hands of respite providers. One caregiver described why she no longer used respite at a facility, reporting her mother asked not to go again because “they hit you there in there.” In another interview study, a caregiver responded that respite services did not offer her a break because she was too worried about the person she cared for.\textsuperscript{6}

**Cultural norms, values, and attitudes.** Some socio-cultural beliefs also deter caregivers from using respite services. A common concern among caregivers is that it is embarrassing to use respite services, believing it demonstrates an inability to provide care or shirking one’s duties.\textsuperscript{9} This belief is most common amongst spousal caregivers.\textsuperscript{6,15} Other cultural norms may also deter seeking outside assistance in order to take a break. The concept of “Marianismo” in Mexican culture denotes a traditional role where certain women in families are expected to provide care. While many women derive contentment from this role, some see inherent expectations as burdensome.\textsuperscript{15} Implicit expectations about who should provide care may prevent these caregivers from accessing respite and other forms of paid services. Another study found African American caregivers are less likely than other caregivers to use respite care, even when it is readily available.\textsuperscript{10} Unfortunately, it is not clear why this is the case, but this finding illustrates a need to learn more about which norms and attitudes with promote or discourage respite use so that services can be appropriately adapted.

**Paying for Respite**

One of the biggest barriers to accessing respite is the high cost. Respite care is expensive. Most caregivers pay for respite care out-of-pocket. According to an AARP report, the average cost for respite


is $587 per year for caregivers. Although some draw a distinction between respite and other types of home care, many caregivers must rely on expensive home-care agencies to pay out-of-pocket for services at a median rate of over $25 per hour in California. This is far beyond what caregivers are willing to pay for someone to simply be present with their care recipient, which ranges between $1.06 and $4.58 per hour. Willingness to pay for services is somewhat higher where the provider is doing something beyond providing companionship. Still, there remains a large discrepancy between costs and willingness to pay.

**Tax credits to pay for respite and other out-of-pocket caregiving costs.** Tax credits are a popular option to help caregivers of pay for the out-of-pocket costs of caregiving, including respite services. Among Americans over the age of 40, more than 80% support tax breaks for people who provide care. Currently, tax codes offer some help for caregivers by allowing them to claim care recipients as dependents, and, in some cases, reimburse medical expenses. To qualify, the relative receiving care must have an income of less than $4050.51 per year, the family member must provide 50% of the older adult’s expenses, and either the caregiver must cohabitate with the receiver or meet certain relationship criteria. Still, tax exemptions in such cases are up to $4,050 and may not cover all costs. Out-of-pocket costs of caregiving beyond 10% of a family’s income may also be deducted from income taxes if the care receiver’s impairment meets certain criteria. Under these provisions, there are many ways in which a family members can be considered ineligible.

There are policy options to expand eligibility for a tax credit covering out-of-pocket caregiving costs, like respite. The Bipartisan Policy Center in partnership with the Urban Institute recently considered one option. The proposed credit would equal 30% of qualified costs for up to $3,000 per family, and would phase out for those earning more than $80,000 for single filers and $120,000 for couples. Results of the analysis suggested that 10.9 million taxpayers would claim the credit, which would cost the federal government $130 billion over 10 years. As of this writing, there are two pieces of legislation at the state and federal levels supporting tax credits which could be used to cover out-of-pocket respite costs. The California Task Force on Family Caregiving voted in April of 2017 to support AB 806 (Kalra) and, at the federal level, S 1151 (Ernst) and HR 2505 (Reed) in June 2017.

**Respite though the Older Americans Act.** For caregivers who are eligible, some publically-available programs provide respite, including some through the Older American’s Act. The National Family Caregiver Support Program was added to the Older Americans Act in 2000, and provides some funding for respite care as a part of Title IIIIE services, largely to low-income caregivers. However, since

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passing, funding for IIIE programs has only reached a maximum of $156.2 million for all services, far below the level of need expressed among caregivers.\textsuperscript{2} In 2006, the Lifespan Respite Care Act was passed to provide respite services to family caregivers, some of which are distributed through the Aging Network. Although the legislation authorized spending ranging from $30 million in 2007 to $94.8 million in 2011, the most ever appropriated was $2.5 million per year, an amount that has been distributed to eligible programs since 2009 by way of competitive grants.\textsuperscript{2,24} The Lifespan Respite Care Reauthorization Act (\$1188, Collins/H.R., 2535, Harper & Langevin) has been proposed to expand access to respite, which would provide $15 million per year in funding to respite though 2022.\textsuperscript{25,26}

**Medicaid-funded respite.** In some cases, Medicaid provides respite options for caregivers. Public funding of respite services through Medicaid began with Katie Beckett waivers in 1982, spurred by parent-advocates to children with a disability who wished to care for their child at home.\textsuperscript{27} Waivers for Home and Community Based Services (HCBS) that allow older adults remain in the community became more widely available after 2000 as a result of the Olmstead Supreme Court decision (see “Overlapping Needs and Services: Caregivers to People with Developmental Disabilities” for more information about this ruling). Some HCBS or Medicaid waivers include respite services.\textsuperscript{2} Interestingly, however, criteria for receiving HCBS respite is determined by the eligibility and needs of the care recipient, not the caregiver. Eligibility depends both upon meeting the low-income threshold for Medicaid eligibility and the care recipient’s functional needs. There is some evidence that even caregivers to people who meet these criteria are denied respite services, and are thus compelled to provide more care than they are willing to or are reasonably able to provide. Illustrating how this happens, Justice in Aging reported on a case in Florida where a caregiver was initially denied respite services because of her “choice” to work.\textsuperscript{28} The decision was overturned, but the other cases included in the report suggest there may be a systemic flaw in assessing respite service eligibility.

**Medicare-funded respite.** Medicare currently provides respite services only to caregivers of those receiving hospice, who must have an estimated 6 months or less to live. Due to this criterion, Medicare respite services are never used by many high-hour caregivers. There has been some discussion to expand respite eligibility beyond hospice benefits. Among Americans aged 40 and older, 78% support a Medicare respite benefit for caregivers.\textsuperscript{19} This benefit would not need to be funded entirely by public coffers; private companies selling Medicare Advantage plans and accountable care organizations could also offer a respite benefit through Medicare. The Urban Institute at the request of the Bipartisan Policy Center estimated that a Medicare respite program where caregivers receive a 96-hour per year benefit would cost the government $29 billion over 10 years for co-residing caregivers attending to someone with at least 2 personal care needs (i.e., ADLs).\textsuperscript{13}

**Respite services provided by volunteers.** Another approach to increasing the availability of respite is to create a volunteer pool of respite providers. Not only would this help address the high cost of services, but could assist with shortages in the number of providers.\textsuperscript{2} Such is the approach taken by the proposed CareCorps Demonstration Act introduced by Representative Lujan Grisham (H.R. 3493 &

\textsuperscript{24} Administration on Community Living. Lifespan Respite Program. Retrieved online at: https://www.acl.gov/programs/support-caregivers/lifespan-respite-care-program


This program would support local programs that would match qualified volunteers with older adults in need of support. Universities are also places where volunteer providers could be readily found. An exploratory study of a social work student-delivered respite care program found that caregivers were largely satisfied with the student-provided service, and appreciated having students engage with the care receiver. Still more informal volunteer options are available, although there are concerns regarding safety and quality of these options. Technology-based solutions, including social networking apps like Nextdoor (https://nextdoor.com), TimeBanks (https://timebanks.org), and Lotsa Helping Hands (http://lotsahelpinghands.com) enable the private exchange and coordination of goods and services, which could be used to provide some respite for caregivers. Some of these programs allow caregivers to request and take advantage of private networks of care.

Respite may support caregivers’ continued engagement in the care role, and delay downstream costs including institutionalization in an SNF. Residence in an SNF, in addition to being undesirable for many older adults, is a service frequently paid for by Medicaid after older adults “spend down” savings to be eligible for the program. At least one study demonstrated a delay in institutionalization among caregivers who received respite early in their care journey. Given potential cost savings, state and federal government have an incentive to help caregiver to attain respite. In countries including Germany, Japan, and Sweden there are far more options for affordable respite, including 4 hours per week of respite for all caregivers in Sweden. On the other hand, meta-analyses—studies which pool previous research and are considered stronger “proof” of scientific results—do not yet support cost savings produced by respite services. Nevertheless, the evidence reviewed was considered low quality, and thus findings may not be reliable. It is very possible that these results do not capture costs benefits for those caregiving dyads where need for respite is greatest.

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Overlapping Needs and Services: Caregivers to People with Developmental Disabilities

In 2012, recognizing the overlapping service needs of the disability and aging populations, the Administration for Community Living was formed. The new department brought together the Administration on Aging, the Office on Disability, and theAdministration on Developmental Disabilities. This change stemmed from recognition that these departments had, for decades, addressed similar service needs for their respective populations.

One of the most profound overlaps between the aging and developmental disability community is the move away from institutionalization to services received in the community. During the first half of the century, older adults and persons with developmental disabilities needing additional support lived in institutional settings, segregated from communities. During the 1960s and through the 1980s, however, grassroots advocacy and investigations headed by journalists and then policy makers helped to change this. These efforts culminated in the 1999 Olmstead ruling by the Supreme Court. Brought under the premise of violations to the Americans with Disabilities Act wherein the government only reimbursed services received primarily in institutional settings, this ruling ushered in the expansion of home and community based services (HCBS) funded by Medicaid since 1981, such that Medicaid services would have to be provided in the “least restrictive environment.” This ruling has since been reinforced by the Center for Medicare and Medicaid Services (CMS), which issued a “final ruling” in 2014 to strengthen HCBS by requiring providers to meet certain service standards promoting community integration to continue receiving funding after March 2019.

During the second half of the twentieth century, community services grew to replace services provided to older adults and persons with disabilities previously provided in institutions. In 1966, the first two Regional Centers opened and began providing community services to individuals with developmental disabilities on waitlists for institutions. Today, there are 21 regional centers across the state. Individuals served at Regional Centers receive an assessment for eligibility and service needs, assistance in creating individual program plans (IPPs), coordination of services, and other supports like education, information and referral, and advocacy assistance. Just one year prior to the opening of the first Regional Centers, the Older Americans Act passed to provide certain services to older adults in the community (e.g., nutrition), followed by creation of the Aging Network and local Area Agencies on Aging in 1971. Today there are AAAs 33 across the California. In addition, to meet the needs of families and caregivers to older adults and others with a cognitive impairment, Caregiver Resource Centers were established in 1984. The 11 CRCs provide assessment, the creation of a care plan, education, respite, and more—services like those found at Regional Centers.

There are two key differences to note between Regional Centers and CRCs/AAAs. While CRCs/AAAs may assess client and family needs and create a service plan, the analogous IPPs provided at Regional Centers are legally binding documents under the Lanterman Act of 1973. Thus, services included in the plan must be provided to individuals by the state, and families have a responsibility to fulfill duties included in the plan that they agreed to. Secondly, Regional Centers are locally governed organizations, following the wishes of parent-advocates suspicious of state bureaucracies due to experiences with state institutions. AAAs are a part of a federalist program that falls under the purview of the Secretary of Health and Human Services, but are run by local directors. This can change the dynamics of services and ability to adapt to local needs.

Another shared experience of the aging and disability communities is a recent history of shrinking supports and growing needs. In California, high debt through the early 2000s followed by economic downturn caused the government to make austere cuts to services. In 2009, funding for California’s CRCs was cut by 74%, for example. Likewise, Regional Centers have been subject to numerous cost-containment efforts. In 2003, eligibility criteria for Regional Center services was raised, and in 2004 the Family Cost Participation Program was introduced such that
services was raised, and in 2004 the Family Cost Participation Program was introduced such that families must contribute to the costs of services on a sliding scale based on income and the number of children they attend to.\(^a\) (Costs for 2017 are available at: http://www.dds.ca.gov/FCPP/Docs/BestTranslations_Pamphlet.pdf). Another threat to community-based services reforms being discussed in Washington to the Patient Protection and Affordable Care Act that would reduce Medicaid funding.\(^1\) If this occurs, it is possible eligibility criteria for Waiver programs will be raised such that fewer people will be served and/or services will be limited.

There remains much to be learned by comparing services for older adults and persons with developmental disabilities as it relates to caregiving. In a scoping review considering literature from each of these fields, for example, researchers found that the developmental disability field focused more on future planning, person-centered planning and self-direction, interventions directly addressing the needs of the care receiver, and focused less on reducing negative outcomes of caregiving.\(^1\) Although some of these difference are inevitable—self-direction may be less feasible for older adults with dementia whose condition is expected to worsen versus a trajectory of increasing independence expected for many with developmental disabilities—others shed light on opportunities to for caregiving research and services to grow. For example, as a part of a national agenda-setting process for supporting caregivers to persons with dementia, it was suggested that interventions directly address the care receiver, which can indirectly benefit the caregiving situation.\(^6\) Other areas were the fields could learn from one another including approaches to increasing access to quality services at lower costs, including innovative waiver programs, provision of person-and family-centered care, and meeting the diverse needs of family caregivers.

\(^a\) Administration for Community Living. (2017). Organizational History. Retrieved online at: https://www.acl.gov/about-ac/history


Accessing Quality Support Groups and Interventions

Support groups allow family caregivers to meet to exchange information and social support. There is little standardization on how groups are conducted. Topics covered in support groups varies, as does the frequency and length of meetings, number of attendees, the delivery mechanism (e.g., in person, by phone), and qualifications of the facilitator. Some groups focus on shared emotional experiences, while others may have a stronger problem-solving focus. This section reviews the effectiveness of support group interventions, best practices, issues related to access and utilization.

The Effectiveness of Caregiver Support Groups

Support group interventions generally show positive, if varying, results. There have been multiple meta-analyses summarizing the effectiveness of support group and group-based interventions for caregivers. An early meta-analysis found that group-based interventions, particularly those using a psychoeducational approach, reduce caregiver burden, improve wellbeing, and improve symptoms in the care recipient. Group-based interventions, however, were less effective at improving caregiver burden and wellbeing when compared to individual interventions. Interestingly, however, group-based therapies had a greater effect on receiver symptoms than individual approaches. Similar findings were reported in a randomized control trial of a support group intervention for caregivers to persons with dementia. Although it is not clear why the support group interventions improved receiver outcomes when only caregivers attended groups, it is possible that caregivers learned ways to prevent so-called problem behaviors in groups or that improved wellbeing in caregivers impacted care receiver behaviors. Indeed, this study also found those participating in support groups have lower reactivity to problem behaviors. In another meta-analysis on support group interventions, authors found that support groups improved psychological wellbeing and social outcomes, while also reducing depression and burden among caregivers.

Best Support Group Designs and Practices

While there is little standardization in support group delivery, there are features which appear important to conducting successful focus groups. For example, groups led by trained facilitators with an interdisciplinary background are more effective than those without a trained facilitator. Long-term use of support groups is also advisable. Research on best practices in caregiver support groups suggests that it is not enough caregivers regularly gather to talk—although this may still be beneficial to some caregivers—but a strategic and planned approach to support groups is more effective.

A key recommendation from previous literature is that support groups should have clear objectives. Caregivers indicated they are most interested in attending groups to share caregiving experiences, access specific information about illnesses, and to participate and listen to candid conversation. These are general topics and objectives that facilitators might use when starting a group. Another approach is to learn more about what a specific community is looking to gain from support

groups, and develop a program with these preferences in mind. This could yield a more culturally relevant service. Groups objectives should be emphasized both when developing and advertising groups so that caregiver who could most benefit are reached.

Similarly, it is advised that support groups be guided by a specific theoretical approach. Herbert and colleagues found a cognitive appraisal and coping strategy to be very effective in group-based interventions. This approach trains caregivers to appraise or evaluate a stressful situation, think through how the situation can be modified, and select an appropriate coping style: problem-solving when the issue can be fixed and emotion-coping or reframing when this is not possible. Appraisal and coping strategies, such as cognitive-behavioral therapies—were found to be very effective in a systematic review of caregiver interventions. At the same time, some theoretical approaches will be more appropriate for certain caregiving situations more so than others. In other words, some support groups will be less appropriate for some caregivers.

Support groups are often a part of a multicomponent intervention (e.g., REACH II). In this way, caregivers can get access benefits found in both individual and group-based intervention. For example, caregiver assessment can occur in one-on-one sessions with the caregiver to identify specific caregiver needs. Once identified, specific issues can be addressed in a support group, such as learning about what to expect while caring for someone with dementia or accessing respite to get a break from caregiving.

Issues with Accessing Support Groups

Despite their considerable benefits, many caregivers do not attend support groups. In some cases, this can be attributed to the personal preference of the caregivers. Caregivers vary in terms of their preferred supports and services and thus may prefer other or no supports, and, for some, only certain types of support groups will be of interest (e.g., psychoeducational compared to more emotional support-focused groups). However, survey data suggests that some caregivers—approximately 30%—do not know about support groups for caregivers, and nearly 6% indicate that support groups are not accessible to them. Awareness is an important barrier to access.

Other factors contributing to support groups attendance stem from the caregiving situation. Monahan and colleagues found that when there was more than one caregiver in a family, it was more likely for caregivers to attend a support group, possible because these caregivers had more opportunity to leave the care recipient to attend. Interestingly, caregivers with more health problems and older caregivers were more likely to attend support groups as well. One interpretation of this finding is that these populations derived greater value from support groups.

The cultural relevance of support groups also affects participation. For example, in one observational study, when support groups were conducted in Spanish, even when all participants could speak English, Hispanic caregivers attended more sessions. Sharing one or more characteristics or experiences besides caregiving can create an increased level of trust amongst caregivers. For example,

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LGB caregivers may prefer groups where sexual orientation is a shared characteristic to avoid intolerance by some heterosexual caregivers. Cultural differences may also impact support group conversations such as the social construction or perception of illness, expectations for providing care to a family members, and what quality care looks like. While different attitudes and opinions can be valuable, in some cases they may be overly disruptive and negate from the benefits of support groups.

Lack of cultural relevance is one reason why participation rates in support groups by racial and ethnic minority caregivers is historically low. To overcome low participation rates amongst ethnic minority caregivers who would otherwise benefit from support groups, Henderson and colleagues released four recommendations based on their own efforts to increase participation rates in one city. They recommend providers have knowledge about the communities which they seek to serve, use flexible designs which can evolve with increased knowledge about communities, use repeated contacts to raise awareness among racial and ethnic minority caregivers who are under-represented in service utilization, and conduct meetings in culturally neutral locations. To accomplish these steps, the researchers recruited and trained support group leaders from the same community as participants, advertised in media targeting specific ethnic minority communities, and offered support groups in different languages. The third suggestion stemmed from a specific experience, wherein it was discovered that the way a support group occurring at one church was advertised to caregivers at other churches violated community norms for these African American caregivers, for whom this would violate norms about loyalty to a particular church. This illustrates the importance of understanding community norms to effectively develop and maintain an effective support group.
Caregivers to Veterans

Caregivers to veterans face unique, and often under-recognized, challenges in their caregiving roles. In recognizing the diverse needs of caregiver, it is important to understand the specific characteristics and needs of caregivers to veterans, who comprise 17% of all caregivers in the U.S. An important nuance in discussing caregiving for veteran populations is the distinction between pre- and post-9/11 veterans. Post-9/11 caregivers comprise 19.6% of all caregivers to veterans and have different needs than other caregivers to veterans. However, differential data is not always available to distinguish between the two groups.

**Characteristics of caregivers to veterans.** The vast majority of caregivers to veterans are women (96%), far exceeding the proportion of women caregivers among civilian caregivers. Seventy-percent provide care to a spouse or partner. Given this, it is unsurprising that more than three times as many caregivers to veterans live with the care receiver (80% compared to 23%). Caregivers to veterans are, on average, younger than caregivers nationally; 41% are between ages 18 and 54. In terms of their caregiving circumstances, caregivers to veterans are less likely to say they had a choice in providing care (29% versus 57% nationally), have been providing care for longer (30% have been providing care for 10 years or more), and spend more time on caregiving per week (43% of caregivers to veterans provide more than 40 hours per week on care compared to 12% nationally). Health conditions among veterans requiring care are also distinct from other care recipients. Over twice as many caregiver to veterans attend to someone with a mental illness or depression (70% compared to 28% nationally). Post-9/11 caregivers are more likely to be younger than pre-9/11 caregivers, care for persons with a mental health condition, are more likely to be non-white, are more likely to be employed, and are less likely to be connected to a support network.

**Impact of caregiving on caregivers to veterans.** Caregiving to veterans has a much more negative impact than for caregivers nationally, although it is not known why this is so. Twice as many caregivers to veterans report they are high burdened (65% versus 31% nationally) and highly stressed (68% compared to 31% nationally). Burden among caregivers to veterans is even higher among those with low educational attainment. Further, caregivers to veterans are much more likely to report financial hardship than caregivers nationally (50% compared to 13%).

**Service needs among caregivers to veterans.** Caregivers to veterans report considerable unmet service needs. Two-thirds of caregivers did not know how the Department of Veterans Affairs could help them and had difficulties getting through bureaucracies to obtain services. Finding support for caregivers’ own health and wellbeing is particularly challenging: 28% report this as very or somewhat difficult, although rates among caregivers to veterans the age of 65 are higher (37%). Caregivers to veterans appear particularly interested in supports to help access information and resources, including a toll-free 24-hour phone line and central website, including digital support groups and forums with other caregivers. An environmental scan by Rand found that few services provide support to caregivers of veterans; supports and services are generally provided incidentally as a part of services to the veteran or caregiver supports for those attending to older adults in general.

**Respite service use for caregivers to veterans.** When asked how easy it would be to take a break, ¾ of caregivers to veterans indicated it would be difficult to do so, despite high levels of burden in this population. Just 15% of caregivers to veterans reported receiving respite services from the VA during a 12-month period. Additional care management, services for post 9/11 caregivers, and even drawing on volunteer pools could help to remedy this.

Military and Veteran Caregiver Services Improvement Act (S. 591; H.R. 1472) would...
Improving Access to Caregiver Interventions

Translating and Scaling of Caregiver Interventions

This review has so far described respite, support group, and group-based interventions. A previous review examined interventions on education and training. There are other types of interventions for caregivers, including counselling, care management, and multicomponent interventions. This section discusses translation and scaling of interventions generally, not just those described in this review.

While caregiver interventions demonstrate promising results in research settings, few have been scaled up and made widely available for caregivers in service settings. For example, Gitlin and Hodgson identified more than 200 interventions for caregivers to people with dementia found in systematic reviews and meta-analyses published from 1966 and 2013, and yet only a handful of these interventions have been scaled up. To be accessible to caregivers, interventions require a translational phase to determine sustainable payment mechanisms, modifications that fit service settings, and tailoring to serve diverse populations of and needs among family caregivers. This section discusses barriers to translating and scaling interventions, as well as possible solutions to increase access.

Challenges with Translating and Scaling Caregiver Interventions

How do interventions work and for whom?

One of the barriers to translating and scaling interventions pertains to lack of research on how interventions work and which caregivers they work for. A stronger evidence-base could resolve this.

Unclear mechanism to explain intervention effectiveness. One of the challenges with current evidence-based interventions is that there is generally no clear mechanism that explains why a particular intervention works (or not) and for whom it works. Unlike when a patient is diagnosed at a physician’s office and is prescribed a medication or other therapy to resolve their health issues, providers cannot match caregivers to an appropriate intervention to address their specific caregiving-related issue. New and innovative approaches such as measuring biomarkers for an intervention and control group (e.g., Klein et al., 2014) can shed light on how interventions work to prevent particular outcomes (e.g., depression) so they can be provided to groups of caregivers who will most benefit.

strong theoretical basis when developing an intervention can also inform which approaches to intervention are likely to work and which will not.

**Uncertainty as to which caregivers most benefit.** Another barrier to matching caregivers with the appropriate intervention is that there is little clear evidence on which caregivers benefit the most from certain kinds of interventions. When providing results, often researchers describe caregivers as one group while the effects of an intervention often vary amongst caregivers. For example, Pinquart & Sorenson found that adult children tend to benefit more from caregiver interventions compared to spouses in their meta-analysis, particularly on burden, depression, subjective wellbeing, and knowledge/skills. Other interventions may show varying results based on caregivers’ race and ethnicity, gender, sexual orientation, age, educational attainment, relationship to the care recipient, level of need (e.g., high burden at the start of an intervention), the severity of the recipient’s condition, whether there are other caregivers involved, and more. Failure to consider such differences may prevent interventions from being appropriately tailored, and could undermine access to interventions that appear to perform poorly on average but are actually quite effective for some caregivers.

Are caregiver interventions “worth it”? 

Although there is a strong evidence-base on the effectiveness of caregiver intervention and, as will be discussed, what little is known on cost-effectiveness demonstrates promising outcomes, the question remains: are interventions “worth it”? Another explanation for the lack of scaling and translation of caregiver interventions is that organizations and caregivers are unconvinced of their value. In focus groups with caregivers, few caregivers mentioned the term “burden,” an outcome that has been studied extensively in the caregiver intervention literature. Previous intervention literature had a strong focus on modifying psychosocial stressors; it is advisable for future intervention work consider objective and practical outcomes, including financial costs, skills, institutionalization, and measureable health outcomes (e.g., blood pressure). Interventions might also consider outcomes for the person receiving care, including institutionalization and quality of life, as most caregivers value these outcomes too. From an organizational perspective, the choice to provide interventions also depends on practical considerations beyond the evidence-base of interventions: do interventions meet the needs of the population served, are they too complex to ask staff to administer, and what are the opportunity costs of offering an intervention versus other programs?

**Opportunities to Scale and Translate Caregiver Interventions**

There are several suggestions solutions to promote scaling and translation of evidence-based and “worthwhile” interventions. This section reviews how intervention design, payment mechanisms, and policy contexts can affect and promote intervention scalability and translation.

**Designing easier-to-implement interventions.** Scalability and maintenance of the intervention should be considered from the time the intervention is developed. When reviewing proven interventions for caregivers to people with dementia, Gitlin found just 8 of an identified 13 mentioned sustainability and only 6 had a sustainability mechanism in place at a federal, state or local level. Funders, including foundations and governmental departments, should consider requiring a plan for sustainability in written proposals. Funders might also consider providing funding opportunities following the “stage model” proposed by the National Institutes of Health. This model suggests

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implementation of evidence-based interventions occurs in an iterative and recursive process. Given this non-linear process, funding opportunities should be made not just for new interventions but also for translational work. There have been few funding opportunities to support dissemination including translation and scaling of evidence-based interventions for caregivers. Although the Administration for Community Living has provided some funding opportunities for translation, funding from this organization is low.

**Targeting outcomes relevant to caregivers.** To ensure interventions are relevant and worthwhile, caregivers should participate in the design of interventions to identify outcomes that are important to them and provide input on feasibility (e.g., how many contacts will be effective without adding burden, which technologies are preferred for intervention delivery). This step is particularly important for providing relevant and effective services to underserved caregivers, including some racial and ethnic minority, immigrant, and rural caregivers, and those caring for people with less common conditions. Such input can also be used to justify changes in service delivery when translating interventions from research to a community setting (e.g., number of participant contacts). Such changes during the translation phase have been criticized because they lacked clear justification.

**Use multicomponent models.** Flexible, person-centered, and multicomponent intervention designs are preferable in terms of scalability, as they can be applied to diverse populations with varying needs. Indeed, the causes of poor caregiver health in one population may be different than causes in another population; flexible and multicomponent designs enable interventionists to use multiple “tools” to address different causes of poor health and other outcomes in caregivers. Such an approach also supports cultural relevance, since some intervention tools may be more appropriate for some caregivers than others. For example, paying for personal care may be more desirable for some caregivers who attend to someone needing assistance with bathing, whereas others would prefer a home modification so they can complete this task themselves more easily. One concern with this approach is that such interventions are challenging to evaluate. However, new analytic methods such as factorial designs (i.e., testing different combinations of intervention tools) and “SMART Designs” where the intervention is adapted with a decision rule (e.g., if the caregiver refuses this service, provide them with this one instead) can be used to evaluate and build an evidence-base for multicomponent interventions.

**Paying for caregiver Interventions.** Another primary barrier to scaling and translating caregiver interventions is lack of payment structures. Although many behavioural interventions have effects that are equal to or greater than those found in FDA prescription medication on certain health outcomes, they rarely are covered by private or public insurers. New and innovative programs in integrated care, however, may yet overcome previous payment barriers. Health systems and insurers where costs have some degree of capitation or containment and integration (e.g., Health Maintenance Organizations, Accountable Care Organizations, and Dual Eligible programs) are more likely than traditional payers and providers to support caregivers. This is because, whereas previous costs from poor caregiver support (e.g., earlier placement of the care receiver in a SNF) were hidden from any one payer or provider, total costs are far more relevant to integrated care programs. For example, if an older adult moves into a SNF after a caregiver finds they cannot provide complex care following a hospitalization, the resulting bill

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would go to Medicaid even though the hospitalization during which the caregiver should have received training on the new complex care task(s) was covered by Medicare. 47

**Policy solutions to support caregiver interventions.** There are several policy options at the state and federal level which could support access to evidence-based caregiver interventions. In the 2016 National Academies report on family caregiving, one of the resulting recommendations was to encourage collaboration between the Centers for Medicare & Medicaid Services and the Administration for Community Living to provide evidence-based caregiver support benefits. 4 Similarly, in their 2014 report, the Senate Select Committee on Aging and Long-Term Care recommended re-investing in Medical and ACL support programs benefiting caregivers that were subject to severe funding cuts, including Community-Based Adult Services (CBAS) and Caregiver Resource Centers. 13 Further, CalMediConnect, the state’s demonstration project for those eligible for both Medicare and Medicaid, may be an appropriate program with which to test integration of caregiver supports into patient care. The demonstration covers non-traditional healthcare needs, such as providing cell phone to covered individuals who are homeless. 48 Indeed, one component of the demonstration project is being offered by Alzheimer’s Greater Los Angeles, which offers training to providers on identifying caregivers in health settings, and assessing and assisting caregiver with referrals. 47

**Do caregiver interventions save costs?**

When describing ways to make services more affordable to caregivers, policy makers should also consider the impact services have on other costs (e.g., health care costs) to understand their value. Unfortunately, few evaluations of interventions have considered cost savings as an outcome. 4,43 Failure to consider cost is likely a result of challenges with measuring program costs and potential savings, including the price of an intervention once it is past the generally more expensive development stage.

Instead of dollar amounts, some authors consider delay in the use of expensive long-term supports and services, including placement in a skilled nursing facility. One of the best-known intervention studies that looks at delay in nursing home placement examines the New York University Caregiver Intervention, where caregivers receive individual and family counseling sessions, are encouraged to participate in weekly support groups, and have access to telephone counseling following in-person supports. The intervention was found to delay SNF placement by 557 days among intervention users compared to controls. 49 In another evaluation of the Family Caregiver Support Program, researchers also found a delay in institutionalization. Researchers at the University of Washington compared service users of the FCSP before and after additional funding was approved in 2012. 50 With the increased funding, providers could expand services to assist those with slightly lower measured need (e.g., burden) and services were provided at a higher intensity. Twelve months after being screened for FCSP services, 9% of care recipients under expanded services were enrolled in Medicaid-funded long term supports and services compared to 11% under usual services. Although Medicaid reimbursement

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for LTSS services is lower than private-pay, annual costs are still in the thousands and tens-of-thousands dollar range, with reimbursement rates varying by state.

There are, however, some caregiver intervention cost evaluations which do suggest at least modest cost effectiveness.4 Eleven years after delays in SNF utilization were reported for the New York University Intervention, it was discovered that the program could yielded $40.4 million in Medicaid cost savings over a 15-year period by keeping 5-6% more Medicaid eligible care recipients in the community per year.51 The Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II) also show promising results in terms of costs, and considered time saved for caregivers. The REACH II intervention provides caregivers with 9 home visits sessions, 3 telephone sessions, and a supplemental telephone support group.52,53 The intervention costed $4.96 per day, was delivered over 6 months, and was found to allow caregivers to engage in 1 hour less of caregiving per day on average. A limitation of this study, however, is that it cannot tell how much caregiver value this added time, and how much the time savings impacted other outcomes like health and financial wellbeing.

While the evidence for cost savings remains limited when considering caregiver interventions, results so far are promising. Building on this evidence-base could encourage federal and state governments to expand intervention access, and prompt public and private insurers to add caregiver interventions to covered benefits.

Using Technology to Expand Access to Supports and Services

**Using technology to lower the costs of interventions.** Technology provides a way to expand services and interventions to caregivers at a lower cost. Explored briefly in the previous review on Education and Training, technology-based interventions can provide more than education. For example, the New York University Intervention included telephone counseling sessions following in-person counseling49, and REACH II included telephone support groups.52,53 Telephone and videophone delivery allows service providers to serve more clients at a lower cost by removing travel time and fees. Interventions delivered via technology-only also show cost savings. The Telehealth Education program for caregivers to persons with dementia included an education component about dementia, information about caregiving skills and resources, training on coping strategies, and group-based support.54 Compared to caregivers receiving usual care from veterans’ services, those involved in the TEP program had lower costs for SNF services at 6 months ($1,057 in savings per care receiver), however savings were not observed at one year.

**The effectiveness of technology-based interventions.** Technology-based interventions also appear to be effective. REACH has been translated to a telephone-based program where caregivers use a voicemail forum to share messages, used an automated menu to access tips on caregiving, and a distraction call for the care recipient as a form of respite.41 This early technology intervention was found to reduce bothersome behaviors, anxiety, and depression amongst those with low mastery levels at baseline compared to those in a control group. REACH II was more recently translated to a videophone intervention, providing a way to reach caregivers at a lower cost.55

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delivery model. Caregivers received two in-person sessions where interventionists assisted with problem-solving, training and stress management, followed by the videophone component. The videophone allowed caregivers to view informational lectures, participate in support group sessions, and access tips and resources on caregiving. Those participating in the intervention experienced decreased burden, increased recognition of positive aspects of caregiving, satisfaction with social supports, and indicated their caregiving skills had improved. However, not all studies show positive results. In another study, caregiver participating in one-hour weekly telephone support groups led by social workers did not show significant improvements in depression or burden compared to a control group.

Emerging technology interventions. A limitation of the technology-based interventions discussed is that they largely pertain to telephone interventions, whereas new caregiver interventions using online, smartphone, and other “Web 2.0” technologies are growing but have largely not been published on. Compared to previous technologies using telephones and televisions, new programs will likely prove far less cumbersome for users, although some caregivers will still prefer “traditional” in-person delivery methods. Video technologies are particularly popular recently, including the Family Caregiver Alliance’s video library (https://www.caregiver.org/fca-videos) and AARP’s Home Alone video trainings on complex care tasks (http://www.aarp.org/ppi/info-2017/home-alone-alliance.html), which is currently being evaluated.

Newer technologies are providing “wrap around” and multicomponent supports for caregivers. One such platform is CareJourney, an online portal for caregivers released by the Family Caregiver Alliance. CareJourney provides access to a self-directed assessment, development of a care plan over the phone with a Care Consultant, monthly check-ins, and access to a dashboard filled with recommended resources including educational written information, videos, and securing messaging with one’s assigned Care Consultant. The Department of Veterans Affairs also released several apps for caregivers, including an online version of Savvy Caregiver called Tele-Savvy. The intervention lasted for 6 weeks and included 6 daily videos using a talk-show format and vignettes, and once-a-week group videoconferencing. A study on a convenience sample indicated high satisfaction with the program, and reduced burden, anxiety, and depression. Unfortunately, it is still too early to draw conclusions on the efficacy of these programs.

There are also many applications caregivers can download on their smartphones developed by non-profits and businesses. Common features on caregiver apps include medication management, reminders, symptom journals, places to keep track of health information, information and tips on caregiving, and ways to coordinate with friends, family, and other members of the care team. Even “mainstream” technologies like calendars, notepads, cameras, and video phones can help caregivers plan, save information (e.g., prescription names), and communicate with other members of the care team to help with caregiving. Another way to use technology to assist caregivers includes providing

technologies to persons with dementia, such as respite provided via app, monitoring devices so caregivers can enjoy worry-free respite time, and social connectivity to reduce isolation.\textsuperscript{43}

**Representativeness of caregivers using technology interventions and supports.** A second limitation of current technologies is the possible under-representation of racial and ethnic minority populations using certain online supports. Although it is difficult to draw conclusions based on current caregiving literature, lessons can be learned from other fields. For example, there are few African American online support groups for individuals with cancer.\textsuperscript{60} This is not necessarily a problem so long as technology supports are developed with cultural-relevance in mind, technology-based solutions do not replace preferred service options (i.e., are provided as a supplemental resource for caregivers), and do not provide benefits greater than those provided by traditional services. For example, in in trying to decipher why utilization of online cancer support groups was so low, it was discovered that African Americans with cancer tend to have more support communities available offline, often prefer face-to-face contact, and perceive cancer as a private issue, all of which discouraged online support group participation. However, other reasons implicated the services themselves for lower utilization. For example, while many African Americans looked to religion as a form of support, religious conversations were viewed as controversial when taking place online and discouraged in forums. In creating new online supports, it is important to consider features which meet the needs of different communities, including technology components (e.g., offering “chat” options, ability to use apps without using cell phone data). Cultural relevance also needs to be considered during implementation (e.g., enabling religious conversation to take place in forums). Indeed, a follow up question on the REACH II videophone intervention was why African American caregivers benefited less than others from the intervention; the authors concluded additional work to tailor the intervention was called for.

**Accessible and Affordable Housing**

Family caregiving can take place in many environments, but it is most likely to occur within the home. Eighty percent of care receivers receive care in their homes, and another 10% receive care in the home of a family member or friend.\textsuperscript{19} While housing does not often enter conversations about caregiving, it is an important issue for California’s caregivers for two key reasons. First, housing is expensive. Caregivers are already a financially disadvantaged population given weakened ties to the labor force and the high costs of caregiving. For many families, the home is their greatest asset, and mortgage and rent payments consume a considerable proportion of incomes each month. Housing—including mortgage and rent payments and home modifications—was found to be the highest out-of-pocket cost faced by caregivers; the average caregiver spends $2845 per year on housing costs.\textsuperscript{16} Affordable housing options can maintain caregivers’ financial wellbeing. Secondly, the home environment can impact caregivers’ ability to provide care. For example, if one’s shower is too small to fit a chair, assisting an older adult with bathing may be more challenging for a caregiver.\textsuperscript{61} Appropriate housing for caregivers and their recipients needs to be both affordable and accessible. In their report on the state of long term care in the state, the Senate Select Committee on Aging and Long Term Care considered housing, including the lack of affordable and accessible units, as a critical policy area.\textsuperscript{13}


Affordable Housing

Housing costs in California are notoriously high. A 2015 report by the state’s Legislative Analyst’s Office found that the average home cost in California ($440,000) is nearly two and a half times that of the national home price ($180,000). There prices would not necessarily indicate a housing crisis if Californians could afford it; however, housing costs in California are also proportionally higher to income than it is in other parts of the country. On average, Californians spend 4% more of their monthly income on housing compared to the rest of the US. Using data from Rand Corporations’ American Life Survey, one can observe how housing costs in California and its largest cities compare to national averages as a proportion of income in Tables 1 and 2. For example, nationally just 24.7% of Americans spend more than 35% of their income on a home; is Los Angeles, 43.4% of homeowners spend more than 35% of their income. Those at the bottom quarter of the income distribution spend an average of 67% of their income on housing, even though it is generally recommended that individuals should spend no more than 30% of their income on housing.

There are several reasons for these high housing costs. California is a highly sought after place to live due to its climate and economic opportunities in some regions. But other factors can also drive up costs, including local policies in coastal metros that discourage new residential building. For example, from 1980 to 2010 housing units grew by 54% in USC metros but just 32% in California’s coastal metros where there is often resistance to new residential development. Increased costs cause “spillover” in neighboring and inland communities, driving up costs in some of these areas as well.

While high housing costs are experienced across the state, some Californians are more acutely impacted. Racial and ethnic minority populations are far more likely to experience housing insecurity both nationally and in California. In a study of Milwaukee housing, it was discovered that among renters, 1 in 5 black women, 1 in 12 Hispanic women, and 1 in 15 white women had been evicted at least once in their adult life. California has slightly different demographics than Milwaukee, and such the profile of those at risk of housing insecurity likely differs to some extent, but still demonstrates differences by race and ethnicity. Data from the Los Angeles Family and Neighborhood Survey collected between 2000 and 2002 shows that 48.3% of African Americans were housing burdened during this period (i.e., spending 30% or more of income on housing) compared to 76.2% of unauthorized Latinos. Interestingly, authorized Latino immigrants face similar risk of housing burden as Whites, suggesting that immigration status also has a major impact on housing affordability in California. However, data from this report is relatively old and does not account for the recent economic downturn. Following the Recession, Latinos are likely more at risk of housing burden given a high proportion of wealth being tied up in housing in this population, an asset that lost value for many Americans.

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Availability of Accessible Housing Units

In addition to being expensive, often housing units in the state do not meet the needs of occupants. Recent trends suggest an increase in disability amongst those approaching old age. As a result, although 87% of older Americans indicate a preference to aging in their own home, homes may have design features which make it difficult to “age in place” or to provide care to a family member or friend in their own home.

The majority of discussion on “aging in place” and “livable communities” has focused on the older adult, but caregivers are well aware of the relevance of accessible housing to their caregiving role. Home modifications are defined as “adaptations to the physical environment that can range from inexpensive railings, rearranged furniture, or extra lighting, to more costly ramps, elevators, roll-in showers, and fully remodeled bathrooms and kitchens”. Home modifications can make it easier for caregivers to provide support and help keep older relatives in their own home. In a national survey, 19% of caregivers report modifying the care receiver’s home and 15% of caregivers reported a need for information on home modification. Caregivers also express a preference for specific design features that support their role. Using interviews with 90 caregivers, Olsen, Hutchings & Ehrenkrantz found that caregivers expressed a preference for eight design features:

- One-level living space;
- A generous amount of space;
- A simple layout without too many hallways and turns;
- An open floor plan;
- Spaces that provide privacy;
- Safe bathroom and kitchens;
- Access outdoor space (e.g., fenced in garden).

Some features were more universally desired than others. Nearly 40% of the sample indicated that housing with one level was an important feature while just 19% reported that spaces providing privacy were important. Some of this discrepancy may be explained by the care recipient’s condition. Many caregivers to older adults with a fall risk can benefit from single-level housing, since a fall can be very dangerous for care receivers and can also increase caregiving demands. However, those with advanced dementia may display “shadowing” behavior that causes caregivers to seek an added degree of privacy in homes that still supports monitoring (e.g., second floor overlooking first-floor living space). Such features may be less important to caregivers attending to receivers with other conditions.

Home modifications can be relatively affordable (e.g., grab bar in the shower) or very expensive (e.g., adding a first-level bathroom). While most people pay for housing modifications out of pocket, there are several programs available to help cover the costs. These include:

• Home equity loans and second mortgages;
• Income tax deductions;
• Assistance from a landlord;
• Department of Veterans Affairs programs;
• Older Americans Act programs delivered by Area Agencies on Aging;
• Community Development Block Grants;
• Some home and community based services waivers.

However, several of the listed programs have strict eligibility criteria to participate, and funding has shrunk in recent years even as need continues to increase. Moreover, the language of the Fair Housing Amendments Act of 1988, which requires landlords to provide modifications in some cases, is also unhelpfully vague. Renters may request “reasonable” accommodations in public housing units, but it is not clear what is considered a “reasonable” accommodation. As a result of high costs and limited support options, home modifications that assist caregivers and older adults with disabling conditions may be prohibitively expensive.

Ideally, new housing stock would be built to incorporate universal design (i.e., built environments that integrate accessibility into aesthetically pleasing designs). One estimate suggests that there is a 60% chance of a newly built housing unity being occupied by a person with a disability during its expected 80 to 100-year lifetime. Poor design can negatively impact both the quality of life of the person with a disability and the caregiver. By integrating accessibility into design from the start, there is less need to make expensive accommodations. Still, even retrofitting homes—particularly public housing units—may be less expensive than the costs of living in a skilled nursing facility covered by Medicaid if the older adult must leave his or her home. Moreover, retrofitting older housing units may be requisite to comply with community living standards since the Olmstead (1999) Supreme Court ruling.

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<th>PROPORTION OF INCOME</th>
<th>US</th>
<th>CALIFORNIA</th>
<th>LOS ANGELES</th>
<th>SAN DIEGO</th>
<th>SAN JOSE</th>
<th>SAN FRANCISCO</th>
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Table 1: SELECTED MONTHLY OWNER COSTS AS A PERCENTAGE OF HOUSEHOLD INCOME (Units with a mortgage)

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<th>PROPORTION OF INCOME</th>
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Table 2: GROSS RENT AS A PERCENTAGE OF HOUSEHOLD INCOME
Conclusions

This review explored why caregivers struggle to access services and supports which are known to be beneficial to health and wellbeing, and discusses several policy avenues that could increase access to services and supports. The supports and services reviewed here largely pertain to those raised by the Task Force at its first meeting, although there are many others which could also have been included (e.g., counseling). Other supports were discussed in previous reviews (e.g., Education and Training).

Not all caregivers need to or want to use services and supports. However, there are a significant portion who do, and who could benefit from the additional support. While some barriers explored in this review pertain to specific types of support, several common issues include lack of awareness, difficulty accessing quality services, services which are not culturally relevant, and the high costs of supports and services.

There is, however, little or no evidence that these issues are insurmountable. There is ample opportunity to increase the access and affordability of services to caregiver so they can continue supporting older Californian’s need for assistance.