VOICES FROM CALIFORNIA'S OVERLOOKED MIDDLE: CHALLENGES AND OPPORTUNITIES IN LONG-TERM CARE

Findings from Consumer and Stakeholder Engagement Sessions on Aging and LTSS

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The images on the cover and throughout the report were generated using Midjourney, a text-to-image AI software.

INTRODUCTION

The California Department of Aging's (CDA) Long-Term Services and Supports (LTSS) Financing and Affordability Initiative aims to identify and recommend strategies to enhance the financing and affordability of LTSS for older adults and people with disabilities who do not qualify for Medi-Cal. As part of this initiative, CDA partnered with Collaborative Consulting and Community Catalyst to conduct engagement sessions. The engagement sessions included diverse participants to capture a range of perspectives. The primary focus was on adults aged 50 and older in the "Overlooked Middle"—those who do not qualify for Medi-Cal but cannot pay out of pocket for long-term supports and services (LTSS).

METHODOLOGY

Seven sessions engaged individuals with disabilities, caregivers of middle-income adults, and participants who spoke Spanish and Cantonese. Additionally, two sessions were held with consumer-facing staff from Area Agencies on Aging (AAAs) and Caregiver Resource Centers (CRCs). We spoke with 50 consumers, 11 caregivers, and 15 professionals. Please see **Appendices A and B** for details on session locations, host organizations, and participant demographics.

During the engagement sessions, we explored participants' experiences, challenges, and priorities regarding aging and LTSS, including navigating, accessing, and affording care. Participants also shared recommendations for improving services and supports. The question guides are in **Appendix C**.

We analyzed and summarized the engagement session data into themes, which serve as the framework for this report. We highlight participants' concerns and suggestions for potential system improvement within each theme. Participants also shared successful initiatives, programs, and services in their communities, which are summarized in **Appendix D**.

To further illustrate consumer experiences, we created images to encapsulate each theme using Midjourney, a text-to-image AI generator.

THEMATIC SUMMARY

Eight themes emerged from engagement sessions across California, highlighting challenges faced by older adults, people with disabilities, and caregivers.

1. **Financial Security:** Rising living costs, inadequate fixed incomes, and expensive long-term care create financial insecurity among older adults and people with disabilities. Many adults lack long-term care insurance and financial planning, face challenges accessing public benefits, and remain vulnerable to fraud that drains limited resources.

2. **Health Care Accessibility and Quality:** A fragmented health care system creates barriers through provider shortages, long wait times, and limited access in rural areas. Language barriers, cultural barriers, and insufficient disability-informed care further compromise access.

3. **Housing Security:** Rising rent, property taxes, utilities, and insurance costs are unaffordable for adults on fixed incomes. Physical barriers require expensive modifications that many cannot afford, while maintenance costs and climate change impacts threaten housing stability and aging in place.

4. **Transportation:** Unreliable, inflexible, and costly transportation services create barriers to independence. People with disabilities face additional challenges accessing expensive adaptive transportation and vehicle modifications, which are rarely covered by insurance.

5. **Social Engagement and Mental Health:** Widespread social isolation among older adults, people with disabilities, and caregivers is worsened by the loss of social networks and difficulty forming new connections. Some programs lack physically or culturally accessible and welcoming environments, while safety concerns and fear of aging alone contribute to mental health challenges.

6. **Public Education and Service Navigation:** Many individuals are unaware of available services or unable to access them, either because they do not qualify, believe they do not qualify, or face language barriers. Complex, inaccessible information systems and digital barriers make navigation frustrating and time-consuming. Fear, stigma, and mistrust create additional obstacles to accessing beneficial programs and resources.

7. **At-Home Care Support:** Most older adults prefer to age at home, but in-home care services are often unaffordable for middle-income individuals, especially when family support is limited. High private agency rates and restrictive public program eligibility create financial barriers. Workforce shortages, high turnover, and difficulty finding culturally appropriate caregivers strain the system.

8. **Family Caregivers:** Family caregivers face financial strain from out-of-pocket expenses for caregiving supplies and services, lost wages due to reduced work hours, and a lack of compensation. Inadequate respite options, complex navigation systems, and insufficient training compound emotional and physical demands.

These interconnected challenges reveal a system that needs improvement to serve California's Overlooked Middle more adequately. The themes underscore the need for policy solutions addressing financing, affordability, and the infrastructure that enables aging in place.

FINANCIAL SECURITY

Participants expressed a growing concern about financial insecurity across California, driven by the rising cost of living, inadequate income, and the high cost of long-term care.

The rising cost of living is pushing older Californians beyond their financial limits. A common sentiment among participants was the divide between adults' income and living expenses. Adults living on fixed incomes (e.g., Social Security, pension) struggle to meet their basic needs as inflation drives up the costs of housing, food, utilities, and health care. To save money, some consumers reported cutting back on outings and social engagements or needing to choose between essential expenses (i.e., "pay the power bill or get food, but not both").

Some adults feel forced to keep working, despite barriers and discrimination. Because their income does not cover all expenses, many adults continue to work part- or full-time, even when they prefer to retire. Adults with disabilities reported experiences of discrimination based on ability while searching for employment, such as being disqualified from applying for jobs that require a driver's license.

"I might live longer than I can afford to."

Paying for long-term services and supports is out of reach for many. As care needs increase, so do costs, whether for in-home help or assisted living. Without Medi-Cal, paying for help with daily activities like cooking, bathing, or laundry becomes prohibitively expensive. This concern came across in multiple sessions but was pronounced among two groups of consumers and their caregivers: Adults in independent living who fear they will eventually need assisted living that they cannot afford, and older adults and people with disabilities living at home who wish to remain there but worry about what will happen if they one day need more intensive support.

"As needs go up, it becomes cost-prohibitive to have long-term care if you're private pay."

Many adults are financially unprepared for their current and anticipated care. Few participants reported having long-term care insurance, either because they did not receive adequate resources or information about it, or because they assumed it would not be necessary. Some adults with disabilities reported a lack of planning because they did not anticipate living into older adulthood based on their predicted life expectancy for their disability. Even among adults who planned for long-term care, there is vulnerability to major, unexpected expenses such as hospital stays. Further, Spanish-speaking adults preferred to prepay for services when possible (e.g., funeral costs) because it would be cheaper than paying at the time of need, but they often lacked the means to do so.

"We are not accustomed to think about finances in the future."

Public benefit programs are considered inadequate, unstable, or difficult to access. Older adults are concerned about strict eligibility criteria and financial penalties. For instance, one participant reported paying $500 monthly late enrollment fees for Medicare. Additionally, state and local budgets do not adequately reflect the size or needs of the aging population. In Marin County, for example, older adults make up over 30% of the

"For low-income adults, there are a lot of programs – just look out the window. But what happens to the rest of us don't qualify? Where do we go?"

population, yet only 3% of the local Health and Human Services budget is allocated to services for older adults. Staff from AAA and CRCs worry that cuts in federal funding will negatively affect consumers' access to assistance and services. Cantonese-speaking older adults expressed a desire for the government to offer better low- or no-cost services for middle-income adults, such as LTSS, to those who qualify for Medi-Cal.

Older adults are vulnerable to fraud, financial exploitation, and scams that target their limited resources. Several participants shared experiences of being targeted through financial scams, phishing schemes, and dating site exploitation. These scams result in emotional and economic harm, especially when individuals are socially isolated or unfamiliar with online safety practices.

Financial Security: Participant Suggestions	
Financial Support	• Increase government investment in older adults through expanded funding for home care, rent subsidies, and prescription drug affordability.
Tax Relief	• Offer more non-medical expense tax credits or deductions that support independent living (e.g., hiring a driver or reader).
Employer Benefits	• Encourage employers to provide Long-Term Care Insurance benefits.
Affordability Policies	• Enact policies to stabilize prescription drug prices and medical costs.
Education	• Create local or statewide campaigns on financial planning education. • Replicate or expand local programs like Marin AAA's financial coaching and credit counseling for older adults. • Launch statewide public education campaigns to raise awareness about scams that target older adults, including financial, digital, and phone-based fraud.
Policy	• Expand benefit programs to moderate-income individuals using a sliding scale, tiered subsidy system, or partial benefit models. • Develop programs for middle-income older adults who do not qualify for Medi-Cal to help offset the cost of long-term care. • Advance state and local policies that increase the affordability of living in California for older adults (e.g., housing, utilities, food).

HEALTH CARE ACCESSIBILITY AND QUALITY

Participants experience California's health care and social service systems as fragmented and strained. There are long wait times, limited provider availability, concerns about care quality, and increasing out-of-pocket costs for essential services not covered by insurance.

A shortage of providers and services is delaying care and limiting choices. Older adults face long wait times (i.e., three to six months is common) for primary care or specialist appointments, with few or no alternatives nearby. One San Diego consumer reported that flying to the Mayo Clinic out of state was cheaper and faster than waiting for a local provider to become available. Lack of availability is severe in rural areas, where access to specialists is minimal. People frequently stay with doctors who may not meet their needs, such as handling unique aging and/or disability related concerns.

"I don't really care for my doctor, but there aren't any new ones, so I'm stuck."

Rural residents face reduced access to services and resources. Participants in rural areas described a lack of local health care options, including specialist care and pharmacies, leaving entire communities without easy access to medication and basic health needs. For example, in Mariposa County, the only pharmacy is closing. Residents in places like Redding shared that they travel as far as Sacramento (over 150 miles) for specialist care. For many, this level of travel is not feasible due to a lack of transportation, inability to drive, or the cost of long-distance travel.

"Because we are very rural, there are not any specialists in our area. Anytime somebody needs to go see a specialist for something, they have to find a ride out of county."

Healthcare costs are rising faster than older adults' ability to pay. For those with Medicare and/or private insurance, premiums increase yearly while incomes remain fixed. However, even those who can keep up with health insurance costs do not receive all the necessary services. Some participants reported forgoing services (e.g., dental work, home modifications) because insurance would not cover them. While these services would have helped adults remain at home safely, their insurance provider did not deem them medically necessary.

"I simply can't afford to get ill."

Language and cultural barriers reduce access and quality of care for diverse older adults. A lack of culturally competent and multilingual providers makes it difficult for many to access safe and responsive care. Spanish-speaking participants noted that even if they speak English, it is important to discuss sensitive health concerns in their native language. When unclear communication leads to confusion, mistrust, or misunderstanding, it results in unaffordable treatment plans or plans inconsistent with the individual's goals. Cantonese-speaking focus group participants at Self Help for the Elderly shared that they rely almost exclusively on Self Help for the Elderly, their local adult day health center, because it provides bilingual and culturally competent services.

"There are no advocates for you. It seems like we're swimming in the bay without a lifeline."

Adults with disabilities and/or chronic conditions often face barriers to accessing care that recognizes and responds to their specific needs. Participants find that their providers lack training in how their disability or chronic illness shapes their aging-related health and support needs. People with disabilities described encountering challenges in clinical and community settings, including inaccessible websites, staff unfamiliar with disability issues, and organizational leadership that does not reflect the communities they serve. Additionally, older adults living with HIV reported stigma from peers and medical providers, and a shortage of providers knowledgeable about how HIV impacts aging. While HIV-specific clinics once served as trusted hubs, many have broadened their focus, leaving longtime patients struggling to find knowledgeable, affirming care.

> *"It is a privilege as a person with a disability to get older, but it's scary once you get there."*

Health Care Accessibility and Quality: Participant Suggestions	
Provider Access	• Increase access to medical and dental providers with expertise in dementia care. • Increase the availability of providers and doctors who make home visits. • Share health care workers across communities to expand provider reach.
Home- and Community-Based Services	• Broaden access to long-term care services delivered in-home. • Expand access to hospice care beyond the current six-month eligibility threshold.
Health Insurance	• Cap annual insurance premium increases to protect affordability.
Telehealth	• Expand telemedicine coverage and offer technical support for older adults.
Care Access	• Allow physicians to address multiple health concerns in a single appointment. • Establish priority waitlists for adults 65+ to improve timely access.
Workforce Development	• Incentivize physicians who specialize in older adult care.
Care Navigation	• Hire, train, and fairly compensate patient advocates to support individuals navigating health care and social services systems. • Improve care coordination for individuals managing multiple conditions, providers, and appointments.
System Reform	• Address ableism within aging/disability service systems.

HOUSING SECURITY

Stable, affordable, and accessible housing is foundational to aging in place. Yet, participants described a severe lack of housing options that support older adults and people with disabilities, including rising housing-related costs and physical environments that do not accommodate aging or disability-related needs.

There are not enough affordable, rent-stabilized housing options available for adults on fixed incomes. Many older adults struggle to secure long-term housing. Additionally, the financial burden of housing is becoming unmanageable due to rising annual rent increases, escalating property taxes, and increasing utility and insurance costs. Homeowners face rising expenses that threaten their ability to remain in their homes.

Maintaining a home becomes more challenging as people age. Home upkeep, such as cleaning, yard work, and repairs, can become physically demanding and financially burdensome. The burden of upkeep leaves many adults looking to move or bring in roommates to split costs. Adults who choose maintenance-free independent living communities often encounter unresponsive property managers.

"A lot of people own their own homes, but because they're on a fixed income, they can't afford the maintenance."

Most housing and neighborhoods are not built with aging or disability in mind. Accessible housing is rare and expensive, making it difficult for people with mobility limitations or other disabilities to find suitable homes. Modifications like walk-in showers, bathroom bars, or wheelchair ramps are often unaffordable. The built environment, in and outside the house, is a significant barrier to independent living.

"I am discovering I am petrified about finances that would enable me to afford safe and accessible housing."

Climate change is disrupting housing stability and affordability. Wildfires, extreme heat, and other natural disasters are displacing residents and driving up utility costs. Fire damage has also contributed to a lack of housing options. For some older adults, especially in rural or fire-prone areas, climate-related risks make their housing unsafe and unsustainable.

"For a lot of people, their home falls in disrepair and they don't qualify for programs in our area to help them."

Housing Security: Participant Suggestions	
Affordable Housing	• Increase the supply of affordable housing specifically designed for older adults. • Develop and promote shared housing models for older adults. • Expand zoning and support for tiny-house communities.
Financial Supports	• Provide government subsidies to help older adults manage rising rent costs. • Offer shallow subsidies for older adult homeowners to help cover expenses such as utilities and minor home costs.

Home Maintenance	• Fund and expand programs that cover home modifications for safety and accessibility (e.g., walk-in showers, ramps, grab bars). • Offer housing maintenance services specific for older adults.
Housing Navigation	• Train and pay housing advocates to assist older adults and people with disabilities with navigating housing issues and securing stable housing.
Eviction Prevention	• Offer eviction prevention services to reduce housing insecurity among older adults.
Information	• Improve access to information and resources to make homes adaptable for aging.
Social Connection	• Develop and promote senior roommate-matching services.

TRANSPORTATION

Transportation is a cornerstone of independence; it enables adults to attend medical appointments, shop for groceries, and engage with their communities. In many areas, especially rural ones, participants said services were inconsistent, unavailable, or inadequate to meet their needs.

Transportation services are unreliable and difficult to navigate. Transportation options are cited as stressful and impractical due to long wait times, booking requirements, and unpredictable pick-up windows. Riders are often assigned different drivers each time, which prevents continuity and complicates communication around mobility needs. Some services offer only one-way rides (e.g., to an appointment but not back home), creating logistical gaps that discourage use. Participants in areas with good public transportation options (i.e., San Diego) recognize how impactful their transportation is, as it allows them to give up their cars and still access what they need in the community.

Cost is a barrier to using alternative transportation options. Services like Uber and Lyft are too expensive for those on fixed incomes, and many participants reported being ineligible for programs that could help offset costs. Some pay out of pocket for all transportation, which limits their ability to leave the house regularly. Across sessions, participants mentioned successful current and past programs that provide low-cost transportation, sometimes specific to older adults or people with disabilities.

> *"[Our area] used to have a ridesharing voucher program. It had a number of restrictions, but it was something, and that's being taken away."*

People with disabilities face challenges in accessing transportation. Modified vehicles and vehicle adaptations are vital for some individuals' independence, yet they are expensive and rarely covered by insurance or benefits. Paratransit options can be hard to schedule and may lack the on-demand flexibility and reliability that many people with disabilities need.

> *"I've used Waymo. As a blind person, I love it because there's no driver to yell at me, threaten me, demean me, or drive off because I have a service animal."*

Transportation systems are fragmented. Traveling across county lines can be frustrating due to service gaps and a lack of coordination between local transit systems. Public transportation requires multiple transfers, long walks, or unfamiliar route navigation, and drivers are not always trained to assist older adults or those with caregiving needs. Several adults reported negative experiences navigating public transportation, including getting lost for several hours after traveling out of town for a doctor's appointment.

> *"Because of good transportation [in San Diego], we've been able to give up our cars. It's a huge advantage to live in an area that has good transportation."*

Transportation: Participant Suggestions	
Transportation Services	• Restore and expand dial-a-ride programs and community shuttle services to improve transportation access for older adults. • Expand reliable and disability-accessible transportation options for essential activities like medical appointments and errands.

	• Establish subsidized rideshare options for older adults. • Increase access to autonomous vehicles and related technologies that can support independent mobility.
Delivery Models	• Expand access to affordable delivery services (e.g., groceries, medications) tailored to the needs of older adults to minimize transportation barriers. • Create volunteer transit programs through community or faith-based organizations. • Develop rideshare programs for community-dwelling older adults with similar destinations or errands, modeled after those used in senior housing.
Tax Relief	• Provide tax credits or deductions for transportation expenses that support aging in the community (e.g., medical rides, rideshare costs).
Awareness	• Increase awareness of transportation benefits available through health plans and systems (e.g., programs through Sharps or UCSD).
Age-Friendliness	• Make communities more walkable and age-friendly to reduce reliance on vehicles.

SOCIAL ENGAGEMENT AND MENTAL HEALTH

Participants emphasized the importance of social connection to overall well-being. Many older adults and people with disabilities face isolation, limited access to inclusive programs, and barriers to participation in community life. They called for more welcoming spaces, accessible activities, and expanded use of technology to foster connection.

Social isolation is widespread and worsens with age. Many older adults lack regular interaction and emotional support. Some avoid reaching out to adult children for fear of being a burden, while others have lost close friends and family, leaving them without a core social network. Forming new friendships becomes difficult as people age out of the workforce or common social spaces. Isolation can also lead to mental health concerns such as depression and anxiety.

"We don't want to be a burden to our kids."

There is a fear of aging alone without a support system. Participants shared concerns about being unable to reach someone in an emergency (e.g., after a fall). For those without children or nearby family, this fear contributes to chronic stress and a sense of vulnerability in daily life.

"I live alone, and I don't have any children. What's going to happen to me when I can't take care of myself?"

Social opportunities are often inaccessible. Many reported that programs are not designed to accommodate people with physical disabilities, or that participation requires a level of independence they cannot meet. Some also fear going out alone due to safety concerns, further limiting their ability to engage with others or participate in community life.

"[My husband] needs a place where he can get some social interaction, meet some friends, and play some games with somebody there to make sure he's safe."

Social Engagement and Mental Health: Participant Suggestions	
Community Programs	• Increase the number of senior centers, with an emphasis on community-run models, and ensure sustained public funding to support them.
Technology Tools	• Implement tech-based wellness checks (e.g., automated calling systems) and emergency alert systems to support safety and reduce social isolation.
Community Building	• Develop intergenerational programs and volunteer opportunities that promote mutual learning and connection across age groups.
Peer Support Models	• Establish informal support groups focused on navigating the emotional aspects of aging and building peer connections.

PUBLIC EDUCATION AND SERVICE NAVIGATION

Participants described California's aging and disability service systems as difficult to understand and navigate, often marked by confusing information, digital barriers, long wait times, and limited coordination across providers. Misinformation, mistrust, and stigma further prevent many older adults, people with disabilities, and caregivers from accessing the support they need.

Many people don't know what services are available or if they qualify. Older adults, people with disabilities, and caregivers often misunderstand what programs are for or assume they're not eligible. For example, some believe Medicare covers long-term services and supports, or they may not realize they can access help from AAAs or CRCs regardless of income. Others don't see themselves as caregivers and therefore don't seek out caregiver-specific resources.

> *"It's impossible to find out what happens in California. It's a big secret."*

> *"I know very little about what AAAs actually do or if they'd be useful to me in any way."*

Information is confusing, inaccessible, or complicated to act on. Navigating programs and benefits can be frustrating and time-consuming when applications are inaccessible to people with disabilities (i.e., not screen-reader friendly) or those with limited or no internet access. Long wait times to determine eligibility and outdated resource information can lead people to give up altogether. Assistive technology users also encounter usability problems, like online forms that time out before completion. Participants frequently reported poor coordination among providers in different sectors. For example, primary care providers don't communicate with home care or other aging service providers, leaving individuals without anyone who completely understands their needs.

> *"A lot of us, as we get older, have frustrations with technology. You have to set up an account and have a password for everything."*

Many resources are available online, but older adults face challenges using digital tools. Participants shared experiences of limited digital literacy, including unfamiliarity with technology, accessibility barriers, or mistrust of online systems. These barriers prevent them from using online services. For some, basic tasks like filling out forms or navigating a website can feel overwhelming or impossible without assistance. When online services are difficult to navigate, older adults struggle to stay informed about programs and services. This is particularly true in rural areas, where internet access is often limited.

> *"I need to know how to get ahold of somebody who is trustworthy."*

Mistrust and stigma prevent some people from engaging with services. Some individuals are reluctant to accept that they need support in areas where they were previously independent, due to self-stigma. This can lead to isolation and missed opportunities to connect with beneficial services, including senior centers. Other participants, especially in immigrant communities, reported fear and mistrust of government-associated service sites due to concerns about immigration enforcement. For these communities, the perceived risk (even among legal residents) outweighs the perceived benefit of attending events or accessing resources such as health fairs, food banks, or social service programs.

Public Education and Service Navigation: Participant Suggestions	
Resource Tools	• Create and regularly update a statewide, vetted resource clearinghouse accessible by phone (with live support), 800 number, and website. • Provide a free, comprehensive printed or digital service directory.
Public Education	• Develop and implement technology education programs for older adults. • Develop and implement a statewide campaign on the services and supports offered by AAAs and CRCs. • Offer “Aging 101” classes to improve understanding of available resources, service systems, and types of care. • Launch a public media campaign that shares bite-sized information about how to access help for common scenarios (e.g., what to do if you fall).
Access Points	• Create in-person spaces where older adults can receive support with tasks like bill paying and form completion. • Develop phone-accessible alternatives to online-only services.
Navigation Support	• Establish a "one-stop shop" model with resource navigators who can help older adults and people with disabilities identify, qualify for, and apply for services. • Encourage collaboration between CDA, AAAs, and Independent Living Centers to align systems and improve shared resource delivery.
Community Engagement	• Partner AAAs with senior centers, senior housing communities, and service providers to build credibility and share success stories. • Rename Senior Centers as “Adult Community Centers” to reduce stigma and attract a broader group of users.

AT-HOME CARE SUPPORT

Participants described a growing gap between the level of support needed to age at home and the services available. Public programs exclude many middle-income individuals, and private care remains out of reach. Workforce shortages, high turnover, and a lack of culturally and linguistically aligned caregivers further strain the system.

Aging at home requires a certain level of care. Most individuals said they prefer receiving care at home, where they feel safe and in control. Participants described reliance on help with daily tasks such as dressing, bathing, preparing meals, and managing medications. These needs grow over time, making consistent care at home necessary for aging in place.

However, in-home care services are limited in availability and affordability for non-Medi-Cal beneficiaries. Paying out-of-pocket for caregiving support is a financial strain for people living on fixed incomes. Agency rates are high, while public programs have restrictive eligibility thresholds, leaving many without support as their needs increase. Regarding availability, one consumer in the rural city of Ridgecrest reported she could not find a single caregiver willing to travel to her home.

"There isn't a good economic answer for people who want to stay in their home but can't afford home help."

Workforce shortages and turnover make it challenging to find consistent, high-quality care. Low wages, burnout, and limited professional support have created a shortage of home care workers. Those who can afford care often face rotating caregivers, which requires retraining and undermines continuity, trust, and safety.

"Even if we could all afford long-term care, there's no way there's enough staffing and facilities available."

Culturally and linguistically aligned caregivers are challenging to find. Even when care is available, it may not feel appropriate for individuals who need services in their preferred language or from someone who understands their cultural background. This lack of alignment creates barriers to accessing safe and personalized care.

"It was very difficult to find assistance in my language. Everything I found was in English."

When abuse occurs, there is limited public awareness and confidence in support systems. Participants noted a lack of knowledge about how to recognize, report, or respond to abuse, whether for themselves or their loved ones. Some described negative or unhelpful experiences with Adult Protective Services, where cases went unresolved, or survivors were unwilling or unable to speak openly about the abuse they were facing. This contributes to ongoing vulnerability and isolation.

"APS visited my sister, and they didn't resolve a lot because the person who was abusing her was in the room too. My sister couldn't speak up."

At-home Care Support: Participant Suggestions	
Services & Supports	• Increase the availability of services that support aging in place, including home-delivered meals, in-home caregiving, medical appointment escorts, and transportation assistance. • Increase government subsidies and assistance programs for home caregiving, modeled on successful programs like San Francisco's Support at Home. • Develop a vetted caregiver referral registry for people with disabilities and older adults seeking private-pay in-home support.
Caregiving Models	• Promote caregiver and home-sharing models to increase affordable options. • Create buddy systems to pair older adults with peer advocates. • Recruit low-income seniors as caregivers for people with disabilities.
Volunteers	• Develop community volunteer programs to provide basic assistance.
Workforce Development	• Recruit and train caregivers fluent in languages beyond English. • Integrate in-home caregiving training into Licensed Vocational Nurse (LVN), Registered Nurse (RN), and Certified Nursing Assistant (CNA) curricula. • Develop career ladders and training programs for caregivers. • Offer practicums and credits for caregiving at junior colleges and nursing schools.

FAMILY CAREGIVERS

Participants underscored the critical role of family caregivers, who often provide extensive support with little recognition, guidance, or relief. Despite their dedication, caregivers face inadequate respite options, limited training, and difficulty navigating complex systems to meet their loved ones' needs.

Caregiving takes a mental, emotional, and physical toll. Participants described chronic stress, guilt, and worry, especially as they balance caregiving activities with aging, health challenges, or family responsibilities. Fear of no longer being able to care for a loved one, whether due to physical decline or death, adds to the emotional weight. Additionally, the physical demands of caregiving can be overwhelming. Tasks like lifting, bathing, and transferring care recipients are physically strenuous. Duties like this can take a serious toll over time, and caregivers worry about what will happen when they cannot perform the demands of caregiving.

"Our plates are full. We don't have time for the research or to leave messages. Then, when the person returns the call, you're not able to pick up the phone. It's a vicious cycle."

Caregiving creates financial strain, with little relief available. Family caregivers incur out-of-pocket expenses for services and lost wages due to time away from paid work. Financial eligibility rules are based on household income rather than individual needs, and access to programs like IHSS or Medi-Cal is restricted. Many bear the burden of their parents' lack of planning around estate or long-term care needs.

"He doesn't trust having strangers coming in, so we have not qualified for any respite whatsoever. I've been paying out of pocket for five years."

Access to respite and training is limited. Even when respite programs exist, they are often tricky to use due to inconsistent providers, quality, and safety concerns about accepting unfamiliar help, or rigid eligibility criteria. For example, some programs require a three-hour minimum or do not allow caregivers to use funds to pay a family member. Many caregivers feel unprepared to care for individuals with behavioral, cognitive, or mental health challenges. There is a need for training, especially for condition-specific care like Alzheimer's and related dementias.

"[As a caregiver], I can't afford not to work and can't afford to work."

Caregivers struggle to navigate complex systems. Finding, understanding, and applying for caregiving resources is difficult. Many rely on outdated websites or make repeated calls to get information.

"I need a live person to help me figure out what I need and what I qualify for, not just give me a list of places to call."

Gaps exist in accessibility, cultural alignment, and emergency preparedness. Finding culturally and linguistically aligned support can be challenging, and many people worry about what might happen during an emergency if they cannot be present. These gaps make caregiving feel more isolating and can create dangerous situations.

Family Caregivers: Participant Suggestions	
Respite Care	• Provide affordable respite care without minimum-hour requirements. • Allow use of respite funds to pay trusted family members for caregiving. • Provide financial incentives or compensation to family caregivers to support income generation while caregiving. • Expand IHSS eligibility to middle-income adults and people with disabilities.
Assistive Devices	• Promote affordable, accessible, and easy-to-use assistive devices. • Expand access to emergency alert systems for caregivers and care recipients.
Resource Navigation	• Establish resource help desks that are accessible by phone or in person. • Assign CRC resource navigators who can research, call, and tailor resource lists to caregivers' needs and eligibility. • Develop peer-support models to assist caregivers with navigating resources.
Education	• Offer training and education on caregiving topics such as lifting and transferring, financial planning, resource navigation, and managing family dynamics.
Mental Health Support	• Provide counseling services, support groups, or social work services to support caregivers' emotional and mental health needs.

CLOSING

Consumer and stakeholder input emphasizes the need for a more accessible, affordable, and coordinated system of care for California's middle-income population. The patchwork of services and supports fails to address the financial realities, cultural needs, and caregiving challenges faced by middle-income older adults and people with disabilities.

Policy and program innovations are necessary to improve the situation, strengthen financial protections, expand affordable in-home care options, and enhance workforce capacity. Additionally, initiatives should simplify navigation, promote public awareness, and improve access to culturally and linguistically appropriate services.

The insights from the engagement sessions yield actionable ideas, underscoring that affordable, long-term services and supports are crucial for individual well-being and for California's broader goal of becoming an age- and disability-friendly state.

Appendix A. Details of Engagement Sessions

Host Organization	Location	Audience	Number of Participants
St. Paul's Senior Service, San Diego	In-person	Overlooked Middle adults	13
Riverside Area Agency on Aging, Riverside	In-person	Overlooked Middle adults	2
Dignity Health Connected Health, Redding	In-person	Overlooked Middle adults	11
Valley Caregiver Resource Center, Fresno	Virtual	Caregivers for Overlooked Middle adults	11
Sourcewise, Santa Clara	Virtual	Spanish-speaking Overlooked Middle adults	6
Marin Center for Independent Living, Marin	Virtual	Adults with disabilities who are working	8
Self-Help for the Elderly, San Francisco	Virtual	Cantonese-speaking Overlooked Middle adults	10
Collaborative Consulting	Virtual	AAA III-E and CRC Program Staff	12
Collaborative Consulting	Virtual	AAA III-E and CRC Program Staff	3

Appendix B. Consumer Demographics[1]

	Number	Percentage
Age		
< 50	3	5%
50-59	5	8%
60-69	19	31%
70-79	21	34%
80-89	11	18%
>90	2	3%
Insurance		
Medi-Cal	1	2%
Medicare	49	80%
Private Health Insurance	27	44%
Other	8	13%

[1] Demographics were collected for all sessions with older adults, caregivers, and adults with disabilities (total of N=61). Medi-Cal coverage and being younger than 50 were not exclusion criteria for the Marin CIL session.

Appendix C. Session Questions

Consumer Session Questions

1. What thoughts or feelings come to mind when you think about getting older?
2. What concerns you most when you think about growing older?
3. How do you think your needs will change as you get older?
4. What services and supports do you think you will need to age well at home or in your place of choice?
5. What would make it easier or harder for you to age at home or in your place of choice within the community?
6. What concerns do you have about the services and supports you will need as you age?
7. What are the 2-3 most important things that need improvement to meet the needs of older adults like you? What are your suggestions for how to make these improvements?
8. What are the most important areas of focus to make it easier for older adults to continue to live where they want to live in the community?

Caregiver Session Questions

1. In a few words, how would you describe your caregiving experience?
2. What concerns you most when you think about the person you care for?
3. What concerns you most about being a caregiver?
4. What support or services would be most helpful to you as a caregiver?
5. What services and supports does the person you care for need to age well at home or in their community?
6. How do existing services and support systems make it harder for you as a caregiver?
7. What are the 2-3 most important things that need improvement to meet the needs of caregivers? What are your suggestions for how to make these improvements?

Stakeholder Session Questions

1. What are consumers' concerns about growing older?
2. What are caregivers' concerns about their role as caregivers?
3. What challenges do consumers and caregivers face in affording LTSS?
4. Besides having more money to pay for services, what would make affording LTSS easier for consumers and caregivers?
5. What services and supports do older adults and caregivers need? What are your suggestions for how to make these improvements?

Appendix D. Participant Cited Successful Initiatives by Theme

Financial Security

- Marin AAA offers one-on-one financial coaching and credit counseling to help older adults reduce debt, build credit, and create budgets.

Housing Security

- Marin AAA is piloting shallow subsidies to stabilize older adult homeowners. The subsidies will cover a portion of utility bills for six months.

Transportation

- Dixon's Readi Ride provides flexible, weekday curb-to-curb service within city limits, with free rides for personal care attendants.
- In Los Angeles, Waymo offers free autonomous vehicle rides for people with disabilities.
- LA Metro provides reduced fares for people with disabilities.
- San Francisco offers one free Uber ride per month and caps ride costs at $5 regardless of distance.

Social Engagement and Mental Health

- Dignity Health Connected Living offers free, dietitian-approved congregate meals with volunteer interaction, including phone-read menus for people with visual impairments.

Public Education and Service Navigation

- Imperial County uses promotores to engage Latino communities through outreach at community sites like food distribution lines.
- San Diego CRC provides staff training on immigration rights to better inform clients.
- Self-Help for the Elderly connects older adults with culturally appropriate services and supports.

At-Home Care Support

- San Francisco's Support at Home provides vouchers for moderate-income older adults and people with disabilities needing help with at least two activities of daily living.

Family Caregivers

- The Family Caregiver Alliance offers free, flexible respite care options, including in-home, day program, and overnight services.