

# Listening to Californians with Complex Needs

## Focus On: People Who Need Support to Live Independently

As the CalAIM (California Advancing and Innovating Medi-Cal) program's Enhanced Care Management and Community Supports reach their fourth year since statewide launch, implementation partners have [reported](#) these services are making a difference for their organizations and the Californians they serve. But how are these programs experienced by the people they are intended to support?

This fact sheet centers the perspectives of those who need support to live independently and their caregivers. Access to in-home and community-based services, expanded social and caregiver support, and trusted care managers are essential for these individuals to navigate complex systems and remain in their homes and communities. For managed care plans and provider implementers, involving people with lived experience as equal partners in program design and implementation increases the likelihood that these services will truly meet people's needs.

## Key Findings

### Strong Preference for In-Home and Community-Based Services

Many older adults prioritized living independently and caring for themselves, even while managing physical challenges or cognitive decline. More than one in three older adults expressed a preference for in-home or community-based services, such as bathing

### About the Study

In 2023 and 2024, Los Angeles research firm EVITARUS conducted the Listening to Californians with Complex Needs study in partnership with CHCF. The research included in-depth interviews with 99 people with complex needs and eight focus groups with caregivers across Alameda, Fresno, Humboldt, and Los Angeles counties. In the [full report](#), participants described their attitudes toward their health and experiences with the health care system. This fact sheet focuses on Californians who need support to live independently and their caregivers.

### About the Participants

More than half of the interview participants (52%) reported needing support to live independently, often due to functional impairments — such as hearing loss, mobility limitations, or cognitive decline — that have led them to require assistance with activities of daily living. This need increases with age: more than three in four (76%) participants needing support were age 60 and older. Given the age distribution, this fact sheet will use the term “older adults” to describe this population. The study included eight focus groups with 41 caregivers who are supporting older parents, adult children, or other relatives with severe physical disabilities, chronic health conditions, mental health conditions such as schizophrenia and PTSD, and substance use disorders. Many caregivers are dealing with their own physical and behavioral health concerns, including trauma related to past substance use and homelessness.

assistance, medication management, and in-home physical and mental health therapies. A 51-year-old White woman in Humboldt County shared that she needed caregivers who could stay with her, help her manage equipment, and offer dignity through home-based care. That support helped her maintain her health and independence. “Sometimes, you just need somebody there,” she said.

Older adults also expressed the need for community-based services to manage depression and the feeling of having “nothing to look forward to.” To address limited mobility and shrinking social networks, they preferred access to engaging and varied adult day services to facilitate social interactions and help them age in place with joy and connection.

Many older adults feared being abandoned, neglected, or misunderstood in institutional settings. As a result, they desired skilled nursing facilities with home-like environments; culturally competent staff; and responsive, professional, and compassionate nursing care.

*“A lot of seniors don’t want to go. They have a fear of going to nursing facilities. . . . But I think hopefully, someday, they can have this idea that a nursing facility is a trustworthy place that they can go to. . . . I think that they can improve nursing facilities so that they can feel assured about going there.”*

—Female Korean-speaking caregiver, Los Angeles County,  
translated from Korean

## Older Adults and Caregivers Need Social Services and Other Supports

Both older adults and caregivers expressed the need for expanded economic and social services as well as additional caregiving support.

Some older adults experienced repeated denials of Supplemental Security Income (SSI) — monthly payments for people with disabilities and older adults who have little or no income or resources — or did not understand the eligibility requirements. They also reported needing increased food assistance and better access to fresh, culturally relevant food options.

Many older adults rely on caregivers for transportation to medical appointments, and their ability to leave their home is significantly impacted when those caregivers are unavailable. To ensure reliable accompaniment to medical appointments, older adults and caregivers emphasized the need for increased [reimbursed caregiver hours for people on Medi-Cal](#). Caregivers also cited the need for increased financial support to cover out-of-pocket expenses, like medications and groceries, and travel reimbursement for long-distance medical appointments and grocery deliveries.

Caregivers reported needing training on navigating the health system and caring for older adults with mental health conditions, including depression, schizophrenia, and PTSD. They also wanted training on handling pessimism among older adults experiencing very challenging health conditions, as well as approaches to handling conditions of cognitive decline, like dementia. Caregivers also expressed needing support with their own mental health, such as counseling or classes on managing stress and the emotional toll of caregiving, especially for family caregivers.

*“I think that the mental health system should offer mental health training to caregivers. Because looking from the outside in, you may see that person [you’re caring for] is not wanting to do nothing, when in fact they may be in depression. And you cannot diagnose it if you have not experienced it or you’re not a mental health professional.”*

—Female caregiver, Alameda County

## Care Managers and Navigators Are Essential Due to System Complexities and Digital Barriers

Many older adults and their caregivers reported relying on trusted staff members at community-based organizations to help them navigate the complex health care system. This includes assistance with scheduling and attending appointments, connecting with needed services, planning in-home and hospice care, and resolving insurance claims.

Some caregivers and older adults reported poor communication and coordination among health care providers and inadequate support for transitions between care settings. Hospital discharges are often rushed, and care managers could help ensure appropriate discharge instructions, planning, and continuity of care.

*“The doctor was supposed to set him up to an [outpatient] facility. They told him to call insurance to do it. We called insurance, and insurance was like, ‘Your doctor was supposed to set that up.’ Now he is like in limbo, and now we are trying to figure out who to call, because they keep saying, ‘Call this person, call that person.’ Then they are, ‘We don’t have nothing available. We’re not taking new patients.’ . . . He needs that so he can walk comfortably, because right now he’s messed up, and it’s frustrating. . . . When we left the hospital and stuff, they don’t tell you how difficult it’s going to be. . . . So I feel like they should give a little bit more tools that can help us a little bit more at home as opposed to being at the hospital.”*

—Female caregiver, Alameda County

Caregivers emphasized the value of working consistently with a single care manager or with a small, familiar group of providers. Caregivers also expressed a strong desire to be included in care planning and discussions with providers, noting that they were often met with dismissive attitudes despite having detailed knowledge of the older adults’ conditions.

Many older adults did not have access to digital technology and had limited digital literacy, making managing appointments and accessing follow-up information challenging. These challenges were often compounded by memory loss, diminished vision, or hearing loss. Rather than relying on inconsistent, informal support from neighbors, staff at their residence, or peers to interpret documents, access health care portals, or navigate digital communications, older adults would benefit from a dedicated care manager who can provide consistent, reliable assistance.

## Resources for Implementers

Here are resources that may improve understanding of both the needs of and services available to people needing support to live independently:

- ▶ Learn more about [Californians who need long-term services](#).
- ▶ Review these explainers about [four home and community-based services programs that are offered through Medi-Cal](#). These services can help people age in place and avoid placement in a nursing home.
- ▶ Check out California’s [largest program that delivers long term services and supports](#).
- ▶ Learn from the experiences of [Cardea Health](#) in Oakland and [Kern County Family Health Services in Bakersfield](#), two organizations using Medi-Cal-funded services to help older adults and their caregivers get the help they need to live well in the community.

### THE TAKEAWAY

Older adults and other people needing support to live independently expressed a strong preference for in-home and community-based care that supports both medical and social needs. Reliable caregivers, accessible transportation, and opportunities for connection are essential. In addition, care managers play a crucial role in helping older adults and caregivers navigate complex systems and maintain stability.

### About the Authors

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### About the Foundation

The [California Health Care Foundation](#) (CHCF) is an independent, nonprofit philanthropy that works to improve the health care system so that all Californians have the care they need. We focus especially on making sure the system works for Californians with low incomes and for communities who have traditionally faced the greatest barriers to care. We partner with leaders across the health care safety net to ensure they have the data and resources to make care more just and to drive improvement in a complex system.

CHCF informs policymakers and industry leaders, invests in ideas and innovations, and connects with changemakers to create a more responsive, patient-centered health care system.