COLLABORATIVE
CONSULTING

CALCARES CAREGIVER NAVIGATION SYNTHESIS: PERSPECTIVES FROM CAREGIVERS

Synthesis of Caregiver Engagement in Imperial, Marin, and Sonoma Counties

March 2026

INTRODUCTION

In alignment with the Administration for Community Living's (ACL) National Strategy to Support Family Caregivers and California's Master Plan for Aging (MPA), the California Department of Aging is implementing a two-year initiative called **Cal**ifornia **C**aregiver **A**wareness, **R**esources, **E**ducation & **S**upport (CalCARES). CalCARES aims to improve awareness, navigation, and educational opportunities for California family caregivers who support older adults and people with disabilities. One objective is to understand how to maximize caregiver engagement and referrals to community services by identifying strategies to strengthen connections across health care and home-and-community-based services (HCBS) organizations. While current efforts are focused on three pilot counties (Marin, Imperial, and Sonoma), the goal is to replicate promising practices statewide.

In service of this objective, Collaborative Consulting conducted engagement sessions with unpaid and paid caregivers from Marin, Imperial, and Sonoma Counties to learn more about how caregivers are navigating information, resources, and referrals in their communities.

METHODOLOGY

Between October and November 2025, 56 caregivers participated in engagement sessions. Caregivers were recruited through word of mouth and by distributing virtual and printed flyers to health care and HCBS organizations in the three counties. All sessions were held virtually, except one, which was held in person at the Imperial County Area Agency on Aging (AAA) to accommodate Spanish-speaking caregivers who were unable to join virtually. During the sessions, caregivers shared their experiences navigating resources and referrals within and outside the health care and HCBS sectors, as well as the challenges they faced in finding what they needed. They also provided ideas for navigating the system more effectively. Please see the Appendix for the engagement session question guide.

To gather additional input from caregivers on the ideas discussed in the engagement sessions, we reached out to the 12 caregivers who registered but did not attend. We invited them to complete an online survey (via Formsite) that included the various ideas caregivers shared during the sessions. The purpose was to understand how these caregivers ranked the importance and value of each idea. A total of six caregivers completed the survey. Their survey responses were integrated into the synthesis.

All themes presented below are drawn solely from caregivers' perspectives, priorities, ideas, and experiences shared during the engagement sessions. We analyzed and synthesized the data into the following sections:

1. Individual Drivers of Caregiver Referral and Navigation | Page 5

2. Caregiver Referral and Navigation Through Health Care and HCBS Organizations | Page 7

3. Caregiver Referral and Navigation Through Informal Networks | Page 10

COUNTY PROFILES[1]

Imperial County is home to approximately 179,700 residents. Imperial is largely rural, spanning 4,175.5 square miles, which makes it the 10th largest county in California by land area. The county's population is predominantly Hispanic or Latino (85%). Median household income is $60,749, well below the state's median. In 2023, an estimated 7% of adults (about 8,000 residents) provided care to a family member or friend with a long-term illness or disability. The county has a substantial In-Home Supportive Services (IHSS) presence, with 8,464 providers supporting 9,714 enrolled recipients, reflecting significant reliance on paid in-home care.

Marin County has a population of approximately 262,200 residents and covers 520.1 square miles, making it one of California's smallest counties by land area. The population is primarily White (68%), followed by a Hispanic/Latino community (19%). Marin is among the most affluent counties in the state, with a median household income of $147,017. In 2023, 13% of adults (about 27,000 residents) reported providing care to a family member or friend with a long-term illness or disability. IHSS enrollment is comparatively modest, with 2,378 providers serving 2,518 recipients, suggesting a caregiving landscape that relies on a mix of formal and informal supports.

Sonoma County is home to approximately 488,900 residents and spans 1,575.3 square miles, ranking 29th in California by land area. The county's population is primarily White (63%), followed by nearly one-third identifying as Hispanic or Latino (29%). Median household income is $107,274. Caregiving needs are substantial: In 2023, 17% of adults (about 65,000 residents) provided care to a family member or friend with a long-term illness or disability. Sonoma County has a large IHSS program, with 8,164 providers serving 8,571 recipients, underscoring the importance of HCBS in supporting residents with care needs.

---

[1] Data Sources

U.S. Census Bureau. (2020). *Decennial Census: Total population and race and ethnicity.*
U.S. Census Bureau. (2024). *American Community Survey 1-Year Estimates: Median household income.* County-level data for Imperial, Marin, and Sonoma Counties.
California Department of Aging. (2024). *Master Plan for Aging Data Dashboard*.
California Department of Social Services. (2025). *In-Home Supportive Services (IHSS) Program Monthly Data.* December 2025 IHSS provider and recipient data.

INDIVIDUAL DRIVERS OF CAREGIVER REFERRAL AND NAVIGATION

Caregivers' referral and navigation experiences vary based on whether they are working with health care organizations, HCBS organizations, or informal networks. However, across all settings, five interrelated drivers influence caregivers' experiences. These individual-level conditions shape how caregivers seek information, make decisions, and navigate referrals:

- Time and Energy
- Finances
- Geography and Transportation
- Proactivity and Resourcefulness
- Caregiver Identity

TIME AND ENERGY

Caregiving functions as a full-time job. Caregiving is a role that demands constant attention and energy. Even caregivers who are retired or have reduced work commitments report that daily management of their loved one's care occupies most of their time, leaving minimal opportunity for self-care or rest.

Information-seeking is shaped by caregiver capacity. It is often easier for caregivers to rely on trusted friends for referrals rather than navigate unfamiliar or fragmented resource systems, prioritizing "the path of least resistance" over exploring other options. Practical barriers, such as arranging transportation or respite, also limit the use of recommended caregiver services (e.g., support groups). Simplifying how caregivers access information, such as through a centralized online portal with pre-vetted local resources filtered by eligibility, could reduce the time required to identify appropriate supports.

> *"There's so much that we have to research constantly."*

Delays in accessing services compound time barriers. Even when caregivers qualify for programs such as respite or In-Home Supportive Services (IHSS), application and approval processes can take weeks or months. Paperwork requirements, agency transitions, and complex eligibility criteria require ongoing follow-up calls and troubleshooting. As a result, some caregivers find that the time and energy required to secure specific supports outweigh the actual benefit, making some programs effectively inaccessible despite being available. Implementing universal intake forms that can be shared across multiple agencies and/or creating fast-track approval pathways for caregivers in crisis could reduce administrative burden and improve access to services.

> *"I've learned what to fight and what to accept, even though it can be frustrating and not right. I only have so much energy at the end of the day."*

FINANCES

Many caregivers fall into a middle-income gap. Many caregivers and their care recipients earn too much to qualify for public programs like Medi-Cal, yet not enough to afford the level of support and services they need. Caregivers are unsure where to turn when neither public programs nor private options are accessible. Clear, accessible education and anticipatory guidance on financial planning and long-term care options help caregivers better understand and plan for available supports.

"A lot of services are income-based, and my mom just falls above the income base for a lot of them. So now where do I go?"

Health insurance influences access to and the affordability of services. Caregivers report frequent, unavoidable out-of-pocket expenses for services, medical equipment, and in-home care. Some experience new costs when their health plan removes previously covered services or when plan changes disrupt access. Coverage determines which providers are willing to order or refer for services, and limited coverage restricts access to necessary care. For example, after switching health plans, one caregiver had to purchase a supplemental plan to cover specialized services (e.g., podiatry, physical therapy) for her husband.

The cost of respite and private caregiving limits caregivers' ability to benefit from needed services. Caregivers who pay privately for temporary support report extremely high costs, making respite or time away from caregiving unrealistic. Without affordable options, caregivers often lack sufficient time to manage their own health and well-being, let alone locate and access the necessary services.

"My experiences all come down to money. If things aren't covered by Medicare, the doctor won't order it."

GEOGRAPHY AND TRANSPORTATION

Geographic and environmental barriers hinder access to services. Caregivers in rural or remote areas (e.g., West Marin, West Sonoma, the Imperial Valley) face limited access to senior centers, community programs, home health care, and other support services. Travel time, infrastructure issues, and distance require extra planning, making engagement less feasible. Participants also mentioned technology challenges in rural or remote areas, such as limited internet access, poor cell phone reception, and the high costs of reliable internet. Investments in technology infrastructure (e.g., subsidized internet access, free equipment for caregivers in need) could expand access to virtual services and reduce geographic isolation.

Caregivers supporting individuals with mobility limitations and/or complex health concerns face heightened transportation barriers. Services that require travel (e.g., dental, specialty care) become inaccessible unless providers offer home visits. Testing creative transportation solutions, such as coordinated volunteer driver networks focused on caregiver respite or medical appointments, could address these gaps where traditional transportation options fall short.

"When you have a person who cannot be transported, we can really only obtain things that we need via providers that will come to the home."

PROACTIVITY AND RESOURCEFULNESS

Proactivity is essential to managing the caregiving workload. Caregivers describe the ongoing effort required to anticipate needs, search for resources, and make decisions under evolving circumstances. However, many caregivers operate reactively. Limited bandwidth makes proactive planning difficult, and many caregivers report that they "don't know what they don't know." Accessible education and training covering a wide range of common caregiving topics would help caregivers build confidence and plan ahead.

"Proactive searching is better than being in a crisis, but unfortunately, that's not usually how it works out."

Caregivers use a range of online and self-directed approaches to locate support and information. Common examples include using search engines such as Google to access reputable sources (e.g., WebMD, the Mayo Clinic, or local community organization websites), as well as participating in online forums such as Reddit or Facebook. Some caregivers also mentioned using resources such as AI platforms (e.g., ChatGPT), attending classes or webinars, watching documentaries, and reading materials (e.g., AARP magazines or online articles). Centralizing resources in one trusted location could reduce duplication of effort and help caregivers identify credible, relevant information.

"Being resourceful and just going online and finding things has really been the way I started in the beginning."

CAREGIVER IDENTITY

The intensity of day-to-day responsibilities can create "tunnel vision" for caregivers. Caregivers remain so focused on immediate care needs that they have little time or cognitive bandwidth to step back, assess their own needs, or proactively seek support. This constant focus on "keeping things going" limits their ability to identify resources, ask questions, or plan.

"When you get so involved with the care, you feel like you're tunnel visioned. You feel like you're the only one on this trip."

A few participants noted they do not identify as caregivers, even though they provide substantial care. When individuals do not perceive themselves as caregivers, they are less clear about what support to request, less likely to view traditional caregiver resources as relevant, and less inclined to seek help. This lack of recognition delays engagement with services and contributes to feelings of being overlooked. Reframing resources and outreach in plain language (i.e., focusing on caregiver needs rather than program names or labels) will resonate with a broader range of individuals who provide care but do not self-identify as caregivers.

"I guess I look at caregivers and I'm thinking, 'I'm not that, I'm different'."

CAREGIVER REFERRAL AND NAVIGATION THROUGH HEALTH CARE AND HCBS ORGANIZATIONS

Caregivers navigate a wide range of health care and HCBS organizations to obtain information, referrals, and services. Many caregivers encounter similar challenges across both sectors, along with barriers unique to each sector.

SHARED CHALLENGES

Quality and responsiveness are inconsistent across organizations. Caregivers experience differences in provider responsiveness, reliability, and clarity of guidance. Even within a single organization or system, some providers offer clear, proactive support, while others are rushed, unavailable, or inconsistent in their approach. This inconsistency requires caregivers to repeatedly explain their situation, seek second opinions, or find new providers who will listen to their concerns. Standardizing caregiver-centered training and protocols across health care staff could reduce variability and improve caregiver trust and continuity of care.

> *"One word to describe referrals: Nightmare. You have to go through doctor after doctor before you find one that is willing to refer you to a specialist that you need."*

System fragmentation places the burden of coordination on caregivers. Caregivers report difficulty in reaching providers between appointments, a lack of follow-up after referrals, and receiving unclear or incomplete information. Fragmentation across programs, departments, or services forces caregivers to act as coordinators and advocates for their needs, often without professional support. A unified communication infrastructure, such as shared referral platforms between health care and HCBS organizations, bridges these gaps.

> *"I am a squeaky wheel. I ask for everything that I think he [my husband] needs, and then I ask again. That's a big thing – being repetitive with the doctors."*

Referrals often lack follow-through and warm handoffs. Caregivers report limited follow-up after referrals or recommendations. Some are given phone numbers or resource lists without check-ins, while others are referred to programs that are full or no longer available, with no alternatives offered. As a result, caregivers are stalled, unsure of next steps, or forced to abandon seeking help. Tracking systems that alert caregivers and referring providers when referrals are received, accepted, delayed, or require additional information could improve accountability and reduce drop-off in the referral process.

Guidance is rarely tailored to the caregiver's circumstances. Caregivers express a need for guidance that considers cultural context, care needs, household dynamics, transportation barriers, and financial constraints. Both health care and HCBS providers deliver general information rather than individualized options, leaving caregivers to determine which services are most relevant to their needs. Assessments that capture individual circumstances and use that information to generate personalized resource recommendations will improve alignment between caregiver needs and available supports.

> *"It felt like a checklist when the social worker came along. Maybe they're overwhelmed with how many patients they have, but it was like 'Here's some forms, here's my card, good luck.'"*

HEALTH CARE-SPECIFIC REFERRAL AND NAVIGATION

Caregivers receive information and referrals from a range of health care professionals, including primary care physicians, mental health providers, palliative care teams, social workers, care managers, neurologists, and health plan representatives.

Social workers and care managers help caregivers understand options and access services. Their involvement makes navigating systems and obtaining referrals more manageable. Caregivers often find that medical providers are not fully aware of local HCBS options and therefore cannot provide explicit recommendations or referrals without involving social work and/or care management. Expanding social work and case management capacity, particularly at transition points such as diagnosis or hospitalization, could help caregivers receive timely, informed guidance.

> *"We have a social worker, and she has been invaluable. She gave me a booklet of resources that has been really helpful."*

Staff shortages, turnover, and limited provider time can hinder timely support, necessitating caregiver persistence. These factors disrupt continuity and limit caregiver access to comprehensive support. Caregivers follow up repeatedly with professionals, request referrals multiple times, or escalate concerns when initial attempts are unsuccessful. Clear protocols for caregiver engagement and referral follow-up could reduce the need for repeated outreach and ease the administrative burden on caregivers.

> *"The VA has some good social workers, but then when you call back, they're gone, and you have to start all over again with someone new."*

Communication gaps are a source of frustration. Caregivers describe long gaps without meaningful contact, difficulty reaching providers between appointments, and limited follow-up after visits involving multiple professionals. While some report success using digital messaging platforms (e.g., MyChart), many struggle to connect with a responsive and knowledgeable provider.

> *"We see [all providers] once or twice a year at a panel appointment. That's when we get all our resources, but otherwise it's very difficult to contact in between those appointments."*

Communication barriers are exacerbated for Spanish-speaking caregivers. Interpreting services are often unavailable or unreliable, and several caregivers report being denied the opportunity to interpret or communicate with medical providers, even when their care recipient wants or needs them to do so. Without the proper legal documents, caregivers may also be excluded from appointments, limiting their ability to share critical information about the patient and to receive updates on care and medications. Many caregivers are unfamiliar with the legal steps required to facilitate their participation in medical visits.

> *"[Doctors] limit you a lot, and they don't want to give you information unless you have an Advance Medical Directive. Sometimes they don't even let [the caregivers] go into the room with the patient."*

Eligibility constraints limit access to appropriate services. Some caregivers face service limitations due to age-related eligibility requirements. For example, one participant who cares for her husband with Huntington's disease does not qualify for needed services (e.g., adult day centers) designed to serve older adults or individuals with developmental disabilities. Transportation and mobility challenges, combined with eligibility restrictions for age-specific programs, further complicate access to appropriate care.

> *"My husband was in hospice, and he got better. His community caregiver would say to me, 'He was in hospice, this is borrowed time.' And now, the VA doctor is saying the same thing, and it drives me crazy."*

HCBS-SPECIFIC REFERRAL AND NAVIGATION

Caregivers engage with a variety of HCBS organizations, including Area Agencies on Aging (AAAs), Caregiver Resource Centers (CRCs), Centers for Independent Living (CILs), senior centers, community centers, adult day programs, Villages networks, Veterans Affairs programs, and disease-specific associations (e.g., Alzheimer's Association).

Caregivers reported relying most on CRCs and senior centers for information and referrals. Caregivers report that these organizations are effective at directing them to the right services, anticipating future needs, and connecting them with other HCBS providers (e.g., meal services, transportation, activities) or informal supports (e.g., local support groups). While some caregivers were aware of their local AAA, most had not utilized its services. Increasing HCBS visibility through targeted outreach in health care settings and popular community spaces (e.g., libraries, gyms) will help caregivers learn about these resources earlier.

Some caregivers report limited awareness of their local CRC or its services. Throughout all sessions, this was most noticeable among Marin County caregivers, who were the only ones to have even heard of the CRC. Factors contributing to this gap include unclear marketing, limited outreach, difficulty accessing resources, or not identifying as a caregiver. Coordinated awareness campaigns across health care and community settings can help normalize caregiver support and improve early engagement.

> *"I've heard of it [the CRC], but I've not contacted them. I don't know what my resistance would be."*

In-home care options are valuable, but some caregivers face challenges in accessing them. Caregivers describe constraints with home health services, including limited flexibility in scheduling for shorter visits and a lack of training among aides for complex medical or behavioral needs, particularly for care recipients with dementia. Some caregivers report that these limitations hindered their ability to access suitable support. Stronger coordination between HCBS providers and health care teams could help align caregiver expectations, service capabilities, and referral appropriateness.

Caregivers describe being passed from one agency to another, with each suggesting they contact someone else. Even when they reach what seemed like the proper organization, the information provided is vague, unclear, or contradictory. Forms, letters, and automated responses were discouraging, leaving caregivers uncertain about what was needed or how to proceed. In addition, there was no clear point of contact to ask questions or seek clarification.

> *"Everybody's pointing the finger at somebody else that you need to go talk to."*

CAREGIVER REFERRAL AND NAVIGATION THROUGH INFORMAL NETWORKS

For many caregivers, informal networks are crucial for supplementing the information, resources, and referrals provided by health care and HCBS systems. Caregivers tap into a variety of in-person and virtual informal networks, including family members, friends, neighbors, and support groups.

For many, support groups are an essential part of the navigation experience. Support groups are a primary space for emotional support, connection, and shared understanding. The opportunity to talk with others who understand their situation helps them manage stress and burnout better. Support groups are a valuable source of practical information and referrals. Caregivers frequently learned about new programs, services, and strategies for addressing caregiving challenges from group facilitators and members.

> *"Every caregiver should be in a support group. It's a huge resource for finding answers to problems."*

Caregivers emphasize the distinct advantages of informal networks. Peers are often able to provide practical advice and solutions that practitioners cannot, offering guidance rooted in real-world caregiving experience. This peer-based knowledge extends to emotional support and information about local programs and services. Applying peer expertise, such as through peer mentorship or navigation programs, could expand these benefits to caregivers who are earlier in their caregiving journey or less connected to informal networks.

> *"They have life experience that even the practitioners don't necessarily have."*

There are barriers to participating in support groups, including scheduling conflicts, time constraints, and potential health risks. Sessions are often scheduled at times that work best for retired or full-time caregivers, making participation difficult for those who are employed or have other obligations. Others are too tired or overwhelmed to attend, even when they want to. One caregiver raised concerns about health risks associated with in-person gatherings and bringing illness home to medically vulnerable loved ones. Hybrid and virtual participation options could help reduce these barriers and make peer support more accessible.

> *"For those of us who work full-time [and] are still raising families, none of those services are available at times that are convenient for us."*

Informal networks within local organizations and community-based programs also play a key role. Models such as Marin Villages and church groups are hubs for word-of-mouth referrals, connecting caregivers to resources, support groups, and services. These networks offer caregivers a community of support, providing access to resources that would have been difficult to find independently. Utilizing formal channels, such as health care providers, AAAs, libraries, and other community spaces, to promote informal networks could help reach more caregivers earlier and more consistently.

> *"Marin Village - the whole Village system is incredibly helpful. That's really where I got all my information, from word of mouth, from friends, and from the Village."*

While participants value informal connections, these networks can be inconsistent and depend on personal relationships. Caregivers describe the system as "loose," meaning that if someone has not previously encountered a knowledgeable individual, certain resources might remain unknown. Additionally, while word of mouth is one of the most common and trusted ways caregivers learn about available resources, some caregivers note that it can also be difficult to rely on. Caregivers find it challenging to locate information when they are unsure of where to begin searching or who to ask. Creating universal entry points into informal networks where any caregiver can access peer support regardless of prior connections could reduce reliance on "knowing someone" and make informal referral pathways more equitable and reliable.

CONCLUSION

Caregivers in Imperial, Marin, and Sonoma Counties use a mix of health care organizations, HCBS organizations, and informal networks to seek referrals and navigate the system. Some common challenges reported by caregivers across health care and HCBS systems include fragmented services, inconsistent provider responsiveness, and referrals that lack follow-through. Providers often give lists rather than warm handoffs, and programs are frequently full or difficult to access. Additionally, any guidance provided to caregivers is rarely tailored to their individual circumstances, including financial constraints, transportation needs, and preferences.

Informal networks offer what formal systems often cannot: personalized, lived-experience guidance; consistent emotional support; and practical advice that reflects the realities of day-to-day caregiving. Even during the engagement sessions, many caregivers used the space itself to exchange information, validate one another's experiences, and offer peer support. However, access to informal networks is often uneven. Time constraints, rural isolation, limited digital access, and a lack of caregiver self-identification keep some from participating. Information shared informally can also be inconsistent.

"Caregivers are stretched beyond their limits. We have a lot of challenges, but we can't lie down. We need to be able to give clear and simple directions as person to person, to support each other, and to be hopeful. We have to focus on our strengths."

Enhancing caregiver navigation in California involves strengthening informal networks, improving formal referral processes, and effectively connecting the two. To ensure caregivers receive timely, personalized, and sustainable support, it is essential to maximize support groups, increase warm handoffs, expand language access, and integrate peer support into formal systems.

FUNDING ACKNOWLEDGMENT

This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $653,546, with $490,000 (75%) funded by ACL/HHS and $163,546 (25%) financed from state, local, or non-federal source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, ACL/HHS, or the U.S. Government.

APPENDIX SESSION QUESTIONS

1. What's the most significant skill or lesson that you've learned from being a caregiver?

2. Have you ever received information or referrals from a health care provider, like a doctor or discharge planner? What's worked well? What hasn't worked well?

3. Have you ever received information or referrals from a community organization such as a Caregiver Resource Center or Area Agency on Aging? What's worked well? What hasn't worked?

4. What other ways have you connected to information that we haven't covered?

5. What would make it easier for you to get the right resources at the right time?
    a. Who would you want to give you the information (doctor, community leader, peer, online)?
    b. How would you want to receive information (phone, in person, text, online)?
    c. What kind of follow-up would be most helpful (warm hand-off, call-back, check-ins)?

6. [For Paid Caregivers] Has becoming paid for your caregiving changed anything about the way you find information or services?