

# Mapping Caregiver Navigation Services

An Environmental Scan  
of Current Practices



National Caregiver  
Support Collaborative



Understanding, Testing,  
and Evaluating Caregiver  
Navigator Services

## PROJECT BACKGROUND

With over 63 million Americans providing unpaid care to family members, friends and loved ones, caregivers often face significant emotional, physical and financial challenges. Informed by the [National Strategy to Support Family Caregivers](#), the U.S. Administration for Community Living-led [National Caregiver Support Collaborative \(NCSC\)](#) is a multifaceted initiative focused on achieving greater recognition, support and inclusion of family, kin and tribal caregivers across the country.

To address the priorities laid out in the National Strategy, the NCSC addresses five goals: increasing awareness and outreach; advancing partnerships and engagement with family caregivers; strengthening services and supports; ensuring financial and workplace security; and expanding data, research and evidence-based practices.

Caregiver navigation intersects with multiple National Strategy goals, functioning as a vital service that connects caregivers with essential resources at the right time and in the right way. USAging, in partnership with ADvancing States, the National Resource Center on Native American Aging, Family Caregiver Alliance and Scripps Gerontology Center, is leading the effort to strengthen caregiver navigation services offered through the National Family Caregiver Support Program and Native American Caregiver Support Program. These programs, funded by Older Americans Act (OAA) Title III-E and VI-C dollars, encompass a range of supports that assist family and informal caregivers regardless of their care recipient's diagnosis.

Area Agencies on Aging (AAAs) and Title VI Native American Aging Programs (Title VI programs) possess an inherent excellence in assisting caregivers. They have been administering these programs for over 25 years and were assisting caregivers even prior to these formalized and funded avenues.

From its inception in 2000, Title III-E has enabled flexibility to meet the unique needs of family caregivers across the country. This flexibility takes into account caregiver needs, availability of other state-specific programs and services, and stewardship of funding. Many caregivers find it difficult to navigate the complex support systems available, often feeling overwhelmed, making the National Family Caregiver Support Program a vital first point of contact for accessing guidance and resources. Thus, the program warrants greater investment to maximize its impact.

This report focuses on Title III-E caregiver navigation efforts that AAAs administer. The grant team is in the process of engaging Title VI Native American Programs administering Title VI-C programs to publish a subsequent edition of this report that reflects caregiver navigation trends in Native American Caregiver Support Programs.

## DISCOVERY PHASE

To assess the current landscape of caregiver navigation services in Title III-E National Family Caregiver Support Programs, the team collected information through a literature review, surveys, listening sessions, and key informant interviews with participants across the Aging Network,<sup>1</sup> representing all 50 states. This also included conversations with family caregivers who serve as the backbone of our nation's long-term care system.

Search findings from published and grey literature suggest there is limited peer-reviewed, evidence-based research on the vast array of caregiver navigation services that the Aging Network administers. Thus, the team prioritized broad national representation in the subsequent listening sessions and key informant interviews conducted with State Units on Aging (SUAs), AAAs and family caregivers.

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<sup>1</sup> The Aging Network is a nationwide system of organizations that supports older adults by providing services, advocacy, and resources. It is built on the infrastructure established by the Older Americans Act (OAA) and includes federal, state, tribal, and local agencies, as well as private and nonprofit service providers. Key components include State Units on Aging, Area Agencies on Aging (AAAs), and Title VI Native American Aging Programs.



USAgging and partners gathered qualitative input through a series of four 90-minute listening sessions. Each listening session was conducted with a separate group of participants—State Units on Aging (11 participants), Area Agencies on Aging (eight participants), family caregivers (11 participants) and technology leaders (five participants). In addition to the listening sessions, 12 key informant interviews were conducted to delve deeper into caregiver navigation processes, protocols, staffing and funding.

## WHAT CAREGIVER NAVIGATION IS AND WHAT IT ISN'T

First, it is important to define what caregiver navigation services encompass. Not to be confused with care navigation that is mainly associated with clinical health programs, the focus of our review was on caregiver navigation that occurs in community-based settings relying on social supports rather than medical care.

**Caregiver Navigation** is designed to support family and informal caregivers—spouses, partners, relatives and friends—by helping them identify and access the resources they need throughout their caregiving journey.

Although AAAs and Title VI programs have implemented caregiver navigation activities for more than two decades, many providers do not recognize themselves as offering this service—much like caregivers who often do not identify as caregivers. Expanding education and broadening perspectives on what caregiver navigation entails, even within Aging Network organizations charged with delivering these services, is essential. Clarifying their role as caregiver navigators fosters a shared understanding of what caregiver navigation is and what it is not.

WHAT IT IS	WHAT IT IS NOT
<ul style="list-style-type: none"> <li>✓ <b>Family Caregiver- Centered:</b> It is focused on informal, unpaid caregivers, including family, friends and families of choice.</li> </ul>	<ul style="list-style-type: none"> <li>✗ <b>Formal Care Providers and Caregiver Recruitment:</b> It does not serve professional care providers or recruit people into formal or informal caregiving roles.</li> </ul>
<ul style="list-style-type: none"> <li>✓ <b>Responsive and Individualized:</b> It is tailored to the unique needs of the caregiver and their journey, including caregivers transitioning out of their caregiving role.</li> </ul>	<ul style="list-style-type: none"> <li>✗ <b>Not Primarily Care Recipient-Focused:</b> It primarily serves the family caregiver, not the person receiving care.</li> </ul>
<ul style="list-style-type: none"> <li>✓ <b>Person-Centered, Collaborative Support:</b> It develops actionable steps with the caregiver, prioritizing the caregiver’s well-being and preferences.</li> </ul>	<ul style="list-style-type: none"> <li>✗ <b>Clinical or Medical Care:</b> It does not include nursing, medical services, or mental health counseling, though these may be offered as referrals.</li> </ul>
<ul style="list-style-type: none"> <li>✓ <b>Comprehensive Assistance:</b> It offers specialized information, referral, assistance, and advocacy.</li> </ul>	<ul style="list-style-type: none"> <li>✗ <b>General Support and Information:</b> It goes beyond general Information &amp; Referral, crisis intervention, and other support programs.</li> </ul>
<ul style="list-style-type: none"> <li>✓ <b>Professionally Delivered:</b> It is conducted by staff with expertise in caregiving, aging, aging-related issues, and local resources provide the service.</li> </ul>	<ul style="list-style-type: none"> <li>✗ <b>Volunteer or Informal Role:</b> It is not conducted by volunteers; rather, it is a specialized service requiring trained professionals.</li> </ul>



## WHAT AGING NETWORK LEADERS ARE SAYING

To enhance the Aging Network’s ability to help caregivers access the resources they need when they need them, discussions with AAAs, SUAs and family caregivers focused on identifying current gaps, best practices and opportunities for growth.

These system-wide perspectives surrounding strengths, challenges, opportunities and obstacles will guide the Aging Network’s ability to enhance and scale effective caregiver navigation services nationwide.

### STRENGTHS

#### Connection facilitated through direct support resonates with caregivers.

Caregivers highlighted direct support from organizations and support groups as major facilitators of their care processes.

Participants emphasized that support groups are a key source of information, shared experiences and emotional support. Connecting with others facing similar challenges helped them gain insight and feel less alone.

#### The Aging Network is adept at strategically leveraging funding sources.

AAAs and SUAs noted strategic use of funding to maximize support services, including contracting with partners to provide specific services needed in their area.

For example, one agency leverages its fund balance to award area plan grants to community-based providers who offer specialized caregiver services in limited quantities. Another agency used one-time emergency funds to design a Caregiver Hub website to permanently house resources and training materials and is exploring long-term funding options through Medicaid.



#### Top 5 Funding Sources that Agencies Use to Deliver Caregiver Navigation Services

##### 1. Title III-E



##### 2. State Funding



##### 3. Title III-B



##### 4. Other Federal Funding



##### 5. Other Funding: e.g. local government, GUIDE model



## Consumer-driven models increase caregiver engagement.

Consumer-driven models enable caregivers to engage in enrollment and access services at their own pace, which participants find particularly beneficial in meeting individual needs and preferences.

Agencies highlighted the value of navigating caregivers to consumer-directed, self-paced models that empower them to choose their own providers, such as family, friends, or neighbors, and access services on their own schedule. Participants view these models as effective tools to address staffing challenges, improve flexibility, and increase caregiver engagement.



...friends and neighbors model helped our agency a lot with the staffing issues from the contracted home health care provider. That's where the client gets to choose their own respite worker, oftentimes a neighbor, who they pay monthly, and then we reimburse the client monthly. It also works because sometimes the scheduling with the contracted providers can be kind of difficult. It's nice because if their neighbor is there, and we can reimburse for five hours a week, they could pop over for an hour when someone goes grocery shopping. This friends and neighbors consumer-driven model, it's actually become the most popular out of our three models that we have. It's been great."

—AAA Staff Member

**66.4%**

of AAA survey respondents reported providing consumer/self-directed services.

**41%**

of AAA survey respondents reported implementing these innovative family, friend and neighbor models.

## CHALLENGES

### Many individuals fulfilling caregiving roles do not identify as caregivers.

A major concern for all participants was a lack of caregiver self-identification. Because many caregivers do not view themselves as caregivers, it becomes difficult for agencies to reach them. This low level of awareness leads to both engagement and service utilization challenges.



Probably our biggest barrier is that if the caregiver doesn't know that these services apply to them or doesn't know that they are a caregiver...they certainly would not click a link that says, 'Click here to explore our caregiver navigation services.' It's just not really realistic for a lot of care situations...it's very hard to get them to click that button... you have to be really thoughtful about the language use."

—Technology Leader



## **The service landscape is complex and varies significantly.**

The service landscape varies significantly across communities, counties and states, creating inconsistencies in access, awareness and navigation.

Rural areas face difficulty providing services due to their remote locations. Many areas do not have access to the internet, which is a major barrier to accessing important caregiving information and resources. Rural communities also tend to have less access to nearby agencies and organizations to provide caregiver support.



## **Quantifiable outcomes are difficult to capture.**

Several AAAs and SUAs identified measuring outcomes as an area in which they could or wanted to improve. At the agency level, outcomes measurement occurs mostly via service utilization metrics, caregiver assessment tools and satisfaction surveys. Some agencies ask caregivers whether services have helped them provide care for longer, resulting in a delay in nursing home placement.

Agencies also highlighted some of the less tangible or quantifiable outcomes that are meaningful to the caregiver navigation work they do but are not tracked due to being more relational or emotion-based. However, these more subjective outcomes are important since they are related to building trust and showing empathy for caregivers in challenging or crisis situations.

## **OPPORTUNITIES**

### **Expanded outreach could increase understanding of caregiving and awareness of caregiving supports.**

Organizations expressed the importance of reaching community members who are serving as caregivers without realizing or embracing their role. Many individuals perform what they see as the natural responsibilities of family and friends, so they do not readily identify with resources and support marketed toward “caregivers.”

To address this, one organization mentioned partnering with local employers to pilot a program that promotes community understanding of what caregiving entails and highlights ways that AAAs and other agencies can support the health and well-being of workforce members and families. Engaging caregivers earlier in their journey may help familiarize them with support available before they encounter a potential crisis, and can help counter perceived myths about eligibility.



**People think that you must be Medicaid eligible for the Area Agencies on Aging to help you. And that’s not true. So, we wanted the broader community to understand that, if you’re doing these types of things [that align with being a caregiver], there are supports and services available.”**

—AAA Staff Member



Organizations also commented on the importance of expanded outreach to both contracted and non-contracted community partners to make sure that everyone knows what services are available and how referral processes should work. Encouraging conversations that support more robust referral networks will help agencies that receive caregiver referrals to institute consistent responses even in the face of staff turnover.

### **Centralized caregiver entry points and referral pathways could streamline services.**

Caregivers shared their desire for service navigation to be streamlined so they could more clearly understand what programs are offered and

whether they and their recipient are eligible to access them. Many caregivers expressed frustration about the fragmentation of receiving multiple referrals they must pursue independently.

Organizations noted that centralizing caregiver navigation services could justify creating dedicated staff positions, providing the necessary capacity to coordinate caregiver support more effectively. They saw this approach as a way to address the challenge of limited staffing and better align funding with the actual needs of caregiving services, especially at the county level.

### **Agencies can better leverage assessment tools to track caregiver outcomes.**

Caregiver assessment tools track outcomes such as stress levels and well-being among caregiver populations. Most agencies that use technology platforms to facilitate caregiver support spoke about their wider platform use, but not specifically about how they use caregiver outcomes to demonstrate value and impact.

When evaluating the effectiveness of their services, AAA survey respondents reported that satisfaction surveys and client feedback are the most used methods (63 percent of respondents). Beyond measuring consumer satisfaction, the most frequently assessed outcomes include reductions in caregiver stress/burden (25.3 percent), service delivery metrics (12 percent), service accessibility and utilization (10.8 percent) and the perceived usefulness of information and resources (10.8 percent). Agencies can leverage these evaluation insights more strategically to strengthen and clearly communicate a compelling value proposition.

## **OBSTACLES**

### **Agencies receive limited and inconsistent funding.**

Funding was the most discussed barrier between AAAs, SUAs and family caregivers. Participants agreed that agencies need more flexible and sustainable funding that they can adaptively use to meet evolving caregiver and community needs. Agencies acknowledge a significant mismatch between the creative solutions they would like to implement versus what they can afford to deliver, feeling like sometimes they fall short because there is not enough funding or person power. Additionally, while Title III-E funding is quite flexible, states may require agencies to meet further criteria under their guidelines or standards.

## Service availability and waitlists hinder responsive support.

Respondents voiced major concerns surrounding staffing shortages among partner organizations, particularly the lack of available personnel to deliver direct services in the field, such as in-home supports. Agencies illustrated the conundrum of investing in systems and processes to conduct comprehensive caregiver intake and assessment only for caregivers to face significant waitlists or hear that a specific service is unavailable in their community. This issue has been especially persistent in rural areas.

Of AAA survey respondents who maintain waitlists, **22.5% have a waitlist for caregiver services** (excluding respite); waitlists are important indicators that demonstrate the intensity of local service needs.

// **One of our barriers has been lack of availability in home health providers. Our contractor providers, who are home health agencies, sometimes struggle to maintain adequate staffing levels to substantiate the need that we have across our 10 counties."**

—AAA Staff Member

## It is difficult for consumers to discern what information is vetted and complete.

With the advent of Artificial Intelligence (AI)- powered digital solutions, the way individuals search, and access information continues to evolve rapidly. Organizations noted the growing proliferation of misinformation as well as technology fatigue, which is an additional barrier to establishing trusted connections with caregivers who could benefit from support. Agencies shared that some of their community members possess concerns surrounding data privacy and reliability of digital platforms.



## THE VOICE OF CAREGIVERS

Insights and feedback from family caregivers are the foundation upon which caregiver services should be adapted and enhanced. In addition to conversations with AAAs and SUAs, the team conducted a caregiver-only listening session to capture their invaluable perspectives on how caregiver navigation currently functions and how the Aging Network can better support their varied and evolving needs.

Although there are many programs and services available, each with different names, access points and eligibility requirements, caregivers expressed

that **the term “navigation” resonated most with their experience.** They described it as an ongoing process of finding and connecting to the right support at the right time. One participant simply defined caregiver navigation as *“finding resources to help you.”*

Caregivers often feel overwhelmed by the sheer volume and complexity of available services. A more coordinated and accessible approach to caregiver navigation could significantly ease their stress and help them focus more fully on caring for their loved ones.

## Perceived Barriers

Caregivers identified perceived barriers and challenges to receiving caregiver navigation and accessing services. These obstacles span from how services are delivered to the day-to-day demands of a caregiver's life. While not all caregivers face all these challenges, these barriers provide valuable insights into how caregiver navigation, and more broadly, caregiver support programs, can be tailored to meet their needs. The chart below summarizes five predominant categories and associated issues:

CATEGORY	KEY ISSUES
Service Delivery	Inconsistent service availability; lack of seamless coordination between referrals and programs
Caregiver Experience	feeling overwhelmed; insufficient support to seek services
Work and Family Balance	Difficulty managing jobs, family and caregiving responsibilities; financial security; limited employer supports
Access Barriers	Eligibility restrictions for certain programs; language needs; limited access to technology
Lack of Specialized Services	Lack of resources for people caring for care recipients with certain conditions, including dementia; lack of understanding by staff offering navigation on state and federal program eligibility and availability

Caregivers expressed feeling overwhelmed and unsupported by existing services. During the listening session, caregivers shared that some existing supports and programs don't meet the level of support they need for their care recipients. One caregiver shared her personal experience with searching for the right support:

// **I haven't quite found what my mom needs most, which is socialization. She's still so aware. So, the Senior Center has some groups, it's just not the right level."**

Caregivers identified another challenge, related to service enrollment rather than navigation, is that some care recipients opt not to receive services, which can also support caregivers, such as respite. Multiple caregivers shared that they experienced difficulty with their care recipient. One caregiver remarked:

// **I'm very well connected in terms of information. However, the person I care for hasn't really cooperated with respite services or companion services or dementia-related programming at the Senior Center. He just isn't interested in those kinds of things. So, while I hear a lot about programs and services, I haven't really been able to participate in any of them yet."**

## Pathways to Success

Caregivers identified two key ways the Aging Network can enhance caregiver navigation: **by streamlining resources and referrals and fostering collaborative support.**

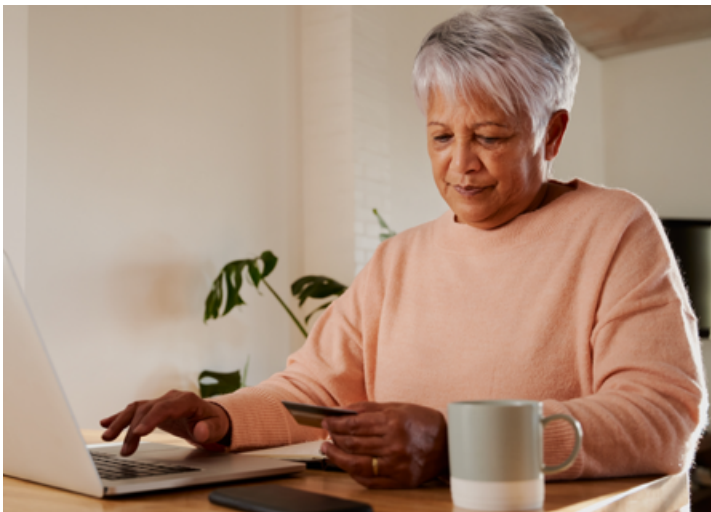
Caregivers expressed a strong desire for a more streamlined navigation process—one that clearly outlines available options and eligibility requirements. Many described their current experiences as confusing and fragmented. One caregiver likened it to "grabbing at puzzle pieces," while another described it as "poking around in the dark," often receiving referrals that didn't match their specific needs. What they need, they said, are more **actionable steps and a clear path forward.**

// ...giving us, like action steps, following up, knowing that we're heard and seen, and there's help on the way, it goes such a long way in this caregiving journey."

Caregivers also deeply value **hands-on support** and the **collaborative nature of support groups and events**. These spaces not only provide practical information and guidance but also offer emotional support and a sense of connection. Caregivers emphasized that shared experiences in these groups helped them feel understood, less isolated, and more confident in their caregiving roles.

// I found when you get a lot of help from the support groups...you can talk to people who are going through the same experiences, and maybe you can get more information from the support groups. I've learned a lot from the support groups and everything."

## CAREGIVER NAVIGATION TECHNOLOGY



More and more, **local agencies are deploying technology solutions** to deliver caregiver navigation services and provide resources and support to family caregivers. These tools range from resource databases and assessment platforms (both formal and informal) to self-guided learning modules, communication apps and peer-to-peer engagement tools.

While local agencies and family caregivers both interact with these technologies, their needs differ significantly—though they often intersect. Agencies use a variety of tools to support their day-to-day service delivery, from basic scheduling

and document-sharing platforms to more advanced systems that streamline referrals, manage caseloads, and aggregate data for reporting and decision-making.

**Family caregivers**, often treated as a single group, **represent a wide spectrum of experiences and preferences**—especially when viewed through the lens of technology use. Generational differences, comfort with digital tools, and exposure to evolving platforms all influence how they engage with caregiving technologies. Caregivers may discover new tools through printed materials, social media, blog posts, targeted ads, or AI-powered search engines. However, **AAAs play a particularly important role in introducing these technologies and supporting their adoption**. As one professional working at the intersection of caregiving and technology noted:

// A AAA is by a community and for a community by and large...And we are sharing this intervention or this tool because we know it fits within our community.... [Our organization is] a cornerstone nonprofit, a cornerstone institution that folks trust. ...And when we give that endorsement of 'this can work,' it typically gives a slight bump [in caregiver end user adoption]."

## Facilitators and Benefits of Technology

Caregiver navigation and broader caregiver support technologies offer a range of benefits that encourage adoption. Caregiving technologies make information accessible to larger audiences with the ability to guide caregivers to tailored, relevant content and information. Some platforms have implemented features to recommend materials to offer new information and further engagement with the caregiver.

Caregiving technology allows a level of anonymity, which serves as a protective layer and fosters more open disclosure about the individual's caregiving role. Caregiving technology developers and leaders have worked to craft messaging that reaches the target audiences without using the words "caregiving" or "caregiver" but rather focus more on practical outreach messaging with emphasis on the tasks, feelings, and empowerment to act resonating more directly with how individuals identify and what they need.

## Considerations for Technology

While technology platforms can bring efficiency and reach the masses in some communities, there are considerations for individuals and agencies that hinder the adoption of technology solutions for caregiver navigation and support. The chart below summarizes the key considerations and barriers shared by caregivers, agencies, and technology thought leaders:

CATEGORY	EXAMPLE CHALLENGES
Access and Infrastructure	Broadband gaps, digital literacy, and outreach to eligible populations.
Usability and Design	Over-engineered tech, inflexible tools, navigation issues.
Trust and Acceptance	Mistrust, psychological barriers, cultural mismatches.
Data and Information	Lack of robust data for information and referrals, misinformation, and poor tailoring of tools to meet the needs of caregivers.
Time and Capacity	User time constraints, organizational bandwidth, low adoption due to overload by both the caregiver and organization.

## The Future and Artificial Intelligence

The success of future technology solutions will depend heavily on the refinement and acceptance of AI-powered tools by both caregivers and organizations. Thoughtful implementation is also required to avoid straining systems and to ensure that funding and investment keep pace with increasing demand for caregiver supports.

**Trust** remains a critical consideration—and barrier—to adoption, a concern that becomes even more pronounced when artificial intelligence is involved. Caregivers seek reliable, accurate information and are understandably cautious about the risks of misinformation or misguidance from AI systems. Despite these challenges, AI holds significant potential to enhance caregiving support—offering personalized guidance, streamlining service delivery, and improving access to timely resources for both caregivers and the organizations that serve them.

## LOOKING AHEAD

The information in this Year 1 report contributes a critical pillar to the emerging evidence base surrounding OAA-funded caregiver navigation services. Caregivers told us directly that they want and need help accessing the resources that will help them care for their loved ones while maintaining their own well-being, underscoring the importance of flexibility and a sense of community. The Aging Network strives to be the bedrock of support: AAAs and SUAs functioning in the AAA capacity serve as cornerstones of their communities, offering responsive assistance and committing to meeting caregivers wherever they are in their journeys.

Yet, significant challenges remain, including lack of caregiver self-identification, complex service landscapes and finite resources. As our nation's caregiving population only continues to grow, funding and infrastructure must expand in tandem to address these challenges and ensure caregiver navigation services remain effective.

To help the Aging Network communicate this need for greater investment in caregiver navigation services, Year 2 of this initiative will implement outcome-based evaluations of 14 program sites nationwide. These evaluations will assess the impact of navigation services on caregiver burden and self-efficacy, two factors central to sustaining the capacity of family caregivers.

In Year 3, the grant team will build on this foundation by developing research-informed resources, such as ready-to-use data collection tools and best practice case examples, for widespread dissemination across the Aging Network.

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