nexus INSIGHTS

Where Am I, Where Do I Go:

The Missing Entry Point to Long-Term Care Solutions for Older Adults and Their Caregivers

September 2022

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Introduction

Imagine a scenario where one of our loved ones who has been hospitalized is ready for discharge. This should be a welcome event for those who are ready and able to resume their daily lives, but for older adults and their caregivers the words, "you're going home," often trigger panic.

Critical decisions about next steps must be made quickly, sometimes within an hour or two, and too often with nothing more than a list of long-term care facilities and service providers as a guide. The questions are overwhelming, and the answers are rarely easy to find.

Can I stay at home? Who will take care of me? What kind of services and supports will I need? Equipment? Physical therapy? Is a nursing home a better option? Assisted living? Who will pay? Medicare? Medicaid?

But a hospital discharge is only one of many events in the life of an older adult that can spark a frenzied search for help. The death of a spouse, a decline in cognitive abilities, a series of falls, or signs of depression can also upend someone's life, especially if it leaves them unable to live safely in their current setting.

Pre-Meeting Interview Participants

William Altman, *health policy consultant*

Kelly Cronin, *deputy administrator and director, Center for Innovation and Partnerships, U.S. Department of Health and Human Services Administration for Community Living*

Tim Driver, *president, Age-Friendly Institute*

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This is the crisis point in the long-term care continuum and thousands of older Americans find themselves there every day.

It is the point at which someone exits the healthcare system, or the post-acute care facility, or the home where they have lived independently, and enters a confusing maze of post-acute and long-term care services and supports. It can be a terrifying and lonely journey filled with dead ends and hidden entrances or exits. Too often, older adults and those who care for them are left to find their way alone.

Creating an integrated and well-funded system to replace the convoluted pathways that older adults and their caregivers must navigate to receive the help they need is an important goal. But pursuing it requires something that people in crisis don't have—time.

We must address this gap now. We can't wait until there are better options. Older adults and their caregivers need immediate help to understand their situation and to connect with the options that are available to them, however imperfect and inadequate those resources may be. At Nexus Insights, we believe that this will require an innovative approach to solving the navigation problem, one that is created and supported by both the private and public sectors.

Attendee Perspective

We've made a system that calls upon elders and those who care about them to flex and adapt in a crisis without preparation or resources. It's a moral failure to take the hardest part of the long-term care equation and throw it on vulnerable patients and families who are ill-equipped to manage it and make it their problem to solve.

Nexus Voices
Bringing Unique Perspectives Together

In early 2022, Nexus Insights launched the first in a series of discussions called *Nexus Voices* to begin designing a way to help older adults and their caregivers better navigate the complex and fragmented array of long-term care and aging services. Our aim was to bring together a wide variety of voices from public policy, academia, senior care provider groups, caregivers and tech-driven startups to imagine an effective navigation support system and determine what creating it would require.

The conversation actually began in the weeks before our gathering in interviews with leading experts from around the country conducted on Zoom. We asked them to identify what they see as the top informational and navigational challenges facing older adults and their families and posed a series of questions to inform our in-person discussions.

Discussion participants met in Washington, D.C. on February 15-16, 2022, for a stimulating discussion that resulted in a wellspring of ideas with each attendee bringing a unique perspective. Highlights of the discussion are summarized in this report, including unattributed quotes from participants. It was an educational experience for everyone. Connecting people and ideas across disciplines is a guiding principle at Nexus Insights. Whatever their background, everyone was united around a common goal: Helping the older adult in crisis.

Nowhere to Turn: Abigail's Story

Abigail, 75, suffered a severe seizure and was sent to the hospital. After her discharge she went to a skilled nursing facility (SNF) where she developed a stage 4 bedsore and developed an infection in her colon. She returned to the hospital and was then sent to a different SNF and then sent home with bedsores and the infection.

She lost more than 30 pounds and cannot walk. She has no family or friends to help and lives on social security. She is cognitively strong and wants to rehabilitate and live at home, but she would prefer a different and more navigable apartment, as well as access to social services such as meals, transportation, and in-home care when she needs to bathe. She has no idea where to turn.

The goal of the discussion was two-fold:

- To examine the current challenges that older adults and their families face in finding and understanding the resources and supports available to them and to identify ways to help them access those programs.
- To identify potential elements of a navigation support system.

It was not to prescribe a solution, but rather, to call attention to a missing and essential piece in the long-term care journey—a clear entry point and path to the supports and services needed and available.

Participants considered a variety of scenarios and the navigational supports required to address them. We've highlighted some of their comments throughout the report and provided case studies that illustrate the real-life challenges that older adults and their caregivers face every day.

Navigating the Road to Nowhere

What older adults and their caregivers need to hear after a health emergency or other drastic life change is *this is what happens next and here's where to go*. In our opinion piece featured in *The Hill*, we argue that America's long-term care infrastructure is a series of dead ends or wrong way streets that fail to lead older Americans to the resources they need. It's a frustrating and lonely journey for older adults when they are at their most vulnerable. What older adults in a crisis need most is a central place to go for help and someone who understands and supports their unique needs and preferences to guide them there.

Those who are discharged from the hospital might require rehabilitation at a post-acute care rehab facility or a skilled nursing home. Those who return home might need help with personal care, like bathing, eating and dressing, and household chores, like cooking and cleaning, and may need transportation. Others will require hospice or palliative care. Someone who recently lost a spouse might need a referral to a grief counselor or other supports. And those who are suffering from depression might require mental health services.

Attendee Perspective

The navigational needs are tremendously missing in hospitals at that transition point. Maybe the social worker gave you a list of three facilities in the area, and in the next four hours, you must make calls to find a place for your elderly loved one. Figuring out where they are going to go, whether home or a skilled nursing facility or some assisted living, and having to make that decision very, very fast with basically no information, is incredibly stressful.

We recognize that there are existing federal, state and community programs and supports, but accessibility to those services and providers is often inconsistent and unreliable. They vary depending on where someone lives, their income level and their job status. For example, someone might live in a city where there is an abundance of supports while someone else might reside in a rural area where there are few. Some can afford to pay privately for the help they need, while others are dependent solely on public programs.

Memory Care on Medicaid: Marisa's Story

Marisa's mother lives in a "board and care" home in Atlanta and receives Medicaid. Marisa is concerned that her mother, whose dementia is getting worse, is not getting the care she needs. Marisa would like to find a nursing home or assisted living facility close to her home and job where her mother can live and receive dementia care in a residential setting that takes Medicaid. She's not sure how to find the right community for her mother. She wonders if she should have her mother live with her and receive home care, but Georgia Medicaid has informed her that there are no services available. She needs help finding the best solution where her mom can use her Medicaid benefits.

Many programs target specific populations or are mandated to certain kinds of issues. The result is a long-term care maze. Our goal is to help older Americans navigate through that maze in their time of crisis to the supports and services that they urgently need.

At Nexus Insights, we believe in creating family-centered navigation resources that support a variety of solutions—whether it's home-based care, senior housing or nursing home care. We recognize that different needs, preferences and financial resources will guide families' decisions about how and where older adults want to age. We each need to recognize the biases we bring to discussions on aging. Instead of leading with our own biases, we need to put the older adult and their family first.

In healthcare, we respect that some people will want to pursue life-saving treatments, while others will opt for palliative care. Yet, in aging, we too often impose judgement about what is best for others, offering strong views for the benefits of aging in place versus those of congregate care communities. In reality, we must forego these biases and respect the heterogeneity of individual choice. Our navigation systems must similarly honor and serve families across whatever long-term care and housing options will be best for them.

Navigation Hubs—A Clear Path to Follow

At Nexus Insights, we support the creation of navigational centers, or hubs, that will serve as central doorways to existing supports and services. The hubs will have a national presence but a local focus with counselors, or navigators, who understand the resources available in their communities and how to help older adults and their families access them. The hubs will provide an outstretched hand for anyone who has lost their way in the long-term care maze.

Attendee Perspective

We are trying to answer the cry for help from someone who is lost and in a panic. The cry could come from an older adult, a family member, or an advocate/caregiver. That is the problem we are trying to solve and if we fail to do that, we are failing all those people who are lost.

Four Main Functions

Discussion participants outlined the primary responsibilities of the navigation hubs:

Discover & Assess
Listen and help people assess their current needs.

Educate
Understand their options for housing and caregiving support, including their financial resources and public program eligibility.

Reevaluate
Check back frequently to reassess caregiving needs and adjust as needed.

Select & Connect
Support decision making, and once families have decided on their preferences, connect them to care.

Discover & Assess

The first step will be learning about someone's long-term care situation and then assessing their needs and determining if and how they are being met. That means understanding what kind of caregiving supports are currently in place. The navigator will also help to identify resources that might be required in the future and evaluate the financial resources available to pay for them.

People rarely think about their own long-term care needs, or those of a parent or loved one, until they are faced with a health emergency or other life changing event. Sometimes the changes happen suddenly, like a health or financial crisis, and sometimes they occur gradually, like cognitive decline or depression. Perhaps mom keeps forgetting to turn off the stove, or dad has fallen three times in one week, or someone has stopped paying the bills.

A navigator with expertise on post-acute care and long-term care needs can help individuals and families create a plan for a new phase in their lives when a loved one's living or care situation is no longer safe or appropriate and anticipate what lies ahead. Whether it's managing a catheter or planning for groceries and cooking, these experts will understand what challenges a family is likely to face in the coming days, weeks and months. This will involve:

Life Events That Can Trigger a Long-Term Care Crisis

- Health emergency
- Death of a spouse
- Cognitive decline, dementia
- Frequent falls
- Depression
- Social isolation
- Changes in financial status
- Losing weight, not eating
- Forgetting or refusing to take medication

Any of these things might require a different approach to an older adult's care, whether it's a change in setting or in services.

- Actively listening to their concerns and understanding their wants and needs.
- Inquiring about the physical arrangement of the person's residence, including access and mobility challenges and risk of social isolation.
- Determining whether there are family or friends nearby who can deliver caregiving support.
- Discussing the family's financial resources available to dedicate to care of the older adult. The availability of income and assets that could pay for care needs will determine what type of professional services are available.

A navigator can also facilitate sometimes difficult conversations about the older adult's needs and wants, especially when they conflict with their family's priorities. Some may wish to age in place while their loved ones feel that is unrealistic. Others may want to move closer to family in order to avoid burdening their loved ones.

Several attendees pointed out that one of the most important things that a navigator can provide during this phase is a sympathetic ear. Caring for oneself or for another person in a crisis can be lonely and stressful. Having someone to talk to can go a long way in addressing the emotional and psychological needs of an older adult and his or her caregivers.

Attendee Perspective

Our whole system is based on an episodic model of care where we've got an issue that we must solve right now. It's not forward looking. There's no one saying to the family "Here's what's going to happen when we get past this situation." In the beginning when they are discharged to go home, there is a swarm of providers—home health and primary care physicians and physical therapists—and when the crisis is over, they're gone. They all check out. And then the client is left with no real plan, no idea what will happen until the next episode. We need to bridge those gaps because what happens in between episodes can decrease hospitalizations and keep costs down.

Hoping for Home Health: Susan's Story

Susan's parents, both in their 80s, were living independently until her father, age 85, went to the hospital for unbearable foot pain. He was treated for gout and sent home with home health. Within a week, he was back in the hospital because he acquired an infection from his previous visit. This time, he was discharged to a skilled nursing facility where he stayed for three weeks before going home. By the time he got home, he could barely walk upstairs to his room and once there, couldn't get out of bed.

Neither Susan nor her mother were able to get home health to help because he didn't have a doctor's order or a recent-enough face-to-face visit to get one. Susan is a mother of two small children, has a full-time job, and lives two hours away. Her mother has signs of cognitive impairment. Susan and her parents have no idea what to do now or where to turn.

Educate

The next step will be presenting families with a full range of long-term care options from paid caregiving to home health services to assisted living. Too often, older adults and their caregivers are handed a list of providers and services without information on the quality of the care being offered or any way to assess it.

Navigators will discuss the pros and cons of each solution. Discussion participants agreed that the needs and preferences of the older adult should always be the navigator's primary concern.

In addition to educating families about the range of housing and care providers available to them, navigators should also talk with families about public programs that can support their care needs. This may include screening individuals for Medicaid eligibility, making them aware of housing vouchers and subsidies, and helping them access their Medicare benefits.

Select & Connect

Once families decide on a set of services and housing options, vetting and selecting specific providers (e.g., assisted living or home health aides) will be a key function of the hubs. The navigators must be well versed in the full range of care options, from affordable to private pay and be able to connect families to public programs and subsidies if they need help covering the costs.

Navigators will discuss the cost and quality of potential providers to make sure that families understand each option. At this point, families may want to visit senior housing properties or interview professional caregivers.

The process of researching and selecting providers can be frustrating and exhausting and most often, it falls squarely on the shoulders of the elderly and their families at one of the most vulnerable times of their lives. Trying to assess availability at various facilities, manage wait lists, coordinate a multitude of in-home services and make vital decisions while in the middle of a crisis is both physically and emotionally draining.

Reevaluate

Although the navigator's goal is to make sure the older adult has the support they need, the job doesn't end there. Ongoing assessment of an older adult's care needs is vital. Navigators must follow up regularly to monitor their situation. A change in health or financial status or another major event can trigger a different set of needs.

Attendee Perspective

I'm a firm believer in individualized assessment, but we get so seduced by assessment. We are all assessed with nowhere to go. Unless the assessment is linked to action, it's like doing an MRI for brain cancer. You can find it, but we must link it to something. So, it's assessment that drives person-centered intervention of some sort.

Meeting the Criteria

Nexus Voices participants agreed on a set of criteria that any new solution to the long-term care navigation problem should address. Here is an overview:

Accessible to All

Navigation hubs should be accessible to all older adults and their family members, regardless of their ability to pay. Although financial resources play a role in the types of aging services that someone can afford, everyone, regardless of income, faces the same void when it comes to finding the support they need. Therefore, the hubs must be accessible to everyone because no one is exempt from getting lost in the maze.

There are services and supports out there, but each one attracts a different clientele. Those who typically turn to public resources for help are likely to find their way to a local Area Agencies on Aging (AAA) or Aging and Disability Resource Centers (ADRC). Those who want and can afford a highly personalized service might choose a geriatric care manager that charges an hourly rate. Others might prefer a senior care referral service like A Place for Mom, which is free to consumers but charges placement fees to senior living communities.

On the other hand, the hubs that we envision would serve everyone, regardless of income. To do this, sufficient public funding and a sliding-scale fee structure that makes services available at an affordable price to all will be required. However, the customer experience will be as personalized and attentive as the service offered by more concierge options, such as geriatric care management.

Nationwide

Navigation hubs must be available with consistent services nationwide.
Currently, most existing models for care navigation are, at least partially, state or locally funded and administered. This creates an uneven patchwork of programs resulting in high-quality, sophisticated supports and services in some geographies, while others have few options.

The AAAs, which were created more than 40 years ago by the federal Older Americans Act (OAA) to support older adults in finding home and community-based care options, are particularly variable across geography. Some states like California, Wisconsin and Ohio have programs that are lauded by experts, while others have little to no infrastructure.

A consistent, nationwide program would better meet the needs of all individuals by ensuring equitable access to support across geographies. This will allow people to receive the same kinds of support if they move.

With a national model, both older adults and family members who live further away would be able to access the service and understand options across multiple locations.

Creating a nationwide footprint will require the hubs to expand beyond brick-and-mortar locations, particularly to serve rural areas. Services would be accessible through a toll-free number like the United Way's 211, which connects people to social services in their area. Websites, apps and video conferencing can extend the hubs' services beyond urban areas. But the main point of contact will always be the navigator. No matter how an individual interacts with the hubs, a live person will be there to talk with them.

Local Context

Building on national infrastructure, navigation hubs will need to be locally focused with a deep understanding of community programs and providers.
To provide impactful, actionable information, navigators must understand state programs that deliver health and housing benefits, including Medicaid and affordable housing. They must also be aware of their state's State Health Insurance Assistance Program (SHIP) for Medicare beneficiaries and their families. Without a federally mandated and funded long-term care program, the benefits, eligibility and providers for these services vary widely by state.

Navigators must maintain and curate a current list of providers and services and update it regularly. This includes information about provider quality, availability/capacity and cost. They will also need to know about other services that older adults may need to stay in their homes, such as home maintenance services like lawn care, home repair, and grocery delivery.

Attendee Perspective

I think that the local stuff is the guy who will plow your driveway. And that's very hard to do except through a local source that knows who that guy is. And that's a lot of what early LTSS is. It's all the homemaker services, the things where you need help to just keep your household going.

Visible

The public must be aware of the navigation hubs and the services they provide when they are needed.
The hubs should be as familiar to residents as the post office, drugstore or local bank. This means that a significant public outreach and education campaign is a critical component of this new system. An awareness campaign that relies on a range of marketing channels is essential to make older adults and their loved ones aware of these resources. Equally, if not more important, is building strong connections to all likely sources of referrals. That involves educating acute care providers and discharge planners about where to send older adults for help while transitioning out of an acute care setting. It also means coordinating with home care and other long-term care providers who may be serving them at the point that they need or want to consider other housing and care options.

Although public visibility is a core part of the AAAs, experts at the discussion pointed out that awareness of these resources remains low and inconsistent. Referral services like A Place for Mom have much higher brand recognition in the market due to their private funding model.

To achieve nationwide visibility, it is likely that the government would need to fund a broad public visibility campaign for the hubs, as it did for COVID-19 vaccine awareness and for the launch of healthcare.gov, the national health insurance marketplace created by the Affordable Care Act.

Neutral

Navigation hubs cannot have a financial incentive to refer to specific service providers.
A number of referral services, such as A Place for Mom and Caring.com, are free to consumers but receive commissions when an older adult moves into to one of their referral partners, such as a senior living provider.

Such placement fees create a direct incentive not only to recommend specific providers, but also to encourage families to select residential care options instead of in-home services. This creates a conflict of interest in which the navigation hub cannot provide neutral counsel to their clients. The hubs we imagine will require a funding model that does not reward any given care delivery model or specific provider.

Attendee Perspective

I think that's why we need to really step up quality measures, because if we want a trusted entity that is truly neutral, then they can't be pointing to a particular place. If they could point to a scorecard and show the consumer, "Here are your choices, here are their ratings," then, it's a choice.

Trusted

Navigation hubs must provide unbiased advice.
Case managers must base their input solely on the needs, preferences and financial resources of the older adults. This means taking the time to listen to their concerns and understand the nuances of their situation. This is especially important when serving families from diverse communities.

By 2030 more than a quarter of older adults will be comprised of racial and ethnic minorities. Fifteen percent of the nation's 25 million individuals who have limited English proficiency are older than 65. Researchers estimate that there are more than one million older adults who identify as LGBTQ. Navigational hubs must be prepared to provide culturally appropriate care to an increasingly diverse older population.

Full Service

Navigation hubs must work with the client until the problem is solved.
Navigators must provide support to older adults and their families from the moment they receive a call for help until a solution is found. And they must follow up frequently with the older adult to monitor changes in their situation and, if necessary, reevaluate and consider new options.

Most public programs today can provide a list of resources to families, but cannot help them secure a bed, find an open room or hire a home health aide. This leaves family members to do the heavy lifting of calling providers to determine their availability, investigating the quality of the options and executing the solution. Even more frustrating to a person in crisis is being given an outdated list of resources. They cannot waste time contacting services and providers that are no longer in business, not accepting new referrals or no longer providing the services they are seeking.

We call this the "last mile problem." A Place for Mom remains popular in part because they solve it by working with families until their loved one is placed into senior housing.

In our proposed navigation hubs, counselors will work with clients until their needs are fully met and they are settled into an appropriate place. And they will continue to reassess their needs as their situation changes.

Attendee Perspective

What AAAs can't do is actually recommend senior living community A or home care agency B. There's a reason A Place for Mom exists. People want to go to a place.

Existing Models

Participants discussed a variety of existing models that seek to address aspects of today's long-term care navigation problem, but none fully meet the criteria that we propose. Many have inherent biases due to funding models or government mandates. However, we can learn from the successes that these models have achieved and from their challenges. Here are a few prominent examples of entities that are working to address the problem and some of the plusses and minuses of each one.

Public Programs

The OAA was passed in 1965 to help the elderly live at home with dignity and independence for as long as possible. Since then, the OAA has been the foundation upon which federal, state and local entities have developed and delivered home and community-based services and supports to older adults and their caregivers. The law also established the Administration on Aging (AoA) to administer the newly created grant programs and services, including information and referrals, health and wellness programs, in-home care, transportation, elder abuse prevention, caregiver support and adult day care.

Eldercare Locator

The Eldercare Locator is a nationwide service that connects older Americans with local support resources, such as meals, home care or transportation, or helping caregivers with training and education. The Eldercare locator is a public service of the AoA, an agency of the U.S. Administration for Community Living. However, without humans to augment the list of resources, the Eldercare Locator cannot provide families with help by listening to their needs and weighing the options available to them.

Area Agencies on Aging

The AAAs are a nationwide network of entities that help older adults live independently in their homes and communities, providing services such as nutrition, health and wellness, caregiver supports, elder rights, transportation and legal service. There are more than 600 AAAs across the country—some embedded within local government and some structured as independent organizations.

Attendee Perspective

There's a lot of evidence building to suggest that the role that AAAs play in their community, if they're positioned well, can really have an impact on people's ability to stay home… AAAs really are this sort of hub for this coordination of assessment and access to services.

The AAAs aim to solve many of the challenges laid out in this paper by centralizing and streamlining existing long-term care programs, providers and funding sources. Their mission could align well with the navigational needs we have identified, but their focus on home-based and community services limits their scope.

In general, the AAAs are designed to help older adults stay in their homes and communities and many agencies have limited awareness of private-pay senior housing options. Some may be hostile toward for-profit providers. This hampers the AAAs ability to provide comprehensive information and options for families who may be interested in considering independent or assisted living options for older adults.

While the AAAs do meet the criteria of neutrality, they may be limited in how much they can guide families toward the best options to meet their needs. Because these systems are publicly funded, they provide neutral advice and have no financial conflicts of interest with providers to whom they may refer. At the same time, their public funding source may limit their ability to engage with a wide range of providers, particularly those providing healthcare and post-acute care services. In addition, it may prohibit them from referring to specific senior living providers, especially if they are for-profit.

AAAs succeed at having local context, because they are deeply rooted in their communities and have a sophisticated understanding of the programs and providers in their area. However, such local knowledge is challenging to scale and is dependent on the quality and funding for the AAA in a given area. Even states with strong programs struggle to stay current on local services and providers—a challenge that requires constant tracking and database maintenance at a high cost. These inconsistencies undermine the goals of visibility and equity that we believe are vital to the success of any national navigational resource.

The biggest obstacle that these public programs face is their variability from region to region in the quality of the services they provide. They are designed to be state and locally run, which allows broad flexibility and customization, but also results in an inconsistent network of services that is dependent upon the funding priorities of the states and geographic areas they are in. Some states have robust programs while others have few to no resources. Without consistent federal funding, there is no path to achieving consistent, nationwide programs.

Attendee Perspective

These programs aren't consistently developed from state to state. There hasn't been a government agency saying you have to make this strong and here's a match to help you fund it. There needs to be buy in across state governments.

Private Pay

For families who can afford to pay for navigation support, there are many private options available to them.

Geriatric Care Managers

These are professionally trained individuals who can help families assess their needs, evaluate providers and coordinate in-home services. These care managers are generally paid by the family, so they can provide neutral advice and a full suite of services. However, as an individual model, the service and expertise vary widely by person, and costs for good geriatric care managers are not affordable for many families.

These professionals, sometimes called "aging life care managers," are usually licensed nurses or social workers trained in senior care. They act as private advocates and guides for family members who want to ensure their loved one is in the best hands, and they generally serve clients and families whose incomes are too high to qualify for publicly financed services.

The cost of a geriatric care manager's initial assessments of a care recipient can range from about $300 in more rural areas to more than $800 in large urban areas, based on a 2017 survey by the Aging Life Care Association, a non-profit representing geriatric care managers. Ongoing hourly rates range from $100 to $200.

Attendee Perspective

I think there are some geriatric care managers that have graduated from the Davis School of Gerontology at the University of Southern California and see this as a career and are really trying to stay up on things and offer that balanced assessment.

Senior Care Providers Offering Navigational Services

Recognizing that the older adults and families they serve need help finding the right care services, a number of senior care providers offer their own navigational services. The models range from those offered to the public at no cost, to those offered for a small monthly subscription fee, to those requiring an up-front buy in and monthly fee. Below are three examples.

Kindred Healthcare

In 2014, Kindred Healthcare, seeing that those who found their way to Kindred properties had experienced challenging navigational journeys, set up a nationwide, free call center for the general public that did not refer only to Kindred properties.The center was deluged with over one million calls demonstrating the tremendous demand that exists for navigational support. However, despite efforts to find partners among payers or physician groups, Kindred was unable to identify a sustainable revenue model for the service and was forced to run it as a cost center, severely restricting any growth or expansion of the model.

Kendal at Home

Kendal at Home, which was launched in 2004, is an at-home care organization that allows people to age in place, offering nutritional support, transportation, home health services and other supports. Kendal at Home also navigates, coordinates and pays for long-term care, if and when it's needed. It offers "retirement living at home for healthy seniors" in a model that

delivers services for a range of needs in exchange for an up-front buy in fee and monthly service fee. The challenge of this and other private pay models that offer care management services as part of their long-term care services is that they are tied to the entity that is providing the care. By design, this model is not neutral across providers, so families only have access to services once they have selected their preferred long-term care provider. And the cost is a barrier to many in need of navigational services.

United Church Homes

In early 2022, United Church Homes (UCH) launched NaviGuide, a service for older adults and their family caregivers featuring a toll-free number staffed by service coordinators. The service has a monthly subscription fee of $29 or about $350 a year, which provides access to the care navigation assistance. The program has only been rolled out in a few of the markets where UCH operates to date, but response has been strong and plans call for expansion to the 75 markets across 15 states where UCH has communities. UCH staffed NaviGuide using their existing care coordinators in the 50 affordable senior housing communities they operate. These care coordinators refer to a range of services, not only UCH-provided services. They are knowledgeable and skilled in connecting older adults and their families to needed supports and services in their local market. UCH hopes the monthly fee can cover much of the initial cost of the service. They are also encouraged by the interest in the service they have received both from insurers wanting to offer this coverage to their members and from employers considering offering the service as an employee benefit.

A Place for Mom

This is perhaps the most well-known private pay resource. It is free to consumers, but the company is paid a commission when they place older adults into one of the communities in their participating network. Although they advertise as a source of free, unbiased advice, A Place for Mom relies on referrals to their selected partners who pay them a commission. For this reason, it fails to meet our standard of being free of financial conflicts.

Attendee Perspective

A Place for Mom is a pay-to-play model. It can be good at times. It can help people in need, particularly with that four-hour time clock or 24-hour time clock, but it can also be self-serving. The providers in the industry, for the most part, hate it and they wish there was a truly neutral alternative because, basically, they're giving up "a substantial amount of money" for the lead, and it's pay-to-play.

The con, it's private pay for the upper echelon person, financially. It's a smaller network with limited options. And then the business model's limitations, given the pay-to-play, there's a big trust question.

Employer-Based Options

In recent years, a variety of new companies that market to employers, such as Wellthy, HomeThrive, Torchlight and Cariloop have launched services to support employees who are acting as family caregivers. These companies rely on technology platforms that connect employees with care coordinators who offer advice and help them find appropriate resources. These online platforms also enable family members to monitor services and communicate with each other.

These tech-enabled, employer-based options meet several important criteria of the hubs, including the core functions of discover & assess, educate, select & connect, and reevaluate. Also, they operate nationally and tout a consistent user experience and high customer service, relying on databases and partners to provide the necessary local customization.

However, each of these models sell to employers and health plans, rather than directly to consumers. Only those who are lucky enough to be employed by companies that offer these services can access them. It is not an option that is widely accessible. Also, these models are primarily designed to serve and support caregivers, rather than the older adult. As a result, they may be more responsive to their priorities than to those of the older adult.

Many tech startups tried direct-to-consumer approaches when they first launched but faced one of the biggest challenges in the private, tech-enabled marketplace: the ability to reach caregivers directly. However, these companies could work well in collaboration with public navigation hubs in public/private partnership through public investment and private innovation.

Attendee Perspective

Wellthy is essentially offering a digital concierge that has modernized and standardized geriatric care management. The company gets to know a family's goals, situation and needs, and then partners with them to be their advocate, their navigator, their expert and help them get things done.

Funding

Together, existing public, private pay and employer-based programs can help us achieve our vision. The public programs operate with existing federal authority that could be better funded and expanded. Private pay models have cultivated a high-touch, custom experience that is designed to meet these needs today. And the new, tech-enabled, employer-funded solutions bring scale, consistency and a novel funding source to the problem. By combining their infrastructure, experience and delivery models, we could build the long-term care navigation hubs that our families need and deserve.

Although this paper does not specifically recommend a funding model for the hubs, we recognize that funding will be a barrier to achieving our vision. Historically, policy options for long-term care have focused on creating a financing system to fund services, which is critically important for supporting families and funding a long-term care workforce. However, policy must also focus on the navigational needs of older adults and their families. To address this specific navigation aim, several potential options could be explored.

First, increased federal funding could expand the publicly funded infrastructure through programs such as the AAAs. Second, health plans and employers could be critical partners in helping to fund navigation services to support families. They understand how gaps in caregiving can affect the physical and mental health of caregivers and how absenteeism impacts their bottom-line. Finally, for the many individuals who are unable to afford high-quality navigational help, we should consider a sliding-scale payment system that delivers free or heavily subsidized assistance for lower-income families while providing a payment option for those who can afford it.

Call to Action

The family in crisis needs help now. At this moment, somewhere in America, an older adult is scrambling to find services after a hospital discharge, needs help with their daily living activities, or is coping with the loss of a spouse and requires mental health support. And most likely there is a panicked family member or friend trying to help them with no idea where to turn.

These individuals cannot wait for lawmakers and government agencies to overhaul the long-term care infrastructure, as needed as that may be. They are not asking for a miracle. They are asking for something that we can give them right now—a lifeline. That is what enabled the Greek hero Theseus to escape the Minotaur's maze. A ball of thread helped him to mark a clear path to his destination. We have the tools and expertise to help older adults and their families find their way through the convoluted and fragmented system of aging services. We can no longer ignore their pleas.

Next Steps

This report highlights the need for a network of navigational hubs to connect older adults and their caregivers to trusted resources and offers a framework for building it. But it is only a first step.

The purpose of the *Nexus Voices* discussion was to shed light on this missing yet vital piece in the long-term care journey. Our attendees spent many hours discussing how to create a family-centered option that is easily accessible and supports a wide variety of long-term care solutions. Their mission was to raise the questions, not to deliver answers, yet. That will take time.

But we must get started now. We cannot afford to wait. Older Americans and their families are crying out for help and their voices will only become louder and more persistent in the coming years. Changing demographics, longer life expectancies and a shifting political landscape will make the long-term care maze even more difficult to navigate.

As a nation, we need to embark on building navigation services for older adults that put families in the center. We need to listen to their needs and help them assess what support services and living arrangements will be best for them. We need to educate families about the housing and care services available and funding sources to pay for that care. We need to support families as they select care providers and establish housing or care for their older adult. Finally, we need to create a safe space to revisit and reassess those choices as individual needs and preferences evolve over time. With these steps, we give all older adults the dignity and support they deserve when facing the uncertainty of aging.

Building on these guiding principles, we must begin to scale existing navigation programs through both public and private funding. We should reevaluate the biases that underpin these programs and seek to make them more accessible, visible, neutral and trusted. We need to work toward scalable, nationwide models that preserve local insight. This requires a national commitment to increased funding and an openness to reimagine existing solutions so that in the future, each of our families has someone to answer the call of “where do I go? What do I do?”