Where Am I, Where Do I Go:

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

Executive Summary

Introduction

When an older adult experiences a healthcare or other life crisis that leads them to need post-acute or long-term care services and supports, they and their caregivers must make critical decisions quickly. What awaits them, however, is a maze of dead ends, wrong way streets, and twists and turns that stand in the way of older adults and their families getting the help they need in a timely manner. All too often, older adults and those who care for them are left to find their way alone on what becomes a terrifying, frustrating and lonely journey. Put simply, American families with aging loved ones have no easily identifiable place to turn for guidance in navigating and accessing the help and services they need.

In early 2022, Nexus Insights—a think tank advancing the well-being of older adults through innovative models of housing, community and healthcare—launched 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. A multi-disciplinary group of aging service providers, caregiver advocates, tech-driven start ups and policy experts met in February 2022 for a stimulating discussion, united around a common goal: Helping the older adult in crisis.

The goals of the discussion:

- 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.

Navigation Hubs—A Clear Path to Follow

During the discussion, participants agreed that solving this problem requires creating navigational centers, or hubs, to serve as central doorways to existing supports and services—whether it's home-based care, transportation or meal services, senior housing or nursing home care. It was agreed that the hubs should 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.

Next, discussion participants outlined four primary responsibilities for the navigation hubs and staff navigators:

- **Discover & Assess:** Navigators should listen to the person in need, family members and caregivers, identify and assess current needs, and help them plan for a new phase in their lives when a loved one's living or care situation is no longer safe or appropriate.
- **Educate:** Navigators should present families with a full range of long-term care options and discuss the pros and cons of each solution including cost and funding eligibility.
- **Select & Connect:** Once older adults, their families and caregivers have decided on their preferences (e.g., what type of services and housing options would work best for them), navigators should vet potential options and connect them to care or services (e.g., assisted living, home health aides or transportation services).
- **Reevaluate:** Navigators should check back frequently to reassess caregiving needs and financial status and adjust as needed.

The discussion participants agreed on a set of criteria that any new solution to the long-term care navigation problem should address:

- **Accessible to All:** Navigation hubs should be accessible to all older adults and their family members, regardless of their ability to pay.
- **Nationwide:** Navigation hubs must be available with consistent services nationwide.

- **Local Context:** Building on national infrastructure, navigation hubs will need to be locally focused with a deep understanding of community programs and providers.
- **Visible:** The public must be aware of the navigation hubs and the services they provide when they are needed.
- **Neutral:** Navigation hubs cannot have a financial incentive to refer to specific service providers.
- **Trusted:** Navigation hubs must provide unbiased advice.
- **Full Service:** Navigation hubs must work with the client until the problem is solved.

Funding Navigation Hubs

Historically, policy options for long-term care have focused on expanding funding for the provision of care, with relatively little attention paid to the navigational needs of older adults and their families. Funding will be a barrier to the navigation hubs; however, by working together existing public, private-pay and employer-based programs could make these hubs a reality by combining their infrastructure, experience and delivery models.

An Urgent Call to Action

The family in crisis needs help now. These individuals cannot wait for lawmakers and government agencies to overhaul the long-term care infrastructure, as needed as that may be. Furthermore, changing demographics, longer life expectancies and a shifting political landscape will make the long-term care maze even more difficult to navigate. Therefore, time is of the essence to build navigation services for older adults that put families in the center. We need to listen to their needs, help assess support services, educate them on services and funding sources available and connect them to the services that best meet their needs. This requires a national commitment to increased funding and an openness to reimagine existing solutions so that in the future, families have someone to answer the call of, "Where do I go? What do I do?"

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.