Research and Policy Considerations for People with Dementia Living Alone Needing Home- and Community-Based Services

Type into the chat:

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What are you most excited about this summer?

CaN-D Quarterly Network Meeting

May 29, 2025

CaN-D Data Workshop at GSA 2025

National Core Indicators (NCI) Survey for Dementia Home and Community-Based Services Research

Where: GSA Annual Meeting - Boston, MA
Date: Saturday, November 15, 2025
Time: 8:00 AM – 12:00 PM ET

Workshop registrations are now open: a fee of $45 applies
https://www.gsa2025.org/Program/GSA-2025-Workshops

CaN-D Working Group Co-Leads

Interventions

Heather Menne, PhD
Associate Professor
Miami University

Kalisha Bonds Johnson, PhD, RN, PMHNP-BC
Assistant Professor
Emory University

State Policies

Alice Prendergast, MPH
Senior Research Associate
Georgia State University

Amy Lastuka, PhD
Lead Research Scientist
University of Washington

Unmet Needs

Sijia Wei, PhD, RN, PHN
Postdoctoral Scholar
Northwestern University

Romil Parikh, MBBS, PhD, MPH
Postdoctoral Research Fellow, Senior Scientist
University of Minnesota

Interested in joining a Working Group?
Email regina.shih@emory.edu with the group name(s) you want to join.

Panel Members

Andrea Cohen, MSW, Caregiver Action Network

Elena Portacolone, PhD MBA MPH, University of California San Francisco

Jean Ball, PT, MEd, CPHQ, HouseWorks

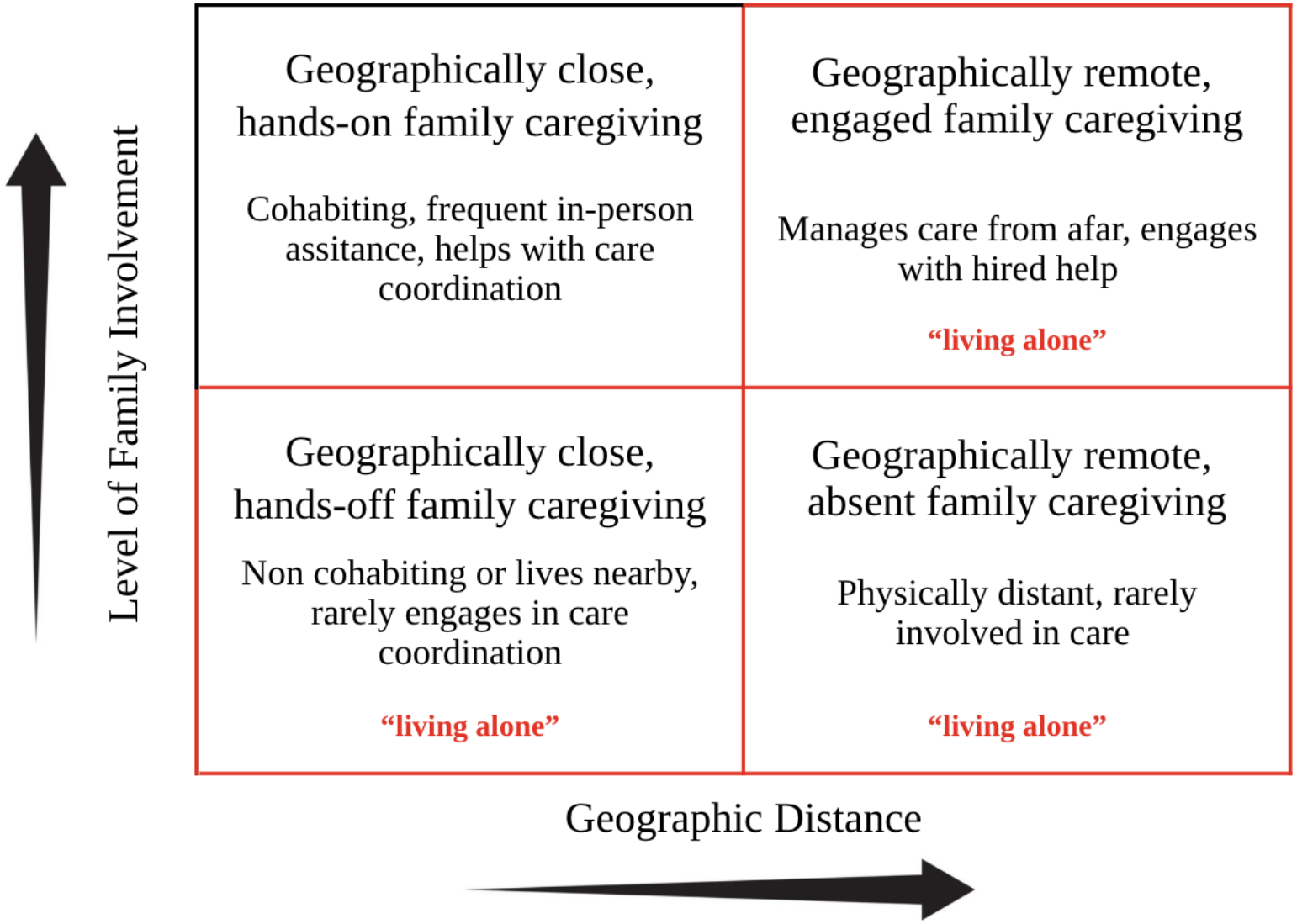
Jane Lowers, PhD, MPA, Emory University

Living Alone:
What does that *really* mean?

Andrea Cohen, MSW

HouseWorks Founder,
Board Chair Caregiver Action Network

Impact of Geographic Distance and Relational Proximity on Caregiving



A Sampling of
Aging in Place Programs & Initiatives

- ✓ Meals on Wheels: https://www.mealsonwheelsamerica.org/
- ✓ The Village-to-Village Network: https://www.vtvnetwork.org
- ✓ Americorps: Senior Companion Program
- ✓ Community Care Cooperative: https://www.communitycarecooperative.org
- ✓ CAPABLE: https://capablenationalcenter.org/
- ✓ Devices: Smart home automation, calendar/clock apps, med reminders, wandering and safety devices, etc.

Research on Care Needs for People with Dementia Living Alone

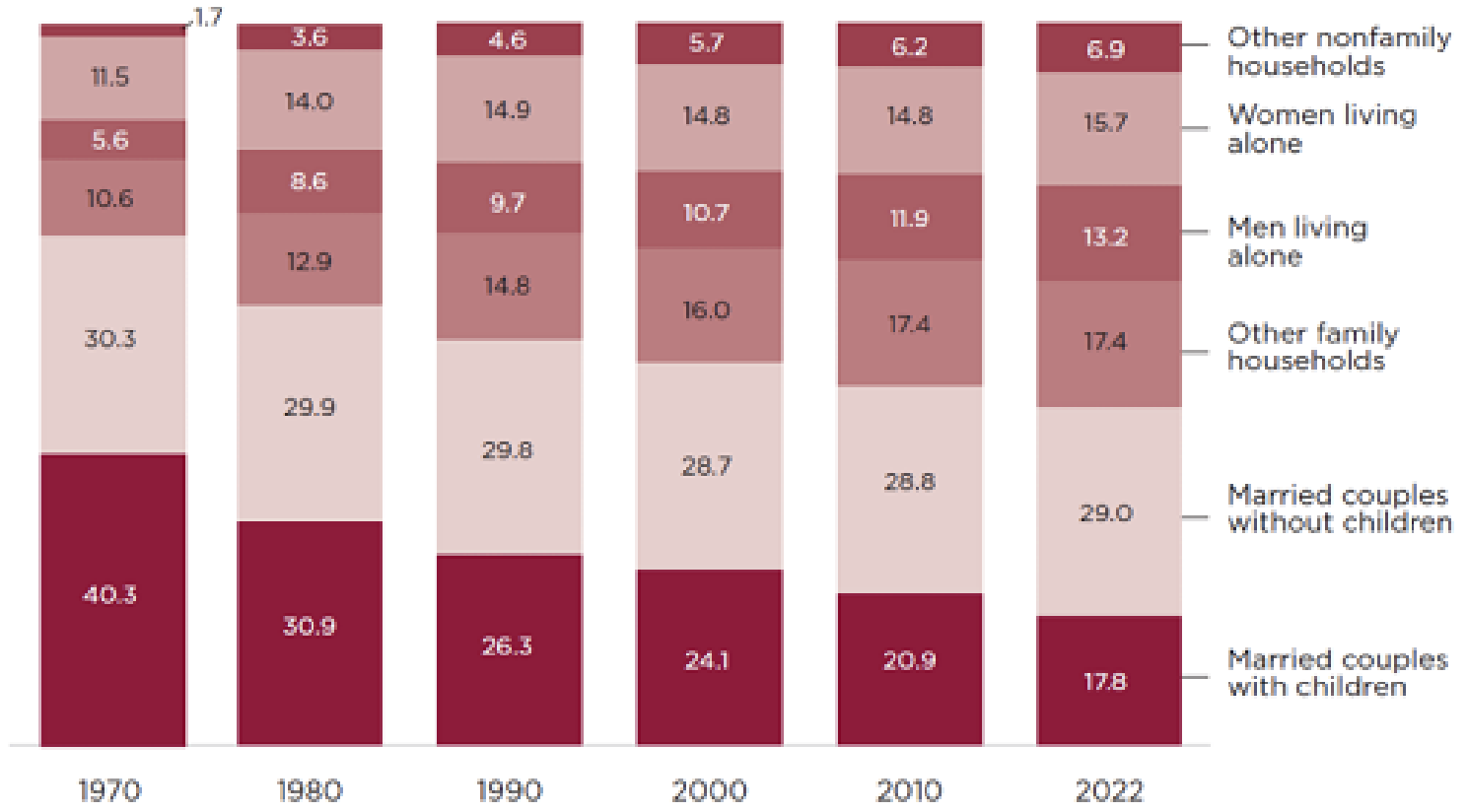
Elena Portacolone, PhD MBA MPH

Professor of Sociology

University of California, San Francisco

Demographic increase of householders living alone

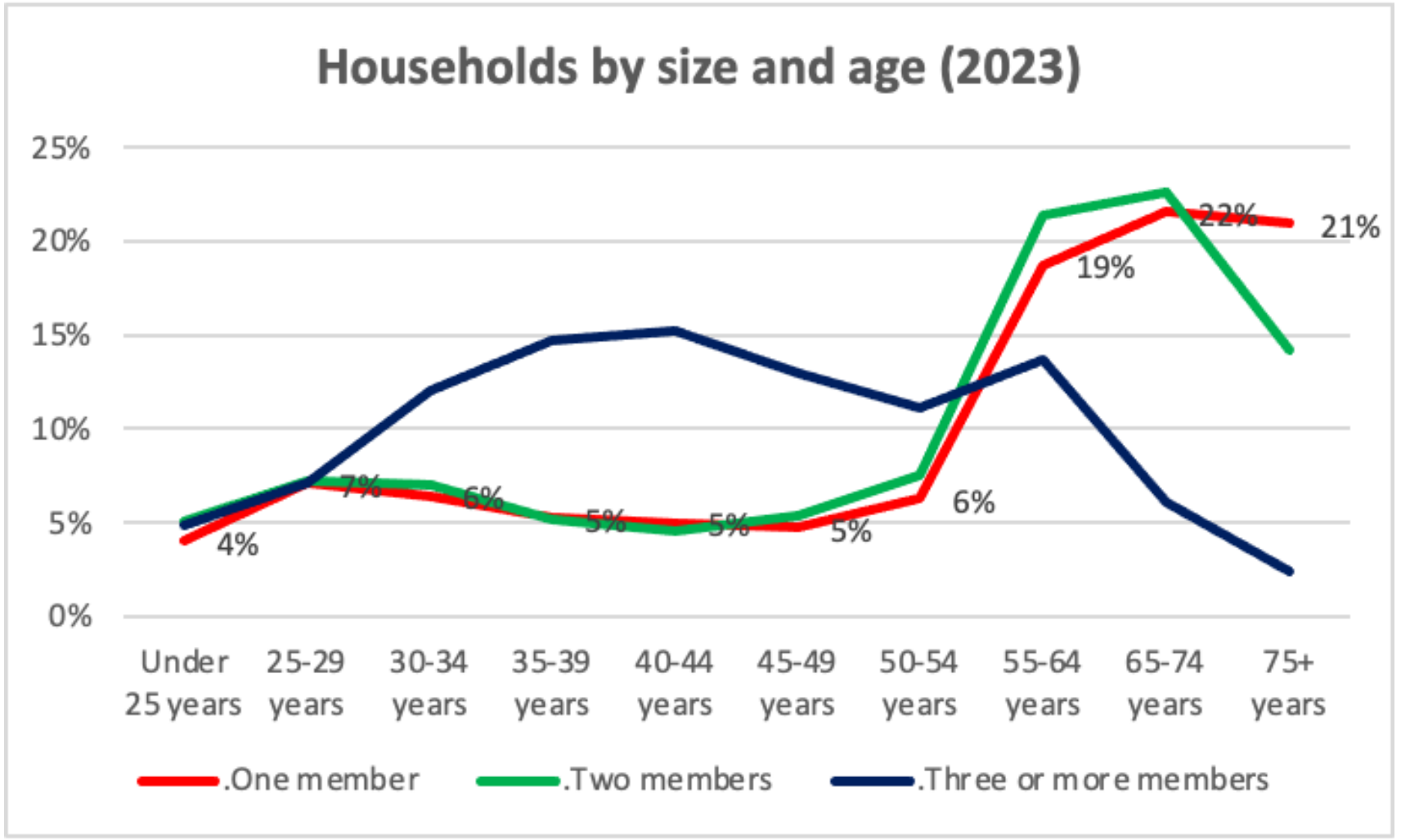
Figure 1.
Households by Type: 1970 to 2022
(In percent)



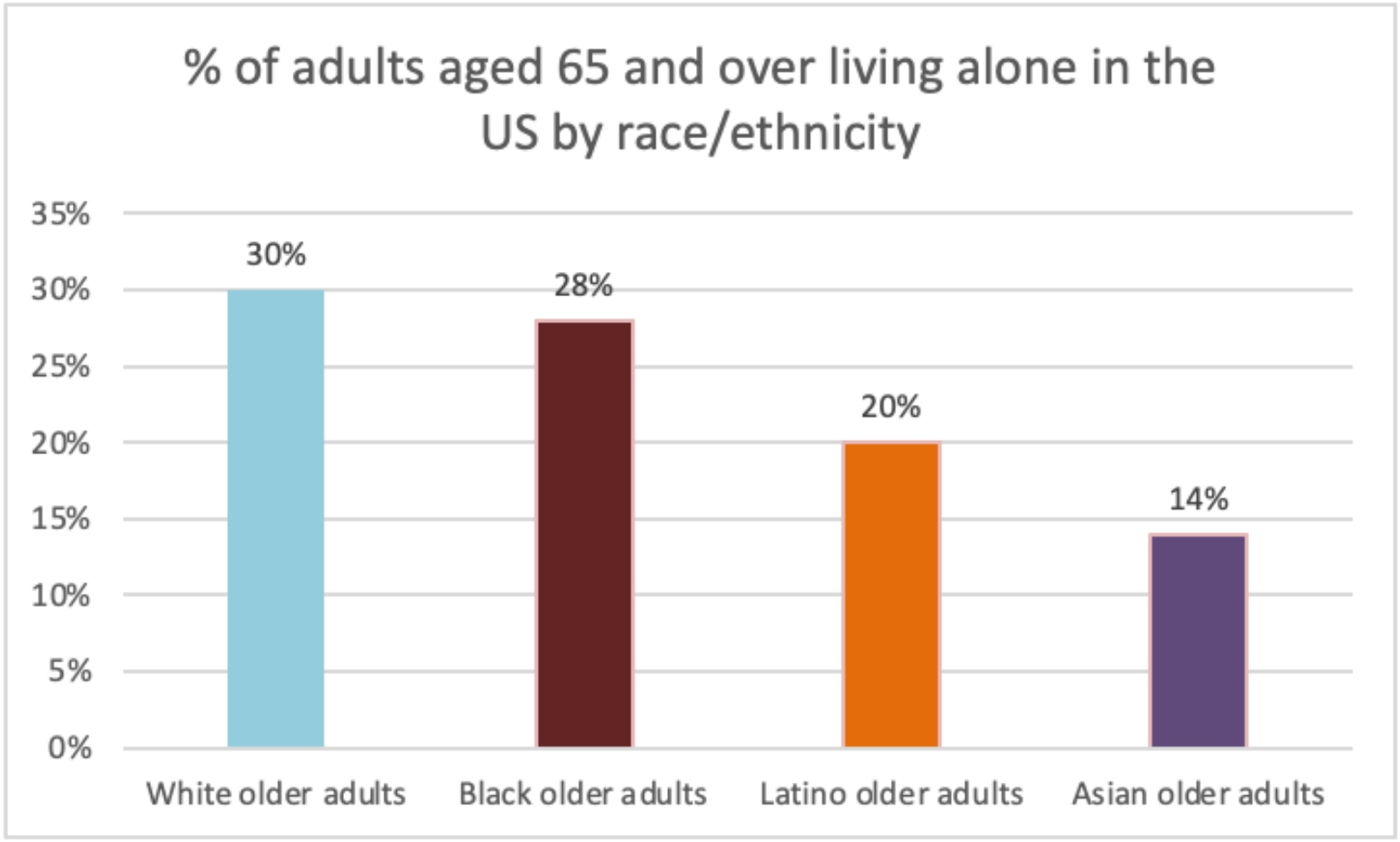
Source: U.S. Census Bureau, Current Population Survey, 1970 to 2022 Annual Social and Economic Supplement.

Living alone is most common in old age

One third of adults aged 65 and over live alone in the US, about 16 million people.



Living alone in old age is common across races and ethnicities



Driving the trend of living alone in old age

- Desire for privacy and independence
- Increased longevity
- Elevated divorce rates
- Decline in marriage rates
- Rise in childlessness
- Families scattered locally, nationwide and globally
- Death/institutionalization of spouses

Living alone with dementia in the United States

- At least one fourth of people with dementia live alone in the US
- Living alone is often a sign that caregivers are not always available
- “I don’t know what to do” is common, sign of precarity
- Home care aides are extremely important, but only available via Medicaid
- Taking one day at the time
- Cumulative pressures
- Dementia often undiagnosed
- Particularly vulnerable during natural disasters

Interviews with 76 professionals caring for older adults Living alone with dementia in the United States

- Stressful population to care for
- Older adults often identified after crises (e.g., falls, dehydration) in Emergency Departments
- Management of medication is often a mystery
- Lack of an advocate is a major issue
- Limited ability of Adult Protective Services to address crises

Portacolone, E., et al. (2023). Perceptions of the role of living alone in providing services to patients with cognitive impairment. *JAMA Netw Open, 6*(8).

Research gaps that can address the challenges of older adults living alone in the US

- How to identify this population, specially those at elevated risk
- How to increase the timely diagnoses of dementia
- How to make the diagnosis of dementia an opportunity to provide long-term supports
- How to create advocates supporting the older adults
- How to better support professionals
- How to increase safety while respecting self-determination
- How to increase access to affordable home care aides
- How to prevent crises
- How to avoid hospitalizations
- How to improve the guardianship system
- How to serve this population during natural disasters

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The Provider's Perspective of Caregiving for Clients living alone with Dementia

Jean Ball, PT, M.Ed., CPHQ

Senior Vice President

Clinical, Compliance, & Quality

HouseWorks Overview

Personal Care Snapshot

- **Geographical Coverage**: PA, NY, CT, MA, NH, ME
- **Service Mix**: 95% Medicaid and 5% Private Pay
- **Dementia Documented in Care Plan:** ~50% of all clients
- **Average Hours of Weekly Care**: ~30 hours (Medicaid & Private Pay)
- **CMS GUIDE Model Partner**

Supporting Families & Clients Living with Dementia

- **Personalized Care Model**
  Every client is paired with a dedicated Case Manager who builds a personalized care plan from day one
- **Coordinated Support**
  Leveraging internal and external (via payor partners) Case Managers serve as the go-to resource for families, offering guidance, reassurance, and timely updates
- **Expert Oversight**
  With Clinical and/or Social Work backgrounds, our Case Managers ensure safe, consistent, and proactive care
- **Engagement & Well-being**
  Our goal is to help seniors living with dementia stay connected, feel safe, and experience meaningful moments every day

Comprehensive Service Offerings

- Personal Care
- Homemaking
- Companionship
- Live-In Care
- Supportive Home Health Aide

- Heavy Chore

- Laundry Services

- Meal Delivery

Training & Resources

- **Caregiver Training**: HomeCare Pulse and Alzheimer's Association resources
- **Care Plans**: Focused on structured routines and medication management
- **Dementia Care Kits**: Supporting dementia care with practical tools for families and Caregivers
- Leveraging additional services & vendors such as Vesta (remote system monitoring), Remo Health, Alzheimer's Association, & PERS devices

Recognition of Need- Living alone with Dementia

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- **Outreach to designated representatives.** Engagement with family and legal representatives is needed long before an older adult has a formal diagnosis of Dementia.
  - How could we encourage the medical system to validate function and safe living as part of the care planning?

- **Outreach and self-assessment is limited.** There's a lack of insight for those living alone with dementia unless friends/family have awareness and observe living conditions or self-care abilities. Does family know what to look for and do we ask older adults to self-assess?
  - As older adults become isolated, this assessment becomes less likely.
  - Reminders for safe Medication management and declining self-care are often first signs of self-neglect.

- **Case management services.** These services are in place for Medicaid-eligible clients through PACE, Senior Care, and Waiver programs, etc. However, for those living alone with Dementia or not enrolled in these comprehensive programs, how do we assess or intervene for decline in medication management, function, safety, basic needs (food, socialization), cognitive ability to manage daily life, etc.? How do we support referrals for in-home assessments?
  - Some larger medical systems engage Social Work services within PCP practices to ensure that some of these connections are made (MGB iCMP program= high risk case management)

Case Examples

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- **Donna R-** 70-year-old woman living alone in her own home
  - **Dementia Diagnosis delayed recognition- subtle changes over time or discovered after an event- Rare dementia with personality changes**
  - **Family engaged immediately- reactive planning** together with legal documents, researched options, planned finances
  - ✓ **Clear family representative roles-** contacts for decisions on care vs. payment were clear and consistent
  - **Care Coordinated-** Search for Community agencies using **Private Pay funds – does not qualify for Medicaid Programs**
  - **Care Continuum- Immediate safety needs** to address for supervision and overnight care- reactive
  - **Care Progressed-** as needs progressed, **care shifts needed to be advocated by family due to placement**
  - ✓ **Care gaps filled by family-** Open shifts/sick calls, overnight support, shopping, feeding, supplies, etc.
  - **Overlapped with Complementary Care- reactive responses to crises or hospitalizations** with advanced directives
  - ✓ Goals of care were clear- consistent communications
  - **Strong relationship** between family representatives and agencies – **self-directed and redefined as care progresses- learn as we go**

- **Mary S**- 101-year-old woman living alone in her own home
  - ✓ **Dementia Diagnosis recognized early-** lived with diagnosis if for +/-15 years. Typical Alzheimer's symptoms of memory/repetitiveness
  - ✓ **Family engaged immediately- proactive planning** together with legal documents, researched options, planned finances
  - ✓ **Clear family representative roles-** contacts for decisions on care vs. payment were clear and consistent
  - ✓ **Care Coordinated- use of Medicaid Senior ASAP service** to assess for core needs and provide in-home care
  - ✓ **Care Continuum- started early with socialization** Adult Day care and least intrusive services per patient/family choice
  - ✓ **Care Progressed-** as needs progressed, the **Medicaid Senior ASAP supported increasing services**
  - ✓ **Care gaps filled by family-** Open shifts/sick calls, overnight support, shopping, feeding, supplies, etc.
  - ✓ **Overlapped with Complementary Care- Palliative Care in community** responses to crises with **Advanced Directives**
  - ✓ **Goals of care were clear-** consistent communications
  - ✓ **Strong relationship** between family representatives and Medicaid Senior Care Coordinators

Conclusions

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- It is possible to age in place with the appropriate coordination of care, clear goals and support services.
    - **NOTE:** this can be challenging for all parties when family representatives are not local to the person living with dementia.
- Navigating these services across dementia progression requires an ongoing learning mentality and team approach among whatever is available among community supports, paid direct care providers, and long-distance family caregivers.
- In two scenarios discussed, without designated motivated representatives, the level of support is not fully assessed, advocated for, nor coordinated over time.
- For those living alone who do not qualify for Medicaid programs that coordinate these needs, the challenge is even greater to navigate systems, identify resources, and coordinate care while using personal funds.

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Policy Considerations for People With Dementia Living Alone Requiring HCBS

Jane Lowers, PhD, MPA

Assistant Professor, Division of Palliative Medicine, Department of Family and Preventive Medicine

Emory University

Policy Recommendations

- Expand access to HCBS, whether through including them in standard state Medicaid plans or expanding criteria for access to waiver-based services
- Revise asset-based eligibility for low-income older adults
- Expand eligibility to older adults with cognitive impairment living alone who are low-income but do not qualify financially for Medicaid-covered home care aide to permit access to those services.[1]
- Allow tax credits for older adults living alone with cognitive impairment who hire home care aides (including refundable tax-credits for low-income older adults who do not pay taxes). [1]

1. Policy Advisory Group of the Living Alone with Cognitive Impairment Project

Policy Recommendations

- Address the continuum of service needs, including both self-directed services for those who can manage their own care, case management services for those who need help, and agency-based care for individuals with complex needs
- Incorporate broad definitions of family and caregivers: Currently, states vary widely in who qualifies as either and how they can participate in person-centered care planning, caregiver training, respite, and paid caregiving programs.
- Explore alternatives to guardianship/conservatorship: Supported decision-making programs can help individuals with diminished capacity continue to engage in person-centered care planning with support from trust others.