ALLIANCE FOR HEALTH POLICY

THE ALLIANCE SIGNATURE SERIES

What is LTSS? and Why It Matters for Millions of Americans

Public Congressional Briefing

Tuesday, September 2, 2025

Welcome Remarks

Claire Sheahan, M.Sc.
President & CEO
Alliance for Health Policy

ALLIANCE PROGRAM LIFE CYCLES

Two Phase Approach

1

INCUBATE

The **SIGNATURE SEMINARS and SERIES** act as labs for insight gathering and innovative, solutions-focused dialogues with leading experts.

The foundational question: What does a good Congressional curriculum look like?

2

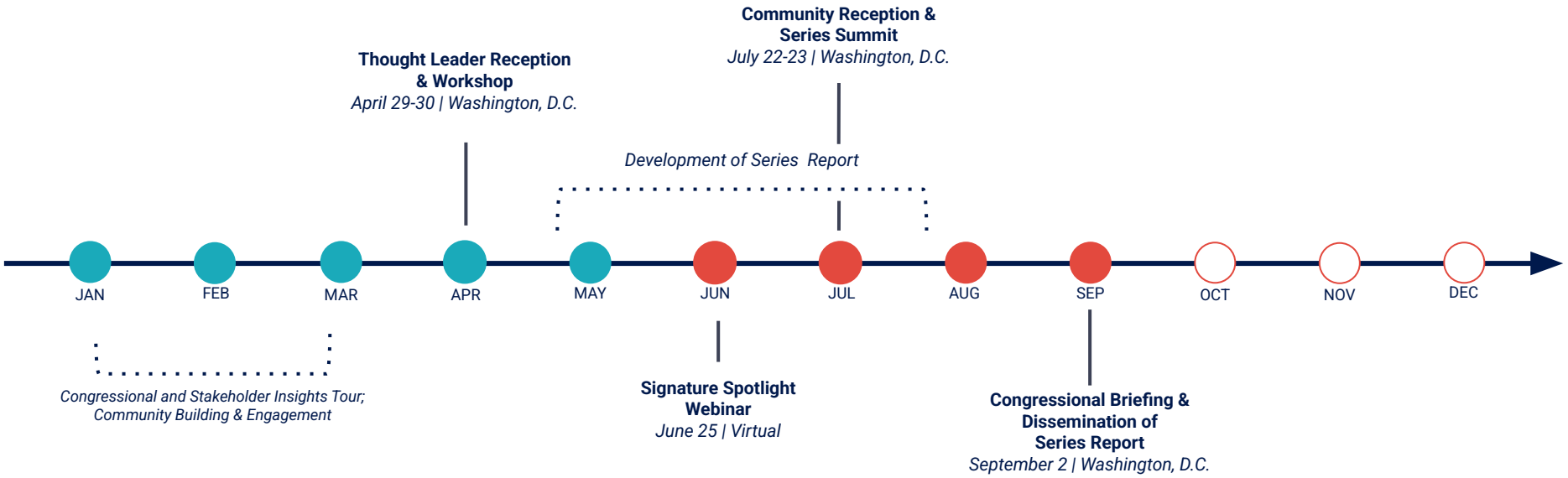
EDUCATE

Our **HEALTH POLICY ACADEMY incorporates findings from the incubate phase and** provides unbiased, trusted education on core concepts and emerging issues to inform better policy solutions for the future.

ALLIANCE
FOR HEALTH POLICY

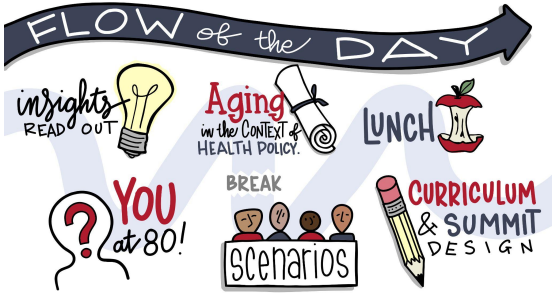
2025 SIGNATURE SERIES TIMELINE

Aging in America



The Alliance's Listen-First Approach

Stakeholder Interviews & Thought Leader Workshop



First-hand Takes on Core Aging Policies

Thought Provoking Perspectives, Interactive Events

Aging Series Report Now Available!

Scan here for your
digital copy!

Original Mission, New Methods: First-ever Fellowship Class

Today's Goals

Goal 1

Discover new ideas, connect, and learn

Goal 2

Find new experts and resources

Goal 3

Join our community

Thank You to Our 2025 Sponsors

You at 80

Imagine yourself at 80.
What will your priorities be?
What's your ideal "day in the life?"

ALLIANCE FOR HEALTH POLICY

You at 80

Happy Birthday! Congratulations you're turning 80!

As you wait for your guests to arrive at your big birthday bash, you take a moment to appreciate where you are in your life. **Describe what that looks like for you:**

Who is coming? Who is in your life daily? Monthly?

What is exciting? What is a challenge?

What does your routine look like? The morning? The evening? What activities are you engaged in?

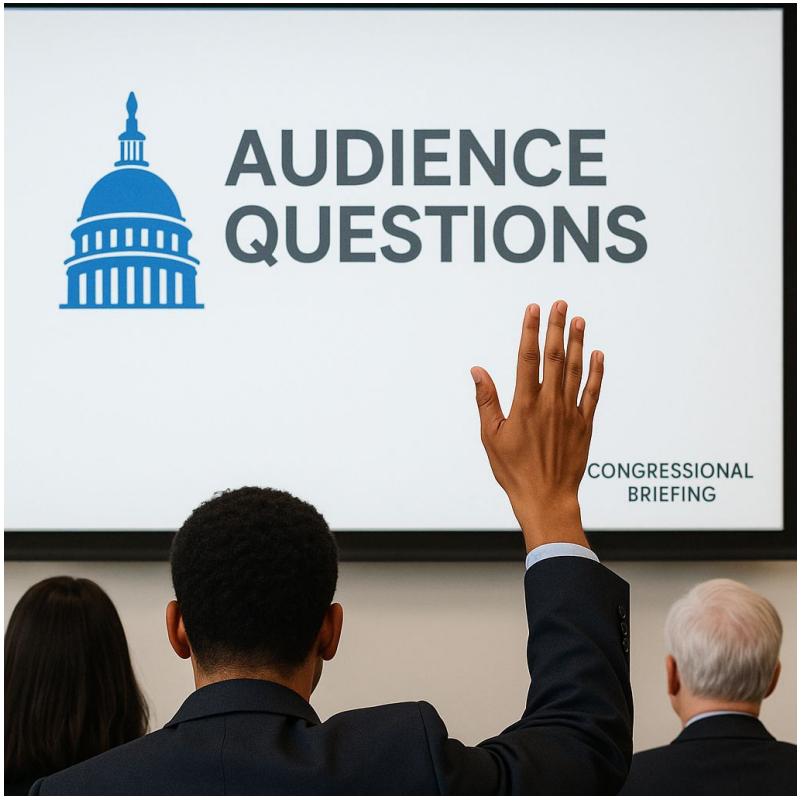
Where do you see yourself living? How will your surroundings contribute to your next years?

Why have you landed here? What choices have enabled you to experience this?

We are eager to hear from you

Question Cards

- Cards at your table
- Fill them in as you think of questions
- We will collect for our Q&A



Moderator

Mike Park, J.D., MPH
Partner
Alston & Bird

Moderator & Panelists

What's LTSS and Why It Matters for Millions of Americans

Alison Barkoff, J.D.
Hirsh Health Law and Policy Associate Professor and Program Director
George Washington University Milken Institute School of Public Health

Kirsten Colello, MPP
Specialist in Health and Aging Policy, Congressional Research Service

Mike Park, J.D., MPH
Partner, Alston & Bird
Moderator

Robert Espinoza, MPA
Distinguished Fellow & Senior Adviser, National Academy of Social Insurance

Anne Tumlinson, MM
Founder and CEO, ATI Advisory

Kirsten Colello, MPP
Specialist in Health and Aging Policy
Congressional Research Service

Congressional Research Service

LONG-TERM SERVICES AND SUPPORTS

Kirsten Colello
Specialist in Health and Aging Policy

September 2025

What are Long-Term Services and Supports (LTSS)?

A broad range of health and social services and supports needed by persons who have limitations in their ability to perform daily activities due to physical, cognitive, or mental disabilities or conditions that are extended in duration.

LTSS is **person centered** and focuses on **quality of life (QOL) outcomes**.

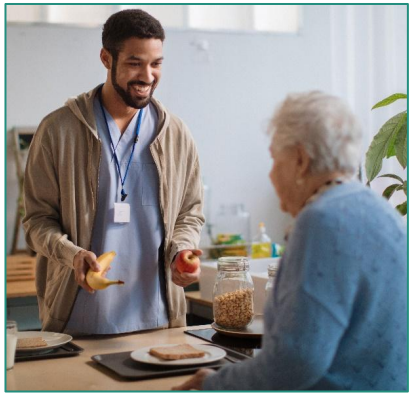
(i.e., physical, mental, social, and functional health)

How is need for LTSS measured?

Need for LTSS is based on **functional limitations** in the ability to perform certain activities.

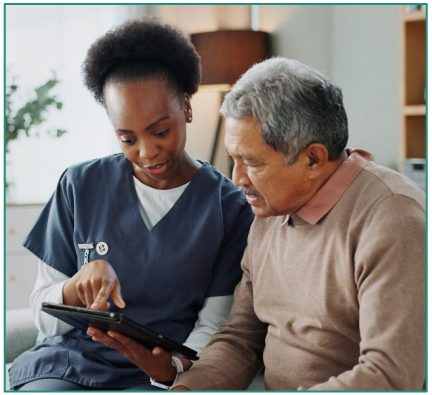
Activities of Daily Living (ADLs)

Eating, dressing, bathing, toileting, transferring from a bed to a chair



Instrumental Activities of Daily Living (IADLs)

Housekeeping, shopping, managing money or medications, meal preparation



Supervision of ADLs and/or IADLs

Due to a cognitive impairment (e.g., Alzheimer's Disease and related dementia)

How does measuring LTSS need apply to public policy?

EXAMPLE 1

Tax-qualified private long-term care insurance

benefit eligibility trigger

"HIPAA Level" =

2+ ADLs or supervision due to severe cognitive impairment that is expected to last at least 90 days

*** Health Insurance Portability and Accountability Act of 1996 (HIPAA, P.L. 104-191; 26 U.S.C. 7702B)**

EXAMPLE 2

Medicaid state-defined institutional level-of-care

need based on:

- ADLs
- IADLs
- Medical needs
  (e.g., intravenous medications, catheters)
- Cognitive impairment
- Behavioral health issues

Where do people receive LTSS?

LTSS is typically provided in the setting where the individual also resides; other types of care may be provided.

Home and Community-Based Settings

- Private home
- Residential community settings
  - Assisted Living Facilities
  - Group homes
- Other non-residential community settings
  - Adult Day Centers

Institutional Settings

- Nursing homes
  - Medicare Skilled Nursing Facilities (SNFs)
  - Medicaid Nursing Facilities (NFs)
  - Veterans Affairs (VA) Nursing Homes
  - State Veterans Homes
- Intermediate Care Facilities for individuals with intellectual disability (ICFs/IID)
- Inpatient psychiatric care

Who needs LTSS?

LTSS affects individuals of all ages and represents a diverse population.

About 17.6 million adults need LTSS (2017-2021).

- Defined as having a self-care or independent living disability
- More than half (51.1%) are 65+

Source: Community Living Equity Center (2024). Who Needs LTSS? [Data dashboard]. The Lurie Institute for Disability Policy. https://heller.brandeis.edu/community-living-policy/clec/who-needs-ltss.html

7.2 million older adults aged 65+ met "HIPAA level" disability criteria in 2020.

Source: Projections of risk of needing long-term services and supports at ages 65 and older (Urban Institute for ASPE, January 2021).

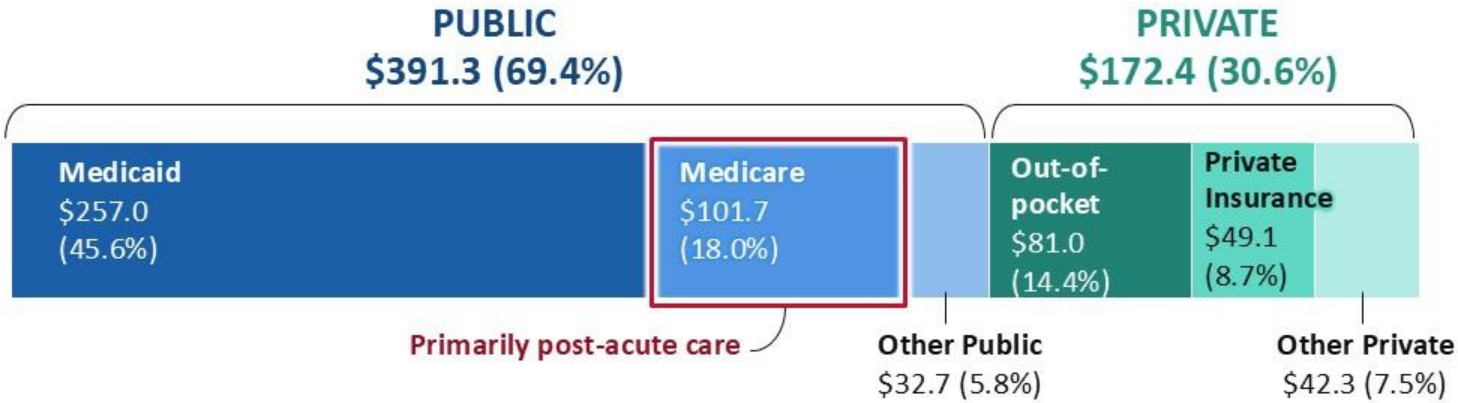
Most live in the community.

About 1.3 million lived in nursing homes in 2020.

Source: CDC, NCHS, National Post-acute and Long-term Care Study, 2022, NPALS - Study Publications and Products

Who pays for post-acute and LTSS in the United States?

Total Spending (2023): $563.7 billion



Not included: estimated economic value of unpaid caregiving, approximately $600 billion in 2021. (AARP, Valuing the Invaluable: 2023 Update, March 2023.)

Chart labels: U.S. $ in billion
Source: CRS analysis of National Health Expenditure Account (NHEA) data obtained from the Centers for Medicare & Medicaid Services (CMS), Office of the Actuary, prepared December 2024.

CONTACT

Kirsten Colello
Specialist in Health & Aging Policy
kcolello@crs.loc.gov

Alison Barkoff, J.D.
Hirsh Health Law and Policy
Associate Professor and Program Director,
George Washington University Milken Institute School of Public Health

Supporting Older Adults Aging in the Community

Alison Barkoff, J.D.
Hirsh Health Law and Policy Associate Professor
and Program Director
GW Milken Institute School of Public Health

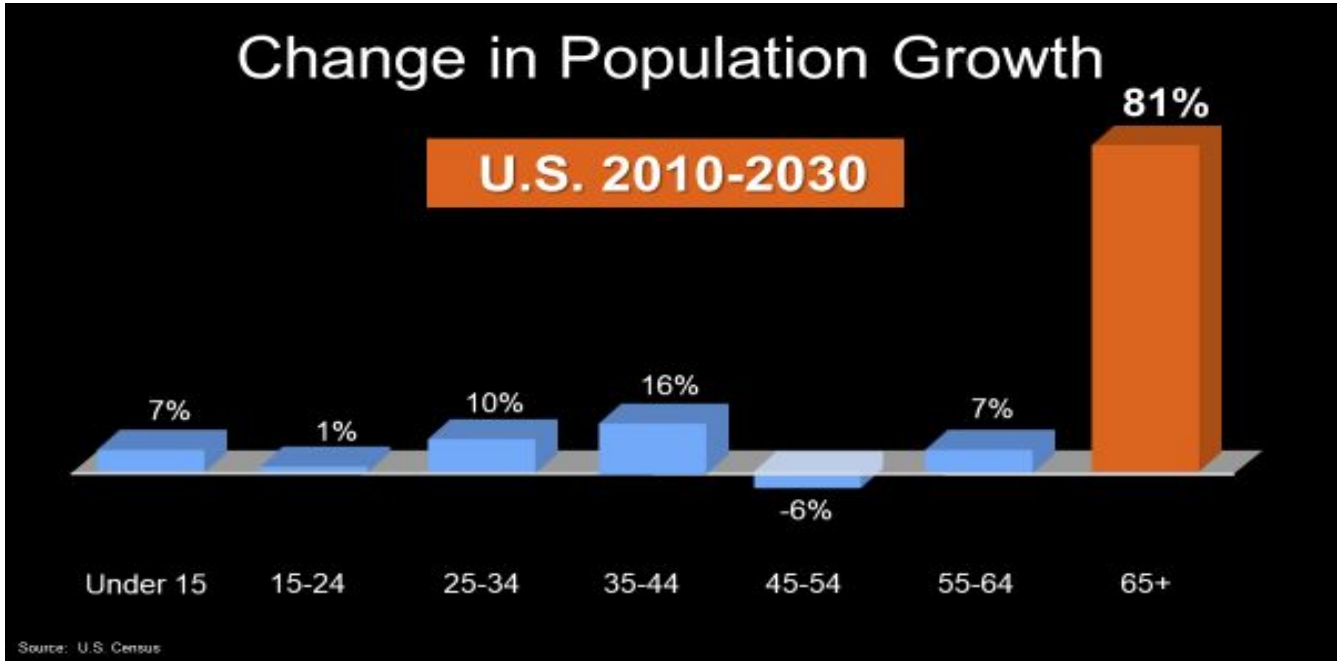
Alliance for Health Policy
2025 Signature Series Congressional Briefing
September 2, 2025

THE GEORGE WASHINGTON UNIVERSITY
WASHINGTON, DC

Aging in the Community

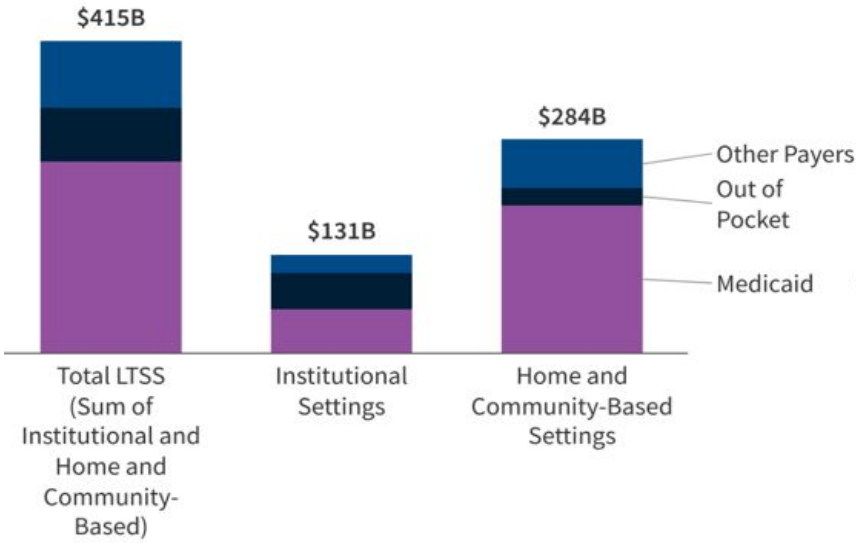
- Vast majority of older adults **want to and are aging in their own homes and communities**.
  - Less than 5% of people 65+ are living in nursing homes
- People **age with or into disability**, including mobility, cognitive, visual and hearing limitations
- For many older adults, they will need **supports with activities of daily living** to stay in the community, called Home and Community-Based Services (HCBS)

Rapidly Aging Population = Growing Need for HCBS



Source: AgeWave, https://agewave.com/do-boomers-have-the-guts-and-wisdom-to-course-correct-our-aging-nation/

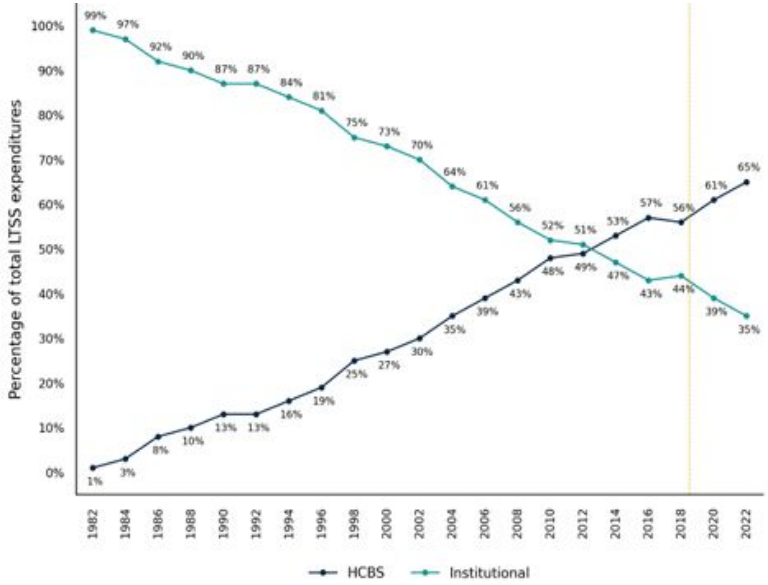
Medicaid-funded HCBS



- **Medicaid is the primary funder of HCBS**
- Many people **mistakenly believe Medicare covers long-term care**, but it does not!
- HCBS is an **optional Medicaid service**, but all states offer it
- HCBS can cover a **range of services** like personal care, adult day, respite, transportation, and home modifications

Source: KFF, https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/

Expanding Access to HCBS



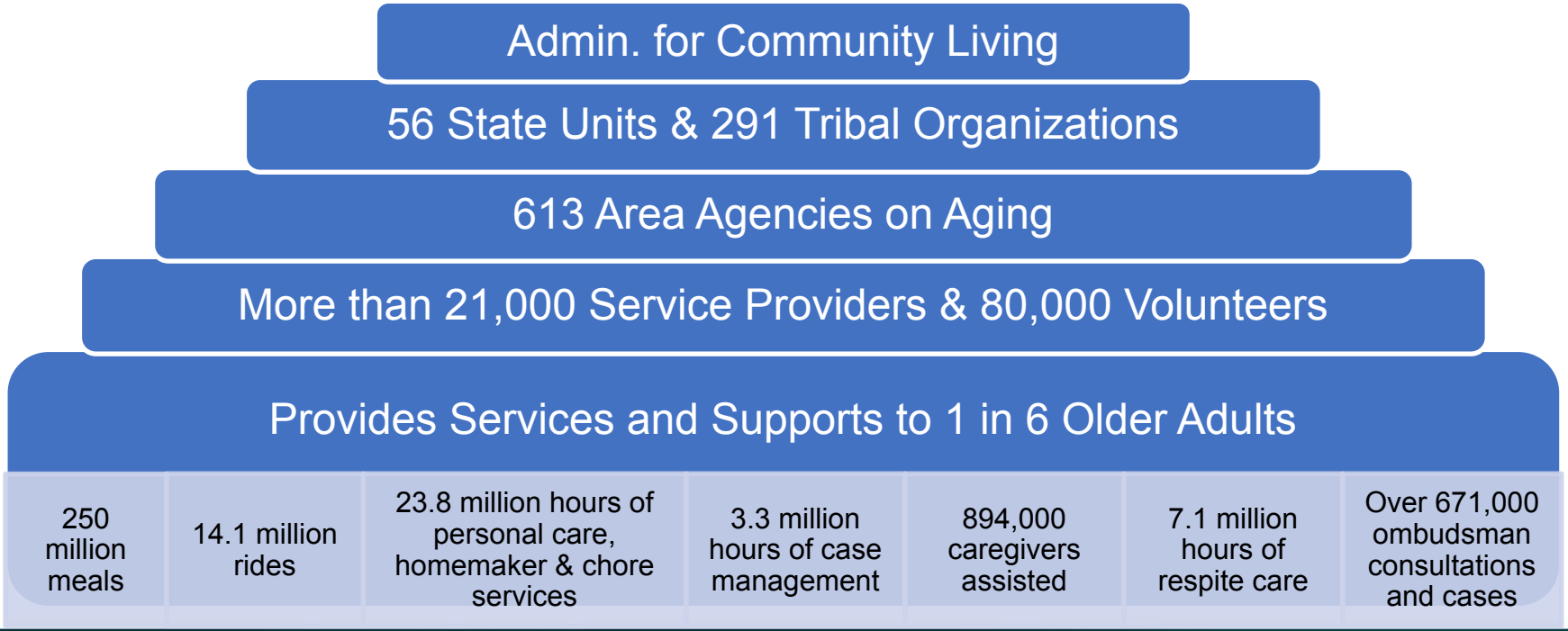
- States have been **"rebalancing" their LTSS systems** to match preferences
- Many **new HCBS initiatives** over the last 25 years, like Money Follows the Person, Balancing Incentive Program, enhanced FMAP in ARPA, and new option in H.R. 1
- **Americans with Disabilities Act** and Supreme Court's ***Olmstead* decision** have also been a driver

Source: CMS, https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2022.pdf

Challenges to Expanding HCBS

- Medicaid has **strict income and asset limits**
- Medicaid has an **“institutional bias”**
  - Institutional care is mandatory, but HCBS is optional
  - More than 700,000 people on HCBS waiting lists
- **Direct care workforce crisis**
- **Families have no choice but to take on caregiving**
- **Potential cuts to optional services** (including HCBS) as states navigate reduced Medicaid funding from H.R. 1

Older Americans Act Programs



OAA: Limited Funding with a Big ROI

3.39x ROI (1)

With **$2,629,085,364** in spending on key home and community-based services, Older Americans Act Programs achieved an estimated **$8,923,610,114** in cost savings by reducing the need for institutional care

Source: https://www.advancingstates.org/sites/default/files/National%20ROI%20Infographic.pdf

Federal Agencies Involved in HCBS

- **Centers for Medicare & Medicaid Services**
  - Administers the Medicaid program, including HCBS
  - Develops policies, guidance, & best practices for states
- **Administration for Community Living**
  - Administers the OAA program
  - Collaborates with CMS on Medicaid HCBS policies
  - Funds initiatives related to HCBS, including around the direct care workforce and family caregiving

Thank you

Alison Barkoff, J.D.
George Washington University
Milken Institute School of Public Health
Alison.Barkoff@gwu.edu

THE GEORGE WASHINGTON UNIVERSITY
WASHINGTON, DC

Anne Tumlinson, MM
Founder and CEO
ATI Advisory

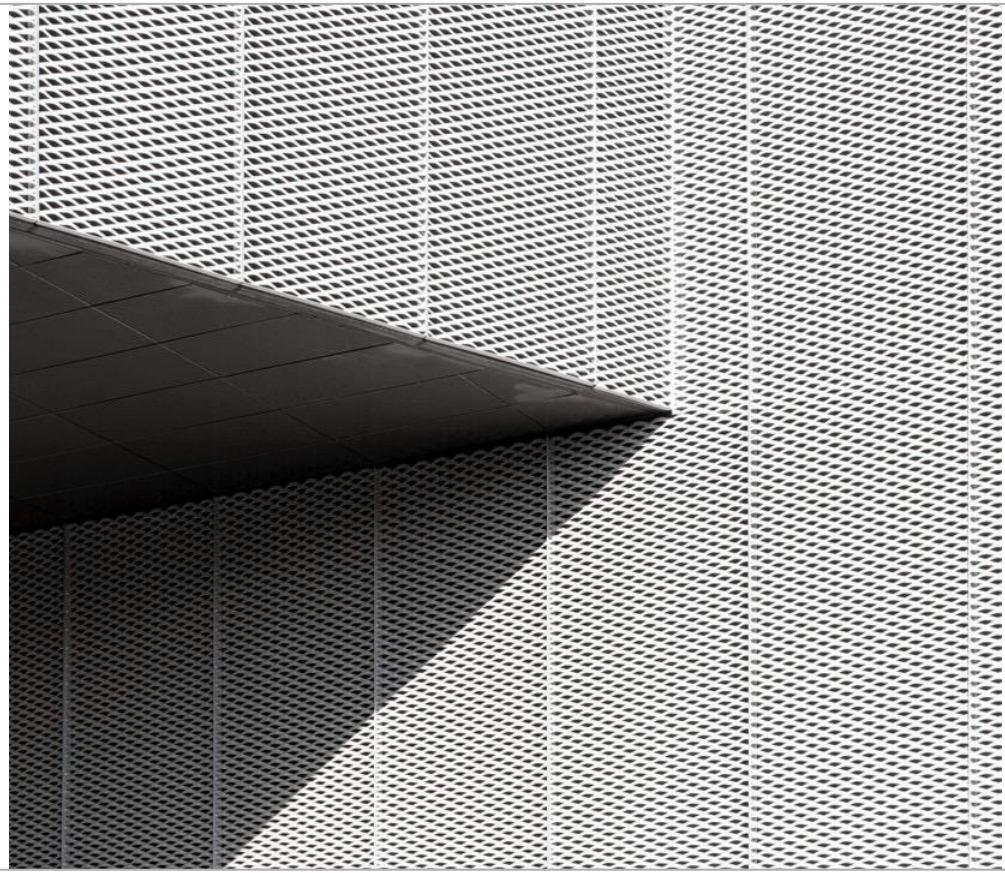
State and Federal Opportunities to Advance LTSS Innovation

2025 Signature Series on Aging in America

Congressional Briefing

September 2, 2025

ATI Advisory

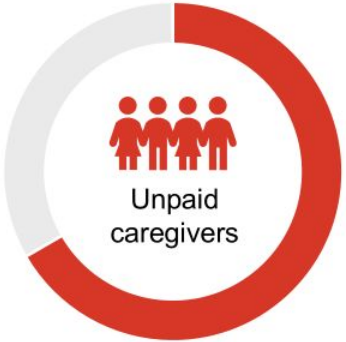


FAMILIES FINANCE AND PROVIDE CARE AT HOME FOR HIGH-NEED OLDER ADULTS

Half of adults age 65+ will need a high level of care at some point

At any point in time, **3/4 older adults** with needs live at home

Nearly **2/3 of older adults** with LTC needs receive help exclusively from unpaid family and friends*



There is no financing system in the U.S. adequate to meet long-term care needs of our aging population

- Much paid long-term services and supports provided to older adults living in the community or in senior living communities is financed through personal savings
- Medicaid contributes the majority of financing for nursing home care
- Traditional Medicare does not cover long-term services and supports and there is no other viable private or public insurance system

Source: Freedman & Spillman (2014), Disabilty and Care Needs Among Older Americans. Table 2; *excludes individuals living in nursing homes

Federal efforts to close LTSS financial gaps are typically categorized by:

- **Creating or expanding public coverage options** to provide coverage to a broad swath of the population and protect against financial risk associated with needing and paying for LTSS, including:
  - New stand-alone public insurance programs
  - Expansions of the existing Medicare public health insurance program (which does not currently cover LTSS)
  - Strengthening or expanding Medicaid LTSS,
  - Hybrid strategies that embrace more than one of these components.
- **Expanding private market solutions,** focusing primarily on changes to federal tax law that effectively reduce the cost of private long-term care (LTC) insurance, as well as:
  - Public awareness campaigns
  - Collaborations between the public and private sector to encourage and support individuals in planning ahead for their LTSS needs have also been pursued.
- **Hybrid solutions** combining private market, public catastrophe coverage, and Medicaid reform

Refer to this compendium of relevant legislation, reports, and research for a comprehensive and organized review of 30+ years of federal policy proposals to reform LTSS financing

Compiled by the LeadingAge LTSS Center @UMass Boston and ATI Advisory.

FEDERAL INVESTMENTS CAN ALSO SUPPORT STATE-LEVEL LTSS FINANCING REFORM INITIATIVES

Federal supports can advance state-level LTSS financing reform for non-Medicaid populations by:

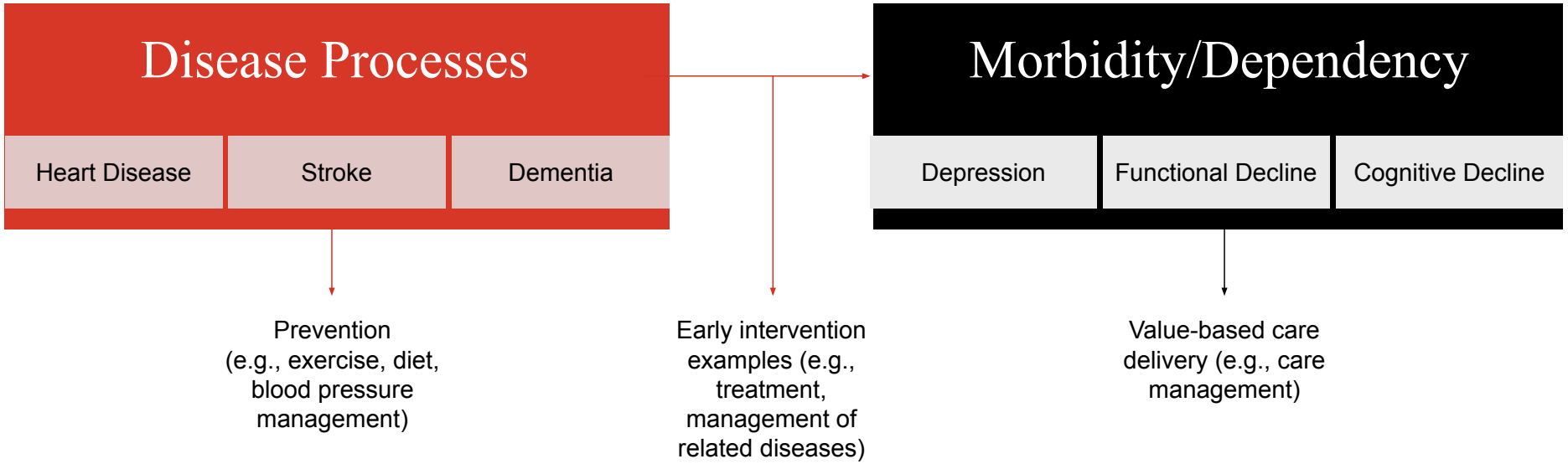
- Creating new financing streams or regulatory authorities for states
- Expanding existing state financing authorities (e.g., via Medicaid or OAA[1])
- Offering technical assistance and other non-financial supports for states
- Developing tax or other incentives or flexibilities for individuals to save for LTSS costs

	Examples of State-level LTSS initiatives
Social Insurance Programs	**Washington WA Cares Fund** is a public long-term care insurance program. All working Washingtonians contribute a small percentage of their income into the fund and can access the benefit when they need care.
Provision of LTSS	**Oregon Project Independence (OPI)**, offers up to 20 hours/month of in-home assistance on a sliding fee scale for those with low incomes and not on Medicaid.
Care Navigation and Public Information	**Most states** participated in the Own Your Future consumer awareness campaign to encourage active planning for long-term care needs. Note that the program is no longer federally supported.
Paid Family Caregiving	**North Dakota Service Payments for the Elderly and Disabled (SPED)** offers limited HCBS, including paid family caregiving.
Unpaid Caregiver Supports	**Hawaii Kupuna Caregivers** offers up to $70 per day in services to caregivers working at least 30 hours a week to enable them to stay in the workforce.
Private Market Incentives	**Most states** offer a Medicaid asset disregard for those with LTC insurance. For each dollar in the benefit, there is an additional dollar disregarded for Medicaid eligibility and protected from estate recovery.
Community Transition Supports	**Minnesota Return to Community Initiative** helps transition private-pay nursing home residents to the community, similar to Money Follows the Person.

1. OAA - Older Americans Act

REDUCING LIFETIME AND HEALTHCARE COSTS MEANS REDUCING RISK FACTORS AND INTERVENING EARLY

Efforts to prevent, intervene early and deliver better care will mitigate and compress morbidity and reduce systemic costs

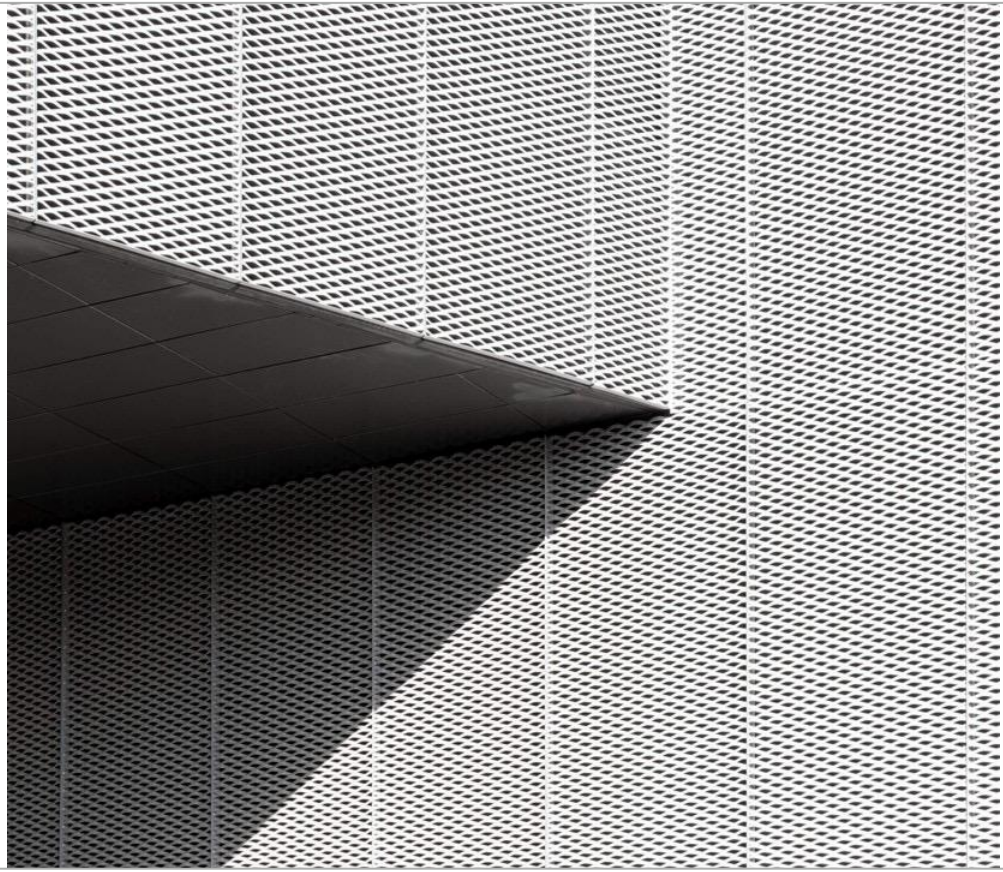


Interested in discussing further?

Contact Information:

Anne Tumlinson | anne@atiadvisory.com

ATI Advisory



Robert Espinoza, MPA
Distinguished Fellow & Senior Adviser
National Academy of Social Insurance

Moderated Discussion and Q&A

ALLIANCE FOR HEALTH POLICY

Closing Remarks

Claire Sheahan, M.Sc.
President & CEO
Alliance for Health Policy

Thank You to Our 2025 Sponsors

Aging Series Report Now Available!

Scan here for your digital copy!

Save the Date!

THE ALLIANCE
SIGNATURE SERIES 2026

Health Care Payment:
Where We Are, Where We Are Going

Stay informed:

ALLIANCE FOR HEALTH POLICY

THANK YOU

Evaluation Survey

ALLIANCE FOR HEALTH POLICY