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**Inclusive Long-Term Care
Policies and Supports**



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Table of Contents

Foreword	3
Legislative Fireside Chat	4
Nicole Jorwic, Representative Debbie Dingell, and Representative Tom Suozzi	
Panel One	5
Federal Policies: Shortfalls and Solutions	
Panel Two	6
State Initiatives Supporting Caregivers	
Panel Three	7
Introducing New Data on States' Medicaid Home and Community Based Services (HCBS) Policies	
Panel Four	8
The Cost of Caregiving & Retirement Security	
Panel Five	9
Workplace Long-Term Care Benefits	
Panel Six	10
Navigating the LTC Landscape: Building a Network Supporting Caregiving Decisions	
About The Harkin Institute	11
Thank You to Our Sponsors!	12

Foreword

The 2025 Harkin Retirement Security Symposium convened policy makers, researchers, and advocacy organizations working on long-term care policy and supports. The program included panels on federal and state policies, workplace supports, and caregiving experiences and their impact on retirement security. The main theme focused on strategies to build an inclusive caregiving system to support all caregiving needs. Presenters pointed out that patchwork policies have failed to address needs and that the burden of caregiving has been placed on families through unpaid caregiving. The lack of an inclusive system reinforces existing inequalities and jeopardizes the retirement security of all Americans.



Caregiving costs are internalized by families in some combination of the following: diminished or lost earned income, early retirement, direct caregiving expenditures, and mental and physical health issues. There is limited federal support for caregiving, mostly through the Medicaid program for low-income individuals, and unpaid family leave. Some states have made more progress through paid family leave and programs supporting home and community-based services (HCBS). While employers are aware of the burden that caregiving places on their employees, there are significant gaps in benefits offered based on occupation and income, and stigma around caregiving responsibilities.

In this publication, we have compiled highlights from the panels with key takeaways and action items for policy makers and advocacy groups. We hope that you can get a glimpse of the community building and high energy surrounding efforts to build a better caregiving system through these summaries. If you would like to revisit the event in more detail, please visit [The Harkin Institute YouTube channel](#) for recordings of all the sessions.

And if you would like to support The Harkin Institute's efforts to address pressing challenges to Americans' financial, retirement, and long-term care, including future Symposia, please visit this [link](#).

Rayna L. Stoycheva, Ph.D.
Director of Retirement Security Policy



Left: Attendees at the 2025 Symposium

Right: Senator Tom Harkin giving welcome remarks.

Legislative Fireside Chat

Discussion Highlights

- Representative Dingell: Shared her personal caregiving story for her late husband, former Congressman John Dingell. Despite her access to resources, she struggled to find adequate 24-hour home care—underscoring how inaccessible the system is for most Americans.
- Representative Suozzi: Reflected on his experience living in a three-generation household. His parents' long-term care insurance allowed them to remain at home into their 90s—an option that is now increasingly unaffordable. He emphasized the need to incentivize insurers to offer innovative, affordable care solutions.



Nichole Jorwic, Representative Tom Suozzi, and Representative Debbie Dingell on stage.

Key Takeaways

- Many Americans must sell assets to access long-term care. The current long-term care system often forces families to deplete savings or liquidate major assets, such as homes, to afford adequate care. This threatens financial stability and widens wealth inequality among aging populations who lack access to affordable options.
- Family caregiving is both a moral and economic issue. Unpaid care is valued at over \$1 trillion annually. Unpaid caregivers represent a critical yet often invisible component of the nation's care infrastructure. The economic value of this unpaid labor highlights the urgent need for policies that provide financial and emotional support for family caregivers.

- Demographic shifts make institutional care unsustainable as the only option. As family structures evolve, the traditional model of relying on relatives for care is becoming increasingly impractical. Without investment in community-based and home care alternatives, the growing aging population will overwhelm institutional care systems.
- Raising awareness and changing perceptions of long-term care insurance are essential. Many individuals misunderstand or underestimate the importance of long-term care insurance until it's too late. Broad public education campaigns are needed to encourage early planning, address stigma, and promote private-and public-sector solutions.
- “We have a moral responsibility in this country to take care of those who have gotten older, to ensure they live with dignity and respect, and to care for those with disabilities.”—Rep. Debbie Dingell

Panelists:

- **Moderator: Nicole Jorwic**, Chief Program Officer, Caring Across
- **Representative Debbie Dingell** (MI-6) (she/her)
- **Representative Tom Suozzi** (NY-3) (he/him)



Representative Debbie Dingell and Representative Tom Suozzi speaking with Senator Harkin after the fireside chat.

Panel One

Federal Policies: Shortfalls and Solutions

- This panel discussed paid leave, long-term care insurance, and provided key historical context for why we need better federal policies. The conversation traced the evolution of U.S. caregiving policy and highlighted critical gaps that persist despite decades of advocacy. Speakers stressed that without a cohesive federal framework, families and states are left to shoulder inconsistent and inadequate solutions.
- Access to long-term care is about dignity, independence, and family stability. Ensuring that individuals can live independently while receiving the care they need strengthens not only personal well-being but also family cohesion. When access is limited, the burden shifts unfairly onto families, often disrupting employment and financial stability.
- Care is a continuum—from childcare to eldercare—and policy conversations should reflect that. The needs of caregivers and recipients span the entire lifespan, and policies must recognize that caregiving does not begin or end with old age. Integrated approaches can promote economic participation and social equity across generations.
- Investment in care infrastructure yields measurable social and economic returns. Expanding access to paid leave, long-term care services, and caregiver support programs drives job creation, stabilizes families, and enhances economic productivity. Policymakers were urged to view care spending as an investment, not an expense.
- The private sector, including companies like Genworth, plays a pivotal role in building sustainable long-term care solutions. Collaboration between government and industry can generate innovative models that balance affordability with quality. The panel highlighted that sustainable solutions must be built on shared responsibility among public, private, and nonprofit actors.

Question and Answer Recap

Question: How are caregiving needs and responsibilities impacting the retirement security of younger generations? And what is the role of the business community in solving these issues?

Answer: It has been extensively documented that the business community is losing money when employees are not supported for their caregiving needs, and so are families. Paid leave is crucial, but so are other programs such as caregiving leave, insurance, and other supports. The government cannot solve this problem on its own; businesses need to be involved in the conversation.

Panelists:

- **Jamala Arland**, President & CEO, U.S. Life Insurance/Genworth [Moderator]
- **Alison Barkoff**, Harold and Jane Hirsh Associate Professor of Health Law and Policy and Hirsh Program Director, George Washington University Milken Institute School of Public Health
- **Connie Garner**, President & CEO, Garner Strategies
- **Dawn Huckelbridge**, Founding Director, Paid Leave for All
- **Narda Ipakchi**, Vice President of Policy and Programs, The SCAN Foundation



Left: Members of panel one onstage.



Right: Dawn Huckelbridge speaking during the panel.

Panel Two

State Initiatives Supporting Caregivers

- This panel discussed specific state policies, including WA Cares, California, and New York, and emphasized coalition building to move policy forward. State-led innovations were presented as models for nationwide reform, with examples showing how diverse political and economic contexts can still yield effective care systems. Building cross-sector coalitions was identified as essential for sustaining momentum and scaling success.
- The care workforce remains underfunded and overstretched. Chronic underinvestment in care jobs results in low wages, limited benefits, and high turnover, undermining care quality and continuity. Strengthening workforce supports—including training, pay, and pathways to advancement—is essential for long-term sustainability.
- States are expanding care programs to improve outcomes and equity. Through targeted initiatives like WA Cares and California’s Master Plan for Aging, states are testing new ways to make care more accessible and equitable. These programs provide valuable insights into scalable solutions that could inform federal action.
- Significant disparities persist among caregivers and recipients. Women, immigrants, and people of color make up the majority of the care workforce yet face systemic inequities in pay and working conditions. Similarly, marginalized communities often experience reduced access to high-quality care services, perpetuating a cycle of inequality.
- Aging issues remain underrepresented in public discourse; advocacy and education are crucial. Despite its impact on millions of families, long-term care rarely dominates national conversations. Building public awareness and mobilizing advocates can help shift policymaking priorities toward the needs of older adults and caregivers.
- States must explore resource reallocation strategies to strengthen long-term care systems. Redirecting existing funds, leveraging public-private partnerships, and integrating social services can help states expand access without overburdening budgets. Innovative financing models could serve as templates for broader national reform.

Question and Answer Recap

Question: What are some ways family caregivers can be at the table and engaged in the conversations surrounding retirement care?

Answer: Every state has organizations that are doing great advocacy. Take the time to learn what your state offers and the ways you can get involved. A great website that was recommended to visit was <https://multisectorplanforaging.org/>.

Panelists:

- **Marc Cohen**, Professor of Gerontology, Leading Age LTSS Center, University of Massachusetts Boston
- **Allison Cook**, Founder, Better Aging and Policy Consulting
- **Kevin Prindiville**, Executive Director, Justice in Aging [Moderator]
- **Ben Veghte**, Director, WA Cares
- **Brandi Wolf**, Policy and Research Director, Service Employees International Union (SEIU) Local 2015



Left: Members of panel two onstage.

Right: Connie Garner speaking during the Q&A.

Panel Three

Introducing New Data on States' Medicaid Home and Community Based Services (HCBS) Policies

- The Center for Retirement Research is creating a database for Home and Community Based Services (HCBS) under Medicaid for adults 65 and older in every state.
- The first segment of the data set will be available in Spring 2026.
- The dataset will have information going back to 2000, searchable by service and by state, and will quantify program rules to analyze variations that are typically specific to the state waivers that have been submitted for the Medicaid program.
- HCBS programs have expanded the range of services available to older adults through the Medicaid program and now constitute about 50 percent of the services offered.
- Expanding HCBS programs can reduce institutionalization and promote independence. Evidence shows that individuals thrive when allowed to age or recover in their homes and communities. Investing in these programs not only saves public funds over time but also enhances the quality of life for millions of Americans.
- The long-term value of this data set is to connect it to other data sets such as the Health and Retirement Survey, so that the impact of HCBS can be connected to individual outcomes.



Jean-Pierre Aubry speaking.

Panelist

- **Jean-Pierre Aubry**, Associate Director of Retirement Plans and Finance, Center for Retirement Research, Boston College



Panel Four

The Cost of Caregiving & Retirement Security

- In 2026, the oldest Baby Boomers will turn 80—the average age when caregiving needs start. As the aging population increases, the cost of caregiving services has been outpacing inflation on average (10 percent increase in 2024, for example).
- The median wage for direct care workers is \$17/hour, which is below the wages of many other occupations that do not require the training and qualifications of the caregiving workforce. Without improvements in pay and conditions, the US will need to fill 9 million caregiving jobs in the next ten years.
- Surveys indicate that family caregivers shoulder economic, physical and mental health costs, and the cumulative impact on their economic wellbeing is substantial.
- Modeling long-term care needs across income groups and over time indicates that about 40 percent of households will not have sufficient resources in retirement to cover those costs, with higher risks for women. However, the severity of long-term care needs varies substantially, which makes it difficult to plan for those expenses.
- Meeting current and future care demands is increasingly difficult under existing models. The combination of rising costs, limited workforce capacity, and an aging population makes the current system unsustainable. Without major policy shifts, both families and government programs will struggle to meet growing needs.
- A new national narrative around care is needed—one focused on shared responsibility and equity. Panelists emphasized reframing care as a collective societal obligation rather than a private family issue. This shift in mindset could galvanize broader support for systemic reforms and funding mechanisms.
- The divide between those who can afford care and those who cannot is widening, posing societal risks. As care costs escalate, access is increasingly determined by wealth, exacerbating inequality. If unaddressed, these disparities could destabilize families, weaken labor participation, and undermine social cohesion.

Question and Answer Recap

Question: How do we reconcile the private market/free market approach with public policy goals to support caregiving?

Answer: A baseline universal insurance program would provide a better structure on which to add other private market solutions such as long-term care insurance, and employer paid leave and caregiving benefits. The payroll tax is an easy vehicle to collect contributions and a universal system would keep costs low, while providing coverage that is not means tested. Medicaid then can supplement for lower income groups, which also relieves pressure from state governments.

Panelists:

- **Spencer Look**, Associate Director, Retirement Studies and Public Policy, Morningstar Investment Management LLC
- **Mark Miller**, Author and Journalist [Moderator]
- **Jason Resendez**, President & CEO, National Alliance for Caregiving
- **Amy Robins**, Senior Director of Policy, PHI
- **Jaimie Worker**, Senior Director of Policy & Research, Caring Across Generations



Left: Members of panel four onstage.

Right: Attendees during the Q&A.

Panel Five

Workplace Long-Term Care Benefits

- Hybrid insurance products combining life and long-term care coverage are emerging, but employee awareness and adoption remain low. While these products offer flexibility and potential cost savings, many workers remain unaware of their availability or advantages. Increasing transparency and education could significantly boost participation rates.
- Employer offerings are limited, often due to a lack of awareness rather than a lack of interest. Many employers underestimate both the demand for and the benefits of caregiving support programs. With better information and incentives, businesses could be more active in expanding access to care-related benefits.
- Expanding education around caregiving benefits is critical to increase participation. Employees often overlook valuable workplace resources simply because they do not understand them or fear stigma in using them. Clear communication and supportive workplace cultures can improve utilization and outcomes.
- The ROI for employers investing in caregiving support is significant—improved retention, reduced turnover, and preserved institutional knowledge. Providing care-related benefits not only supports employees but also strengthens organizational resilience. Companies that invest in caregiving policies often see long-term gains in morale, loyalty, and productivity.
- Employers should view caregiving not just as a personal issue but as a workforce and productivity issue. Recognizing caregiving as integral to workforce planning can drive innovation in benefits design. This perspective ensures that care support becomes part of a company's broader talent and retention strategy.

Question and Answer Recap

Question: What new types of workplace long-term care (LTC) products are emerging, and what challenges accompany them?

Answer: Hybrid insurance products that combine life insurance with long-term care benefits are becoming more common. However, many employees are unaware that these products exist or do not understand their advantages. Low awareness—not lack of value—remains the main barrier to adoption.

Panelists:

- **Bridget Bearden**, Research and Development Strategist, Employee Benefit Research Institute (EBRI)
- **Amy Chinn**, Vice President of Long-Term Care Claims and Risk Management, One America Financial
- **Indivar Dutta-Gupta**, Founder & CEO, Blue Lotus Strategies [Moderator]
- **Theresa Roma**, Head of Insurance Solutions, Wellthy
- **Chantel Sheaks**, Vice President, Retirement Policy, US Chamber of Commerce



Left & Right: Members of panel five onstage.

Panel Six

Navigating the LTC Landscape: Building a Network Supporting Caregiving Decisions

- Caregiving in the US report highlights a substantial rise in the number of family caregivers in the last decade (63 million) who provide a wide range of services, including complex medical care.
- NCOA is working with the Administration for Community Living and 18 states on strategies to develop and improve the direct care workforce.
- NCOA Benefits Enrollment Centers provide resources to family caregivers about services that they are eligible for, as well as connections to other supports.
- CareScout emphasizes a wholistic approach to caregiving planning, including insurance, financial planning, and caregiving navigation. Additionally, the CareScout Quality Network identifies, credentials, and certifies providers and offers preferred pricing. The solutions must center on public-private partnerships that accommodate different caregiving needs.
- Caregiving is natural and something that we all participate in, but it has been reframed as a burden. Instead of focusing on the burden, we should focus on how we support the natural cadence of caregiving throughout the lifetime. Framing caregiving as a burden focuses on who deserves care and how much they deserve, which reinforces inequalities.
- The cost and need for care continue to rise, with inequities across race, gender, and income. Systemic barriers mean that historically marginalized groups shoulder disproportionate caregiving burdens while receiving less support. Without targeted interventions, these disparities will only deepen as demand for care grows.

Question and Answer Recap

Question: Why is continued advocacy essential in the LTC space?

Answer: To ensure that caregiving and long-term care remain central to national conversations about retirement security, advocates must remain engaged in legislative and regulatory processes. Care policy must be integrated with pensions, savings, and social insurance reform to create comprehensive solutions.

Panelists:

- **Rita Choula**, Interim Vice President, Family, Home and Community and Senior Director of Caregiving, AARP Public Policy Institute
- **Mia Ives-Rublee**, Senior Director, Disability Justice Initiative, Center for American Progress
- **Rebecca Vallas**, Chief Executive Officer, National Academy of Social Insurance [Moderator]
- **Andrea Lynn White**, President & CEO, Care Scout Insurance
- **Daniel Wilson**, Senior Director of Government Affairs, National Council on Aging (NCOA)



Left: Mia Ives-Rublee onstage.

Right: Members of panel six onstage.

About The Harkin Institute

The Harkin Institute for Public Policy & Citizen Engagement is a nonpartisan policy research institution focused on the main policy areas that shaped Senator Tom Harkin's career: people with disabilities, retirement security, and wellness and nutrition.

Vision: A future where everyone has equal access to opportunity, well-being, and dignity.

Mission: The Harkin Institute advances inclusive, evidence-based public policy by connecting research, civic learning, and diverse lived experiences. We provide access to trusted information and empower robust civic engagement to promote the public good.

Legacy: We are inspired by Tom and Ruth Harkin's decades of public service. Their enduring legacy demonstrates that all of us are interconnected, bound together in a single circle of inclusion, with no one left out.

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