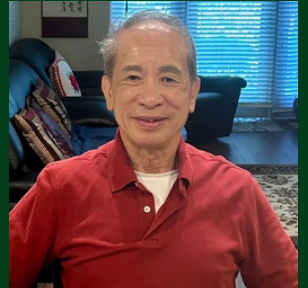


MASSACHUSETTS AT A CROSSROADS

*A Vision for a Dignified Long-Term
Care Future*



FACING A PREDICTABLE CRISIS

A SPECIAL PROJECT OF
DIGNITY ALLIANCE MASSACHUSETTS

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The Cover

Keepers of the Flame

The Power of Dignity Alliance is its message and its people – advocates, older adults, people with disabilities and caregivers. The story of Dignity Alliance is one of dedication, persistence, and caring.

The photos on our cover are just a small sample of the amazing men and women of Massachusetts who, for the past five years, battled the pervasive societal attitude of ageism to create our vision of dignity and independence for countless older adults, people with disabilities and caregivers. Every person's story is heroic. The fight continues!

Top Row (left to right): Attorney John Ford; Author Margaret Morganroth Gullette; Activist Chris Hoeh; Elder Law Attorney Clarence Richardson; Caregiver Sam Chan.

Bottom Row (left to right): Nursing Home Resident Advocate Penelope “Penny” Shaw; Disability Advocate Charles Carr; Priscilla Reilly, Lachlan Forrow, MD, and Independent Living Advocate Meg Coffin; Care recipients Marie and Jack Alves; Social Worker Advocate Sandy Novack and with Housing Attorney and Disability Activist A. Joseph Ross.

Massachusetts at a Crossroads: A Vision for a Dignified Long-Term Care Future

Executive Summary: Facing a Predictable Crisis

Massachusetts is on a collision course with a predictable long-term care crisis, and we are flying blind. While recent reports warn of a nursing home bed shortage, the true emergency is a profound failure of comprehensive planning. The population of residents aged 85 and older is set to surge by an estimated 40% over the next decade, yet state agencies and private sector entities appear to be relying on dangerously flawed and inadequate demand projections for all types of long-term services and supports in facilities as well as home and community settings. This isn't just a statistical error; it is a failure of a core governmental duty to prepare for the needs of its most vulnerable citizens.

This lack of a credible, data-driven plan has trapped Massachusetts in a "white noise" debate over disconnected solutions, obscuring the clear and present danger. Without an honest accounting of future demand, we risk misallocating billions of dollars, deepening the workforce crisis to catastrophic levels, -and creating a system where low-income individuals who rely on MassHealth and other subsidized services are crowded out of essential services.

Our message to policymakers is therefore crystal clear and urgent:

We call on the Governor, Legislative Leadership, and the Secretaries of Health and Human Services and of Aging and Independence, and heads of other state agencies to immediately convene a public process to produce a validated, transparent, and realistic projection of Long-Term Services and Supports (LTSS) demand for the next five and ten years.

Three fundamental questions need to be addressed:

1. What is the true scale of the coming demand, and how will we align state and other resources to meet it?
2. What innovations should we anticipate or pursue to ensure long term services and support are most cost effective, accessible, and desirable?
3. Why has our state's planning efforts failed so severely and what governance changes are needed to ensure this does not recur?

Only with a comprehensive and honest assessment can we pursue a viable, dual-track strategy: radically reinvesting in the home- and community-based services that residents overwhelmingly prefer, while strategically modernizing a limited number of institutional settings. The time for haphazard efforts which are not evidence based is long over. We call for an immediate course correction to ensure a future of dignity, choice, and security for all Massachusetts residents as they seek necessary services.

Our Commonwealth is facing an imminent and profound challenge: a surge in demand for high quality, affordable, and accessible Long-Term Services and Supports (LTSS) that will test the limits of our current system. While recent projections warn of a nursing facility bed shortage by 2029, **the fundamental issue is not a simple lack of capacity, but a deep misalignment of resources with the values and desires of our citizens.** An overwhelming 90% of older adults and persons with disabilities want to age in their homes and communities, yet our state's trajectory continues to favor institutional expansion. This document outlines a dual-track strategy for a sustainable and humane future. We must engage in pragmatic, evidence based planning for inevitable demand growth while executing a decisive pivot toward a community-based, person-centered system that honors the dignity, autonomy, and preferences of all Massachusetts residents.

The Moral Imperative: Dignity and Preference

While pragmatic planning is essential, it must not override the values that define compassionate care. Dignity Alliance rightly emphasizes that nearly 90% of older adults and persons with disabilities prefer to remain in their homes and communities. Building more institutional beds without addressing this preference is not just inefficient and more expensive, it's a betrayal of public trust. Unwanted and Understaffed Facilities Are Not Solutions: A bed does not give care. Without a robust, well-compensated workforce, new construction is a hollow gesture.

Home Care Is a Strategic Priority, not just a Budget Line: Freezing or underfunding home and community-based services (HCBS) are akin to cutting off the water supply during a fire. We must expand the availability of and training for home health aides as well as increase adult day programs and other community services, accessible transportation, and other supports which make remaining in the community viable.

The Demographic Imperative

The need for action is not a distant concern; it is immediate, even urgent. In Massachusetts today, approximately 1.22 million residents—over 17% of our population—are aged 65 or older and another 12%, 800,000 persons have at least one disability. By 2030, the number of older people will swell to encompass more than 21% of the state's population, with the fastest-growing segment being those aged 80 and older. With the average age of entry into a skilled nursing facility around 81, this demographic wave is set to place unprecedented pressure on our entire long-term care infrastructure. Services for people with disabilities are spread and fragmented among several agencies without real coordination considering the current and future multiple needs of the whole person. It is vital to keep the process locally based, but with improved coordination. We must act with foresight now, or we will be forced to react in a continuous state of crisis later.

Core Challenges Facing the Commonwealth

Our path forward is obstructed by three interconnected challenges that demand a comprehensive and coordinated response.

1. A System Misaligned with Public Will: The foundational model of long-term care is outdated. It has essentially been unchanged for 75 years. It prioritizes large-scale institutional settings with mostly shared rooms despite the clear preference for aging in place and privacy. Expanding the current nursing home model—without evolving it to be more homelike, with smaller units and private rooms—is both an inefficient use of resources and a direct contradiction of the public will. A bed is not care, especially if it is in a facility that fails to meet the 21st-century needs of its residents.

2. A Deepening Workforce Crisis: The entire LTSS system, from skilled nursing facilities to home care services, is threatened by critical staffing shortages. This crisis is fueled by a failure to provide a living wage, benefits, and career pathways that respect the dignity of direct care workers. It is being magnified currently with the misguided federal attack on immigrant worker, both documented and undocumented. We also fail to adequately support the immense contributions of family and other caregivers. Without a robust, well-compensated, and stable workforce, any plan for expansion is a hollow promise that jeopardizes the quality of care for everyone. Profit-making ownership of providers need to partner with government to provide a living wage and benefits with a career ladder for incentives to provide quality outcomes.

3. Systemic Gaps in Housing and Governance: The lack of accessible, affordable, supportive housing is exacerbating homelessness among older adults and people with disabilities, placing further strain on the LTSS system. Compounding this issue is a fragmented state government structure that impedes effective service coordination. The needs of our aging population and people with disabilities require dedicated, cabinet-level leadership and integrated planning, not a siloed approach.

4. Housing Shortage: The lack of a sufficient supply of affordable, accessible, supportive housing, increasing residential costs both for homeowners and renters – especially homeowners’ insurance, and slow progress implementing the zoning change allowing accessory dwelling units (ADU’s), harm the ability of older adults, people with disabilities, and caregivers to age in place. While the Affordable Housing Act has begun to help, a sustained effort to address housing needs is critical.

5. Economy: Massachusetts has the highest cost of living in the continental United States. The Massachusetts economy is showing an increase in older adults and people with disabilities at poverty levels and many who are staying or returning to the workforce after traditional retirement ages. In addition, there is a growing level of food insecurity among older adults and people with disabilities

6. Uncertainties of Federal Funding: Medicaid provides health coverage to seventeen million older adults and people with disabilities in the United States. Medicaid requires all states to cover low-income older adults and people with disabilities. States also have the flexibility to expand coverage to additional populations of older adults and individuals with disabilities, such as those who need home and community based services (HCBS). In addition, forty states (including MA) have implemented Medicaid expansion under the Affordable Care Act. This allows states to cover many people with low income and disabilities who do not otherwise meet Medicaid’s strict definition of disability. Medicaid provides states with guaranteed federal funding to help cover the actual cost of providing care to these populations regardless of how health care costs change. Continuation of such funding and added restrictions put this source in contention.

7. State Government Inaction: Despite years of lofty promises and scattered proposals, Massachusetts continues to fall dangerously short in delivering safe, dignified, and effective long-term care for all who need it. Legislative initiatives and executive plans have offered glimpses of hope—but without enforcement, funding, or sustained leadership, these efforts remain hollow gestures.

a. Systemic Failures and Accountability Gaps

- The Department of Public Health has repeatedly failed to investigate resident complaints in a timely manner, drawing sharp criticism from both the State Auditor and the Inspector General for Health and Human Services.
- The State Plan on Aging (2026–2030), like its predecessors, is riddled with vague aspirations but lacks concrete goals, timelines, detailed, evidence-based plans, or mechanisms for meaningful, timely accountability.

b. Legal Battles with High Stakes

- *River Terrace Operator LLC v. Massachusetts DPH*—a pivotal case challenging the state’s authority to limit nursing home room occupancy to two residents per room—has been stalled since May 2022. A decision in favor of the Commonwealth would be a landmark win for resident privacy and infection control.
- *Marsters v. Healey*—a federal case rooted in the state’s failure to uphold the Olmstead Decision—demands the reintegration of at least 2,400 nursing home residents into community settings over eight years. Although decided in June 2024, implementation is crawling forward slowly, risking further harm to vulnerable populations.

c. Glimmer of Progress

- E.O. 642 requires state agencies to demonstrate how they are building an “age-friendly” government. Initial reports are due this November, and Dignity Alliance has stepped up to support agencies in crafting meaningful, measurable policies.

A Strategic Path Forward: A Dual-Track Vision

Instead of framing the debate as a choice between institutional beds and home care, Massachusetts must pursue a unified strategy that bridges pragmatic reality with compassionate reform.

Track One: Radically Reinvest in Home and Community-Based Services (HCBS)

We must aggressively shift our budgetary and policy priorities to build a world-class HCBS infrastructure. This is the most direct way to honor consumer preference and create a more resilient system.

- **Expand Critical Services:** Immediately unfreeze and increase funding for essential supports that make aging in place possible, including adult day health, home health aides, transportation, meal delivery, and other HCBS services. Aggressively implement the settlement in *Marster v. Healey* as a model for helping people to return home or remain in their communities. Accept as foundational that everyone in an institutional setting wants to go home.
- **Empower Family Caregivers:** Recognize and support family caregivers with financial resources, training, and respite services
- **Promote Proactive Planning:** Launch a sustained public awareness campaign to encourage residents to begin planning for their long-term care needs by age 50, fostering a culture of preparedness.

Track Two: Modernize and Target Institutional Care

We must acknowledge that even with a robust HCBS system, the sheer volume of our aging and disability populations will require enhanced high-acuity institutional capacity. However, this cannot be a continuation of the status quo.

- **Adopt a New Model:** Future development must abandon the outdated institutional model in favor of a small-home concept, featuring private rooms and baths that prioritize privacy, universal workers, and person-centered care.
- **Focus on “LTC Deserts”:** Limit new construction to strategically identified, underserved regions (i.e. urban neighborhoods and rural communities, ensuring development is tied to demonstrable need, stringent quality standards, and workforce readiness. Give residents a geographic choice to be near their family and friends.
- **Review Chapter 197 Commission and Task Force Reports:** At the direction of the Legislature, several task forces and commissions were created to further explore innovations in long-term care. Their recommendations need to be transformed into specific, actionable policies, legislation, and regulations. They should be reviewed and expanded upon rather than limited by input from those who opposed change.

Foundational Reforms for Success

To enable this dual-track vision, we must implement foundational changes.

1. Launch a Statewide LTSS Demand Analysis: Commission an unbiased, actuarial study of LTSS needs over the next 5, 10, and 15 years. This data-driven foundation is critical for all future planning and resource allocation.
2. Overhaul State Governance: Restore the Secretary of Aging and Independence (formerly Elder Affairs) to a full, independent cabinet-level position. Establish an Interagency Coordinating Council with consumer and worker representation to break down silos and create a seamless service experience. Create an Office of the Older Adult Advocate to serve as an independent watchdog, ensuring accountability and responsiveness.
3. Address the Workforce Crisis Head-On: Implement a statewide initiative to significantly improve wages, benefits, and career pathways for all direct care workers in both institutional and community settings. A livable wage is not just a moral imperative; it is an economic necessity for a functioning care system. Support legal immigrants who want to provide care as well as family caregivers who need support.
4. Enact Legislation: that begins to provide a foundation for the enhanced system of care. There are many opportunities in the current legislative session, such as:
 - a) New Model for Institutional Care
 - Reduce number of residents per room in SNF (H1381; S480/H795)
 - Raise the Personal Needs Allowance (S887/S482/H1411)
 - Strengthening Workforce and Capital Fund (S491/H761)
 - Improve quality of nursing home medical directors (S488/H797)
 - Improve care for Alzheimer's and Dementia patients (H4302)
 - Preventing discrimination against people with disabilities in health care (H1360)
 - Strengthening oversight of health care spending (H1355)

b) Expand Opportunities for Community Living

- Ease the burden of aging in place (S1953/H3252)
- Support cooling assistance (S959/H1495)
- Emergency Homelessness Prevention for Older Adults (H261)
- End homelessness among older adults (S475/H4015)
- Improve Pedestrian Safety (S2419/H3804)
- Respect and support wheelchair users (H4358)

Restore funding for ECOP, independent living, behavioral health for older adults, and housing subsidies in a supplemental budget.

Expand BHOAPs throughout Massachusetts. Every older adult should have access to appropriate behavioral health services.

- Promote housing stability for older adults across the Commonwealth (S475/H3015)
- Provide for supported decision-making (H261)
- Update Open Meeting Law to provide virtual and in-person participation (S2205)

c) Workforce Initiatives:

- Establish minimum wage for direct care workers. (S877)
- Establish a livable wage for human service workers (S130/H223)
- Credential guardians as health care providers for MassHealth support. (S.154)
- Authorize spouses to receive compensation for care. (S914/H4258)
- Strengthening Workforce and Capital Fund (S491/H761)
- Advance Geriatric Training at all levels of health care.

d) Improve Oversight of Long-Term Care

- Create the Office of Older Adult Advocate (S481/H796)
- Increase accountability for nursing home management (S496/H794)
- Reorganize EOHHS (H4025) with amendments to restore Secretary of Aging and Independence to full cabinet status and establish a department for nursing home regulations and enforcement distinct from DPH.
- Open records of people with disabilities who resided in state institutions (H3335)
- Require disclosure of Continuing Care Retirement Community entrance fees (S478)
- State should maintain dollar value of state share of MassHealth even if federal match is reduced.
- End Private Equity Ownership of long-term care facilities (S721/H1221)

5. Support Enactment of Key Federal Legislation and Budget:

- Older Americans Act Reauthorization Act of 2025 (S4776 of 2024)
- Elder Justice Act Reauthorization and Modernization Act of 2025 (H.R. 2718 of 2023)
- Essential Caregivers Act of 2025 (H.R. 8331 of 2024)
- Funding the Older Americans Act Program
- Investing in Programs that Prevent Falls
- Support expansion of Hospital at Home funding
- Protecting the Supplemental Nutrition Assistance Program
- Saving the Senior Community Service Employment Program

6. Adopt Regulation and Support Enforcement:

- Update minimum staffing ratios using evidence-based research.
- Enforce the current requirement for not more than two residents per room, and offer incentives to move to single rooms and baths.
- Fully vet sale or closure of facilities with adequate public notice and hearings and require transfer within a reasonable distance, preferably to home in preference to another institution.
- Expand consumer protection regulations to include assisted living.
- Conduct a fire safety audit in all assisted living residences and rest homes.

Areas for further Action.

Several studies were authorized pursuant to Chapter 197 of the Acts of 2024. The recommendations of these studies may offer additional suggestions for consideration by policymakers and advocates. A significant factor in the less than robust recommendations, however, is that most, if not all, of the study groups only released recommendations for which there was consensus among the members. This means that any member objecting could veto a recommendation. Since the makeup of the groups was determined in statute to include industry representatives with a vested interest in the outcome, some promising ideas were not recommended.

Dignity Alliance plans to develop an evaluation of several reports, including comments.

- Rest Home Task Force – Section 27 - April 1, 2025
- Continuing Care Community Task Force – Section 29
- TAC-PAC Task Force Section 25 - July 31, 2025
- Viability and Sustainability of Long-Term Care Facilities Task Force Section 31, August 14, 2025
- DPH Guardianship Study
- Special Commission on Assisted Living -Section 32

Dignity Alliance has identified the following topics which warrant detailed study and recommendations:

- Public guardianship
- Guardianship reform
- Supported decision making
- Dementia support for individuals and caregivers
- Behavioral health
- Substance abuse by older adults
- Nutrition services and education
- Access to quality primary care services for older adults and persons with disabilities
- Family caregiving information and training
- Accessible transportation

Conclusion

Massachusetts cannot afford to wait for the predictable demographic surge to become an unmanageable crisis. The values of our Commonwealth are clear: we believe in dignity, autonomy, and community. The path forward requires us to be both pragmatic in our planning and bold in our reforms. Without immediate, coordinated action, the Commonwealth risks deepening a crisis that undermines public trust, endangers lives, and violates basic human rights. By integrating a modernized, targeted approach to institutional care with a profound reinvestment in home and community-based services, Massachusetts can lead the nation in building a long-term care system that is sustainable, compassionate, and works for everyone.

Dignity Alliance Massachusetts is a broad-based group representing a wide range of stakeholders, including nursing home resident advocates, disability rights organizations, legal service entities, mental health organizations, health policy experts, faith-based groups, and labor organizations, and those representing the voices of older adults and individuals with disabilities. Our aim is to advance policies that revolutionize long-term care, putting the dignity of individuals first, ensuring affordable options for community living, and providing living wages and benefits for caregivers and service workers in facilities and home and community-based settings.

Dignity Alliance Massachusetts is dedicated to transformative change to ensure the dignity of older adults, people with disabilities, and their caregivers. We are committed to advancing new ways of providing long-term services, support, living options, and care, while respecting choice and self-determination. Through education, legislation, regulatory reform, and legal strategies, this mission will become reality throughout the Commonwealth.

www.DignityAllianceMA.org