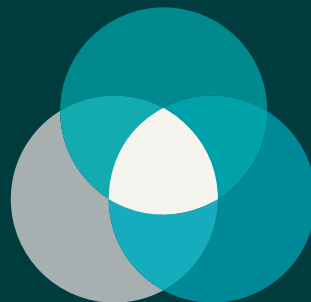


Reimagining the future of long- term care and services in **Massachusetts**



**Dignity
Alliance
Massachusetts**

Respect • Self-determination • Choices



Dignity Alliance Massachusetts, a grass-roots coalition of aging and disability service and advocacy organizations and supporters, is dedicated to secure fundamental changes in the provision of long-term services, support, and care.

We are pursuing an array of efforts to secure new public policies and to expand access to essential service and care options and living alternatives emphasizing the dignity of those receiving the care as well as those providing it.

Learn more at dignityalliancema.org

Dignity Alliance Massachusetts commends the Senate Committee on Reimagining the Future of Massachusetts

on the October 2021 release of such a forward-looking document and policy proposals. There is much in the report to be applauded by older adults, people with disabilities, caregivers, and their advocates.

However, there are also areas where we will respectfully offer suggestions or expand on points made in the report.

Scope of the Challenge:

There are few populations more disproportionately affected by COVID than older adults, persons with disabilities, and nursing home staff and other caregivers. There are few economic sectors more adversely impacted than the care economy, especially long-term care. However, the crisis is also creating opportunities for substantive transformation if we take advantage of them. The significant decline in nursing home occupancy and pervasive and chronic staffing shortages are inviting the meaningful and creative reimagination of systems of health care, housing, and supportive services to optimally meet the needs and personal choices of older adults and people with disabilities.

Dignity Alliance urges decision makers, as they reimagine Massachusetts post-COVID, to look beyond what divides us and recognize the dignity and humanity we share in common. We must acknowledge that the Covid-19 pandemic has exposed a vast array of dignity-decimating fault lines in our society. An unconscionable number of our neighbors have suffered disproportionately during this time, including persons in nursing homes, Black and Brown individuals, people with disabilities who rely on home and community-based services, and paid and unpaid caregivers.

For these neighbors, concerns about dignity ring hollow, especially given our nation's founding commitment to ensure the "unalienable rights" to "life, liberty, and the pursuit of happiness."

Reimagining the future of Massachusetts gives all of us in the Commonwealth a chance to step back and consider what we can do to ensure that individual dignity is not a right reserved for a fortunate few.

We believe that the problems laid bare by the pandemic stem from a critical flaw: Our systems and safety nets have not been designed with dignity in mind. Because of this "design flaw," minor tweaks cannot achieve necessary fundamental changes. **We must commit to true transformation.**

A Commonwealth-wide commitment to a dignity-centered redesign can drive the changes we need. For frail elders, dignity often means living at home in their final months or years. For people with disabilities, it means living in the community of their choice rather than being isolated in a facility. For caregiving staff, it means being treated with respect and earning a living wage that can support a family.

What needs to be done?

For starters, we must increase supports to give older adults and people with disabilities the opportunity to live out their lives in their homes of their choice. For those who prefer or need to live in a long-term care setting, we must ensure that they get optimal care and absolute protections from abuse and neglect. We must halt building large “institutions” and ensure person-centered care. Dr. Bill Thomas’s successful “Green House” model, which we endorse conceptually, offers a home-like structure and a community-oriented environment to those in need of individualized, comprehensive care.

We must also ensure that people with physical disabilities have affordable, accessible housing and functioning wheelchairs, and that our transportation system works so that all people can get to work and appointments on time, with their dignity intact. We must, finally, meet the promise of the Americans with Disabilities Act (ADA) and make certain that all buildings and facilities—workplaces, public buildings, restaurants, theaters, gyms, and outdoor spaces—are accessible and welcoming. We must better recognize, train, and compensate caregiving staff, and we must assist family members, including spouses, who struggle heroically to care for and keep their loved ones at home.

This crisis has shown us that when people have digital devices and broadband, they can fully participate in myriad family, work, and civic events. Thanks to the Internet and Zoom, the voices of many seniors and people with disabilities throughout the Commonwealth, once muted, can now easily be heard. Decision-makers, whether in the Legislature, long-term care facilities, home care agencies, or other organizations, must include older adults and persons with disabilities throughout the transformative process—from planning and budgeting to implementation and evaluation.

Doing this right will cost money and require legislative commitment. Several current Massachusetts bills and increased federal support already exist to begin to address these issues. Most of us have family members, friends, or neighbors who are older, frail, or disabled. One day, most of us will become so, too. Don’t we want a Commonwealth that allows each of us to live our lives with dignity, however each of us defines it? Isn’t that a society of which we want to be part?

The Senate report includes this statement: “Propose policy solutions that can expand opportunity, narrow racial inequities, and generally improve the lives of people across Massachusetts.” Dignity Alliance recommends alternative language: “Propose policy solutions that can expand opportunity, narrow racial inequalities, and generally improve the lives and respect the dignity of people across Massachusetts.”



Dignity Alliance respectfully offers the following for policy consideration. In some instances, we identify pending legislation and current funding opportunities which could expedite implementation of several key aspects of the Senate report. Enactment in the current legislative session would jump start implementation of the goals contained in the Committee's report.

1. The Digital Divide

Dignity Alliance applauds recommended policy solutions to close the current Massachusetts “digital divide.” In particular, we applaud steps taken by the state to expand the use of technology providing services to older adults and persons with disabilities.

Another important innovation arising from the pandemic experience is the opening of access to legislative hearing at the State House through video conferencing technology. Not only does this technology allow older adults and persons with disabilities to play a more active role in civic affairs, but all citizens from across the Commonwealth are able to participate in democratic activity through video conferencing. Prior to COVID, anyone wishing to support, oppose, or amend pending legislation had to give up the better part of a day, travel to Boston, and pay for expensive parking in order to offer in-person testimony. The time and expense of participating in public hearings can be minimized through this technology especially if the three virtual hearings could occur simultaneously.



Current legislation would continue the ability to offer remote testimony post-pandemic if S2104/H3214 An Act updating the Open Meeting Law to support remote participation were enacted.

2. Child Care, Early Education, Intergenerational Care and the Care Economy

Senior Care

Older Adults are often victims of ageism – discrimination based on age. Any reimagining of the future for Massachusetts residents must clearly address the issue of ageism.



Current legislation that could assist people to live in their homes or in the community, include:

- **Senate 397/House 747, An Act to increase awareness of community-based PACE Programs for older adults**
- **Senate 748/House 227, An Act to support equal access to community care for elders and the disabled.**



As long as large skilled nursing facilities are licensed in the Commonwealth, Dignity Alliance respectfully urges enactment of several bills that would bring transformative change to long-term care.



It is indeed clear from the COVID experience that long-term care as delivered in large skilled nursing facilities is not successful in consistently delivering safe, quality care. While many of the deficiencies of nursing homes were well-known prior to the pandemic, they were amplified during COVID. Few residents of Massachusetts would voluntarily choose an existing nursing home to live out their lives. Residents are deprived of their dignity and any reasonable control of their lives.

They are:

- **Senate 414/House 727 An Act to ensure quality of care in nursing homes**
- **Senate Bill 413 An Act to improve employer standards for Massachusetts nursing homes**
- **Senate 1476 An Act to improve infection control in long-term care facilities**
- **Senate 1482 An Act Ensuring Access to a Resident Representative in Long-Term Care Facilities**
- **Senate 412 An Act increasing the personal needs allowance for residents of long-term care facilities**
- **Senate 422 An Act relative to reserving beds in nursing homes during certain leaves of absence**
- **Senate 1506 An Act to protect patients with Alzheimer's, dementia, and other psychiatric illnesses**

Massachusetts must transition from large, impersonal institutions in favor of expanded home and community-based supports and services. For individuals who need more intensive care, Dignity Alliance recommends the Small Home model of care. A plan and timetable must be developed to implement this transition. Dignity Alliance respectfully urges enactment of **Senate Bill 406 to advance the small house concept.**

In addition, we strongly believe that, in the wake of the tragedy that COVID-19 visited

on nursing homes, the **Nursing Home Resident Bill of Rights** urgently needs to be updated and revised along with the development of simplified guidance on how to take advantage of those rights as well as the implementation of a robust process for enforcing the rights.



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In a related matter, military veterans, whether older adults or with disabilities, need a better system of long-term care than that offered by the two large state soldiers' homes (Chelsea and Holyoke). The U.S. Veterans Administration Small House Model should be implemented in every region of the Commonwealth so that aging and infirmed veterans can remain close to families, friends, and communities (e.g., two Small Houses in each Congressional District).

We are pleased that the Governor and the Legislature have authorized, through a bond, \$200 million to deploy the Small House model for veterans throughout the Commonwealth. (**Acts of 2021, Chapter 15, Section 2, Item 4000-2027**). Dignity Alliance respectfully urges that hearings be held in 2022 in various geographical regions to evaluate the need for long-term veterans-care and potential locations for Veterans Small House projects.

People with Disabilities

People with disabilities are often victims of “ableism,” discrimination of people on account of a wide-range of disabilities and conditions – physical, mental, and behavioral.



There are several bills in the current legislative session that could make significant improvement in this post-COVID society.

A major step in improving access to housing for older adults and people with disabilities is to enact **Senate 1627 An Act building a more accessible Massachusetts expanding the scope of the Architectural Access Board.**

Senate 745/House 1256 An Act to prevent discrimination against people with disabilities in the provision of health care would be an important step, especially in times like a pandemic when health care could be rationed as it has been in some other states.

People with disabilities who use wheelchairs lose their independence and their ability to participate in work and community life when their wheelchairs need repair and they have no back up equipment. **Senate 184/House 446 An Act expanding wheelchair warranty protection for consumers with disabilities** would offer a relatively simple, but effective, resolution of this issue.

Workers in the Care Economy

The care workforce working in the field of long-term care for older adults and persons with disabilities in any reimagining of Massachusetts includes a significant percentage of women, recent immigrants, and low-income workers. The pandemic demonstrated the high level of risk and responsibility of these caregivers working in facilities and in home care. To attract qualified workers, they must be compensated with living wages and benefits. They must be employed in sufficient numbers to meet high standards of care as required by regulations. Whenever, the ratio of caregivers to care receivers falls below state standards, facilities must be prohibited from accepting new residents.

Even with a living wage, and a professional pathway, it is unlikely that sufficient numbers of care workers can be readily recruited in the foreseeable future to guarantee safe, high-quality care. Therefore, barriers to attracting new workers such as language and cultural differences must be addressed. Furthermore, barriers that prevent family members, especially spouses, from being compensated, need to be removed.

Dignity Alliance urges that skilled nursing facilities be specifically licensed for post-acute rehabilitative care or for long-term care, but not for both. The needs of each population differ sufficiently to require different skill levels among caregivers and operating policies.



Current legislation which would assist the workforce in the care economy include:

- **Senate 403/House 724 An Act to improved nursing home job standards and care quality**
- **Senate 419/House 748 An Act to Create safe environments for home care workers and consumers**
- **Senate 404/House 756 An Act to strengthen emergency preparedness for home care workers**

Current legislation which eases the shortage of care givers in home care is **Senate 89, House 268, House 1305, to permit spouses to be compensated.**

A current bill which helps to reduce inequity in caring for older adults is **House 2246 An act relative to CNA training** that directs the Department of Public Health to offer certified nursing assistant (CNA) exams in Chinese and other languages.

3. New Paths to Economic Opportunity

Retirement used to mean the end of one's working life. But having a job during one's elder years is now becoming increasingly common. That means more older people are figuring out how to make money after retirement. Just look at these numbers:

By 2024, one in four workers will be older than 55, according to Reuters. That's double what it was in 1994. Close to half of the new jobs created in 2018 were filled by 55-and-older workers, making seniors the age group with the biggest job growth that year. About one in three workers expect to be 67 or older when they retire.

In addition, many employers now actively look to hire older adults. More employers recognize and value the loyalty, positive work attitude and strong work ethic of experienced and mature workers. These same characteristics can also be found among persons with disabilities. The Committee's goals of expanded broadband and use of technology will greatly benefit workers who are older or are persons with disabilities who can, in many cases, work from home.



Current legislation such as **House 2419 An Act removing barriers to work that discriminate against persons with disabilities, mobility impairments and seniors** cries out for early enactment.

4. Housing Prices and Real Estate

Reimagining the cost of housing in the Commonwealth should include enhanced funding for additional rental assistance vouchers. The vouchers are essential for adults under age 60 with disabilities and living in skilled nursing facilities in many cases to secure appropriate accommodations to live successfully in the community with home and community-based supports and services.

Programs which support integrated, accessible, and affordable housing for people with disabilities, including the Home Modification Loan Program, the Community Based Housing Program, and the Alternative Housing Voucher Program, are important and need additional financial support. As we seek to reimagine Massachusetts in a post-COVID world, housing remains a critical concern for people with disabilities. Dignity Alliance and other organizations advocate increased funding for the Alternative Housing Voucher Program (AHVP), which provides rental assistance to low-income people with disabilities. We also support housing opportunities with appropriate funding for adults with behavioral health concerns.

Dignity Alliance expresses genuine concern that, although the Governor and Legislature authorized a bond issue of \$200 million for small homes for veterans in all regions of the Commonwealth, no action appears to have been taken to implement this program that would dramatically improve housing opportunities for aging and disabled veterans. For that matter there also does not appear to be any real progress on the initial \$400 million allocated to improve the Soldiers Home in Holyoke and adopt the small house model to replace that outdated facility.

Another strategy which could keep people from the need to consider residing in a nursing home is to develop a program for home improvements to make homes more accessible, so that older adults could age in place and not have to move.



Related to this effort is current legislation that would allow accessible living units to be added to existing homes without the complication of local zoning permits. **House 205, An Act to livable home modification program and associated funding** would be a positive step. **Senate 900/House 1407 An Act to prevent and respond to bullying of elderly and disabled residents** would also provide added protection in public housing.

Another key step is also needed to protect the homes of older adults on MassHealth. **Senate 749/House 1246 An Act Protecting the Homes of Seniors and Disabled People on Mass Health** would provide relief against loss of homes when a loved one needs extensive health care. **Senate 418/House 745 An Act to establish personal care homes for older adults** would help people who need more care than can be provided in their home to benefit from group homes rather than resort to nursing home care. This concept could also be considered in the development of Green House/Small Home style residences.

5. Transit and Transportation

Addressing the unique issues older adults and people with disabilities face in accessing and using transportation options are important concerns as we reimagine Massachusetts in the coming years.

We urge engagement of older adults and people with disabilities before new transportation options are created and to use their insights and experiences to improve transportation programs and policies. Older adults and persons with disabilities know about the transportation choices available in their community and understand how to access these options. One-on-one assistance should be available to assist older adults and persons with disabilities to select the best transportation options to meet their needs and use the transportation options available in the community.

Transportation for older adults and persons with disabilities is a key area in need of reimagining. Dignity Alliance applauds recommendations such as reduced MBTA fare cards for older adults and free bus fares.

Conclusion



Dignity Alliance Massachusetts, and many of our member organizations, stand ready to work with the Legislature in the process of reimagining Massachusetts in this post-COVID era. As we have pointed out in this statement, the Legislature has before it, numerous pieces of legislation as well as funding opportunities that would make a significant start in bringing about the advances envisioned in the Committee's report.

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Endorsement

This statement has been endorsed by forty-two Dignity Alliance Massachusetts participants including the following organizations and individuals:

- Rebecca Belesky, Mutual Support Consulting, LLC
- Boston Center for Independent Living
- Center for Living & Working, Inc.
- Disability Law Center
- Disability Policy Consortium
- Disability Resource Center
- Easter Seals Massachusetts
- Lachlan Forrow, MD
- John J. Ford, Esq.
- Greater Lynn Senior Services, Kathryn Burns, CEO
- Independence Associates, Inc.
- LifePath
- Massachusetts Advocates for Nursing Home Reform, Arlene Germain, Policy Director
- Paul Spooner, MetroWest Center for Independent Living
- Judi Fonsh, MSW
- Wynn Gerhard
- Fred Grosso
- Sandy Hovey
- Anne Johansen
- Paul J. Lanzikos
- James A. Lomastro PhD, Larchmeadow Associates
- Posie Mansfield, President and Co- Founder, COP Amputee Association-COPAA
- Massachusetts Councils on Aging
- Melrose Council on Aging, Stacey Minchello, Director
- Mary Margaret Moore
- Former Senator Richard T. Moore
- Sandy Novack, MBA, MSW
- Older Adult Behavioral Health Network (formerly the MA Aging and Mental Health Coalition)
- SeniorCare, Scott Trenti, CEO