

2022

Annual Report



**Dignity
Alliance
Massachusetts**

Respect • Self-determination • Choices

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Letter from Paul J. Lanzikos:

Dear Friends and Colleagues,

In many ways, 2022 was a turning point for Dignity Alliance Massachusetts (DignityMA). Since coming together as an all-volunteer, ad hoc group during the COVID-19 pandemic, we have now established ourselves as an organization wholly committed to transformational systems change for older adults, people with disabilities, and their caregivers.

Two major events marked the year. First, we launched [Dignity Votes 2022](#), a non-partisan education and advocacy campaign that sought to educate and engage candidates for state constitutional and legislative office on relevant issues. We provided candidates with educational materials and invited them to share their thoughts, through a questionnaire and recorded interviews, with constituents, advocates, elected and government officials, and others. We posted the interviews and the surveys on our website.

We continue to be grateful to all those who took the time to learn about the issues that impact some of our most vulnerable fellow residents and look forward to forging strong working relationships with many elected officials in 2023 and beyond.

The second event that marked a turning point for DignityMA this year was our merger with the [Massachusetts Advocates for Nursing Home Reform \(MANHR\)](#) and our assumption of its non-profit 501(c)(3) status. For more than 20 years, MANHR was the only statewide consumer group advocating for improvements in the care, dignity, and quality of life for Massachusetts nursing home residents. With MANHR's leadership approaching retirement, the organization has now transitioned into a critical educational program of DignityMA, complementing the organization's ongoing advocacy around long-term care options. MANHR continues to maintain a comprehensive website to educate the community on long-term care issues: www.manhr.org, which can be accessed directly or through the DignityMA website www.dignityalliancema.org.

Building on the advocacy and education work of DignityMA—now well established and recognized by policymakers—we plan, for the first time, to sponsor legislation, while continuing to endorse bills filed by others that address our values, mission, and goals.

Warmly,

Paul J. Lanzikos

Co-Founder and Coordinating Committee Chair

Former Secretary, Massachusetts Executive Office of Elder Affairs

April 2023



Our Mission: 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.

Learn more at dignityalliancema.org

“You can’t throw any more money into this institutional model [of long-term care]. It’s the model that’s broken and needs to be changed.”

Fiona Whittington-Walsh, a disability studies scholar at Kwantlen Polytechnic University in Canada and the president of the board of directors for Inclusion BC, an organization that has fought the institutionalization of people with developmental disabilities in British Columbia. *Quartz*, June 25, 2020, “Coronavirus is renewing a call to abolish nursing homes” <https://tinyurl.com/CallToAbolishNursingHomes>

Our Story:

Dignity Alliance Massachusetts (DignityMA) was formed in mid-2020, motivated by the tragedy of so many deaths from COVID-19 in long-term care facilities. People from aging and disability service and advocacy organizations, individual advocates, policy makers, legal service organizations and attorneys, and concerned citizens came together to accelerate the process of transforming the Commonwealth's antiquated model of long-term care, which inhibits older adults and people with disabilities from living their lives with dignity.

DignityMA is working to transform the Commonwealth's long-term care system from one focused on large institutional facilities, such as nursing homes sheltering hundreds of residents, to the Small House model favored by the U.S. Veterans' Administration when institutional care is needed or preferred, and to change the Commonwealth's emphasis from large-scale institutional care to home and community-based care that allows people to remain in their homes and/or communities. We are also working to improve the quality of care and safety for people living in facilities, homes, and communities and to recognize and support caregivers in their careers so that they, too, can live their lives with dignity.

There are many pieces to this long-term care puzzle that must be put in place, and DignityMA is committed to working with state agencies, the Legislature, the provider sector, and community members to ensure that state-of-the-art long-term services, care, and a full array of living choices are available for all who require them within an "Age and Disability Friendly Commonwealth".

2022 Objectives:

This year, our aim was to continue our efforts to advance policies that revolutionize long-term care, put the dignity of individuals first, ensure affordable options for community living, and provide living wages and benefits for caregivers and service workers in facilities and home-and-community-based settings.

Goal 1: Build a More Resilient and Higher Quality Long-Term Care System

- Ensure that nursing homes provide the highest practicable quality of care and quality of life for those of us who require nursing home care while increasing the ease, availability, and funding for Long-Term Services & Supports (LTSS) services in the community to ensure we can live at home as long as possible.
- Secure resident-centered care with single occupancy rooms, full-time infection prevention, falls prevention, abuse prevention, strengthened family councils, and small (max. 12 residents) facilities.
- Establish minimum nurse and staff ratios, including an update of social work regulations from the 1970s.
- Implement safe visitation policies in all long-term care facilities, including congregate and home care.
- Ensure that nursing homes are the last option among choices for long-term care.
- Improve care and treatment for older, frail inmates of correctional institutions.



Goal 2: Give Meaning and Purpose to More Age-Friendly Communities

- Adopt a Community First 1915 Medicaid Waiver.
- Expand community options and supports to ensure integrated opportunities so that people can remain in their homes and home communities.
- Ensure age-friendly, Americans with Disabilities Act (ADA)-compliant communities with affordable, accessible housing and public transportation.
- End Ageism and Ableism in every community in the Commonwealth.

Goal 3: Protect and Promote Caregivers of Older Adults and People with Disabilities

- Provide a living wage and enhanced benefits for caregivers.
- Provide the broadest possible education in geriatrics for health care professionals and staff.
- Offer behavioral health and wellness programs for long-term care staff.

Goal 4: Strengthen Age-Friendly Emergency Procedures and Response

- Implement enhanced emergency plans, adequate supplies of testing, PPE equipment, and vaccinations for residents, skilled nursing facilities staff and home care aides.

Goal 5: Increased Oversight, Accountability, & Transparency of Long-Term Care Providers

- Increase number of surveyors and complaint personnel to strengthen nursing home oversight, including improving responses to complaints and deficiencies in skilled nursing facilities.
- Increase non-profit ownership of long-term care provider organizations.
- Support meaningful financial penalties for noncompliance to ensure quality care.
- Implement comprehensive licensure vetting process (including management companies).
- Require nursing home closure process that includes the voices of all stakeholders and ensures the safety and well-being of residents transferred to new locations.
- Reinforce safeguards to prevent the misuse and overuse of psychotropic drugs, particularly antipsychotics.

Education & Advocacy

A major part of Dignity Alliance Massachusetts' outreach and advocacy efforts includes informing state agencies, members of the Legislature, the provider sector, the media, and interested citizens on issues affecting older adults, people with disabilities, and their caregivers.

Dignity Votes 2022

Dignity Votes 2022 asked candidates for constitutional and legislative office about topics and issues of concern to older adults, persons with disabilities, their family members, and caregivers. The effort gleaned understanding of candidates through written questionnaires prepared specifically for each office. Recorded interview conversations with candidates for constitutional office were conducted with a panel of DignityMA members. The written submissions and recorded conversations are available at <https://dignityalliancema.org/state-candidates/>.

The Dignity Digest

Throughout 2022, DignityMA published 52 issues of [The Dignity Digest](#), a free weekly compilation of news articles, quotes, studies, conferences and other material to inform readers and spur opportunities for engagement. Currently, the Digest has more than 700 recipients.

Collaboration

DignityMA includes participants from more than 30 service and advocacy groups as well as individuals from around the state who meet bi-weekly via Zoom. This year, we reached out to additional organizations to broaden the reach of DignityMA.

Media

DignityMA subject experts provided more than a dozen deep background and on-record interviews to print and broadcast outlets around long-term care, disability, and caregiver issues. Published letters and op-eds contributed by work group subject experts have served to educate the public on critical issues regarding people with disability, older adults, and their caregivers.





2022 ACTIVITIES & ACCOMPLISHMENTS

Legislative

The Legislative Work Group studies the current Congressional, State Senate and House legislation to identify those bills that align with DignityMA's mission and goals. The group recommends bills for endorsement to the Coordinating Committee and then polls DignityMA participants for potential endorsement. Participants are also given the opportunity to add their own or their organization's endorsement.

In addition, the Legislative Work Group manages the DignityMA Awards process for legislators, develops and presents information on the legislative process for DignityMA participants, and works closely with other work groups to advance bills that best serve older adults, people with disabilities, and their caregivers.

Legislative Advocacy

Dignity Votes 2022

As part of Dignity Votes 2022, candidates for the Legislature were polled regarding their support for addressing issues, if they were elected, that would benefit older adults, people with disabilities, and their caregivers. The survey helped to inform candidates about important issues while helping us forge relationships with future elected officials and potential legislative allies.

Communications with the Legislature

The Legislative Work Group submitted testimony to the relevant legislative committees on bills endorsed by DignityMA. In addition, we wrote to legislative leaders urging an override of the Governor's veto of the pooled trust bill; urged leaders to enact legislation for a COVID-19 Remembrance Day; and wrote to House Ways and Means in support of several budget items. We also wrote to House Ways and Means to urge favorable action on five DignityMA-endorsed bills that were engrossed in the Senate and to advance the bill for nursing home reform with our suggested improvements.

Legislative Training

In cooperation with the Dignity Communications Work Group, a virtual legislative training workshop was held on March 8, 2022, with Jessica Costantino, AARP Massachusetts Legislative Director, to provide an orientation for members of the Legislative Work Group and other interested DignityMA participants.

STATE LEGISLATION ENDORSED BY DIGNITYMA

Legislative Accomplishments

- Chapter 126, Section 144 - (H 4691) to establish a special commission to study and report on the history of state institutions for people with intellectual or developmental disabilities or mental health conditions in the Commonwealth including, but not limited to the Walter E. Fernald state school and the Metropolitan state hospital.
- House 2246 An Act relative to CNA training. The text of the bill was included in H15374 as section 115, and was enacted as part of Chapter 268, but the section was returned by the Governor. Section 115 requires the Department of Public Health (DPH) to offer certified nurses' aide (CNA) exams in languages other than English to nurses' aides who receive their training or work in facilities with primarily non-English speaking populations. DignityMA continues to advocate for this section with language requiring DPH to implement the section on or before October 1, 2023.

Chapter 126 of the Acts of 2022 (House 5050) FY '23 State Budget Priorities

- Maintained the amount (a flat \$72.80) and language for the Personal Needs Allowance.
- Maintained the Bed Hold for nursing home residents, 20 medical leave-of-absence days (includes an observation stay in a hospital in excess of 24 hours), 10 nonmedical leave-of-absence days.
- Increasing amount for Elder Mental Health Outreach Teams (EMHOTS) in line item 9110-1640 by \$1.0M for a total of \$3.5M.
- Fully funded Alternative Housing Voucher, including roll-over funds from the preceding year for a total of \$19.2M million.
- Fully funded accessible affordable housing grants at \$2.5M.
- Funded Geriatric Mental Health services at \$3.5M million.

In Progress

Several Dignity-endorsed bills made significant progress during the 192nd General Court:

- [House 4792](#) (Senate 773/H1274) - An Act to Preserve Special Needs Trusts for Disabled Seniors. Filed by MassNAELA, and endorsed by DignityMA, the legislation made it to the Governor's desk but was vetoed by Governor Baker. DignityMA urged the legislative leadership to return to formal session and override the veto.

- [Senate 2695](#) An Act Relative to Pharmaceutical Access, Costs and Transparency. This law marks a major step in guaranteeing access to affordable healthcare across the Commonwealth.
- [Senate 2848](#) An Act relative to supported decision-making allows individuals with disabilities to make choices about their own lives with support from a team of people they choose.
- [Senate 3136](#) An Act expediting wheelchair warranty protections for consumers with disabilities – protects consumers on repair and replacement of wheelchairs.
- [House 2012](#) An Act to establish a COVID-19 Remembrance Day – Though the bill received significant publicity, it did not get through either branch.

FEDERAL LEGISLATION ENDORSED BY DIGNITYMA

Legislative Accomplishments

- Enacted A.B.L.E. Age Adjustment Act. The Achieving a Better Life Experience Act, one of several federal bills endorsed this term by DignityMA, operates as a long-term savings account for disability beneficiaries without running the risk of losing additional federal benefits, such as Social Security Income and Medicaid.
- Extended funding for the Money Follows the Person program through 2027. This program has already helped more than 100,000 people nationwide to move out of nursing homes and other institutions and back into their communities, and we will continue fighting for it to be made permanent.

In addition, DignityMA endorsed 15 other bills in 2022 related to nursing home improvement and accountability, protections for older adults, people with disabilities, and caregivers, and more.

OUTSTANDING LEGISLATOR AWARDS

Based on nominations by DignityMA participants, the Legislative Work Group honored several state legislators for their exceptional work on long term services and support, as well as their support of key DignityMA endorsements and activities with the organization's first Dignity Awards.



DignityMA Co-Chair Paul Lanzikos and Kim Driscoll, Massachusetts Lieutenant Governor

Lifetime Dignity Achievement Awards

- Senator Harriette Chandler
- Representative Linda Dean Campbell

Outstanding Dignity Legislators

- Senator Patricia Jehlen
- Representative Ruth Balser



Senator Harriet Chandler received DignityMA's "Lifetime Dignity Achievement" Award.



From left: DignityMA participants Chris Hoeh, Lachlan Forrow, Senator Richard Moore, Susie Backstrom, Maura Donahue, and Bill Henning with Representative Linda Dean Campbell (third from left), recipient of DignityMA's "Lifetime Dignity Achievement" Award.

Honorable Mention

- Senator Joanne Comerford
- Senator Julian Cyr
- Senator Jamie Eldridge
- Senator Cindy Friedman
- Senator Michael O. Moore
- Representative Christine Barber
- Representative Josh Cutler
- Representative Marjorie Decker
- Representative Kate Lipper-Garabedian
- Representative Thomas Stanley



From left: Paul Lanzikos, Senator Patricia (Pat) Jehlen, Nino Lombardi (artist), Representative Ruth Balser and Senator Richard Moore following the presentation of DignityMA's "Outstanding Dignity Legislator" Awards.

“As Wall Street firms take over more nursing homes, quality in those homes has gone down and costs have gone up. That ends on my watch.”

President Joe Biden, After Nursing Home Push, Home Health Reform Could Be Up Next, *Home Health Care News*, March 2, 2022, <https://tinyurl.com/HomeHealthReformNext>

Facilities

The Facilities Work Group (Nursing Homes, Rest Homes, and Assisted Living) addresses quality of care and quality of life issues affecting residents. The group develops policy recommendations on many issues, including residents' rights, safe staffing levels, workforce training and wages, COVID-19 pandemic issues, oversight and enforcement, nursing home licensure, closure and financing policies, and more.

In 2022, the Facilities work group was very active in Dignity Votes 2022, our non-partisan campaign to provide information to state (MA) and national candidates. The group developed fact sheets and briefs summarizing the major issues facing residents and caregivers in Massachusetts nursing homes; prepared questions for candidates; and participated in panel interviews with candidates for Governor, Lieutenant Governor, Secretary of State, Attorney General, and State Auditor.

Additionally, the work group provided dozens of written/oral testimony and research on a wide range of nursing home issues, often in tandem with our Legislative work group. Below is just a small sample of this group's efforts.

Massachusetts Advocacy - Highlights

To protect and support nursing home residents and their caregivers, we submitted comprehensive responses to Elder Affairs Committee follow-up questions on the legislation below that was previously heard by the Committee in 2021:

- [S.413/H.733](#) An Act to improve employer standards for Massachusetts nursing homes: addresses nursing home licensures, workforce annual survey, and comprehensive review of nursing home finances.
- [S.414/H.727](#) An Act to ensure quality of care in nursing homes addresses 4.1 hours per resident per day staffing standard, outbreak response plans, social isolation prevention policies, blueprint to minimize congregate living.

- [H.4780](#) An Act to Improve Quality and Oversight of Long-Term Care. Stakeholders, including DignityMA, were included in the development of the legislation that makes several critical reforms in Massachusetts laws governing long-term care and was before the House Ways and Means Committee.
- [S.406](#) An Act relative to Small House Nursing Homes addresses construction of “small home” nursing homes which house 10-14 residents, a more personalized setting than current large facilities, in order to return control, dignity, and a sense of well-being to residents, while providing high-quality, person-centered care.
- [S.424](#) An Act to prevent patient abuse and death in nursing homes sends a strong message that the failure of facilities to protect residents will carry a hefty financial penalty by raising the maximum fine for Massachusetts nursing home regulatory violations from \$50/day to the federal maximum fine, currently over \$22,000/day per infraction.

Federal Advocacy - Highlights

Centers for Medicare and Medicaid Services (CMS) issued a [Request for Information \(RFI\)](#) regarding implementation of a minimum staffing standard in nursing homes, the most important and significant increase in protections for nursing home residents in decades. CMS promised to propose a minimum staffing standard within one year: Submitted extensive response supporting implementation of minimum staffing standard to provide quality care to nursing home residents.

Additional Facilities Work Group efforts to support nursing home residents:

Co-Authored Letter to Department of Public Health (DPH) Commissioner Cooke requesting increased DPH resources to hire additional qualified surveyors to investigate resident and staff complaints in a timely fashion, including complaints the facility claims resulted in “no harm.”

Co-Authored “Resolution Honoring Victims and Survivors of the COVID-19 Pandemic in Massachusetts,” urging the Legislature to enact H.4224 Resolutions establishing the annual observance of COVID-19 Remembrance Day each March.

Reviewed 2023 MA Legislation (filed in December 2022) seeking a wide range of care improvements for nursing home residents.

National Networking

DignityMA interacts with an array of other aging, disability, and long-term care advocacy organizations and individuals throughout the country, including The National Consumer Voice for Quality Long-Term Care (Consumer Voice) in Washington, DC, the Long Term Care Community Connection Coalition in New York, Justice in Aging in California, Tall Grass Economics in Kansas City, Missouri, the Moving Forward Coalition, and Charlene Harrington, Ph.D. RN, Professor Emerita, Department of Social & Behavioral Sciences at the University of California San Francisco.

In 2022, Arlene Germain completed six years on the Board Leadership Council of The Consumer Voice. Richard Moore was elected to the Board in December 2022. Additionally, Richard Moore and Paul Lanzikos are “subject matter experts” with the [Moving Forward Coalition](#).

“We need to grow home and community-based care options while reimagining what a nursing home might look like.”

David Grabowski, Harvard University health care policy professor, Home health, nursing homes look for year-end breaks in spending deal, Axios, October 4, 2022,

<https://tinyurl.com/YearEndBreaks>

Home & Community-Based Services (HCBS)

The Home and Community-Based Services Group focuses on improving and promoting access to home and community-based services as an essential component of the Commonwealth’s long-term services and support continuum.

The group advocates for programs and services that keep individuals in their homes and communities so that they can receive the care they need in the least restrictive setting and prevent unnecessary admissions to nursing homes. It also works to enhance the Commonwealth’s long-term services and support continuum so that nursing home residents, who desire it, might transition home or back to their community with appropriate care. This Work Group also examines the many factors that impact one’s ability to receive care at home, including service capacity and delivery and the state’s waiver and other specialty programs.

In 2022, our HCBS Work Group provided testimony on behalf of:

- S89/H1305 Act allowing a Spouse to Be a Caregiver
- S148/H745 Act to Establish Personal Care Homes
- S184/H446 Warranty Protection for Persons with Disabilities
- S749 Estate Recovery Bill
- S1629 An Act Building a More Accessible Massachusetts
- H 2420 An Act Relative to Expanding the Availability of Adaptable Housing for Consumers with Disabilities, Mobility Impairment and Seniors
- H2419 An Act Removing Barriers to Work that Discriminate against Persons with Disabilities, Mobility Impairments, and Seniors

And undertook the following outreach:

- Submitted letter to the Joint Committee on Ways & Means & House Committee with recommendations on Federal Stimulus
- Sent correspondence to various stakeholders with recommendations on ARPA Spending.
- Sent recommendations to various stakeholders on alleviating the homecare staffing crisis.

Housing

The Housing Work Group advocates for affordable and available housing that will enable nursing home residents to move back into the community if they are able to and so desire.

The group supported the Alternative Housing Voucher Project (AHVP) to provide 50 vouchers to transition people out of nursing homes through the independent living center network. In 2021, the Housing Work Group supported the creation of the AHVP Nursing Home Pilot and advocated for the Department of Housing and Community Development (DHCD) to create a pilot program with the independent living center (ILC) network. The pilot allocated 50 vouchers specifically for people coming out of nursing homes. These individuals would receive support from the ILCs to tackle and turn in the necessary paperwork to receive these vouchers and undertake searches for housing.

In 2022, 13 people secured housing using the AHVP voucher and 12 people found housing through working with ILC staff through the pilot but didn't end up using the voucher. The AHVP Nursing Home Pilot is ongoing. The emphasis on housing as a key to transitions from nursing home facilities back to the community will continue.

The housing working group is also supporting legislation to increase funding for the Alternative Housing Voucher Program, Bills SD1305/ H2598, which will make improvements to AHVP to make the program more usable and the Accessible, Affordable, Housing Grants which create accessible apartments.

Behavioral Health

This workgroup examines current behavioral health practices for older adults and people with disabilities services and advocates for services that are accessible, appropriate, and effective.

Older Adults

We worked with our Legislative Work Group colleagues to effectively advocate for increased funding and services at line item 9110-1640 (Executive Office of Elder Affairs). The budget for Elder Mental Health Outreach Teams (EMHOTs) increased from \$2.5M to \$3.5M, increasing the number of sites in Massachusetts that now offer organized behavioral care services for older adults. These behavioral health services are enabling more older adults to remain in their homes

and communities instead of nursing homes and have decreased the need for visits to hospital emergency rooms.

It is important to note that some of the sites currently providing behavioral services were only budgeted to do so for this fiscal year. Additionally, there are cities and towns in the Commonwealth that do not offer behavioral services for older adults, including Lawrence and some surrounding towns, Cape Cod, north central Massachusetts and parts of Boston, and there are insufficient services for non-English speakers, Black and brown older adults, and the LGBTQ community. Some sites have begun to reach out to these specific groups.

We continued our advocacy efforts on behalf of older adults with behavioral issues who remain in hospitals because nursing homes, despite thousands of available beds across the Commonwealth, cannot adequately care for them due to severe staffing shortages.

People Under Age 60 With Disabilities

More people under the age of 60, many of whom have behavioral and/or addiction challenges, are living in nursing homes. We believe that a modified replication of the EMHOT system would be an effective alternative for this population, both for those currently in nursing homes and those at risk in the community.

This year, we worked with the Massachusetts Rehabilitation Commission (MRC) to advocate for program funding. We helped MRC to obtain AARP funding, which was allocated to individuals currently in nursing homes but not to those at risk in the community.

Nursing Home Social Workers

Social workers are the only professionals who address relationships and behavioral and mental health issues in nursing homes, and they are leaving nursing homes in droves. The Massachusetts regulations for nursing home social workers, written in the 1970s, are outdated. In 2022, we developed nursing home proposals that include recommendations for updating social work regulations.

Legal

The Legal Work Group provides feedback and guidance to other work groups and to the organization as a whole pertaining to laws and procedures. Additionally, the group analyzes cases for their relevance to DignityMA and helps draft and edit position papers for other work groups.

DignityMA's Support for Litigation Efforts

Simmons v. Baker – In October 2022, six people with disabilities who are unnecessarily institutionalized in nursing facilities, joined by the Massachusetts Senior Action Council, filed an Olmstead class action lawsuit in federal district court seeking to compel the Commonwealth to expand its existing residential and community programs so that people with disabilities, including older adults, in nursing facilities can make informed choices and have meaningful options to live

successfully in the community. DignityMA issued a statement of support for a prompt resolution by the Commonwealth of the Americans with Disabilities Act and the Medicaid Act claims against it.

Commonwealth v. Clinton – In 2020, the Commonwealth brought charges stemming from the deadly outbreak of Covid-19 at the facility against former Holyoke Soldiers' Home Superintendent Bennett Walsh and former medical director Dr. David Clinton. In November 2021, the trial court dismissed the charges against the defendants. The Attorney General appealed the dismissal, and the Supreme Judicial Court heard arguments on whether to revive the indictments in January 2023. DignityMA has supported the Attorney General's efforts to hold the former administrators of the Soldiers' Home responsible for the criminal neglect and mistreatment of elderly and disabled people.

River Terrace Operator LLC, et al. v. The Commonwealth of Massachusetts, et al. – In May 2022, several nursing facilities sued the state over regulations requiring them to house no more than two people per room. A state Superior Court judge entered a preliminary injunction preventing the rule from going into effect. The nursing facility industry continues to fight the state's attempts to de-densify nursing facility occupancy – efforts directed at improving infection control and resident quality of life. DignityMA has been working with the Attorney General to defend the new regulations.

Veteran Services

The Veteran Services work group continued to advocate for the development of Small Homes as the replacement for the Holyoke Soldiers' Home. DignityMA is advocating that the state use the \$400 million in authorized bond funding to build these Small Homes and to create additional ones throughout each of the other eight Congressional Districts using the other \$200 million authorization. In 2023, we will work with the new Healey-Driscoll Administration to continue our efforts to better serve veterans requiring long-term care services and support.

Communications

The Communications Workgroup raises awareness of DignityMA and initiatives and shares topical news and resources. Members of this group update the website, brainstorm content, campaign ideas and educational opportunities, and advocate through social media and public relations.

In 2022, the Communications Work Group advocated for change through media outreach, support of the development of Dignity 2022 educational materials, and other efforts, including coordinating communications planning and execution, as needed.

Follow us on social!



Note: Please visit our Work Group pages at <https://dignityalliancema.org> for more information on each group's activities

Selected Quotes from Various Media Sources

“To care for them, you have to give them dignity. That is the main factor they stress at the job, yet you don’t give us the staff to provide that. They look to you for comfort, but then when you don’t have time to adequately give them the comfort they deserve, it’s not fair and then it’s on your conscience.”

Holly Ward, a geriatric nursing assistant at a Baltimore MD nursing home, Nursing home residents suffer from staffing shortages, but the jobs are hard to fill, *NPR*, April 6, 2022, <https://tinyurl.com/StaffingShortagesHardToFill>

About 420,000 nursing home workers have left the industry since the start of the pandemic, according to the U.S. Bureau of Labor Statistics data, as nursing homes have lost 15.2% of the industry’s total workforce.

Inside the Race to Certify Temporary Nurse Aides as End to Waiver Nears, *Skilled Nursing News*, May 4, 2022, <https://tinyurl.com/RaceToCertify>

“Improving nursing home performance and the care they provide is my number one priority. When those facilities and their owners fail to protect our most vulnerable populations, OIG will not hesitate to implement its powerful exclusion tool to safeguard HHS programs and the people they serve.”

Inspector General Christi A. Grimm, HHS-OIG Issues Notice of Exclusion to Owner of 7 Louisiana Nursing Homes, *U. S. Health and Human Services Office of Inspector General*, May 23, 2022, <https://tinyurl.com/7LANursingHomesExcluded>

“I am a caregiving expert. How did I end up in bankruptcy? . . . I made my choices and did my best for my parents. If it can happen to me, it could happen to anyone.”

Amy Goyer, AARP’s family and caregiving expert, Caring for Older Relatives Is So Expensive That Even AARP’s Expert Filed for Bankruptcy, *Wall Street Journal*, February 20, 2022, <https://tinyurl.com/CaringForOlderRelatives>

“I got you.” (Lady Gaga to Liza Minelli). “I know.” (Liza’s reply)

Lady Gaga’s moment with Liza Minnelli was a beautiful example of caring with dignity, *Upworthy.com*, March 30, 2022, <https://tinyurl.com/LadyGagasMoment>

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“This is not any average population that’s being displaced. These are frail, at-risk individuals and disrupting them in even relatively modest ways can be problematic.”

Paul Lanzikos, DignityMA Massachusetts Coordinator, Assisted living residents given 90 days to move out, *Salem News*, April 21, 2022, https://salemnews-cnhi.newsmemory.com/?publink=1d80c79a7_1348429

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“It’s hard to get people interested in older adults. Challenging ageism is one of our efforts and that includes raising the consciousness of people, because it’s truly affecting the self-esteem of older adults.”

Patricia Zaido, Founder and Chair, Salem for All Ages Task Force, Age-Friendly Salem, Massachusetts, *AARP Livable Communities*, May 2022, <https://tinyurl.com/AgeFriendlySalem>

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“For too long, our society has devalued the elderly and people with disabilities as well as the workers who help them lead more enriched and independent lives. It is no coincidence that women—particularly women of color and immigrants—perform much of this hands-on care work, both paid and unpaid, in homes and in residential long-term care settings.”

Julia Wolfe, former Economic Policy Institute state economic analyst and co-author of the report: The state of the residential long-term care industry, *Economic Policy Institute* media release, July 27, 2022, <https://tinyurl.com/EPILTCReportMediaRelease>

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“As Wall Street firms take over more nursing homes, quality in those homes has gone down and costs have gone up. That ends on my watch.”

President Joe Biden from his State of the Union Address January 2022, When Private Equity Takes Over a Nursing Home, *New Yorker*, August 25, 2022, <https://tinyurl.com/PrivateEquityTakesOver>

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“All nursing facility residents should be able to enforce their right to be free from chemical restraints and illegal discharges. When nursing facilities violate these rights, the residents need to be able to seek the protection of the courts.”

Maame Gyamfi, senior attorney for the AARP Foundation, Why a Nursing Home Case Heard by SCOTUS Could Have Sweeping Implications, *Skilled Nursing News*, November 4, 2022, <https://tinyurl.com/SCOTUSSweepingImplications>

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It’s time for real transparency and full disclosure to justify any more taxpayer bailouts for an industry that older adults and others believe has failed them.

Former State Senator Richard T. Moore, Chair DignityMA Massachusetts Legislative Workgroup, Are nursing homes really in tough shape?, *CommonWealth Magazine*, November 26, 2022, <https://tinyurl.com/NursingHomeToughShape>

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The United States is one of the few developed countries that does not have a national long-term care planning and financing strategy to respond to the needs of a growing aging population that wants to receive affordable care in their homes and communities.

A Focus on Health Care: Five Key Priorities for the Next Administration, *Massachusetts Blue Cross Blue Shield Foundation*, December 2022, <https://tinyurl.com/FocusOnHealthCare>

.....

As governor, I’m going to continue to stand up for the tens of thousands of homecare workers who are providing vital care, compassionate care, to ensure that people are able to live independently, safely and with dignity. We deprive ourselves as a Commonwealth when we fail to recognize the dignity, the worth and the capacity of each person in this state.

Governor-elect Maura Healey, Healey vows to address shortage of personal care attendants, *Hampshire Gazette*, December 27, 2022, <https://tinyurl.com/HealeyVowsToAddressShortage>

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“I don’t think I’ve found anybody in Massachusetts who thinks we have enough people playing in the behavioral health space to take care of the people who are trying to access services. [We] had issues with respect to access to those services before the pandemic.”

Gov. Charlie Baker, Gov. Baker: Bill would expand mental health care services, *AP News*, March 15, 2022, <https://tinyurl.com/BakerExpandMentalHealth>

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IN MEMORIAM

Paul W. Spooner

April 17, 1955–October 8, 2022



Governor Maura Healey, Paul Spooner (center) & Bill Henning

Paul Spooner was one of the earliest participants in Dignity Alliance Massachusetts. He brought to every membership and coordinating committee meeting both his professional expertise as the Executive Director of MetroWest Center for Independent Living and his personal commitment to the dignity and independence of individuals with disabilities. Paul spoke with both directness and clarity on the changes needed to improve the lives of people with disabilities, as well as the lives of those who help care for them.

DignityMA is grateful for the collaboration and friendship Paul shared with us. We dedicate this 2022 Annual Report in his name and in celebration of a life well lived.

“Paul Spooner’s fingerprints are on “too many bills, programs, civil rights complaints, and other advances for people with disabilities to count.”

Statement from The Boston Center for Independent Living as appeared in the *MetroWest Daily News*, Oct. 11, 2022

“Paul was instrumental in creating a vision for our commission that would modernize accessibility rights in Massachusetts. He was driven, passionate and strategic in his advocacy, where his voice impacted policy and programs that improved the lives of countless individuals with disabilities.”

Chairwoman Rep. Denise Garlick, Commission on the Status of Persons with Disabilities, *MetroWest Daily News*, Oct. 11, 2022

“I think everyone was in awe of Paul. He could balance his incredible expertise on ...public policy with an incredible humanity and a real forward-looking vision.”

Alex Green, public policy professor, Harvard Kennedy School of Government, *WGBH*, October 11, 2022

Media Coverage

In 2022, we provided more than a dozen in-depth media briefings, participated in many interviews, and developed several op-eds and letters to the editor in response to news coverage related to our mission. We continue to appreciate the opportunity to work with the media to educate the public and the legislature on critical issues affecting older adults, people with disabilities, and their caregivers.

Healey Vows to Address Shortage of PCAs

by Henry Kuczinski

Daily Hampshire Gazette, December 26, 2022

Comments by DignityMA's Bill Henning and Charlie Carr

<https://dignityalliancema.org/2022/12/28/healey-vows-to-address-shortage-of-personal-care-attendants/>

Crisis of Care for Older Adults should be a Call to Action, not a Plea for More Tax Dollars.

By Paul Lanzikos, Arlene Germain, Richard Moore, Lachlan Forrow. MD

Boston Globe, December 23, 2022

<https://dignityalliancema.org/2022/12/28/how-to-better-care-for-our-elderly-and-frail/>

Consolidation of senior care homes is uprooting hundreds across Massachusetts

Article by Robert Weisman, Globe Staff

Boston Globe, October 9, 2022

<https://dignityalliancema.org/2022/10/10/consolidation-of-senior-care-homes-is-uprooting-hundreds-across-massachusetts/>

I-Team: Advocates say nursing home crisis could be looming

CBS Boston I-Team, September 15, 2022

<https://dignityalliancema.org/2022/10/04/i-team-advocates-say-nursing-home-crisis-could-be-looming/>

This persistent ageism is no laughing matter

Response to Globe article by Margaret Morganroth Gullette, DignityMA MA member

Boston Globe

Letter to the editor, September 28, 2022

<https://dignityalliancema.org/2022/10/03/birthday-cards-about-aging-the-joke-lands-with-some-not-others/>

Plans to create day of remembrance for COVID-19 victims are languishing

State and federal proposals for commemorations remain bottled up amid partisan divide.

By Robert Weisman

Boston Globe, Updated September 27, 2022

<https://dignityalliancema.org/2022/09/29/COVID-19-day-of-remembrance/>

‘A hostile act’: CDC eases masking rules for hospitals and nursing homes, but they won’t apply to Mass. yet.

By Felice J. Freyer Globe Staff

Boston Globe, updated September 27, 2022

<https://dignityalliancema.org/2022/09/29/masking-in-facilities/>

The Legislature’s Missed Opportunity—Failure to Reform Nursing Homes in Massachusetts

An op-ed by Sen. Richard Moore of DignityMA

CommonWealth, August 8, 2022

<https://dignityalliancema.org/2022/08/08/the-legislatures-missed-opportunity-failure-to-reform-nursing-homes-in-massachusetts/>

Dignity Alliance Massachusetts Support for White House’s Proposed Nursing Home Reforms.

[*Gloucester Daily Times*](#), Paul Lanzikos, March 9, 2022

[*Salem News*](#), Paul Lanzikos, March 9, 2022

[*Greenfield Recorder*](#), Arlene Germain, March 9, 2022

Dignity Alliance Massachusetts Co-Founders:

- Arlene Germain, Co-founder, Massachusetts Advocates for Nursing Home Reform (MANHR) founded in 2000, and as of 2022, a program of DignityMA.
- Bill Henning, Executive Director, Boston Center for Independent Living
- Paul J. Lanzikos, former Secretary, MA Executive Office of Elder Affairs
- Richard T. Moore, former MA Senate President Pro Tempore

Coordinating Committee

- Co-Chair Paul J. Lanzikos, former Secretary, Mass. Exec. Office of Elder Affairs
- Co-Chair Bill Henning, Executive Director, Boston Center for Independent Living
- Frank E. Baskin, LICSW, Geriatric Care
- Charles Carr, former Commissioner, Mass. Rehab. Commission
- Meg Coffin, CEO, Center for Living and Working, Inc.
- Lachlan Forrow, MD, Senior Fellow, Harvard Medical School Center for Bioethics
- Shaya French, Senior Community Organizer, the Boston Center for Independent Living
- Arlene Germain, MANHR
- Chris Hoeh, M.Ed., Advocate
- Jeni Kaplan, Esq., Center for Public Representation
- Barbara L'Italien, former Massachusetts State Senator
- James Lomastro, Ph.D, Larchmeadow Associates
- Richard T. Moore, former MA Senate President Pro Tempore
- Priscilla O'Reilly, Partner, O'Reilly Communications
- Clarence Richardson, Esq., Executive Director, MassNAELA
- Sue Rorke, Web Manager

Dignity Alliance Work Groups

Coordinating Committee – Co-Chairs: Bill Henning & Paul Lanzikos

Legislative – Chair: Richard T. Moore

Facilities & Regulations – Chair: Arlene Germain

Home & Community Based Services – Chair: Meg Coffin

Behavioral Health – Chair: Frank Baskin

Housing – Co-Chairs: Shaya French & Bill Henning

Legal – Chair: Jeni Kaplan

Veteran Services – James Lomastro, Ph.D

Communications – Co-Chairs: Priscilla O'Reilly & Lachlan Forrow



Participants

Michael Banville	Dennis Heaphy	Lauren Petit
Doris Bardwell	Bill Henning	Vicky Pulos
Frank Baskin	Sandy Hovey	Sue Rorke
Joe Bellil	Alyssa LaJoie	Yashira Ruiz
Rachel Broudy	Lisa Lezooni	Marlene Sallo
Charles Carr	Jeni Kaplan	Stephen Schwartz
Rachel Chartier	Michael Kennedy	Penelope A. Shaw
Meg Coffin	Candy Keubel	Kate Symmonds
Cassie Cramer	Colin Killick	Betty Tegel
Marianne DiBlasi	Alyssa LaJoie	Scott Trenti
Ellen DiPaolo	Linda Landry	Joe Tringalli
Maura Donahue	Paul Lanzikos	Caroline Villers
Michael Festa	Ana Lin	Alison Weingartner
Judi Fonsh	James Lomastro	Dorothy Weitzman
John J. Ford	Barbara L'Italien	Jaime Willmuth
Lachlan Forrow	Nina Lowenstein	Brianna Zimmerman
Nomita Ganguly	Posie Mansfield	
Wynn Gerhard	Sheila Maloney	
Arlene Germain	Dale Mitchell	
Pamela Goodwin	Richard Moore	
Anna Gosline	Taylor Nelson	
Fred Grosso	Charlene Neu	
Margaret Gullette	Sandy Novack	
Lisa Gurgone	Daniel O'Leary	
Jerry Halberstadt	Priscilla O'Reilly	
Scott Harshbarger	Lisa Orgettas	

Participating Organizations

Ad Lib, Inc.

Alzheimer's Association of Massachusetts & New Hampshire

Boston Center for Independent Living

Cape Organization for the Rights of the Disabled

Center for Living & Work

Center for Public Representation

COP Amputee Association

Disability Law Center

Disability Policy Consortium

Disability Resource Center

Easter Seals of Massachusetts

Greater Boston Legal Services

Greater Boston Chapter, United Spinal Association

Honoring Choices Massachusetts

Hospice and Palliative Care Federation of Massachusetts

Independence Associates

Institute for Human Centered Design

Massachusetts Advocates for Nursing Home Reform

Massachusetts Association for Serious Illness Care

Massachusetts Guardianship Policy Institute

Massachusetts Law Reform Institute

Massachusetts Senior Action Council

MetroWest Center for Independent Living

Mystic Valley Elder Services

Mass NAELA (National Academy of Elder Law Attorneys)

MetroWest Center for Independent Living

Mystic Valley Elder Services

National Academy of Elder Law Attorneys (NEALA)

Northeast Independent Living Program

Older Adult Behavioral Health Network

O'Reilly Communications

Public Partnerships

SeniorCare, Inc.

Somerville Cambridge Elder Services

Southeast Center for Independent Living

Stavros Center for Independent Living

Stop Bullying Coalition

Get Involved

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.

As a grass-roots coalition of aging and disability service and advocacy organizations and supporters, DignityMA works to secure fundamental changes.

We invite you to join us in any way that you are able:

Join a workgroup or attend our bi-weekly Zoom gathering of advocates, supporters, and concerned citizens by emailing info@dignityalliancema.org

Sign-up for our weekly Dignity Digest [here](#).

To donate, please click [here](#)

Dignity Alliance Massachusetts

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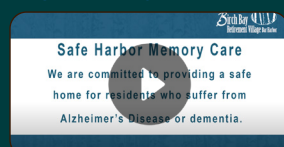
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Follow us on social!



Printing courtesy of Lachlan Forow, in honor of the staff at Birch Bay Village in Bar Harbor, ME for their superb dignity-affirming COVID-free memory unit care for Eleanor Reid Forrow (1924-2021)

<https://www.youtube.com/watch?v=vVNZXgYTRFU>



SCAN ME

EDITOR: Priscilla O'Reilly, O'Reilly Communications

DESIGNER: Alyssa Lajoie, Corporation for Independent Living (CIL)

PHOTOS: Sue Rorke, MetroWest Center for Independent Living



**Dignity
Alliance**
Massachusetts
Respect • Self-determination • Choices