



The Dignity Digest

Issue # 235

May 6, 2025

The Dignity Digest contains information compiled by Dignity Alliance Massachusetts concerning long-term services, support, living options, and care issued each Tuesday.

	*May require registration before accessing the article.
DignityMA Zoom Sessions	Dignity Alliance Massachusetts participants meet via Zoom every other Tuesday at 2:00 p.m. Sessions are open to all. To receive session notices with agenda and Zoom links, please send a request via info@DignityAllianceMA.org .
Spotlight	<p><u>State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools</u></p> <p>Blue Cross Blue Shield of Massachusetts Foundation</p> <p>April 30, 2025</p> <p>A well-functioning health care system should provide affordable and timely access to needed health care for all residents, without regard to their race, ethnicity, income, zip code, age, gender, or sexual orientation. The Massachusetts health care system, despite many exemplary qualities, does not do this, and recent access, affordability, and equity challenges for individuals and certain population groups, such as people of color, have highlighted the shortcomings of a system that is determined largely by market forces and the decisions of private entities. Given the pressures on the current system, there is a renewed interest in exploring how the process of state health planning can improve the allocation of health care resources in service to access, quality, and affordability.</p> <p>This issue brief offers background on health services planning, describing the concept and outlining its history, including its rise and fall in the United States and in Massachusetts. The bulk of the brief is a catalog of the regulatory and policy tools that Massachusetts uses today that incorporate some aspects of health services planning, and how these tools do and do not interact. The brief concludes with a discussion of the gaps Massachusetts needs to fill to realize a complete, comprehensive health services planning initiative.</p> <ul style="list-style-type: none"> • <u>Executive Summary: State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools</u> • <u>Issue Brief: State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools</u> • Webinar: Wednesday, May 28, 2025, 11:00 a.m. For details, see "Webinar" Section below. <u>Click here</u> to register for the webinar.
Quotes	<i>There are extraordinary parallels between today and back then, and that's not a good thing. If we get rid of many of the social supports that exist for disabled</i>

people to live in our communities and go to school and be part of society, we're going to start seeing that world again where people are chained up in yards, hidden in attics, and abused terribly.

*Having interviewed hundreds of people who lived and worked in institutions over the years, I came away with one simple assertion: Any form of institutionalization is wrong. It is impossible to do it without depriving people of basic rights and harming them more than you are helping them. That's something that [Walter E.] Fernald himself realized at the end of his life. To watch politicians of all stripes, who are not disabled, say certain people belong in institutions is just an astonishingly outrageous and barbaric idea. I hope my book **[A Perfect Turmoil: Walter E. Fernald and the Struggle to Care for America's Disabled]** helps put that idea to rest.*

Alex Green, visiting fellow at the Harvard Law School, [Why a trailblazer of disability care eventually disavowed his own theories](#),

***Boston Globe**, April 29, 2025 (updated)

"[There's a] huge missing hole in the U.S. long-term care system, what do we do with people who aren't sick enough for a nursing home but probably shouldn't be at home. Right now, they stay at home, they're lonely, they're not getting services, their kids are super-stressed out, and they're pulling millions of people out of the labor force, especially women. Everyone is unhappy about it, and they're not growing GDP, so it's hurting our economy and our well-being."

Jonathan Gruber, Ford Professor of Economics and MIT Department Head, [The age-old problem of long-term care](#), **MIT Press**, May 5, 2025

"If anything might be bipartisan, it could be long-term care. Everybody has parents. A solution has to be bipartisan. Long-term care may be one of those areas where it's possible."

Jonathan Gruber, Ford Professor of Economics and MIT Department Head, [The age-old problem of long-term care](#), **MIT Press**, May 5, 2025

	<p><i>A well-functioning health care system should provide affordable access to needed health care in a timely way for all residents, without regard to their race, ethnicity, income, zip code, age, gender, or sexual orientation. The Massachusetts health care system, despite many exemplary qualities, does not do this. Recent challenges and crises have brought into relief the shortcomings of a system that is largely governed by market dynamics and the decisions of private parties. Though the Commonwealth moved away from most planning practices years ago, there is new interest in exploring how planning can improve the allocation of health care resources in service to access, quality, and affordability. Policymakers and administrators can learn from past and present experience to enhance the health care system in a way that benefits all people in Massachusetts.</i></p> <p><u>State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools</u> (Blue Cross Blue Shield of Massachusetts Foundation, April 30, 2025)</p>
<p>Commentary by DignityMA participants</p> <p>Jim Lomastro is a member of DignityMA's Coordinating Committee and Chairs DignityMA's Facilities Workgroup and Veteran Affairs Workgroup. He lives in Conway, MA.</p>	<p><i>Remembering All Victims: The Necessity of Painful Memory</i> By James A. Lomastro, PhD (submitted for publication)</p> <p>As we mark the 50th anniversary of the Vietnam War's conclusion in 2025, we confront anew the enduring questions that follow in the conflict's wake. How do societies move forward while honoring the truth of what occurred? The answer lies not in convenient forgetting but in the difficult practice of remembrance. There exists a fundamental distinction between forgiveness and amnesty and an even sharper distinction between amnesty and amnesia. While societies may grant legal pardons or establish reconciliation processes, these mechanisms cannot and should not erase the collective memory of suffering.</p> <p>This challenge of comprehensive remembrance extends beyond traditional warfare. As we still grapple with the aftermath of the COVID-19 pandemic, we must ask ourselves how long it will take for our society to memorialize its millions of victims properly. Like war, political narratives and statistical abstractions obscure the pandemic's toll. The question remains: when will we create physical or cultural spaces that honor the individual suffering behind the numbers? How many years or decades might pass before we fully acknowledge this collective trauma? The difficulty we face in remembering pandemic victims reveals our broader societal discomfort with mass casualty events that don't fit neatly into heroic narratives.</p>

	<p>Memory serves as both a memorial and a safeguard. By remembering the full spectrum of war's devastation, we create a psychological barrier against future aggression. The painful knowledge of previous conflicts becomes preventative—a societal immune response that recognizes the early symptoms of dehumanization and militarism before they can again manifest as violence. When we forget these painful lessons, we remove the protective warnings that history provides.</p> <p>The Vietnam Veterans Memorial in Washington, D.C., exemplifies this approach to remembrance. As we reflect on half a century since the war's end, this memorial takes on heightened significance. Unlike traditional war monuments celebrating victory or glorifying combat, the memorial's black granite wall simply lists names—a somber acknowledgment of lives interrupted. Visitors don't come to celebrate conquest but to mourn the loss and contemplate the consequences. In its design and purpose, the memorial shifts focus from abstract geopolitical narratives to concrete human suffering.</p> <p>This reframing is essential. Wars are too often remembered through the lens of strategy, politics, or national mythology rather than through their human cost. When we remember Vietnam, we should remember not just American casualties but Vietnamese civilians, soldiers on both sides, and entire communities irreparably damaged by the conflict.</p> <p>Many who participated in war often did so under various illusions—that they were liberators rather than occupiers, defending freedom rather than geopolitical interests, and that their sacrifice would lead to meaningful change rather than strategic stalemate. Acknowledging this complexity does not diminish their sacrifice but contextualizes it within systems that routinely convert human lives into strategic resources.</p> <p>By remembering all victims—including those once designated as enemies—we perform an act of moral restoration. We acknowledge the shared humanity that conflict obscures and recover the ethical perspective that war inevitably distorts. Comprehensive remembrance of the war or pandemic is not merely retrospective justice for past victims but prospective protection for potential future ones.</p> <p>The pandemic offers a parallel lesson in remembrance. Unlike war, where we have established rituals and monuments, our collective memory of COVID victims remains fragmented and incomplete. There is no wall listing their names, and no national day of remembrance is firmly established in our calendar. The sheer scale of loss and its uneven distribution across communities have made comprehensive mourning difficult. Yet remembering these deaths is equally essential for preventing future catastrophic failures of care and response. Our ability to honor pandemic victims will test whether we can extend our capacity for remembrance beyond traditional forms of conflict.</p> <p>The uncomfortable truth remains: war is often pointless. Whatever strategic objectives might be achieved through violence could almost always be better accomplished through other means. When calculated against the narrow interests of those in power, the moral, psychological, economic, and cultural costs invariably outweigh any</p>
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benefits. By remembering war's futility alongside its brutality, we strengthen a collective resolve to find alternatives. Societies that honestly confront their violent histories—acknowledging complicity rather than clinging to sanitized narratives—develop stronger resistance to future militarism. This 50th anniversary provides an occasion for remembrance and an opportunity for renewed commitment to learning from our past. Memory becomes not just a backward-looking commemoration but a forward-looking prevention. We remember not to perpetuate trauma but to ensure its non-recurrence. In this way, the painful act of remembering transforms from burden to gift—something we owe not just to those who suffered in past conflicts but to generations yet unborn who deserve to inherit a world where such suffering has become increasingly rare. True remembrance honors all victims by working toward a future without more.

Facing Our Dobbs Moment for Disability Rights

Non-Profit Quarterly

By James A. Lomastro, PhD

April 14, 2025

The impact of the US Supreme Court's [Dobbs](#) decision that overturned the constitutional right to an abortion extends far beyond reproductive rights. This legal decision revealed the compounded barriers that individuals at the intersection of disability, race, and gender face.

By enabling state-level abortion restrictions, the court's decision raised alarming parallels for disability rights advocates, particularly regarding [individual autonomy in medical decision-making](#), access to essential healthcare, and the [protection of established legal rights](#). Understanding these intersecting challenges is crucial for both reproductive rights and disability rights advocates, as both movements face fundamental concerns about bodily autonomy and legal protections. By acknowledging the [complex](#) interconnectedness of these two movements, while maintaining a clear focus on specific goals, advocates can work to protect and advance both reproductive and disability rights in a post-*Dobbs* landscape.

Hard-Won Gains at Risk

Two laws have been foundational to US disability rights. One is well known: the [Americans with Disabilities Act](#) (ADA), initially passed in 1990 and signed into law by former President George H.W. Bush. The lesser known law is Section 504 of the Rehabilitation Act, [originally passed in 1973](#), which ensures individuals with disabilities are not discriminated against in programs and activities that receive federal funds.

Both laws come out of decades of civil rights [activism of people with disabilities](#). This movement is rooted in the notion that true equality and inclusion require approaches encompassing strong legal and statutory frameworks, cross-movement coalition building, new models, and education of the public to combat ableism; along with a strong commitment to intersectional advocacy that addresses the complex interplay of disability with other social identities.

As Martin Luther King Jr. wrote in his "[Letter from Birmingham Jail](#)" in 1963, "We are caught in an inescapable network of mutuality, tied in

	<p>a single garment of destiny. Whatever affects one directly, affects all indirectly.” Accessibility and inclusion strengthen the fabric of society. In the face of these threats, people with disabilities are actively organizing to counter the administration’s actions.</p> <p>As with many rights movements, progress is not a straight line. During the Joe Biden administration, disability rights were making significant progress. Updated Section 504 regulations, published as a “final rule” in 2024, promote economic and social inclusion by proactively strengthening obligations for federally funded entities to eliminate barriers and balance civil rights imperatives with economic realities.</p> <p>By expanding beyond physical accessibility to include digital access, healthcare equity, and employment protections, the rules ensure medical decisions are based solely on clinical criteria, eliminating biases and stereotypes about disability.</p> <p>These rules prohibit any metrics devaluing life extension based on disability status and address how healthcare systems evaluate and allocate resources among patient populations. They provide important protections for parents with disabilities, requiring parenting evaluations that focus on actual parenting skills rather than disability status.</p> <p>Community integration receives renewed emphasis in the rule, building upon the US Supreme Court’s Olmstead v. L.C. decision in 1999, which bans the institutional confinement for people who can handle and benefit from community settings.</p> <p>These updates present a person-centered-care approach with emphasis on specific timeframes for implementation and clear standards for compliance. It demonstrates a commitment to meaningful rather than aspirational change.</p> <p>In the past, some disability advocates argued that the ADA’s emphasis on economic participation reflects a neoliberal framework, commodifying disability rather than advancing broader social justice. Its implementation over the last 30 years revealed gaps between legislative intentions and practical outcomes, problems in enforcement and persistent barriers in employment and healthcare access. The updated 504 regulations provided corrections to those gaps.</p> <p>But now with the administration of President Donald Trump and the implementation of Project 2025, many of these recent gains are at risk, including student accommodations, healthcare access, workforce protections, and more. In the face of these threats, people with disabilities are actively organizing to counter the administration’s actions.</p> <p>Stories of Resistance from the Field</p> <p>Current resistance to the chipping away of rights and protections has emerged from multiple sectors with distinct concerns. These days, for example, gender dysphoria, as a protected disability under federal anti-discrimination laws, is being deployed as a wedge issue like the HIV controversy in the 1990s.</p> <p>Many people impacted by these regulations fear the loss of protections. A professional service provider cared for her daughter, recently deceased, who suffered a neurological health issue, told <i>NPQ</i> that she cannot comprehend why her daughter would not have</p>
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	<p>been afforded the same rights as other women her age or received equal protection under the law.</p> <p>“I struggle between the emotions of being completely grief stricken and would do anything to have her back, to the comfort of knowing she is at peace, and nobody can strip away her rights,” she said. Imagine that statement as a parent, and the devastating realization that death might be the only circumstance where a child’s rights could no longer be violated. This person’s dual perspective as a parent and healthcare professional provides a unique insight into the systems that should protect vulnerable individuals.</p> <p>In another instance, a woman who is a poet and a person living with a spinal cord injury offered her reflections on what it would mean for women with disabilities to face additional marginalization.</p> <p>“People with disabilities already face immense challenges—poverty, lack of healthcare, mobility barriers, and limited resources,” she told <i>NPQ</i>.</p> <p>“Abortion restrictions,” she observed, “added another layer of hardship, making access nearly impossible for disabled individuals who may need it due to financial instability, illness, or assault. Many cannot afford to travel to states with protections, lack accessible transportation, or risk losing vital government benefits.”</p> <p>The <i>Dobbs</i> decision, she noted, further endangers their health. Restrictions will not stop the need for abortions but will just make them even more dangerous for disabled people who are already marginalized. “I cannot imagine what it will be like if protections afforded by the 504 regulations are weakened or taken away.”</p> <p>Most concerning is the careful calculation that now precedes any public statement.</p> <p>Fear—and a Path Forward</p> <p>Several agencies contacted for inclusion in this article were reticent to provide information, despite their agreement that the rights of people with disabilities need to be defended.</p> <p>Groups across the country are undertaking comprehensive reviews of their public-facing materials, scrutinizing documents, web pages, and publications for language that might draw unwanted attention from federal agencies. They are overhauling their communications strategies and reassessing the terminology and framing used to discuss sensitive issues.</p> <p>Many are finding themselves forced to limit participation in certain media, coalitions, or campaigns, even when these collaborations align with their organizational missions. Most concerning is the careful calculation that now precedes any public statement. Issues that previously would have received robust commentary are now subject to risk assessments and strategic evaluations.</p> <p>Cross-movement solidarity is a powerful strategy. In solidarity, there is strength.</p> <p>Organizations are weighing the importance of advocacy against the potential consequences of speaking out. This situation has led many to establish firewalls between their federally funded programs and advocacy work, creating artificial divisions within unified missions and diminishing their possibilities to address 504 and other rights issues. But effectively addressing the complex and critical challenges following the <i>Dobbs</i> decision and challenges to 504 require strategies</p>
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	<p>that combine legislation, litigation, coalition building, new models, and initiatives to educate the general public. Strengthening existing statutory protections under federal and state law is essential to support the enforcement of Section 504 in healthcare settings. New state and federal legislation is required to address gaps that emerge from legal developments. Given the present federal administration, advocates right now are focused on incorporating federal protections into state statutes.</p> <p>Advocacy organizations, especially those not dependent on federal funds, must continue tracking outcomes, documenting violations, and pushing for accountability when healthcare providers or institutions fail to meet their obligations to the disability community. They must be willing to litigate issues with private, state, and federal authorities. State attorneys general also have a role in promulgating consumer protection regulations.</p> <p>Strategy Rooted in Solidarity</p> <p>In this context, cross-movement solidarity is a powerful strategy. In solidarity, there is strength. Disability advocates should connect with other social justice activists working toward age, gender, and reproductive rights, as threats to bodily autonomy impact many medical decisions and care policies. By forming coalitions among disability, aging, reproductive, and gender justice movements, advocates amplify their collective voice and impact and ensure violations are not compounded.</p> <p>Public awareness can build a broader understanding of disability rights as part of comprehensive healthcare reforms, rather than as an afterthought. In addition, a primary focus on disability rights advocacy involves promoting, for example, supported decision-making as an alternative to traditional guardianship models. Such efforts align with many aging community concerns about current guardianship models. The struggle for disability rights exists at a critical intersection of civil rights, healthcare equity, and social justice, where market pressures and ideological resistance continue to create barriers to full inclusion. Like the <i>Dobbs</i> decision's impact on reproductive rights, recent challenges to disability protections reveal the vulnerability of civil rights gains and underscore how different forms of systemic discrimination—including ableism, racism, and sexism—create compounded barriers for marginalized communities.</p> <p>True progress requires a comprehensive approach that combines legal advocacy, coalition building, and public engagement to not only defend existing protections but also advance toward a society where healthcare equity and human dignity are guaranteed for all.</p>
<p>DignityMA Supporters in the News</p> <p>For more than a decade, Alex Green, a lecturer at the Harvard Kennedy School and a DignityMA supporter, has taken a particular interest and been a central figure in the debate over what should become of the Fernald's</p>	<p><u>Why a trailblazer of disability care eventually disavowed his own theories</u></p> <p>*Boston Globe April 29, 2025 (updated) By Oliver Egger</p> <p><i>A new biography untangles the complicated legacy of Walter E. Fernald.</i></p> <p>The Walter E. Fernald State School in Waltham, which operated from 1848 to 2014, is remembered as an emblem of America's shameful warehousing and abuse of the disabled. In the mid-20th century,</p>

buildings and grounds. His work sparked an inevitable interest in the school's namesake and third superintendent, Walter E. Fernald (1859-1924).

Information about Alex's newly published book, ***A Perfect Turmoil: Walter E. Fernald and the Struggle to Care for America's Disabled***, is available below in the section *Books by DignityMA*.

resources at the school were few, buildings were crumbling, and abuse and neglect were rampant. In 1993, [this newspaper discovered](#) that, from 1946 to 1953, as part of a study led by Harvard and MIT and with the participation of Quaker Oats, 74 boys ages 10 to 17 at the Fernald were fed radioactive isotopes in their oatmeal. By 1972, the Fernald's deplorable conditions were used as evidence in [Ricci v. Okin](#), a class action suit that led the courts to assume oversight at the Fernald and other state institutions across Massachusetts. The staffing and funding increases that resulted from that case improved residents' care and quality of life so much that, by 2014, when the decision was made to close the institution, some families of residents protested [to keep it open](#).

Since its closure, however, thousands of [confidential patient records](#) and [boxes of state police evidence](#) have been discovered blowing about the sprawling, 196-acre campus. In the last four months, two major fires have destroyed two of the oldest buildings on the campus: a girl's [residential hall](#) built in 1892 and the [school house](#) built in 1891.

The fruit of Green's curiosity about Fernald is a new book, "[A Perfect Turmoil: Walter E. Fernald and the Struggle to Care for America's Disabled](#)." Fernald was a psychiatrist who revolutionized the care of the disabled in the United States. As Green discovered, Fernald's work was positive in some ways and barbarous in others. He helped establish special education. He also advocated for segregating the disabled from society, a development that contributed to mass institutionalization and the subsequent abuses recorded at the Fernald and hundreds of [institutions like it](#).

Fernald was my great-great-grandfather. For a long time, I have struggled to make sense of his complicated legacy. So, I was eager to talk to Green about his new book. This interview has been edited and condensed.

People have heard about Fernald, the institution. What drew you to Fernald, the man?

What people know about the Fernald School is what happened after World War II: the big legal fights and the [radiation scandal](#) there. But nobody I spoke to knew the broader history. So, I started by trying to figure out: Who is this guy that this place is named for? And one of the first things I found was that when Fernald died in 1924, the governor of Massachusetts ordered all of the flags in Massachusetts flown at half-staff. And I thought, *In my lifetime, has that ever been done for someone who devoted their life to working with children with disabilities? This guy must have been incredibly influential.*

How did he become so influential?

In 1887, when Fernald took over what was then called the Massachusetts School for the Feeble-Minded, it had fallen into ruin and was overcrowded, and the people living there were being abused and treated terribly. But he was young and he had an enormous amount of energy. When he inherited a plan from the school to move from its location in Boston to Waltham, he took over that move with a radical vision to try to build a utopia and to improve the outcomes for those in his care. But what really caused word to spread around Boston, and then around the country, is that he created an

educational program that lived up to the word “school.” And in that way he was creating what we now see as special education.

What was his central idea?

Fernald understood that large-scale institutions, like the one that he was running and rebuilding, were never going to have enough space to provide for all of the kids he felt needed care. He was getting letters from all over the country from parents who were desperate. People were doing things that are unimaginably horrifying: chaining their kids up in the yard while they went to work, leaving them in attics all day. And disabled children were often sent to delinquency schools rather than being provided with an education.

In 1896, Fernald received a letter from Rhoda Esten, an administrator at Providence Public Schools who asked if he had any ideas about how to work with their disabled students. He went on to develop the curriculum for the disabled students in Providence, which was really the first special education program ever created in a public school in America. The idea soon spread, and by the time Fernald died, there were thousands of special education classes all over the country.

A key part of Fernald’s legacy, though, was his advocacy for eugenics. What drew him to it, and what was his impact on that field?

Eugenics was the idea that certain human traits could be weeded out and others encouraged through “better breeding,” which is a phrase that eugenicists used a lot. People — Fernald included — became enamored with the idea that they could help shape a better world by intervening in this way.

In 1905, two young women at Fernald’s institution lured another woman into a bathroom and drowned her in a bathtub. I think Fernald really despaired. He started to get these very dark ideas: *What if one way that people are disabled is that they express their disability by doing bad things?* And bad things to him meant everything from sexual immorality to crime. He started looking around for what he called the “defective delinquent,” a type of person whose disabilities were expressed through criminality. And of course, once you name it and you go looking for it, you’re going to find it, whether it’s real or not. He latched this idea onto the broader philosophical movement of eugenics and advocated for those labeled defective delinquents to be segregated from society and put in institutions for the rest of their lives.

What happened next?


This led Fernald to lock down his whole institution, which experienced a rapid growth in population [as aging residents remained and younger ones were admitted]. It also led to new institutions popping up across the country. He traveled all over as the leading expert on this, saying, “You too should build institutions, and you should segregate your disabled people into them, and it’s best for them.” He shifted from saying “I’m going to create a utopia where a world that picks on disabled people can no longer pick on them” to “I’m going to keep the world safe from these disabled people.”

Fernald eventually renounced these beliefs. What drew him away from them?

Fernald was a relentless figure, constantly testing ideas and never settling on them. In the early 1910s, he began to check the work of

	<p>some of the leading eugenicists in the world, and the more he looked at their research and conclusions, the more he realized that it really didn't check out. He discovered this by sending out his own workers to see how his former inmates — some had escaped, others had sued for their release, and others had been removed by families against Fernald's wishes — were doing. Fernald found that, rather than committing crimes, as the eugenicists of the day would have predicted, they were living peaceful lives in community, working, and raising families. This study coincided with a further schism, brought about by eugenicists' call for the forced sterilization of disabled people, which Fernald was vehemently against.</p> <p>Two things then happened in pretty quick succession: In 1916, Fernald opposed forced sterilization so forcefully in the New York case Osborn v. Thompson that New York repealed its forced sterilization law. And in 1919, he wrote a widely distributed pamphlet debunking his entire notion of institutionalization. There was no place in society for large-scale institutions of the kind that he had helped create, he wrote. Rather, disabled people should live in communities.</p> <p>But institutionalization and sterilization continued for years. Why?</p> <p>Fernald died in 1924, only a few years after defying the eugenicists on forced sterilization and putting forth his radical vision for a better way to care for the disabled. The void in leadership is very clear because the history that follows was the dystopian opposite of everything that he fought for. Buck v. Bell legalized sterilization in the United States. Institutions proliferated after World War II. By the late '60s, more than 200,000 intellectually and developmentally disabled people were inmates of large-scale institutions.</p> <p>Today, we are seeing various threats to funding to disability programs, such as the lawsuit Texas v. Becerra, which aims to dismantle a federal law that funds special education programs, as well as a rise in eugenicist language from politicians. Is history rhyming?</p> <p>There are extraordinary parallels between today and back then, and that's not a good thing. If we get rid of many of the social supports that exist for disabled people to live in our communities and go to school and be part of society, we're going to start seeing that world again where people are chained up in yards, hidden in attics, and abused terribly.</p> <p>Having interviewed hundreds of people who lived and worked in institutions over the years, I came away with one simple assertion: Any form of institutionalization is wrong. It is impossible to do it without depriving people of basic rights and harming them more than you are helping them. That's something that Fernald himself realized at the end of his life. To watch politicians of all stripes, who are not disabled, say certain people belong in institutions is just an astonishingly outrageous and barbaric idea. I hope my book helps put that idea to rest.</p>
<p>Call for Presentations</p>	<p>Massachusetts Councils on Aging (MCOA) 2025 Fall Conference Call for Presentations</p> <p>Planning for the MCOA 2025 Fall Conference is now underway. This year's theme is "Facing the Future Together". MCOA's call for presentations is officially open. The organizers are looking for engaging, innovative, and</p>

	<p>impactful sessions to make this year's conference the best one yet. If you have knowledge, insights, or creative solutions to share with the aging services network, you are encouraged to submit a proposal. Submissions are due by May 19, 2025.</p> <p>Learn More & Apply</p> <p>National Consumer Voice for Quality Long-Term Care</p> <p>Call for Presentations</p> <p><i>Session Proposals for the Consumer Voice Conference Due May 2</i></p> <p>2025 Consumer Voice Conference at the Renaissance Arlington Capital View Hotel in Arlington, Virginia, November 3-6, 2025.</p> <p>Consumer Voice's Annual Conference educates and empowers long-term care consumers and consumer advocates. The conference covers long-term care issues, including current trends, best practices, advocacy opportunities, and new research. Attendees have the opportunity to learn, network, and exchange ideas with advocates from all over the country. Submit a Proposal to Present a Session:</p> <p>Review the Call for Proposals and Presenter Requirements.</p> <p>Submit your proposal via SurveyMonkey. NOTE: You will not be able to save incomplete submissions in SurveyMonkey, so you may want to review and print or save the PDF version of the proposal questions so you can plan your responses prior to starting the submission.</p> <p>Proposals are due by May 2, 2025. Late or incomplete proposals will not be considered.</p>
Recruitment	<p>See: Listings on MASsterList.com's Job Board for all current listings</p>
Guide to news items in this week's <i>Dignity Digest</i>	<p>Nursing Homes Voters Reject \$126 million for town-run nursing home (The Inquirer and Mirror, May 3, 2025)</p> <p>Health Care Topics State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools (Blue Cross Blue Shield of Massachusetts Foundation, April 30, 2025)</p> <p>Aging Topics Dr. Vonda Wright Shares the Longevity Habits You're Not Thinking About (and That You Can Start Doing Today), (www.mariashriversundaypaper.com, March 15, 2025) Fostering Stability in Aging (American Bar Association, December 10, 2024)</p> <p>Environmental Topics How higher temperatures and more pollen are affecting the health of Boston residents (CommonWealth Beacon, May 1, 2025)</p> <p>Public Policy The age-old problem of long-term care (MIT Press, May 5, 2025)</p> <p>From Around the Country Union sets May 19 strike deadline at 51 nursing homes (CT Mirror, May 1, 2025)</p>

<p>DignityMA Study Sessions</p> <p><i>Special Focus on Changes in Federal Policies, Programs, and Services</i></p>	<p>Unprecedented public policy changes have been occurring since the onset of the Trump Administration three months ago. Programs, policies, and initiatives of importance to older adults, persons with disabilities, and caregivers are not exempted. The implications are starting to become known. The impacts will be experienced in the months and years ahead.</p> <p>No sector is being spared. Health care, social services, Social Security, civil rights, housing, and more are all under historic attack. Some areas are being “downsized,” some are being disrupted or radically modified, and others are being eliminated outright.</p> <p>Dignity Alliance Massachusetts has invited three nationally known experts regarding public policy and programs affecting older adults, persons with disabilities, and caregivers to share up-to-the-minute information, their analysis, and strategies for individuals and organizations to adopt in response.</p> <p>The presenters are:</p> <ul style="list-style-type: none"> • Bob Blancato, National Coordinator of the bipartisan 3000-member Elder Justice Coalition • James Roosevelt, JD, former Associate Commissioner, U.S. Social Security Administration • Steven Schwartz, JD, Special Counsel, Center for Public Representation <p>See below for dates, times, details, and registration information.</p>
<p>DignityMA Study Session</p>  <p>Bob Blancato, National Coordinator, Elder Justice Coalition</p>	<p><i>Aging Policy Update: What We Know, What We Don't Know, and What We Should Fear</i></p> <p>Wednesday, May 21, 2025, 2:00 p.m.</p> <p>Presenter: Bob Blancato, National Coordinator of the bipartisan 3000-member Elder Justice Coalition</p> <p>Registration required: https://us02web.zoom.us/meeting/register/kQRVG7FiR2iVrmQWN52M6g</p> <p>Bob discusses the current state of aging policy at the national level under the new Congress and Administration. This presentation will focus on key shifts in aging policy, identifies emerging challenges, and outlines advocacy opportunities that will protect and shape services for older Americans in the coming year.</p> <p>Bob is also the Executive Director of the National Association of Nutrition and Aging Service Programs. He spent 17 years on the staff of the U.S. House Select Committee on Aging and has participated in four White House Conferences on Aging, including as the Executive Director of the 1995 White House Conference on Aging.</p>
<p>DignityMA Study Session</p>	<p><i>Social Security: It's history, current issues, and advocacy options</i></p> <p>Thursday, May 22, 2025, 2:00 p.m.</p> <p>Presenter: James Roosevelt, JD, former Associate Commissioner, U.S. Social Security Administration</p> <p>Registration required: https://us02web.zoom.us/meeting/register/t5wRZ6KJTVKqmn-T6RIRhA</p> <p>Jim advises health care payers, providers, trade associations, and service providers on business matters, legislative and regulatory issues, governance, and personnel matters. He regularly represents</p>



James Roosevelt, former Associate Commissioner, U.S. Social Security Administration

medical device and medical process startups, including with respect to telehealth, artificial intelligence, and treatment utilizing legal psychedelics. He is also a national speaker and author on the Affordable Care Act, Medicare and Medicaid policy, and Social Security.

For more than 10 years, Jim was CEO of Tufts Health Plan, where he led a turnaround that nearly doubled the membership and achieved consistent profitability while attaining #1 ranking in the United States from the national accrediting organization. He was previously in-house General Counsel and was a former partner in the Health Care Practice Group of Choate, Hall and Stewart in Boston. Before joining Tufts Health Plan, he served as Associate Commissioner of the U.S. Social Security Administration.

In 2016, Jim was a visiting fellow at the Institute of Politics of the Harvard Kennedy School of Government. He continues as a clinical instructor in the Public Health and Community Medicine Department of Tufts University School of Medicine.

DignityMA Study Session



Steven Schwartz, JD, Special Counsel, Center for Public Representation

The New Legal Landscape: The Administration's Campaign to Erase Disability Rights, Protections, and Protectors

Thursday, June 5, 2025, 11:00 a.m.

Presenter: Steven Schwartz, JD, Special Counsel, Center for Public Representation

Registration required:

<https://us02web.zoom.us/meeting/register/WNnuimt0T3Sh64qXKJeZ2g>

This session will review the Trump Administration's coordinated attack on disability rights, through the issuance of executive orders that eliminate legal claims and disability rights, rescind disability regulations, and challenge important disability precedents. It will discuss strategies to oppose these efforts, particularly in light of the drastic reduction in civil rights enforcement by the Department of Justice.

Steve serves as special counsel, after founding the Center in 1976 and then serving as its executive director for 38 years and litigation director for 13. After graduating from Harvard Law School in 1971, he represented thousands of people with disabilities over the past fifty years. He has testified before Congress on numerous occasions, successfully resolved a number of damage cases for institutionalized individuals with disabilities, and litigated dozens of class action cases that challenge the unnecessary segregation of people with disabilities in psychiatric hospitals, developmental disability institutions, nursing facilities, and juvenile justice settings.


May Recognitions

Mental Health Awareness Month

Since 1949, Mental Health Awareness Month has been a driving force in addressing the challenges faced by millions of Americans living with mental health conditions.

Older Americans Month 2025

Every May, the Administration for Community Living (ACL) leads the nation's observance of Older Americans Month (OAM), a time to

 <p>OLDER AMERICANS MONTH</p> <p>FLIP THE SCRIPT ON AGING: MAY 2025</p>	<p>recognize older Americans' contributions, highlight aging trends, and reaffirm our commitment to serving older adults.</p> <p>The 2025 theme, Flip the Script on Aging, focuses on transforming how society perceives, talks about, and approaches aging. It encourages individuals and communities to challenge stereotypes and dispel misconceptions. This year, join us in honoring older adults' contributions, exploring the many opportunities for staying active and engaged as we age, and highlighting the opportunities for purpose, exploration, and connection that come with aging.</p> <p>On this site, find materials to help you celebrate, including this year's logo, poster, social media graphics, and activity ideas. Use #OlderAmericansMonth on social media to share your thoughts and activities and see what others are doing!</p>
<p>Events</p>	<ol style="list-style-type: none"> <p>1. Providers' Council</p> <p>Thursday, May 8, 2025, 10:30 a.m.</p> <p>Great Hall, State House, Boston</p> <p><u>Caring Force Rally</u></p> <p>Providers' Council hosts its annual Caring Force Rally and lobby day. Senate President Spilka gives remarks, and Rep. Sabadosa and Sen. Miranda receive the Caring Bear Award. Advocates are supporting bills to create a student loan repayment program (S 119 / H 283), as well as proposals (S 130 / H 223) that aim to eliminate pay disparities between state workers and individuals working at community-based human services nonprofits.</p> <p>2. Disability Community Forum</p> <p>Thursday, May 8, 2025, 2:00 p.m.</p> <p>Suffolk University School of Law, 120 Tremont St., Boston</p> <p>Boston hosts its annual Disability Community Forum, featuring a presentation of the Commission on Persons with Disabilities and the Disability Advisory Board's annual report from Kristen McCosh, ADA coordinator and disability commissioner.</p> <p><u>Register and Livestream</u>)</p> <p>3. Older Adult Behavioral Health Network, MAMH and MA Housing and Shelter Alliance</p> <p><u>Aging at Home: Advancing Supports for Older Adult Homelessness. Housing Stabilization and Community Living Annual Conference</u></p> <p>Tuesday, May 13, 2025, 8:00 to 4:00 p.m.</p> <p>The Hogan Center, College of the Holy Cross, 1 College Street, Worcester</p> <p>Older adults are the fastest growing segment of the homeless population not only in Massachusetts but nationwide. This year, the OABHN's annual conference will shed light on this issue, bringing together people from both the homeless/housing network and aging services to encourage greater collaboration and strengthen partnerships. It's a great networking event for all professional working with adults with behavioral health concern.</p> <p>Confirmed Speakers</p> <p>Secretary Robin Lipson, <i>MA Executive Office of Aging and Independence</i></p> <p>Secretary Ed Augustus, <i>MA Office of Housing and Livable Communities</i></p> <p>Beth Lucas, <i>MA Department of Mental Health</i></p> <p>Morning Keynote Panel - Collaborative Solutions: State Programs for Older Adult Homelessness and Housing Stabilization</p>

	<p>Emily Cooper, <i>MA Executive Office of Aging and Independence</i> Josh Cuddy, <i>MA Office of Housing and Livable Communities</i> Carmina Andrade, <i>MA Department of Mental Health</i> Afternoon Keynote Panel - Older Adult Homelessness in MA: Insights from Data, Lived Experience, and Clinical Perspectives Efrain Gomez Samara Scheckler, PhD Meagan Hickey, LICSW Confirmed Workshops</p> <ul style="list-style-type: none"> • Community-Based Aging Supports in MA: Overview of Older Adult Protective Services, State Homecare, and Councils on Aging and PACE Programs • Navigating Homeless Shelter and Housing Resources in Massachusetts • Introduction to Hoarding Behavior and Interventions • Brain Injury and Behavioral Health: Critical Factors in the Housing Crisis for Older Adults • Using Reasonable Accommodations and Modifications to Preserve Tenancies • Elder Justice Shelter at the Center for the Prevention of Elder Abuse and Neglect (CPEAN) <p>Register Here.</p>
Webinars and Online Sessions	<p>4. Washington Post Live Tuesday, May 6, 2025, 12:00 p.m. <i>Conversations on cancer care advancements</i> Medical and scientific advancements have given new hopes for the treatment and prevention of cancer. On May 6 at 12:00 p.m. ET, join Washington Post Live for a series of conversations about the progress made and ways to promote trust, access and care. In a segment presented by Pfizer Oncology, Tina Deignan, Commercial President, sits down with Wayne A. I. Frederick, MD, MBA, interim CEO of the American Cancer Society (ACS) and the ACS Cancer Action Network, to discuss the obstacles many people face when it comes to accessing timely cancer screening and care, and their organizations' work to "Change the Odds" against cancer and improve health outcomes in medically underrepresented communities. REGISTER</p> <p>5. The Arc of Massachusetts Thursday, May 8, 2025, 12:30 p.m. The Importance of Medicaid-Funded Supports A webinar about the breadth and importance of programs funded by Medicaid. These supports allow individuals with disabilities to stay safe and have meaningful lives in the community. This webinar will provide a clear overview of Medicaid-funded programs including Day Habilitation, Adult Family/Foster Care, PCA services, and more. Hear from experts in the field and families with lived experience—and learn the tools to advocate to protect these critical programs from potential federal cuts!</p> <p>6. Blue Cross Blue Shield of Massachusetts Foundation Wednesday, May 28, 2025, 11:00 a.m. State Health Planning to Improve Access to Care in MA: Needs and Current Tools The Blue Cross Blue Shield of Massachusetts Foundation is hosting a webinar on Wednesday, May 28th from 11:00 AM – 12:00 PM with</p>

	<p>author, Robert Seifert, who will review key findings from the brief, <u>State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools</u>, which is intended to lay the groundwork for future research and analysis on state health planning. The webinar will also feature remarks from the Massachusetts Health Policy Commission focused on the recently enacted law that established the Office of Health Resource Planning, which as the name suggests, has a clear health planning mandate.</p> <p>Click here to register for the webinar.</p>
Previously posted webinars and online sessions	<p>Previously posted webinars and online sessions can be viewed at: https://dignityalliancema.org/webinars-and-online-sessions/</p>
Nursing Homes	<p>7. The Inquirer and Mirror May 3, 2025 <u>Voters Reject \$126 million for town-run nursing home</u> By Joshua Balling Voters narrowly shot down spending up to \$134 million on a new town-run nursing home on the campus of the Sherburne Commons adult-living community off South Shore Road, rejected the \$14 million appropriation for town employee housing on Waitt Drive and approved the \$140.6 million municipal operating budget. The vote on Article 13 was 450-283 in favor of a new Our Island Home nursing home, but approval required a two-thirds majority, or 488 votes. The decision followed approval of an amendment by Select Board member Dawn Hill Holdgate updating to \$116 million the amount of spending to be appropriated, on top of the \$8.5 million already approved, and including language allowing the town to accept donations, gifts and grants to help offset the cost. Former Nantucket health director Richard Ray called Our Island Home a “structure for humanity.” “We are the only town-funded nursing home in the state of Massachusetts. Let’s keep the lights on,” he said. Opponents, including the Advisory Committee of Non-voting Taxpayers, raised multiple questions about the cost, and expressed concerns that it will be even more difficult to staff a new facility than the current one, giving housing needs and pay. They also pointed to the \$5 million-plus annual operating deficit taxpayers have been covering for nearly a decade as another cost that is not going to go away and will probably only rise. The Finance Committee also reversed its recommendation in favor of the new facility following an increase in the estimated cost from \$104 million in December 2024 to \$126 million last month. The total cost of up to \$134 million includes a number of contingencies, including tariffs and increases in materials costs, which may not be realized.</p>
Health Care Topics	<p>8. Blue Cross Blue Shield of Massachusetts Foundation April 30, 2025 <u>State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools</u> A well-functioning health care system should provide affordable and timely access to needed health care for all residents, without regard to their race, ethnicity, income, zip code, age, gender, or sexual orientation. The Massachusetts health care system, despite many exemplary qualities, does not do this, and recent access, affordability, and equity</p>

	<p>challenges for individuals and certain population groups, such as people of color, have highlighted the shortcomings of a system that is determined largely by market forces and the decisions of private entities. Given the pressures on the current system, there is a renewed interest in exploring how the process of state health planning can improve the allocation of health care resources in service to access, quality, and affordability.</p> <p>This issue brief offers background on health services planning, describing the concept and outlining its history, including its rise and fall in the United States and in Massachusetts. The bulk of the brief is a catalog of the regulatory and policy tools that Massachusetts uses today that incorporate some aspects of health services planning, and how these tools do and do not interact. The brief concludes with a discussion of the gaps Massachusetts needs to fill to realize a complete, comprehensive health services planning initiative.</p> <ul style="list-style-type: none"> • Executive Summary: State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools • Issue Brief: State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools
Aging Topics	<p>9. www.mariashriversundaypaper.com March 15, 2025 Dr. Vonda Wright Shares the Longevity Habits You're Not Thinking About (and That You Can Start Doing Today) By Meghan Rabbitt Here's a summary of the conversation with Dr. Wright: Your early career as an oncology nurse profoundly shaped your perspective, exposing you to the unique struggles and the critical role of women as decision-makers in their health and their families' well-being. This experience highlighted the importance of understanding and addressing women's suffering. Becoming a mother in a blended family further solidified your awareness of the long-term impact of health choices, leading you to conceptualize "generational health." This concept emphasizes how a mother's health decisions and habits create a health legacy for her children and future generations, much like generational wealth in finance. You recognized the powerful influence women have on the health of their families and the potential to create significant positive change within a single generation by focusing on women's health. This realization, combined with your observations as an orthopedic sports surgeon seeing a pattern of musculoskeletal issues in midlife women, motivated you to focus your live events and charitable work on women. You recognized the need for a unifying framework to understand these symptoms, drawing inspiration from the OB-GYN community's success with the Genitourinary Syndrome of Menopause (GSM). This led you to coin the term "Musculoskeletal Syndrome of Menopause (MSM)" to categorize the interconnected musculoskeletal symptoms women experience due to the decline in estrogen during and after menopause. You saw the potential of this nomenclature to facilitate conversations, research, and ultimately, better care for women in this life stage.</p> <p>10. American Bar Association December 10, 2024 Fostering Stability in Aging</p>

	<p>Fostering Stability in Aging is a collaboration by the ABA Commission on Homelessness and Poverty and the ABA Commission on Law and Aging designed as a resource hub to equip attorneys and other advocates representing and/or supporting older adults at risk of poverty and homelessness.</p> <p>It lists multiple online resources under three categories:</p> <ul style="list-style-type: none"> • American Bar Association • U.S. Department of Health and Human Services • National Organizations & Resources
<p>Environmental Topics</p>	<p>11. CommonWealth Beacon May 1, 2025 <u>How higher temperatures and more pollen are affecting the health of Boston residents</u> By Maya Mitchell <i>Heat is the leading weather-related cause of death in the US, and Boston has not been built to withstand it</i></p> <p>Summary: Dr. Robyn Riseberg, a pediatrician in Boston, has observed a worsening of respiratory illnesses like asthma and allergies, as well as longer flu and RSV seasons, over her 20 years of practice. Experts attribute these trends to climate change, which causes more extreme temperatures, impacting air and water quality. Hotter days exacerbate heatstroke and allergies, while colder temperatures worsen respiratory issues. Boston, traditionally adapted to cold winters and moderate summers, is increasingly vulnerable to heat, with projections showing a significant rise in 90-degree days. Buildings designed to retain heat in winter now trap it in summer, posing risks, especially for children and seniors. The city has implemented a heat resilience plan, including measures like shade structures, improved public transit, green spaces, and tree planting. However, rising temperatures also lengthen growing seasons, leading to more potent pollen and worsening seasonal allergies. Additionally, increased temperatures can trap air pollutants, negatively impacting respiratory and cardiovascular health. Air quality varies within Boston, with areas like East Boston being particularly affected by emissions. Advocates emphasize that the impacts of climate change are not uniform, disproportionately affecting vulnerable communities.</p>
<p>Public Policy</p> <div data-bbox="110 1377 287 1444" data-label="Image"> </div> <div data-bbox="110 1444 479 1642" data-label="Image"> </div> <p>In the new book, "Long-Term Care around the World," MIT economist Jonathan Gruber and others explore how different countries approach long-term care for the elderly. Credit: Courtesy of Jonathan Gruber</p>	<p>12. MIT Press May 5, 2025 <u>The age-old problem of long-term care</u> By Peter Dizikes</p> <p>Caring well for the elderly is a familiar challenge. Some elderly people need close medical attention in facilities; others struggle with reduced capabilities while not wanting to leave their homes. For families, finding good care is hard and expensive, and already-burdened family members often pick up the slack.</p> <p>The problem is expanding as birthrates drop while some segments of the population live longer, meaning that a growing portion of the population is elderly. In the U.S., there are currently three states currently where at least 20 percent of the population is 65 and older. (Yes, Florida is one.) But by 2050, demographic trends suggest, there will be 43 states with that profile.</p> <p>In age terms, "America is becoming Florida," quips MIT economist <u>Jonathan Gruber</u>. "And it's not just America. The whole world is aging</p>

rapidly. The share of the population over 65 is growing rapidly everywhere, and within that, the share of the elderly that are over 85 is growing rapidly.”

In a newly edited volume, Gruber and several other scholars explore the subject from a global perspective. The book, [“Long-Term Care around the World,”](#) is published this month by the University of Chicago Press. The co-editors are Gruber, the Ford Professor of Economics and chair of the Department of Economics at MIT; and Kathleen McGarry, a professor of economics at Stony Brook University.

The book looks at 10 relatively wealthy countries and how they approach the problem of long-term care. In their chapter about the U.S., Gruber and McGarry emphasize a remarkable fact: About one-third of long-term care for the elderly in the U.S. is informal, provided by family and friends, despite limited time and resources. Overall, long-term care is 2 percent of U.S. GDP.

“We have two fundamental long-term care problems in the U.S.,” Gruber says. “Too much informal care at home, and, relatedly, not enough options for elders to live with effective care in ‘congregate housing’ [or elder communities], even if they’re not sick enough for a nursing facility.”

The nature of the problem

The needs of the elderly sit in plain sight. In the U.S., about 30 percent of people 65 and over, and 60 percent of people 85 and over report limitations in basic activities. Getting dressed and taking baths are among the most common daily problems; shopping for groceries and managing money are also widely reported issues. Additionally, these limitations have mental health implications. About 10 percent of the elderly report depression, rising to 30 percent among those who struggle with three or more types of basic daily tasks.

Even so, the U.S. is not actually heavily dotted with nursing homes. In a country of about 330 million people, with 62 million being 65 and over, it’s unusual for an elderly person to be in one.

“We all think of nursing homes as where you go when you’re old, but there are only about 1.2 million people in nursing homes in America,” Gruber observes. “Which is a lot, but tiny compared to the share of people who are elderly in the U.S. and who have needs. Most people who have needs get them met at home.”

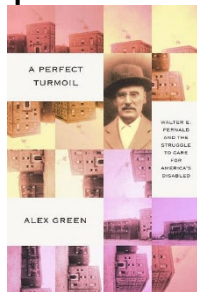
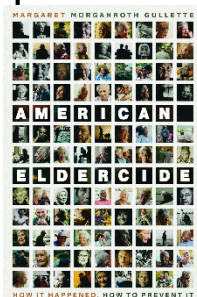
And while nursing homes can be costly, home care is too. Given an average U.S. salary of \$23 per hour for a home health care aide, annual costs can reach six figures even with half-time care. As a result, many families simply help their elderly relatives as best they can.

Therefore, Gruber has found that we must account for the informal costs of elder care, too. Ultimately, Gruber says, informal help represents “an inefficient system of people taking care of their elderly parents at home, which is a stress on the family, and the elders don’t get enough care.”

To be sure, some people buy private long-term care insurance to defray these costs. But this is a tricky market, where insurers are concerned about “adverse selection,” people buying policies with a distinct need for them (beyond what insurers can detect). Rates therefore can seem high, and for limited, conditional benefits. Research by MIT economist Amy Finkelstein has shown that only 18 percent of long-term insurance policies are used.

“Private long-term care insurance is a market that just hasn’t worked well,” Gruber says. “It’s basically a fixed amount of money, should you

	<p>meet certain conditions. And people are surprised by that, and it doesn't meet their needs, and it's expensive. We need a public solution."</p> <p>Congregate housing, a possible solution</p> <p>Looking at long-term care internationally helps identify what those solutions might be. The U.S. does not neglect elder care but could clearly broaden its affordable options.</p> <p>"On the one hand, what jumped out at me is how normal the U.S. is," Gruber says. "We're in the middle of the pack in terms of the share of GDP we spend on long-term care." However, some European countries that spend a similar share and also rely heavily on informal elder care, including Italy and Spain, have notably lower levels of GDP per capita. Some other European countries with income levels closer to the U.S., including Germany and the Netherlands, do spend more on long-term elder care. The Netherlands tops the list by devoting about 4 percent of its GDP to this area.</p> <p>However, in the U.S., the issue is not so much drastically changing how much it spends on long-term elder care, but how it spends. The Dutch have a relatively more extensive system of elder communities — the "congregate housing" for the elderly who are not desperately unwell but simply find self-reliance increasingly hard.</p> <p>"That's the huge missing hole in the U.S. long-term care system, what do we do with people who aren't sick enough for a nursing home, but probably shouldn't be at home," Gruber says. "Right now, they stay at home, they're lonely, they're not getting services, their kids are super-stressed out, and they're pulling millions of people out of the labor force, especially women. Everyone is unhappy about it, and they're not growing GDP, so it's hurting our economy and our well-being."</p> <p>Overall, then, Gruber thinks further investment in elder-care communities would be an example of effective government spending that can address the brewing crisis in long-term care — although it would require new federal legislation in a highly polarized political environment.</p> <p>Could that happen? Could the U.S. invest more now and realize long-term financial benefits, while allowing working-age employees to spend more time at their jobs rather than acting as home caregivers? Making people more aware of the issue, Gruber thinks, is a necessary starting point.</p> <p>"If anything might be bipartisan, it could be long-term care," Gruber says. "Everybody has parents. A solution has to be bipartisan. Long-term care may be one of those areas where it's possible."</p>
<p>From Around the Country</p>	<p>13. CT Mirror May 1, 2025 <u>Union sets May 19 strike deadline at 51 nursing homes</u> By Keith M. Phaneuf</p> <p>This article from the Connecticut Mirror details a potential strike by about 5,700 nursing home workers across 51 facilities in Connecticut, represented by SEIU 1199NE. The union has set a deadline of May 19th for state officials to address their demands.</p> <p>Here's a breakdown of the key points and figures:</p> <ul style="list-style-type: none"> • Number of workers potentially striking: Approximately 5,700 • Number of nursing homes affected: 51 • Union demand for starting pay: \$25 per hour (current average is \$18-\$22 per hour)

	<ul style="list-style-type: none"> • Union demand for most employee pay: Around \$30 per hour (over several years) • Estimated additional Medicaid funding needed: \$550 million over the next two fiscal years (an average of \$275 million annually) • Estimated annual cost to the state (after federal reimbursement): \$137.5 million • Potential Medicaid cuts over the next decade (federal level): \$880 billion • Potential annual Medicaid cuts for Connecticut (modeled): \$186 million to \$880 million • Connecticut Appropriations Committee's proposed budget exceeding the spending cap: \$215 million • Union members voting to authorize a strike: Approximately 99% of ballots cast • Nursing home occupancy rate (March 2021): 73.4% • Nursing home occupancy rate (March 2025): 88.6% • Number of homes involved in the 2021 strike threat: 26 • Proposed elimination of inflationary increases in Lamont's budget: \$111.4 million over the next two fiscal years
<p>Books by DignityMA Participants</p>  <p>About the Author: Alex Green teaches political communications at Harvard Kennedy School and is a visiting fellow at the Harvard Law School Project on Disability and a visiting scholar at Brandeis University Lurie Institute for Disability Policy. He is the author of legislation to create a first-of-its-kind, disability-led human rights commission to investigate the history of state institutions for disabled people in Massachusetts.</p>	<p><u>A Perfect Turmoil: Walter E. Fernald and the Struggle to Care for America's Disabled</u> By Alex Green</p> <p>From the moment he became superintendent of the nation's oldest public school for intellectually and developmentally disabled children in 1887 until his death in 1924, Dr. Walter E. Fernald led a wholesale transformation of our understanding of disabilities in ways that continue to influence our views today. How did the man who designed the first special education class in America, shaped the laws of entire nations, and developed innovative medical treatments for the disabled slip from idealism into the throes of eugenics before emerging as an opponent of mass institutionalization? Based on a decade of research, <i>A Perfect Turmoil</i> is the story of a doctor, educator, and policymaker who was unafraid to reverse course when convinced by the evidence, even if it meant going up against some of the most powerful forces of his time.</p> <p>In this landmark work, Alex Green has drawn upon extensive, unexamined archives to unearth the hidden story of one of America's largely forgotten, but most complex, conflicted, and significant figures.</p> <p><u>Buy the book here</u></p>
<p>Books by DignityMA Participants</p>  <p>About the Author:</p>	<p><u>American Eldercide: How It Happened, How to Prevent It</u> By <u>Margaret Morganroth Gullette</u></p> <p>A bracing spotlight on the avoidable causes of the COVID-19 Eldercide in the United States.</p> <p>Twenty percent of the Americans who have died of COVID since 2020 have been older and disabled adults residing in nursing homes—even though they make up fewer than one percent of the US population. Something about this catastrophic loss of life in government-monitored facilities has never added up. Until now. In <i>American Eldercide</i>, activist and scholar Margaret Morganroth Gullette investigates this tragic public health crisis with a</p>

<p>Margaret Morganroth Gullette is a cultural critic and anti-ageism pioneer whose prize-winning work is foundational in critical age studies. She is the author of several books, including <i>Agewise</i>, <i>Aged by Culture</i>, and <i>Ending Ageism, or How Not to Shoot Old People</i>. Her writing has appeared in publications such as the <i>New York Times</i>, <i>Washington Post</i>, <i>Guardian</i>, <i>Atlantic</i>, <i>Nation</i>, and the <i>Boston Globe</i>. She is a resident scholar at the Women's Studies Research Center, Brandeis, and lives in Newton, Massachusetts.</p>	<p>passionate voice and razor-sharp attention to detail, showing us that nothing about it was inevitable. By unpacking the decisions that led to discrimination against nursing home residents, revealing how governments, doctors, and media reinforced ageist or ableist biases, and collecting the previously little-heard voices of the residents who survived, Gullette helps us understand the workings of what she persuasively calls an eldercide.</p> <p>Gullette argues that it was our collective indifference, fueled by the heightened ageism of the COVID-19 era, that prematurely killed this vulnerable population. Compounding that deadly indifference is our own panic about aging and a social bias in favor of youth-based decisions about lifesaving care. The compassion this country failed to muster for the residents of our nursing facilities motivated Gullette to pen an act of remembrance, issuing a call for pro-aging changes in policy and culture that would improve long-term care for everyone.</p> <p>Buy the book here.</p>
<p>Bringing People Home: The Marsters Settlement</p>	<p>Webpages: https://www.centerforpublicrep.org/court_case/marsters-et-al-v-healey-et-al/ https://marsters.centerforpublicrep.org/</p>
<p>Support Dignity Alliance Massachusetts</p> <p>Please Donate!</p>	<p>Dignity Alliance Massachusetts is a grassroots, volunteer-run 501(c)(3) organization dedicated to transformative change to ensure the dignity of older adults, people with disabilities, and their caregivers. We are committed to advancing ways of providing long-term services, support, living options and care that respect individual choice and self-determination. Through education, legislation, regulatory reform, and legal strategies, this mission will become reality throughout the Commonwealth.</p> <p>As a fully volunteer operation, our financial needs are modest, but also real. Your donation helps to produce and distribute <i>The Dignity Digest</i> weekly free of charge to almost 1,000 recipients and maintain our website, www.DignityAllianceMA.org, which has thousands of visits each month.</p> <p>Consider a donation in memory or honor of someone. The names of those recognized will be included in The Dignity Digest and posted on the website.</p> <p>https://dignityalliancema.org/donate/</p> <p>Thank you for your consideration!</p>
<p>Dignity Alliance Massachusetts Legislative Endorsements</p>	<p>Information about the legislative bills which have been endorsed by Dignity Alliance Massachusetts, including the text of the bills, can be viewed at: https://tinyurl.com/DignityLegislativeEndorsements</p> <p>Questions or comments can be directed to Legislative Work Group Chair Richard (Dick) Moore at rmoores8473@charter.net.</p>
<p>Websites</p>	<p>Fostering Stability in Aging https://www.americanbar.org/groups/public_interest/homelessness_poverty/initiatives/chp-cola-initiative/ American Bar Association</p>

	<p>Fostering Stability in Aging is a collaboration by the ABA Commission on Homelessness and Poverty and the ABA Commission on Law and Aging designed as a resource hub to equip attorneys and other advocates representing and/or supporting older adults at risk of poverty and homelessness.</p> <p>It lists multiple online resources under three categories:</p> <ul style="list-style-type: none"> • American Bar Association • U.S. Department of Health and Human Services • National Organizations & Resources <p>State Health Planning to Improve Access to Care in Massachusetts: Needs and Current Tools https://www.bluecrossmafoundation.org/publication/state-health-planning-improve-access-care-massachusetts-needs-and-current-tools</p> <p>Blue Cross Blue Shield of Massachusetts Foundation</p> <p>This issue brief offers background on health services planning, describing the concept and outlining its history, including its rise and fall in the United States and in Massachusetts. The bulk of the brief is a catalog of the regulatory and policy tools that Massachusetts uses today that incorporate some aspects of health services planning, and how these tools do and do not interact. The brief concludes with a discussion of the gaps Massachusetts needs to fill to realize a complete, comprehensive health services planning initiative.</p>	
Blogs		
Podcasts		
YouTube Channels		
Previously recommended websites	The comprehensive list of recommended websites has migrated to the Dignity Alliance MA website: https://dignityalliancema.org/resources/ . Only new recommendations will be listed in <i>The Dignity Digest</i> .	
Previously posted funding opportunities	For open funding opportunities previously posted in <i>The Tuesday Digest</i> please see https://dignityalliancema.org/funding-opportunities/ .	
Websites of Dignity Alliance Massachusetts Members	See: https://dignityalliancema.org/about/organizations/	
Contact information for reporting complaints and concerns	Nursing home	Department of Public Health <ol style="list-style-type: none"> 1. Print and complete the Consumer/Resident/Patient Complaint Form 2. Fax completed form to (617) 753-8165 Or Mail to 67 Forest Street, Marlborough, MA 01752 Ombudsman Program
MassHealth Eligibility Information	MassHealth / Massachusetts Medicaid Income & Asset Limits for Nursing Homes & Long-Term Care Table of Contents (Last updated: December 16, 2024) Massachusetts Medicaid Long-Term Care Definition Income & Asset Limits for Eligibility Income Definition & Exceptions Asset Definition & Exceptions Home Exemption Rules Medical / Functional Need Requirements Qualifying When Over the Limits Specific Massachusetts Medicaid Programs How to Apply for Massachusetts Medicaid	

Money Follows the Person	<p>MassHealth <i>Money Follows the Person</i> The Money Follows the Person (MFP) Demonstration helps older adults and people with disabilities move from nursing facilities, chronic disease or rehabilitation hospitals, or other qualified facilities back to the community. Statistics as of March 31, 2025: 344 people transitioned out of nursing facilities in 2024 49 transitions in January and February 2025 910 currently in transition planning Open PDF file, 1.34 MB. MFP Demonstration Brochure MFP Demonstration Brochure - Accessible Version MFP Demonstration Fact Sheet MFP Demonstration Fact Sheet - Accessible Version</p>
Nursing Home Closures	<p>List of Nursing Home Closures in Massachusetts Since July 2021: https://dignityalliancema.org/2025/04/07/nursing-home-closures-since-july-2021/</p>
Determination of Need Projects	<p>List of Determination of Need Applications regarding nursing homes since 2020: https://dignityalliancema.org/2025/04/07/list-of-determination-of-need-applications/ Pending: Town of Nantucket – Long Term Care Substantial Capital Expenditure</p>
List of Special Focus Facilities	<p>Centers for Medicare and Medicaid Services <i>List of Special Focus Facilities and Candidates</i> https://www.cms.gov/files/document/sff-posting-candidate-list-march-2025.pdf Updated March 26, 2025 CMS has published a new list of Special Focus Facilities (SFF). SFFs are nursing homes with serious quality issues based on a calculation of deficiencies cited during inspections and the scope and severity level of those citations. CMS publicly discloses the names of the facilities chosen to participate in this program and candidate nursing homes. To be considered for the SFF program, a facility must have a history (at least 3 years) of serious quality issues. These nursing facilities generally have more deficiencies than the average facility, and more serious problems such as harm or injury to residents. Special Focus Facilities have more frequent surveys and are subject to progressive enforcement until it either graduates from the program or is terminated from Medicare and/or Medicaid. This is important information for consumers – particularly as they consider a nursing home. What can advocates do with this information?</p> <ul style="list-style-type: none"> • Include the list of facilities in your area/state when providing information to consumers who are looking for a nursing home. Include an explanation of the SFF program and the candidate list. • Post the list on your program's/organization's website (along with the explanation noted above). • Encourage current residents and families to check the list to see if their facility is included.

- Urge residents and families in a candidate facility to ask the administrator what is being done to improve care.
- Suggest that resident and family councils invite the administrator to a council meeting to talk about what the facility is doing to improve care, ask for ongoing updates, and share any council concerns.
- For long-term care ombudsmen representatives: Meet with the administrator to discuss what the facility is doing to address problems and share any resources that might be helpful.

Massachusetts facilities listed (updated)

Newly added to the listing

- Salem Rehab Center, Salem
<https://www.adviniacare.com/adviniacare-salem/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225644/>
- Fall River Healthcare
<https://www.nextstephc.com/fallriver>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225723/>

Massachusetts facilities which have graduated from the program

- Marlborough Hills Rehabilitation and Health Care Center, Marlborough
<https://tinyurl.com/MarlboroughHills>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225063>
- Somerset Ridge Center, Somerset
<https://somersetridgerehab.com/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225747>
- Tremont Healthcare Center, Wareham
<https://thetremontrehabcare.com/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225488/>

Massachusetts facilities that are candidates for listing (months on list)

- AdviniaCare Newburyport (13)
<https://www.adviniacare.com/adviniacare-country-center/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225332>
- Brandon Woods of New Bedford (1)
<https://brandonwoodsnewbedford.com/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225264/>
- Cape Cod Post Acute, Brewster (9)
<https://capecodrehabhc.com/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225667/>
- Charwell House Health and Rehabilitation, Norwood (37)
<https://tinyurl.com/Charwell>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225208>
- Life Care Center of Merrimack Valley, Billerica (2)
<https://lcca.com/locations/ma/merrimack-valley/>
Nursing home inspect information:

	<p>https://projects.propublica.org/nursing-homes/homes/h-225546/</p> <ul style="list-style-type: none">Medway Country Manor Skilled Nursing & Rehabilitation, Medway (1) https://www.medwaymanor.com/ Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225412Pine Knoll Nursing Center, Lexington, (3) https://www.longtermcentersgroup.com/About-Pine-Knoll-Nursing-Center-Rehab Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225049/RegalCare at Glen Ridge (20) https://www.genesishcc.com/glenridge Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225523West Newton Healthcare, West Newton (9) https://www.nextstephc.com/westnewton Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225324/ <p>No longer operating</p> <ul style="list-style-type: none">South Dennis Healthcare, South Dennis https://tinyurl.com/SpecialFocusFacilityProgram																																																
Nursing Home Inspect	<p>ProPublica Nursing Home Inspect Data updated April 23, 2025 This app uses data from the U.S. Centers for Medicare and Medicaid Services. Fines are listed for the past three years if a home has made partial or full payment (fines under appeal are not included). Information on deficiencies comes from a home’s last three inspection cycles, or roughly three years in total. The number of COVID-19 cases is since May 8, 2020, when homes were required to begin reporting this information to the federal government (some homes may have included data on earlier cases). Massachusetts listing: https://projects.propublica.org/nursing-homes/state/MA Deficiencies By Severity in Massachusetts (What do the severity ratings mean?)</p> <table><tr><th>Deficiency Tag</th><th># Deficiencies</th><th>in # Facilities</th><th>MA facilities cited</th></tr><tr><td>B</td><td>315</td><td>222</td><td>Tag B</td></tr><tr><td>C</td><td>106</td><td>82</td><td>Tag C</td></tr><tr><td>D</td><td>7,445</td><td>1,401</td><td>Tag D</td></tr><tr><td>E</td><td>2,133</td><td>767</td><td>Tag E</td></tr><tr><td>F</td><td>676</td><td>314</td><td>Tag F</td></tr><tr><td>G</td><td>517</td><td>339</td><td>Tag G</td></tr><tr><td>H</td><td>58</td><td>35</td><td>Tag H</td></tr><tr><td>I</td><td>3</td><td>2</td><td>Tag I</td></tr><tr><td>J</td><td>53</td><td>28</td><td>Tag J</td></tr><tr><td>K</td><td>27</td><td>9</td><td>Tag K</td></tr><tr><td>L</td><td>9</td><td>3</td><td>Tag L</td></tr></table> <p>Updated April 23, 2025</p>	Deficiency Tag	# Deficiencies	in # Facilities	MA facilities cited	B	315	222	Tag B	C	106	82	Tag C	D	7,445	1,401	Tag D	E	2,133	767	Tag E	F	676	314	Tag F	G	517	339	Tag G	H	58	35	Tag H	I	3	2	Tag I	J	53	28	Tag J	K	27	9	Tag K	L	9	3	Tag L
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Nursing Home Compare	<p>Centers for Medicare and Medicaid Services (CMS) <i>Nursing Home Compare Website</i> Beginning January 26, 2022, the Centers for Medicare and Medicaid Services (CMS) is posting new information that will help consumers have a</p>																																																

	<p>better understanding of certain staffing information and concerns at facilities.</p> <p>This information will be posted for each facility and includes:</p> <ul style="list-style-type: none"> • Staff turnover: The percentage of nursing staff as well as the number of administrators who have stopped working at a nursing home over the past 12-month period. • Weekend staff: The level of weekend staffing for nurses and registered nurses at a nursing home over a three-month period. <p>Posting this information was required as part of the Affordable Care Act, which was passed in 2010. In many facilities, staffing is lower on weekends, often meaning residents have to wait longer or may not receive all the care they need. High turnover means that staff are less likely to know the residents, recognize changes in condition, or implement preferred methods of providing care. All of this contributes to the quality-of-care residents receive and their quality of life.</p> <p>https://tinyurl.com/NursingHomeCompareWebsite</p>		
Data on Ownership of Nursing Homes	<p>Centers for Medicare and Medicaid Services</p> <p><i>Data on Ownership of Nursing Homes</i></p> <p>CMS has released data giving state licensing officials, state and federal law enforcement, researchers, and the public an enhanced ability to identify common owners of nursing homes across nursing home locations. This information can be linked to other data sources to identify the performance of facilities under common ownership, such as owners affiliated with multiple nursing homes with a record of poor performance. The data is available on nursing home ownership will be posted to data.cms.gov and updated monthly.</p>		
DignityMA Call Action	<ul style="list-style-type: none"> • Advocate for state bills that advance the Dignity Alliance Massachusetts' Mission and Goals – State Legislative Endorsements. • Support relevant bills in Washington – Federal Legislative Endorsements. • Join our Work Groups. • Learn to use and leverage social media at our workshops: Engaging Everyone: Creating Accessible, Powerful Social Media Content 		
Access to Dignity Alliance social media	<p>Email: info@DignityAllianceMA.org</p> <p>Facebook: https://www.facebook.com/DignityAllianceMA/</p> <p>Instagram: https://www.instagram.com/dignityalliance/</p> <p>LinkedIn: https://www.linkedin.com/company/dignity-alliance-massachusetts</p> <p>Twitter: https://twitter.com/dignity_ma?s=21</p> <p>Website: www.DignityAllianceMA.org</p>		
<p>Participation opportunities with Dignity Alliance Massachusetts</p> <p>Most workgroups meet bi-weekly via Zoom.</p>	Workgroup	Workgroup lead	Email
	General Membership	Bill Henning Paul Lanzikos	bhenning@bostoncil.org paul.lanzikos@gmail.com
	Assisted Living	John Ford	jford@njc-ma.org
	Behavioral Health	Frank Baskin	baskinfrank19@gmail.com
	Communications	Lachlan Forrow	lforrow@bidmc.harvard.edu
	Facilities (Nursing homes and rest homes)	Jim Lomastro Arlene Germain	jiplomastro@comcast.net agermain@manhr.org
	Home and Community Based Services	Meg Coffin	mcoffin@centerlw.org
	Legislative	Richard Moore	rmoore8743@charter.net

Interest Groups meet periodically (monthly, bi-monthly, or quarterly). Please contact group lead for more information.	Legal Issues	Stephen Schwartz	sschwartz@cpr-ma.org
	Interest Group	Group lead	Email
	Housing	Bill Henning	bhenning@bostoncil.org
	Veteran Services	James Lomastro	jimlomastro@comcast.net
	Transportation	Frank Baskin Chris Hoeh	baskinfrank19@gmail.com cdhoeh@gmail.com
	Covid / Long Covid	James Lomastro	jimlomastro@comcast.net
	Incarcerated Persons	TBD	info@DignityAllianceMA.org
<i>Bringing People Home: Implementing the Marsters class action settlement</i>	Website: https://marsters.centerforpublicrep.org/ Center for Public Representation 5 Ferry Street, #314, Easthampton, MA 01027 413-586-6024, Press 2 bringingpeoplehome@cpr-ma.org Newsletter registration: https://marsters.centerforpublicrep.org/7b3c2-contact/		
<i>REV UP Massachusetts</i>	REV UP Massachusetts advocates for the fair and civic inclusion of people with disabilities in every political, social, and economic front. REV Up aims to increase the number of people with disabilities who vote. Website: https://revupma.org/wp/ To join REV UP Massachusetts – go to the SIGN UP page .		
<i>The Dignity Digest</i>	For a free weekly subscription to <i>The Dignity Digest</i> : https://dignityalliancema.org/contact/sign-up-for-emails/ Editor: Paul Lanzikos Primary contributor: Sandy Novack MailChimp Specialist: Sue Rorke		
Note of thanks	Thanks to the contributors to this issue of <i>The Dignity Digest</i> : <ul style="list-style-type: none">• Wynn Gerhardt• Jim Lomastro• Dick Moore Special thanks to the MetroWest Center for Independent Living for assistance with the website and MailChimp versions of <i>The Dignity Digest</i> . <i>If you have submissions for inclusion in <u>The Dignity Digest</u> or have questions or comments, please submit them to Digest@DignityAllianceMA.org.</i>		
<i>Dignity Alliance Massachusetts is a broad-based coalition of organizations and individuals pursuing fundamental changes in the provision of long-term services, support, and care for older adults and persons with disabilities.</i> <i>Our guiding principle is the assurance of dignity for those receiving the services as well as for those providing them.</i> <i>The information presented in “The Dignity Digest” is obtained from publicly available sources and does not necessarily represent positions held by Dignity Alliance Massachusetts.</i> <i>Previous issues of The Tuesday Digest and The Dignity Digest are available at:</i> https://dignityalliancema.org/dignity-digest/ <i>For more information about Dignity Alliance Massachusetts, please visit www.DignityAllianceMA.org.</i>			